



Funded by the
Erasmus+ Programme
of the European Union

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The Erasmus + project involves 5 participating countries across the EU and commenced in September 2017 and ends by December of 2020.



The objective of this initiative is to create a set of modules which will assist persons of an intellectual disability to engage in independent living. This will be achieved by focusing on the current need to enhance communication, literacy and numeracy skills of persons with an intellectual disability so that they will have the means to be fully integrated within the social and economic national frameworks and also to be able to realize their inherent rights for independent living.

By means of this project the creation of a number of Modules is being underlined in order to improve the communicative, literacy and numeracy skills for persons of an intellectual disability (i*) living on their own; (ii) living with immediate or extended families; and (iii) living in residential/communal homes. The developed Modules will reflect the different needs of the mentioned categories of this project's target group.

The activities of this project will be the following:

- 1) Research
- 2) Development of Modules
- 3) Pilot Activities
- 4) Evaluation
- 5) Multiplier Event

Many researchers have shown that persons with an intellectual disability are very vulnerable and more likely to have a denser propensity per capita to be listed as low skilled or low qualified adults in a country's demographic employment analysis. However, no research to date has professionally and methodically analysed what type of services and subsidies - be they regional, national, transnational or indeed offered by civil society pressure groups - are presently available throughout the various EU countries for this population grouping. Thus, before the development of each Module, this project will constitute a research study

(encompassing all the EU countries) which will seek to list and catalogue available subsidies, programmes and incentives in this field for the intellectually disabled. The research will also seek to establish if such available opportunities are being maximized by the grouping in question and, if not, why are there such shortfalls in the respective jurisdictions which will be monitored. Additionally, this research will inevitably underline harmonious and quasi-identical initiatives in this sector evident in the various EU countries and highlight initiatives and regulations which are available in some jurisdictions but not available in all the EU jurisdictions.

Enhancing our target group's communication and other skills should be seen in the context of providing this group with the necessary tools for integration within society and for stratification betterment of the individuals in question. The project will also segment the various groupings related to persons with intellectual disabilities in order to fully pinpoint the specific needs of the target groups.

Following the completion of each Module, each participating organisation will provide training to 20 person of an intellectual disability by using the methodology that would have been included in the particular Module. By means of this system the participating organizations will be testing the Modules and at the same time providing training to a total of 360 individual by the end of same project.

As part of the above-mentioned three year project financed by Erasmus+, the coordinating country organisation (MFOPD – the Malta Federation of Organisations Persons with Disability) and all the partner organisations unanimously agreed in their first trans-national meeting held at the New Dolmen Hotel, Bugibba, Malta, in 2017, that specialised researchers from a suitably experienced organisation would be entrusted with researching on what is presently happening around Europe with regards to persons with intellectual disabilities and the services and programs available to them in the various European jurisdictions.



Further transnational meetings were held on the subject in question in Belfast, Northern Ireland; Orebro, Sweden; Athens, Greece and Brussels, Belgium during the period 2017-2020.

¹<https://ec.europa.eu/programmes/erasmus-plus/projects/eplu-project-details/#project/a637f790-0cdc-493e-89cb-776fb3c2634c>

The below is the result of the first phase of the research period, covering the last two quarters of 2017 and the first quarter of 2018. This report will be updated and constantly available for input throughout the three year period of the Erasmus + Project (2017 – 2020). The research has been edited, amalgamated and overseen by the undersigned during the period in question.

All data and information presented in this report is in the public domain and, as can be noted by the extensive footnotes within the research, all sources of such data and information have been duly credited. Care has also been taken in ensuring that the editor remains faithful to the meaning and scope of all data and information as intended by the original source, hence the extensive, non-interpolated citations and extracts from the original sources.

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Introduction

Intellectual disability is commonly recognized as to be characterized by impediments encountered by a person regarding both adaptive behaviour as well as intellectual functioning. Consequently, this condition is undeniably a dominant factor in one's life. On the one hand, it affects the mental capacity to solve problems or apply logical reason, resulting in a generally lower IQ. On the other hand, it also deters progress as well as capacity in a diverse range of skills.

Studies imply that within a population of 1000 people, at least four have severe intellectual disabilities, resulting in an approximate IQ of 50 or less. Intellectual disability affects about 2–3% of the general population. Seventy-five to ninety percent of the affected people have mild intellectual disability. Non-syndromic or idiopathic cases account for 30–50% of cases.² About a quarter of cases are caused by a genetic disorder and about 5% of cases are inherited from a person's parents.³ Cases of unknown cause affect about 95 million people as at 2013.⁴ However not all of these cases tend to not be considered as requiring specialized assistance in adult life.

Intellectual disability (ID) is also known as general learning disability⁵ and mental retardation (MR)⁶. Thankfully, the latter terminology has been mostly withdrawn from use throughout the Western world due to its negative labelling effects on the persons in question and is now shunned and normally not used by society in general.⁷ Intellectual disability is subdivided into syndromic intellectual disability, in which intellectual deficits associated with other medical and behavioural signs and symptoms are present, and non-syndromic intellectual disability, in which intellectual deficits appear without other abnormalities. Down syndrome and fragile X syndrome are examples of syndromic intellectual disabilities.⁸

² Daily DK, Ardinger HH, Holmes GE (February 2000). "Identification and evaluation of mental retardation"

³ "Definition of mentally retarded". Gale Encyclopaedia of Medicine.

⁴ Global Burden of Disease Study 2013, Collaborators (5 June 2015). "Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013"

⁵ Tidy, Colin (25 January 2013). "General Learning Disability". Patient.info. The term general learning disability is now used in the UK instead of terms such as mental handicap or mental retardation. The degree of disability can vary significantly, being classified as mild, moderate, severe or profound.

⁶ "Rosa's Law" (PDF). Washington, D.C.: U.S.G.P.O. 2010.

⁷ Ansberry, Clare (20 November 2010). "Erasing a Hurtful Label from the Books". The Wall Street Journal. Decades-long quest by disabilities advocates finally persuades state, federal governments to end official use of 'retarded'.

⁸ Wilmshurst, Linda (2012). *Clinical and Educational Child Psychology an Ecological-Transactional Approach to Understanding Child Problems and Interventions*. Hoboken:Wiley.p.168. ISBN 9781118439982.

By most definitions, intellectual disability is more accurately considered a disability rather than a disease. Intellectual disability can be distinguished in many ways from mental illness, such as schizophrenia or depression. Currently, there is no "cure" for an established disability, though with appropriate support and teaching, most individuals can learn to do many things.

There are thousands of agencies around the world that provide assistance for people with developmental disabilities. They include state-run, for-profit, and non-profit, privately run agencies. Within one agency there could be departments that include fully staffed residential homes, day rehabilitation programs that approximate schools, workshops wherein people with disabilities can obtain jobs, programs that assist people with developmental disabilities in obtaining jobs in the community, programs that provide support for people with developmental disabilities who have their own apartments, programs that assist them with raising their children, and many more. There are also many agencies and programs for parents of children with developmental disabilities.

Beyond that, there are specific programs that people with developmental disabilities can take part in wherein they learn basic life skills. These "goals" may take a much longer amount of time for them to accomplish, but the ultimate goal is independence. This may be anything from independence in tooth brushing to an independent residence. People with developmental disabilities learn throughout their lives and can obtain many new skills even late in life with the help of their families, caregivers, clinicians and the people who coordinate the efforts of all of these people.

There are four broad areas of intervention that allow for active participation from caregivers, community members, clinicians, and of course, the individual(s) with an intellectual disability. These include psychosocial treatments, behavioural treatments, cognitive-behavioural treatments, and family-oriented strategies.⁹ Psychosocial treatments are intended primarily for children before and during the preschool years as this is the optimum time for intervention.

¹⁰ This early intervention should include encouragement of exploration, mentoring in basic skills, the celebration of developmental advances, guided rehearsal and extension of newly acquired skills, protection from harmful displays of disapproval, teasing, or punishment, and exposure to a rich and responsive language environment.

¹¹ A great example of a successful intervention is the Carolina Abecedarian Project that was conducted with over 100 children from low SES families beginning in infancy through

⁹ Mash, E., & Wolfe, D. (2013). *Abnormal child psychology*. (5th ed., pp. 308–313). Wadsworth Cengage Learning.

¹⁰ Hodapp, R.M., & Burack, J.A. (2006). Developmental approaches to children with mental retardation: A second generation? In D.Cicchetti & D.J.Cohen(Eds.), *Developmental psychopathology*, Vol. 3: Risk, disorder, and adaptation (2nd ed., pp. 235–267). Hoboken, NJ: Wiley.

¹¹ Ramey S.L.; Ramey C.T. (1992). "Early educational intervention with disadvantaged children—To what effect?" *Applied and Preventive Psychology*. 1: 131–140.

pre- school years. Results indicated that by age 2, the children provided the intervention had higher test scores than control group children, and they remained approximately 5 points higher 10 years after the end of the program. By young adulthood, children from the intervention group had better educational attainment, employment opportunities, and fewer behavioural problems than their control-group counterparts.¹²

Core components of behavioural treatments include language and social skills acquisition. Typically, one-to-one training is offered in which a therapist uses a shaping procedure in combination with positive reinforcements to help the child pronounce syllables until words are completed.¹³ Sometimes involving pictures and visual aids, therapists aim at improving speech capacity so that short sentences about important daily tasks (e.g. bathroom use, eating, etc.) can be effectively communicated by the child.¹⁴

In a similar fashion, older children benefit from this type of training as they learn to sharpen their social skills such as sharing, taking turns, following instruction, and smiling.¹⁵ Concurrently, a movement known as social inclusion attempts to increase valuable interactions between children with an intellectual disability and their non-disabled peers.¹⁶

Cognitive-behavioural treatments, a combination of the previous two treatment types, involves a meta-strategical learning technique that teaches children math, language, and other basic skills pertaining to memory and learning. The first goal of the training is to teach the child to be a strategical thinker through making cognitive connections and plans. Then, the therapist teaches the child to be meta-strategical by teaching them to discriminate among different tasks and determine which plan or strategy suits each task.¹⁷

Finally, family-oriented strategies delve into empowering the family with the skill set they need to support and encourage their child or children with an intellectual disability. In general, this includes teaching assertiveness skills or behaviour management techniques as well as how to ask for help from neighbours, extended family, or day-care staff.¹⁸

¹² Campbell F.A.; Ramey C.T.; Pungello E.; Sparling J.; Miller-Johnson S. (2002). "Early childhood education: Young adult outcomes from the Abecedarian Project". *Applied Developmental Science*. 6: 42–57

¹³ Matson J.L.; Matson M.L.; Rivet T.T. (2007). "Social-skills treatments for children with autism spectrum disorders: an overview". *Behavior Modification*. 31 (5): 682–707.

¹⁴ Van der Schuit M, Segers E, van Balkom H, Verhoeven L (2011). "Early language intervention for children with intellectual disabilities: a neurocognitive perspective". *Research in Developmental Disabilities*. 32 (2): 705–12.

¹⁵ Kemp C.; Carter M. (2002). "The social skills and social status of mainstreamed students with intellectual disabilities". *Educational Psychology*. 22: 391–411.

¹⁶ Siperstein G.N.; Glick G.C.; Parker R. (2009). "The social inclusion of children with intellectual disabilities in an out of school recreational setting". *Intellectual and developmental disabilities*. 47 (2): 97–107.

¹⁷ Hay I.; Elias G.; Fielding-Barnsley R.; Homel R.; Freiberg K. (2007). "Language delays, reading delays and learning difficulties: Interactive elements requiring multidimensional programming". *Journal of Learning Disabilities*. 40 (5): 400–409.

¹⁸ Bagner D.M.; Eyberg S.M. (2007). "Parent-child interaction therapy for disruptive behaviour in children with mental retardation : A randomized controlled trial". *Journal of Clinical Child and Adolescent Psychology*. 36: 418–429.

As the child ages, parents are then taught how to approach topics such as housing/residential care, employment, and relationships. The ultimate goal for every intervention or technique is to give the child autonomy and a sense of independence using the acquired skills he/she has.

Although there is no specific medication for intellectual disability, many people with developmental disabilities have further medical complications and may be prescribed several medications. For example, autistic children with developmental delay may be prescribed antipsychotics or mood stabilizers to help with their behaviour. Use of psychotropic medications such as benzodiazepines in people with intellectual disability requires monitoring and vigilance as side effects occur commonly and are often misdiagnosed as behavioural and psychiatric problems.¹⁹

Although the above is the common scientific and academic consensus on how to assist persons with intellectual disabilities in attaining partial or full independence and societal integration, the modus operandi utilised in various countries and jurisdictions differ greatly. Whilst the broad brushes of imparting skills mostly adhere to the above different methodologies, different organisations, regions, countries and jurisdictions have different programs and push forward differing programs as the main catalysts for ensuring skill building is properly imparted to persons with intellectual disabilities. Therefore, this research seeks to focus on the varying initiatives being undertaken throughout Europe in this regard.

But before going anywhere further, one needs to identify the most important skills which need to be imparted.

Undoubtedly, one of these most important skills is numeracy. The ability to grasp conceptual matters and comprehend them in such a way that one could explain it to another person is deemed to be of the utmost importance to be imparted and should be considered as the cornerstone of skill building vis-à-vis the persons we are focusing on.²⁰ A numerically literate person can manage and respond to the mathematical demands of life.²¹ By contrast, innumeracy (the lack of numeracy) can have a negative impact. Numeracy has an influence on career decisions, and risk perception towards health decisions. For example, innumeracy distorts risk perception towards health decisions²² and may also negatively affect economic choices.²³

¹⁹ Kalachnik, J.E.; Hanzel, T.E.; Sevenich, R.; Harder, S.R. (Sep 2002). "Benzodiazepine behavioural side effects: review and implications for individuals with mental retardation". *Am J Ment Retard.* 107 (5): 376–410.

²⁰ Brooks, M; Pui (2010). "Are individual differences in numeracy unique from general mental ability? A closer look at a common measure of numeracy". *Individual Differences Research.* 4. 8: 257–265.

²¹ Statistics Canada. "Building on our Competencies: Canadian Results of the International Adult Literacy and Skills Survey". p. 209.

²² Reyna, V. F.; Nelson, W. L.; Han, P. K.; Dieckmann, N. F. (2009). "How numeracy influences risk comprehension and medical decision making". *Psychological Bulletin.* 135 (6): 943–973. doi:10.1037/a0017327

²³ Gerardi, K.; Goette, L.; Meier, S. (2013). "Numerical ability predicts mortgage default". *Proceedings of the National Academy of Sciences.* 110 (28): 11267–11271.

"Greater numeracy has been associated with reduced susceptibility to framing effects, less influence of non-numerical information such as mood states, and greater sensitivity to different levels of numerical risk".²⁴ Although such terminology might be deemed as too scientific and/or specialised for the modest needs that persons with intellectual disabilities have to face in their daily lives, one must constantly keep in mind that this field also significantly includes daily applications such as the use of money or keeping track of time.

Without such skills, one would not be capable of advancing enough in order to be able to achieve employment or even be self-dependent. A person with such an issue would not be able to keep track of their own finances, let alone anyone else's. Moreover, it greatly decreases the chance that this person could be depended on as a team player in the future, be it in a family scenario, a job-related scenario or even amongst one's peer and friends. This could also lead to a failure to communicate properly, whether it be to family, friends or peers.

Which brings us to the ability to communicate. Communication is a crucial part of every person's life. This is why it is vital to ensure that persons with intellectual disability are equally capable of using this skill, whether it be through conventional methods such as speech or writing, or however is most efficient. Unfortunately, lacking adaptive behaviour gives rise to more issues regarding social skills.²⁵

Even the terminology one uses with regards to intellectual disability may be complicated. A vast difference can be noted between terminology used in clinical terms and terminology used in everyday language. For example, in clinical terms intellectual disability is often defined in terms of the severity of the condition. Therefore:

Clinical term	Percentage	IQ
MILD intellectual disability	75	55-70
MODERATE intellectual disability	20	30-55
SEVERE intellectual disability	05	under 30

The use of the word "MILD" suggests a disability of little consequence. This is far from accurate.

A person with mild intellectual disability will have significant difficulty managing their lives effectively without support and training. Many people with mild intellectual disability live independently but struggle with many everyday issues. Many try to cover up their difficulties. Many receive no assistance. A person with mild intellectual disability would have great difficulty in understanding what is happening at court and what is required of them (eg bail conditions, court orders) without assistance.

²⁴ Weller, J. A.; Dieckmann, N. F.; Tusler, M.; Mertz, C. K.; Burns, W. J.; Peters, E. (2013).

"Development and Testing of an Abbreviated Numeracy Scale: A Rasch Analysis Approach". *Journal of Behavioural Decision Making*. 26 (2): 198–212.

²⁵ Harper, Douglas. "Communication". *Online Etymology Dictionary*. 2013-06-23.

Intellectual disability should be assessed by a psychologist and some people with intellectual disability may have more than one disability. For example some people with intellectual disability might also have a mental illness (dual diagnosis). These people figure highly in the group who come into contact with the criminal justice system and are often least well assisted by services.

Increasing capacity by changing environment and support to decrease effects of intellectual disability: a constructive way to look at intellectual disability is to define it in terms of the support needs of people. This approach sees the effect of the disability as something that will vary and can be increased or reduced by external factors. It does not view intellectual disability as an unchangeable characteristic of the individual. The effect of the disability or the capacity of the person is a function not only of the disability but also a function of their environment and the support they receive.

Therefore, adjusting the environment and the support to meet the person's needs can increase the person's capacity and reduce the effect of the disability. Whatever the programs and skill building exercises one embarks upon, it is important to convey simple messages when communicating with people with intellectual disability. When one analyses the type and style of programs and projects which are available throughout the European Union countries and jurisdictions, all the programs in question abide by the following simple rules and guidelines, irrespective of the methodology used in the program in question. The following communication tools are always useful to enhance the effectiveness of communication with such a client:

Give permission to say "*I don't get it*".

Acknowledge that this is hard stuff. For example, "*I need to make sure I explain it properly. Please tell me if I'm not clear enough*". Most people with an intellectual disability will try to bluff their way through rather than ask.

Check that the person understands – but own the checking or the person may think they gave you the wrong answer.

Use short sentences, simple language, no jargon.

One idea at a time.

Slow down.

Abstract concepts are especially difficult: be concrete, for example: time may be a difficult concept; connect to something meaningful to the person – "*before or after dinner*", or "*what was on television at the time?*"

Expect an answer but be prepared to wait. With some people you may need to wait an uncomfortable time to ensure there has been time for the person to process the information.

- Try not to interrupt. Do not finish the person's sentences.
- Sign post "OK, that's all I need to know about that. Now can we talk about ..."
- Open questions and encourage free recall – let the person tell their story.
- Remember body language messages - they are essential for someone with an intellectual disability.
- Minimise distractions.
- Breaks are essential – the person is likely to have limited concentration.
- Reinforce the important messages.²⁶

The European Union Area vis-à-vis intellectual disability

People with intellectual disabilities represent one of the most disadvantaged social groups in European countries. The pervasive nature of intellectual disabilities creates very high levels of need for assistance often throughout every aspect of the individual's existence and over the whole of the person's life. Traditional patterns of care have been heavily based on institutions, which tend to segregate and isolate people from the mainstream of society.

This same assistance is also essential for youths with disability. One might even go so far as to say that it is even more so important, due to youths facing a lifetime of potential social and employment related integration needs. Thus, with regards to EU structures and programs, both disability and youth need to be key concerns in formulating any policy.

Owing to the Helios programmes, some positive changes were made in the EU programmes such as Socrates, Youth for Europe, Leonardo da Vinci, Daphne, Phare, Tacis 14 in relation to participation of people with disabilities.²⁷ The Youth in Action Programme pays particular attention to increasing the opportunities, in a broad sense, of young people with disabilities; financing specific costs related to disability needs, can be provided. SALTO booklet "No Barriers, No Borders" informs how to run international mixed ability projects for young people with and without a disability²⁸. Data for Youth in Action Programme in 2010 show that 8% of total granted projects on decentralised level had a primary theme "disability" (271 projects); 9% of total granted projects had "disability" as a secondary theme (298 projects); 16% of total granted projects aimed at the inclusion of young disabled and/or directly involving disabled young people (543 projects).

However, as identified by research, access to education alone is a grave problem - not to speak of active participation. The main challenges in the context of youth and disability policies can be condensed to the following:

²⁶ <http://www.idrs.org.au/education/about-intellectual-disability.php>

²⁷ https://ec.europa.eu/info/funding-tenders/funding-opportunities/funding-programmes/overview-funding-programmes_en

²⁸ www.salto-youth.net/rc/inclusion

- There is limited information regarding the direct impact of (generic) EU policies on people with disabilities²⁹, young people with disabilities alone;
- People with disabilities are in some EU countries are absent from discussions on social inequality, exclusion and poverty³⁰;
- The level of poverty among people with disabilities remains high;
- The current policy measures have not been able to offer to people with disabilities a safety net that would bring them out of the poverty trap and enable them to lead dignified lives³¹;
- Limited progress has been made in the area of lifelong learning;
- Women with disabilities are particularly under-represented in recreational activities, culture and sport – in terms of participation, leadership, management and media coverage³². Similarly, children with disabilities face significant barriers when evaluating participation in recreational activities, culture and sport, and remain poorly served by provision of education³³;
- Possibilities for accessing mainstream education tend to be unavailable for children with severe disabilities³⁴, and segregation is still widespread all over Europe³⁵ (e.g. in Germany only 15.7 per cent of all children and adolescents with disabilities attend school together with non-disabled pupils)³⁶;
- Young people with disabilities are far less likely to attend school or to stay in school than their non-disabled peers³⁷. Even in countries that are close to achieving universal primary education, people with disabilities represent the largest group still out of school³⁸. One issue seems to be that families are less likely to prioritise education for children with disabilities, believing they are not capable of learning³⁹.

²⁹ Communication on the European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe

³⁰ Priestley, M., 'Synthesis report on disability mainstreaming in the 2008-2010 National Strategy Reports for Social Protection and Social Inclusion (NSRs)', Oct. 2008, Academic Network of European Disability Experts, p. 16

³¹ Academic Network of European Disability Experts (ANED) (2009), 'The implementation of EU social inclusion and social protection strategies in European countries with reference to equality for people with disabilities', p. 33

³² Study on the situation of women with disabilities in light of the UN Convention for the Rights of Persons with Disabilities, p.34-35

³³ Study on the situation of women with disabilities in light of the UN Convention for the Rights of Persons with Disabilities, p. 135

³⁴ Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs, p. 73

³⁵ Ibid, p.74

³⁶ Federal Ministry of Labour and Social Affairs (Germany): 2009 Disability Report

³⁷ World Health Organization, World Report on Disability 2011

³⁸ UNESCO, Reaching the Marginalised: Education for All Global Monitoring Report 2010

³⁹ Groce, N.E. (2004) Adolescents and youth with disability: Issues and Challenges. Asia Pacific Disability Rehabilitation Journal. 15(2): 13- 32

Some countries are now beginning to replace these with more individualised, more integrated services which aim to support inclusion of people with intellectual disabilities in society.⁴⁰ In the European context, comparison between countries is useful in this enterprise, for three main reasons:

1. Comparison may lead to actual harmonisation of practice and thereby to improvement in the quality of life of people with intellectual disabilities and to greater social cohesion in the European Union.
2. Improvement in services may result from comparison, as a broader range of possibilities are considered by Member States due to the dissemination of good practice. Comparative studies increase the range of possible innovations in service organisation, design and delivery.
3. Greater understanding of the process of service development may result from comparison, due to the identification of contextual factors which may be implicit in the national account but are necessary conditions for implementation elsewhere.⁴¹

These, and several other factors, necessitate the comparing of social and economic inclusion initiatives which are essential for independent living. Comparison requires, first of all, a description of the situation in the different countries involved. This report presents descriptions of each participating country, prepared to a common template. It is intended as a starting point for comparative analysis. One needs to focus on the nature of intellectual disability: the way in which it is defined in different countries, the implications of intellectual disability for the individual's legal status and the implications of definition and status for eligibility for services.

One should then look at the policy framework in each country, addressing specific policies relating to people with intellectual disabilities produced by central, regional or local governments (for example, specifications of the kinds of intellectual disability services that should be provided), but also extending to general policies produced for other reasons which nevertheless have an impact on services for people with intellectual disabilities (for example, specifications of which public authorities are responsible for social welfare services) and the policies and guidance produced by other organisations (for example, professional organisations) which, though not carrying the authority of government policy, are still influential in services for people with intellectual disabilities.⁴²

⁴⁰ Mansell & Ericsson, (Eds.). (1996) *Deinstitutionalization and Community Living:*

Intellectual Disability Services in Britain, Scandinavia and the USA. London: Chapman Hall

⁴¹ Jones, 1985, p4, *Patterns of social policy: an introduction to comparative analysis.* London: Tavistock.

⁴² <http://www.enil.eu/wp-content/uploads/2012/07/Intellectual-Disability-in-Europe.pdf>

**Population and total area of the 28 member states of the European Union
(1 January 2016 estimate^[2])**

Member State	Population	Percent of total EU pop.	Total area km ²	Percent of total EU area	Pop. density People/km ²
 EU	510,284,430	100.00%	4,324,782	100.00	116.0
 Austria	8,690,076	1.70%	83,858	1.9	99.7
 Belgium	11,311,117	2.22%	30,510	0.7	352.0
 Bulgaria	7,153,784	1.40%	110,912	2.5	68.5
 Croatia	4,190,669	0.82%	56,594	1.3	75.8
 Cyprus	848,319	0.17%	9,250	0.2	86.6
 Czech Republic	10,553,843	2.07%	78,866	1.8	132.8
 Denmark	5,707,251	1.12%	43,094	1.0	128.1
 Estonia	1,315,944	0.26%	45,226	1.0	29.6
 Finland	5,487,308	1.08%	337,030	7.6	15.8
 France	66,759,950	13.08%	643,548	14.6	99.6
 Germany	82,175,684	16.10%	357,021	8.1	229.9
 Greece	10,783,748	2.11%	131,957	3.0	85.4
 Hungary	9,830,485	1.93%	93,030	2.1	107.8
 Ireland	4,724,720	0.93%	70,280	1.6	64.3
 Italy	60,665,551	11.88%	301,320	6.8	200.4
 Latvia	1,968,957	0.39%	64,589	1.5	35.0
 Lithuania	2,888,558	0.57%	65,200	1.5	51.4
 Luxembourg	576,249	0.11%	2,586	0.1	190.1
 Malta	434,403	0.09%	316	0.0	1,305.7
 Netherlands	16,979,120	3.32%	41,526	0.9	396.9
 Poland	37,967,209	7.44%	312,685	7.1	121.9
 Portugal	10,341,330	2.02%	92,931	2.1	114.4
 Romania	19,760,314	3.87%	238,391	5.4	90.2
 Slovakia	5,426,252	1.06%	48,845	1.1	110.8
 Slovenia	2,064,188	0.40%	20,253	0.5	101.4
 Spain	46,445,828	9.10%	504,782	11.4	93.4
 Sweden	9,851,017	1.93%	449,964	10.2	20.6
 United Kingdom	65,382,556	12.81%	244,820	5.5	251.7

⁴³ https://en.wikipedia.org/wiki/Demographics_of_the_European_Union

As previously stated, the issue of intellectual disability is not an isolated case. It is because of this that certain groups and organisations have formed partly in order to deal with such issues on an international or global scale.

European Disability Strategy.

Additionally, such organisations and entities work very hard in order to influence and execute the implementation and constant betterment of the European Disability Strategy 2010-2020. The European Disability Strategy 2010-2020 (EDS) constitutes a comprehensive multiannual framework for implementing the United Nations Convention on the Rights of Persons with Disabilities (CRPD) at EU level. The EDS and CRPD are thus closely intertwined. Whilst many stakeholders had called for a revision of the EDS, the recent European Commission progress report suggests instead to maintain the Strategy's objectives for the remaining period. However, given that the current Strategy ends in 2020, preparation of the future disability framework will need to start before much longer. The most recent briefing, prepared by the Ex-Post Evaluation Unit of the European Parliamentary Research Service (EPRS), aims to outline the scope and objectives of the EDS and to analyse its implementation. It has been drafted in support of the implementation report on the EDS, which is currently being drawn up by the Committee on Employment and Social Affairs (EMPL) in close consultation with disability organisations, in response to the Commission's progress report.⁴⁴

Disability strategies within Europe was not something that was set in stone from time immemorial. Although the predecessor of the European Union, the European Economic Community (EEC) was formed in 1957, it was not until 25 years later, shortly after the end of the International Year of Disabled People in 1981, that the then EEC introduced the first action programme on the integration of disabled people. Prior to this, one or two NGOs had benefited from small amounts of funding from other actions such as the Youth Programme, but generally disability per se had been ignored.

The first action programme on the integration of disabled people provided an opportunity for NGOs - primarily those which already had an international dimension, for example the World Blind Union and the World Federation of the Deaf - to meet and form European Community networks. Small amounts of funding, usually between 5,000 - 10,000 ECUs, were made available to them to implement such a network. At the same time the European Commission held meetings of these NGOs with the aim of developing the framework and focus for the second action programme.

The impetus for cooperative NGO activity came from the European Commission, and not from the NGOs themselves. Also, the bases for development tended to be the medical model of disability underpinned by a social welfare approach. However, the Head of Division at the time, Pat Daunt, was a great believer in the right of disabled people to represent themselves, and he did all he could to support directly representative organisations of disabled people.

⁴⁴ [http://www.europarl.europa.eu/thinktank/en/document.html?reference=EPRS_BRI\(2017\)603252](http://www.europarl.europa.eu/thinktank/en/document.html?reference=EPRS_BRI(2017)603252)

As one can imagine during this gestation period the small group of European NGOs in existence at that time concentrated their efforts on establishing themselves as viable organisations and on agreeing internal policies concerned with a particular impairment. For example, in 1987 ECRS, the newly formed European Deaf organisation,⁴⁵ held a major conference in Athens on the education of deaf children and published its Education Charter. Overall the NGOs did not operate as one unit and therefore did not address major cross-disability issues, either at a policy or at parliamentary level. Meanwhile, the European Commission had set up local model activities in cooperation with Member States, but only a very few disabled people or their NGOs were involved, and once again the focus was very much on the traditional medical model, individual rehabilitation and social welfare approach.

In 1988, the second 4-year action programme started - this was the HELIOS 1 programme. The objectives of HELIOS 1 had been drawn up by the European Commission with minimal consultation with European NGOs. However, this second action programme did for the first time establish a Liaison Committee, where twelve European NGOs selected by the Commission sat alongside government representatives from the Member States and Commission officials, and they were able to give their opinion on the various elements of the programme.

It was also during this period that the European NGOs began to become a cohesive force. They formed 'NGOs in Consultation', an ad hoc group of European NGOs which met outside the Liaison Committee to determine a common position on a whole range of issues, most of which were items on the Liaison Committee's agenda. Such an innovative approach for that time ensured that the NGOs' voice be properly heard and their opinions taken note of by the Commission. It also gave the European NGOs a forum in which they could express their solidarity and act as a single body.

At the beginning of HELIOS 1, the budget for NGO activity had been decided at 900,000 ECUs for the first year. It was a considerable increase on the budget of the first action programme, but considered as woefully inadequate by the European NGOs whose number was growing each year, and whose aspirations had been fired by the opportunities presented within the European Community. So much so that the European NGOs conducted their first joint campaign and persuaded the Parliament, which is the budgetary authority, to increase the overall budget of the HELIOS programme, but particularly the budget for NGO activity to 2 million ECUs in 1989, and then again to 3 million ECUs in 1990 and 1991.

In 1991 the Europrogramme of the NGOs comprised 150 different activities ranging from study visits to major conferences, covering a range of issues important to disabled people and their families. Furthermore, during the life of HELIOS 1, a few European NGOs moved individually into the political arena; for example in 1988, ECRS, the deaf organisation, worked with the Parliament to introduce a Parliamentary Resolution on the status of sign languages within the European Community. And in 1989, ECRS successfully challenged the Community's institutions concerning the driving licence directive, which in its draft form had discriminated against deaf drivers.

⁴⁵ <https://uia.org/s/or/en/1100018113>

By the time HELIOS 1 came to an end, a certain number of leading NGOs began to feel the constraints of being marginalised within a specifically designated disability programme, and without the opportunity of influencing mainstream policies which affected everyday living. A feeling of frustration developed too as the Commission continued to operate its own agenda without the true and full involvement of disabled people. It was also a period when the Disability Movement really began to get its message across concerning the need to move away from the medical model and towards adopting the social model of disability. National umbrella disability organisations, where they existed in the Member States, had seen their European counterparts grow in strength and influence, and they too wished to play a part within the European Community.

It was against this backdrop that proposals for the HELIOS 2 programme were put forward by the Commission for consultation. Unfortunately, debates concerning the new initiative were conducted in a climate of conflict - between the Commission, Parliament and the Council, with the NGOs, working with the Parliament, attempting to bring in changes which would give disability organisations a greater say and influence.

Eventually, in 1993 - one year after it should have been introduced - the Council's Decision was published and HELIOS 2 started up. Although Parliament had managed to ensure the establishment of a European Disability Forum within the programme, which for the first time involved national councils of disabled people, the philosophical base of the programme still did not recognise disability as a human rights issue or the social model of disability. Furthermore the Commission continued to ignore the NGOs' pleas for a greater involvement of disabled people within the programme as a whole, particularly within the information and exchange activities, and in relation to the development of information services by the NGOs.

However, in 1993, there came a turning point, and it was as if overnight there was a recognition by most of the players within HELIOS 2 that disability was a human rights issue, that the social model should be adopted, and that future discussions should be based on the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.

The catalyst for this change was a DPI initiative, the European Day of Disabled Persons. In this case, perhaps the greatest influence was the first European Disabled People's Parliament held on 3 December. Inside the European Parliament's own debating chamber nearly 500 disabled people from throughout the Union, representatives of the Commission and parliamentarians gathered to hear disabled people present their own experiences of discrimination. This had a profound impact, and the resolution adopted by the Disabled People's Parliament has since been acted on by both the Commission in its White Paper on Social Policy, and its medium term social action programme, and by the Parliament in various resolutions and actions. The resolution included requests to the European Commission to outline its plans to initiate Community legislation for the adoption and implementation of the UN Standard Rules; to the Community institutions and the Member States to support studies on human rights of disabled people; and to the Community institutions and Member States to ensure that at the time of revision of the Treaty on European Union ('Maastricht') a general anti-discrimination provision is included.

At the same time that this was happening, the European Disability Forum had elected a disabled person as its Chair, and as a group it was growing in confidence and solidarity. So much so that it decided, with the support of the Commission, to establish an Independent Disability Forum which would have a broader brief than the HELIOS Disability Forum. The aim was that the Independent Disability Forum would be able to be both re-active and pro-active on a whole range of issues, and not be confined to only commenting on matters within the remit of the HELIOS programme.

Parliament too welcomed the opportunity to have a dialogue with a truly representative body of disability organisations. NGOs themselves started to be keen to ensure that disability is no longer marginalised and restricted to just one or two special programmes, and they considered the Independent Forum as the only way in which disabled people themselves can ensure that their particular needs are taken into account throughout mainstream Union policy and legislation, while at the same time recognising it will be an uphill struggle and that both individuals and institutions will not change their behaviour overnight.⁴⁶

As the EU population is getting older, the number of Europeans with disabilities is rising significantly. It is expected that, by 2020, approximately 120 million Europeans will have a disability. The share of women with disabilities in the overall population is higher than the share of men (29.5% vs 24.5%)⁴⁷.

The Commission has developed disability-related, EU-level indicators linked to the Europe 2020 targets for employment, education and poverty reduction to closely monitor the situation of people with disabilities in the Member States and at EU level.⁴⁸ The indicators show a clear gap with the rest of the population.⁴⁹ Persons with disabilities have the right to work on an equal basis with others, and the Employment Equality Directive prohibits discrimination in employment. However, access to the labour market remains one of the main challenges for people with disabilities today. The economic crisis has made it difficult to improve the employment situation of persons with disabilities. At only 48.7%, the employment rate of people with disabilities remains much lower than the one of people without disabilities (72.5%).⁵⁰

Access to an inclusive, quality education remains elusive for many people with disabilities. Indeed, close to 22.5% of young people with disabilities are early leavers from education and training, compared to 11% for pupils without disabilities. Moreover, about 29.5% of persons with disabilities (age group 30-34) have completed tertiary education or equivalent, compared to 42.5% for persons without disabilities.

⁴⁶ Presentation by Arthur Verney, Development Worker, Disabled Peoples' International - European Union Committee in Stockholm, 10 June 1996.

⁴⁷ EU SILC 2014.

⁴⁸ Annual indicators are produced on the basis of the EU-SILC data by the Academic Network of European Disability experts (ANED). Employment and education indicators are based on a proxy as the official data source does not disaggregate the data by persons with disabilities.

⁴⁹ The data on the indicators is taken from EU-SILC 2014. EU-SILC is based on own responses to questions on "activity limitation" due to health problems for at least the last 6 months, and is used as a proxy for disability. EU-SILC covers all individuals aged 16 and more and living in private households. It does not cover children or people living in residential institutions

⁵⁰ https://www.ifglobal.org/images/SWDProgressReportEDS_EN.pdf. Pg. 4

Finally, 30% of people with a disability are at risk of poverty or social exclusion in the EU, compared to 21.5% of people without disabilities. The degree of disability - severe vs moderate - does increase significantly the risk of poverty or social exclusion. However, this risk significantly decreases for people aged 65 and over in almost all EU Member States mainly due to the social protection provided by pensions after retirement.

All these elements clearly confirm the relevance of the main objectives of the European Disability Strategy 2010-2020.

As mentioned above, the employment rate of people with disabilities remains very low at 48.7%.⁵¹ The public consultation conducted in support of this report reveals that the lack of equal opportunities in the labour market is the most frequently mentioned problem for the respondents. The Strategy aims at enabling more people with disabilities to earn their living on the open labour market. The employment situation of women and men with disabilities needs to be improved through quality jobs in open, inclusive and accessible work environments.

Progress in these spheres since 2010 include the following:

- Adoption of a revised Commission Regulation declaring certain categories of aid compatible with the internal market and providing for exemption of aid schemes for the recruitment of disadvantaged workers⁵² (2014);
- Launch of a comprehensive package of policy initiatives on education and employment: Youth on the Move - as part of the Europe 2020 Strategy, complemented by the Youth Guarantee to support employment of all young people, including those with a disability, and ensure that they do not stay out of a job, apprenticeship, traineeship or education for more than four months (2010 & 2013);
- Mainstreaming of disability issues in the European Semester process and policy publications;
- Support for work-life balance for people with disabled relatives, including publication of thematic reports by the European Social Policy Expert Network and organisation of an in-depth thematic review by the Social Protection Committee (2016);
- Launch of the Social Business Initiative, the European roadmap for the development of social enterprises⁵³ (2012);
- Ongoing support to implementation of national Diversity Charters⁵⁴ in 12 countries;
- Ongoing work of the High Level Group on Disability, including regular publication of reports with analysis on employment⁵⁵;

⁵¹ Source: ANED estimations based on EU-SILC 2014.

⁵² Commission Regulation (EU) No 651/2014 of 17 June 2014:
http://ec.europa.eu/competition/state_aid/legislation/block.html

⁵³ http://ec.europa.eu/growth/sectors/social-economy/enterprises/index_en.htm

⁵⁴ http://ec.europa.eu/justice/discrimination/diversity/charters/index_en.htm

⁵⁵ <http://ec.europa.eu/social/main.jsp?catId=1137&langId=en>

- Study on Supported Employment for People with Disabilities in the EU and EFTA/EEA, with good practices and recommendations⁵⁶ (2011);
- European Parliament report on Reasonable Accommodation and Sheltered Workshops for People with Disabilities⁵⁷ (2015);
- In-depth Employment Analysis conducted by social partners⁵⁸ (2015);
- Study on Public Employment Services (PES) for sustainable activation of people with disabilities⁵⁹ (2013);
- Use of the European Social Fund to enhance labour market participation - around 6.1 million participations were reported, of which 16% were identified as persons with disabilities between 2007 and 2013;
- Introduction of a condition to use at least 20% of the allocation of the European Social Fund for social inclusion actions, including for people with disabilities (2014);
- Various education projects to promote career advancement of people with disabilities, through the Erasmus programme;
- Funding of actions supporting the implementation of the reasonable accommodation obligations.

The Strategy promotes inclusive education and lifelong learning for pupils and students with disabilities. EU actions support national efforts to facilitate access of people with disabilities to quality general education systems, with effective individualised support measures.

To date since 2010, the following initiatives were noted as progress on this subject matter:

- Launch of Youth on the Move⁶⁰ to improve young people's education and employability for all including people with disabilities⁶¹ (2010 onward);
- Joint Report of the Council and the Commission on the implementation of the Education and Training 2020 (ET2020) Strategic Framework, with priority given to enhanced access to quality and inclusive mainstream education and training for all learners (2015);
- Ongoing collaboration – and financial support - with the European Agency for Special Needs and Inclusive Education (EASNIE)⁶² to collect data on the participation of learners with special needs in education around the EU;
- Collection of data and analysis on the education-related EU2020 targets and the gaps between pupils with and without disabilities at EU level, by the Academic Network of European Disability experts⁶³;
- Annual publication of the Education and Training Monitor⁶⁴ with comparisons of early school leaving and tertiary education attainment rates by disability status;

⁵⁶ http://ec.europa.eu/justice/discrimination/files/cowi.final_study_report_may_2011_final_en.pdf

⁵⁷ http://www.europarl.europa.eu/RegData/etudes/STUD/2015/536295/IPOL_STU%282015%2953629 58 https://www.busseurope.eu/sites/buseur/files/media/reports_and_studies/

⁵⁹ <http://webcache.googleusercontent.com/search?q=cache:3ryNY0viCXcJ:ec.europa.eu/social/BlobServlet%3Fdoctid%3D10932%26langId%3Den+&cd=1&hl=en&ct=clnk&gl=be>

⁶⁰ http://ec.europa.eu/youthonthemove/index_en.htm

⁶¹ According to the last available data, in 2014 there were more than 100 000 participants in Youth Exchanges out of which 3 800 declared special needs, and 9100 volunteers including 300 with special needs.

⁶² The support is in the form of an annual grant of approx. 1 M€ under the Erasmus+ programme.

⁶³ <http://www.disability-europe.net/theme/education-training>

⁶⁴ http://ec.europa.eu/education/tools/et-monitor_en.htm

- Definition of a whole school approach to tackle early school leaving by the ET2020 Working Group on Schools Policy (2014-2015), with an on-line European Toolkit for Schools gathering best practices to improve educational achievement for all;
- Mainstreaming of disability issues in Erasmus+, including specific funding available for the participation of students and staff with disabilities in mobility actions⁶⁵ and inclusion of accessibility and reasonable accommodation criteria in all relevant calls for proposals;
- Funding of projects to improve the digital skills of persons with disabilities;
- Inclusion and Diversity Strategy⁶⁶ applied to the Youth strand of Erasmus+ to ensure that young people with fewer opportunities have equal access to the programme, including young people with disabilities (2014 onward).

To monitor the situation of people with disabilities and address the barriers they are facing, data collection is an essential – albeit challenging – factor. The implementation of the Strategy has yielded progress in both the collection of periodic disability-related statistics and in the development of indicators to monitor the evolution of the situation.

To implement the Strategy, the annual EU Statistics on Income and Living Conditions (EU-SILC) is being used, as it collects data on long-standing activity limitation due to health problems, as an appropriate proxy for disability. In addition, Eurostat annually publishes tables corresponding to the main SILC indicators (risk of poverty or social exclusion, material deprivation) using the Global Activity Limitation Indicator (GALI) as a proxy to monitor the situation of disabled people. EU-SILC data is also used by ANED to produce estimations of the Europe 2020 indicators on employment and education in relation to disabled persons.

Moreover, other specific modules and surveys have been undertaken to collect disability related data, including:

A 2011 Labour Force Survey ad hoc module, looking at the situation of disabled people on the labour market compared to people without disabilities;

The European Health Interview Survey, which collects data every 5 years on the level of functioning and activity limitations in the population, health status, health determinants and healthcare use;

The 2012/2013 European Health and Social Integration Survey, the most comprehensive EU source of data on the barriers to participation for people having a health problem or a basic activity difficulty, covering a wide range of socio-economic, health and participation aspects.

While these surveys provide important information, they do not yet collect data concerning people living in institutions (particularly old disabled people and children) or children in

⁶⁵ More than 800 students and staff with special needs have participated so far in activities funded by Erasmus+.

⁶⁶ http://ec.europa.eu/youth/news/2015/0130-youth-inclusion-diversity-strategy_en.htm

households (SILC starts from age 16). To further harmonise data collection on disability in all its components, the Commission has been working to introduce the Global Activity Limitation Indicator (GALI) as a 'core' social variable in all relevant surveys.

Negotiations between Eurostat and the EU Member States are ongoing to insert this disability variable into the Labour Force Survey once every two years, thus creating a reliable monitoring tool on the employment of people with disabilities. The 2017 SILC module on children will also include a disability perspective (GALI variable adapted for children), thus bridging the knowledge gap regarding children with disabilities in households.

The Commission has also been working closely with the Academic Network of European Disability Experts (ANED)⁶⁷ to analyse data on the situation of persons with disabilities in the Member States. ANED produces annual reports with data and indicators on specific topics such as transition to employment, political participation or social protection. Moreover, ANED monitors disability in the Europe 2020 targets and produces country reports within the European Semester process. Finally, ANED runs the Disability Online Tool of the Commission (DOTCOM) to monitor the state of the key political and legal instruments needed for the implementation of the UNCRPD.

In addition, since the adoption of the strategy in 2010, it has been confirmed that a long term perspective is needed for the alignment of EU policies, laws and programmes to the UNCRPD. These efforts must be maintained to ensure the completion of the Strategy within the time horizon set for 2020. In view of the work still to be achieved, the Concluding Observations from the UN Committee on the Rights of Persons with Disabilities provide indispensable guidance. All this work also feeds the reflection to shape future EU disability policies, in cooperation with people with disabilities, their representative organisations and all relevant stakeholders.

The World Health Organisation.

Of course, the most familiar organization responsible for aiding the endeavour of entreating people with a disability or illness is the World Health Organisation⁶⁸. One cannot research such a subject related to this project issue without commenting on the work of WHO. WHO was founded when its Constitution came into force on 7 April 1948 – a date that is now celebrated every year as World Health Day. WHO are now more than 7000 people strong, working in 150 country offices, in 6 regional offices and with their headquarters in Geneva.

It is very active within Europe, as well as in the regions of Africa, the Americas and Asia. Naturally, it is officially responsible for public health within the United Nations. For this report, the WHO Regional Office for Europe (WHO/Europe) is the most relevant.

Comprised of 53 countries, it spans across the Atlantic to the Pacific, ensuring that particular topics and grievances are acted upon and dealt with. This group is often referred to when seeking general definitions as well as a general law or directive with which a person or group

⁶⁷ <http://www.disability-europe.net/>

⁶⁸ <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/country-work>

ought to comply with regards to health. Additionally, government legislation throughout the continents, including Europe, is normally geared in ensuring harmony and synergy with the findings and guidelines of WHO initiatives in the fields in question. All European Union governments in fact appoint their representatives to act as liaison officers and interlocutors between the state and WHO. This is due to the fact that all countries which are Members of the United Nations may become members of WHO by accepting its Constitution. Other countries may be admitted as members when their application has been approved by a simple majority vote of the World Health Assembly. Territories which are not responsible for the conduct of their international relations may be admitted as Associate Members upon application made on their behalf by the Member or other authority responsible for their international relations. Members of WHO are grouped according to regional distribution (194 Member States).⁶⁹

It is according to their research that “*Mental ill health accounts for almost 20% of the burden of disease*” in their organisation alone.⁷⁰

As a general example, Europe contains six out of the 20 countries with the highest rates of suicide, often caused by mental illness. Other conditions such as intellectual disabilities are also dealt with.⁷¹

According to the WHO, around 10 per cent of the world's children and young people, some 200 million, have sensory, intellectual or mental health impairment. Estimates suggest that there are between 180 and 220 million youth with disabilities worldwide and nearly 80% of them live in developing countries. The number of youth with disabilities is likely to increase due to youthful age-structures in most developing countries and medical advancements which promote higher survival rates and life expectancy after impairment-causing diseases, health conditions, and injuries.

There is a significant dearth of research on the prevalence and consequences of disabilities among youth. The data that does exist shows that young people with disabilities face many more challenges than their non-disabled peers. They often face prejudice and/or negative attitudes which hinder their participation, self-determination and inclusion in the society.⁷²

In the EU, presumably, people with disabilities are the largest social minority – about 80 million Europeans have a disability.⁷³ There are no reliable statistics on the number of youth with disabilities in Europe, partly because youth with disabilities as a group are not quite visible on the policy and research agenda, and partly for the reason that overall disability statistics varies accordingly to the different understanding of a disability across the states.

⁶⁹ <http://www.who.int/countries/en/>

⁷⁰ <http://www.who.int/mediacentre/factsheets/fs396/en/>

⁷¹ <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/country-work>

⁷² <https://pjp-eu.coe.int/en/web/youth-partnership/youth-and-disabilities>

⁷³ Facts and figures about disability in the EU.

The WHO response to such an international situation is effectively projected by means of WHO's Mental Health Action Plan 2013-2020, endorsed by the World Health Assembly in 2013, which recognizes the essential role of mental health in achieving health for all people.

The plan includes 4 major objectives:

- more effective leadership and governance for mental health;
- the provision of comprehensive, integrated mental health and social care services in community-based settings;
- the implementation of strategies for promotion and prevention; and
- strengthened information systems, evidence and research.

WHO's Mental Health Gap Action Programme (mhGAP), launched in 2008, uses evidence-based technical guidance, tools and training packages to expand service in countries, especially in resource-poor settings. It focuses on a prioritized set of conditions, directing capacity building towards non-specialized health-care providers in an integrated approach that promotes mental health at all levels of care.⁷⁴

The UN Disability Convention and its Impact on European Equality Law.

On the 23 December 2010, the European Union (EU) ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). It was the first time in its history that the EU had become a party to an international human rights treaty.⁷⁵ The CRPD was ratified just weeks after the European Commission published the European Disability Strategy 2010-2020 which set out a detailed programme of action to empower people with disabilities so that they can enjoy their rights, and benefit fully from participating in society and in the European economy.⁷⁶

Ratification means that the EU is now bound to ensure that the rights of persons with disabilities are respected, protected and fulfilled. It also mirrored the obligations of the 16 member states of the European Union that have ratified the CRPD and the remaining 11 that have signed it. Since 2000, the EU has taken on an important role in setting down minimum standards with respect to disability discrimination law within member states. Alongside this, the European Court of Human Rights (ECtHR) has very recently handed down decisions which have broadened the scope of protection for persons with disabilities within the Council of Europe's borders. Yet, there are many issues relating to disability discrimination which are underdeveloped in comparison to other grounds of discrimination.

⁷⁴ <http://www.who.int/mediacentre/factsheets/fs396/en/>

⁷⁵ European Commission, EU ratifies UN Convention on disability rights, Press Release, Brussels, 5 January 2010.

⁷⁶ European Commission, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, SEC(2010) 1324 final, Brussels, 15 November 2010

The wide range of impairments that fall within the term “disability” make the definition far broader than that applying to any other vulnerable group. Persons with disabilities include persons with physical, mental,⁷⁷ intellectual⁷⁸ and sensory impairments. It is noteworthy that protection from discrimination on grounds of disability is also often extended to persons living with medical conditions such as HIV/AIDS or diabetes on the basis of the discrimination which such persons are likely to experience following their diagnosis.⁷⁹

While many disabled people may experience similar discriminatory treatment, the causes of disadvantage differ and depend on their individual impairment. For example, issues affecting the equality outcomes for a person who has schizophrenia may differ entirely to the issues that affect the equality outcomes for persons living with HIV/AIDS or those who have lost a limb or a sensory function. In light of this, the human rights definition of persons with disabilities contained in Article 1 of the CRPD offers a holistic approach to defining disability. Article 1 provides that: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Disability discrimination is a historical legacy which is ingrained in the fabric of all societies.⁸⁰ In Europe, this legacy is reflected in the continued acceptance of many practices that acutely discriminate against persons with disabilities. Persons with disabilities are often assumed to be incapable of undertaking productive work, attending schools on a level playing field with children without disabilities, or make active contributions to their communities, and often discussions on developing equalising measures for persons with disabilities are underpinned by such assumptions.

According to the International Labour Organisation, in Europe, a person with a disability aged between 16 and 64 has a 66% chance of finding a job; this rate falls to 47% for a moderately disabled person and 25% for a person with a severe disability.⁸¹ Furthermore, inequality is not restricted to sectors such as employment. The European Union Fundamental Rights Agency has recently concluded that in 17 out of 27 EU member states, persons with mental health problems and persons with intellectual disabilities are excluded from political participation or are only permitted limited political participation.⁸²

⁷⁷ For example, schizophrenia or bipolar disorder.

⁷⁸ For example, learning limitations caused by Down’s syndrome.

⁷⁹ In Britain, HIV infection constitutes a disability under Schedule 1, Part 1, Para 6 of the Equality Act 2010. Further, the European Court of Human Rights has held that discrimination against a person living with diabetes constituted discrimination on the ground of disability in the case of *Glor vs Switzerland*, Application No. 13444/04, 30 April 2009.

⁸⁰ Colin Barnes, for example, argues that institutional discrimination is embedded in the excessive paternalism of contemporary welfare systems which systematically ignore or inadequately meet the needs of disabled people. See Barnes, C., *Institutional Discrimination Against Disabled People: A Case for Legislation*, British Council of Organisations of Disabled People, London, 1991.

⁸¹ International Labour Organisation, Factsheet: Discrimination at Work in Europe.

⁸² European Union Agency for Fundamental Rights, *The Right to Political Participation of Persons with Mental Health Problems and Persons with Intellectual Disabilities*, October 2010

Symptoms of disability discrimination such as stigma, stereotyping and prejudice are still common and corrosive influences which marginalise persons with disabilities. These symptoms stifle clear and constructive thought about how processes and procedures could be made more accessible and inclusive for disabled people. For example, in many European countries disabled persons are marginalised from political and legal decision-making processes because of the historical perception that they do not have the capacity to be involved and actively participate.⁸³

Of deeper concern is the stigma and prejudice which is frequently formalised in policy, resulting in egregious human rights violations against persons with disabilities in some countries. In the recent past, the European Committee on Social Rights has condemned the practice of segregating children with intellectual disabilities in educational institutions in France⁸⁴ and Bulgaria.⁸⁵ There has also been widespread media attention in the United Kingdom in respect to violent attacks on persons with learning disabilities. In one widely reported case, a 64 year old man suffering from mental and learning difficulties died of a heart attack after being harassed and verbally abused by two youths in Manchester.⁸⁶ This case is not an isolated event. Instead, it represents a trend which demonstrates that intolerance toward disabled persons is growing and becoming more visible.

One reason for this trend may be that violence against persons with disabilities is ignored, underestimated or misunderstood. The latest hate crimes report by the Organisation for Security and Cooperation in Europe (OSCE), which states that only nine European countries reported to the OSCE that they recorded any data on crimes against persons with disabilities, suggests that underreporting is a significant barrier too.⁸⁷ Consequently, the contention that ignorance or misunderstanding of the issue is a dominant factor which causes widespread discrimination must be matched with the fact that there is also a lack of effective monitoring and reporting of attacks.

⁸³ For example, Belgium, Czech Republic, Germany, Ireland, Poland and Portugal exclude persons with mental health problems and numerous persons with disabilities from the right to political participation.

⁸⁴ See European Committee on Social Rights, *International Association Autism Europe v France*, Complaint No. 13/2002, 4 November 2003.

⁸⁵ European Committee on Social Rights, *Mental Disability Advocacy Centre (MDAC) v Bulgaria*, Complaint No. 41/2007, 3 June 2008. In this case the European Committee on Social Rights handed down the opinion that a failure to take appropriate measures to take account of existing differences may amount to discrimination. Consequently, the Committee found a violation of Article 17 (2) of the Revised European Social Charter read in conjunction with Article E because of the discrimination against children with moderate, severe or profound intellectual disabilities residing in homes for mentally disabled children as a result of the low number of such children receiving any type of education when compared to other children.

⁸⁶ See Shakespeare, T., "The Cruel Toll of Disability Hate Crime", *Comment is Free*, Guardian Newspaper (Online Edition), 12 March 2010.

⁸⁷ The nine countries are Belgium, Cyprus, Finland, France, Georgia, Germany, Moldova, the Netherlands, and the United Kingdom. See Organisation for Security and Cooperation in Europe, *Hate Crimes in the OSCE Region - Incidents and Responses: Annual Report for 2009*, Office for Democratic Institutions and Human Rights, October 2010.

Moreover, in its short lifetime, the CRPD has already added an extremely important new dimension to the fight against discrimination on grounds of disability in Europe. It has consolidated legal concepts such as reasonable accommodation, guided the jurisprudence of the ECtHR and energised European countries to develop new safeguards and measures to entrench disability rights and promote effective equality for persons with disabilities. Whether the European Court of Justice will follow the example of the ECtHR and take into consideration the CRPD when handing down decisions on disability-related issues is yet to be tested. However, in light of the increased protection from discrimination and the promotion of equality on the ground of disability required by the Charter of Fundamental Rights of the European Union, one would expect that the CRPD would be a natural source of guidance.

The CRPD has been described as “a paradigm shift” in relation to how human rights are to be understood in the 21st century.⁸⁸ This would be a significant burden to bear for any piece of international law, let alone a law which protects the rights of individuals who have for so long been overlooked in society. Yet in the short period since its entry into force, the impact of the CRPD offers much promise.

In Europe, it has been accepted almost universally that there is a need for strong human rights protection for persons with disabilities. The CRPD has already begun to shape EU policy and ECtHR jurisprudence and in many areas it is proving to be a key instrument for promoting law reform and requiring states to re-examine how persons with disabilities are perceived. Often it has asked fundamental questions of the paternalistic welfare policy adopted by most European countries towards disabled persons.

Nonetheless, in Europe, paternalistic rhetoric still underpins disability law, policy and practice. Consequently, these strategic developments will only lead to effective equality for persons with disabilities in key areas such as education, employment, healthcare, criminal justice and political participation once the initial enthusiasm and goodwill shown to the CRPD is transformed through the difficult task of putting in place practical solutions for the challenges encountered by persons with disabilities. Undoubtedly, a global convention on disability was needed due to the large gaps that existed in national, regional and international human rights and non-discrimination protection. The CRPD has visibly started to influence the European Union and the Council of Europe mechanisms and institutions. But such mechanisms should also have an impact on law and policy development at local levels. At these local levels it is clear that discrimination and intolerance against persons with disabilities is still pervasive throughout Europe. ‘Whether the CRPD will be able to fulfil its promise will depend on how national authorities grapple with complex issues such as legal capacity during implementation. In any case, the energy and vision that the CRPD has imparted on the struggle for equality for persons with disabilities should not be underestimated.’⁸⁹

⁸⁸ United Nations, Convention on the Rights of Persons with Disabilities: Advocacy Toolkit, 1 July 2008

⁸⁹ Jarlath Clifford, consultant for The Equal Rights Trust; points based on a presentation given at a conference on “Legal Problems of the Prohibition and Prevention of Xenophobia and Other Forms of Intolerance” held at the University of Vilnius, Lithuania, on 19 November 2010.

Networks and Organisations covering the European Union

Despite the World Health Organisation (already mentioned above) being effective as it is worldwide, its uniqueness sometimes verges on its solitary position due to there being hardly any other similarly specialised groups on such a large, trans-national scale.⁹⁰ That said, there are a number of institutions, comprising various networks, platforms and organisations, which may be referred to since they directly influence and lobby within the EU structures as well as published works in favour of improving the situation⁹¹.

In 2008, a document was issued regarding “*Policies and practices for mental health in Europe*”⁹². This acknowledges that most countries have indeed recognized the issue that intellectual disability presents. It regards the issue of mental health legislations which, by now, should be present in all EU countries. In spite of this, the matter regarding capacity or guardianship goes beyond this issue. Regardless, these are imperative for protecting the human rights of people with such intellectual disabilities.

As a brief example, it may be noted that the rate of suicides was found to be estimated at 15.1 per 100,000. Moreover, neuropsychiatric disorders appear to rank as the first-ranked cause of years lived with disability (YLD) in Europe. Other significant causes include unipolar disorder, schizophrenia and Alzheimer’s disease.

We will now take a look at the main players which directly and/or indirectly affect the implementation of inclusion and independent living policies and services within the European Union. Some deal on a European level, whilst others operate on a trans-national level. Most are independent NGOs registered as charity organisations or limited liability companies. Some are autonomous units within the machinations of the European Union institutions or a work of synergy and joint ventures between EU institutions and independent NGOs. Some are based on accumulating research whilst some are dedicated to operate as service providers. Some include direct governmental involvement whilst others are solely composed of civil society institutions.

European institutions have also found the logistical and administrative necessity in amalgamating distinct European civil society organisations in order to present a common front in specific issues, including social issues. Thus, the subject of inclusion and independent living also falls under the remit of specific umbrella platform synergies such as Equinet. Equinet, the European Network of Equality Bodies, brings together 46 organizations from 34 European countries, which are empowered to counteract discrimination as national equality bodies across a range of grounds including age, disability, gender, race or ethnic origin, religion or belief, and sexual orientation.⁹³

⁹⁰ http://news.bbc.co.uk/2/hi/special_report/1998/health/47191.stm

⁹¹ <http://www.mentalhealthpromotion.net/?i=portal.en.links>

⁹² http://www.euro.who.int/__data/assets/pdf_file/0006/96450/E91732.pdf ⁹³ <http://www.equineteurope.org/-About-us->

Other EU Networks and Platforms include:

*Social platform*⁹⁴

The Platform of European Social NGOs (Social Platform) is the alliance of representative European federations and networks of non-governmental organisations active in the social sector.

*AGE-Platform Europe*⁹⁵

AGE, the European older people's platform, represents and promotes the interests of older people in the European Union and raises awareness of the issues that concern them the most.

*European Anti Poverty Network (EAPN)*⁹⁶

The EAPN is an independent network of non-governmental organisations (NGOs) and groups involved in the fight against poverty and social exclusion in the Member States of the European Union.

*European Network Against Racism - ENAR*⁹⁷

ENAR is a network of European NGOs working to combat racism in all EU member states. ENAR aims to fight racism, xenophobia, anti-Semitism and Islamophobia, to promote equality of treatment between EU citizens and third country nationals, and to link local/regional/national initiatives with European initiatives.

*European Roma Information Office - ERIO*⁹⁸

ERIO is an international advocacy organisation which promotes political and public discussion on Roma issues by providing factual and in-dept information on a range of policy issues to the European Union institutions, Roma civil organisations, governmental authorities and intergovernmental bodies.

*European Women's Lobby- EWL*⁹⁹

The European Women's Lobby is the largest umbrella organisation of women's associations in the European Union. The EWL Secretariat is based in Brussels, but the EWL has member organisations in 25 Member States of the EU. The European Women's Lobby aims to promote women's rights and equality between women and men in the European Union

*European Youth Forum - YJF*¹⁰⁰

The European Youth Forum works to empower young people to participate actively in the shaping of Europe and the societies in which they live, and in improving the living conditions of young people as European citizens in today's world. The European Youth Forum defends the interests of all young people in Europe.

⁹⁴ <http://www.socialplatform.org/> ⁹⁵ <http://www.age-platform.eu/>

⁹⁶ <https://www.eapn.eu/>

⁹⁷ <http://www.enar-eu.org/>

⁹⁸ <http://www.erionet.eu/>

⁹⁹ <https://www.womenlobby.org/>

¹⁰⁰ <http://www.youthforum.org/>

*ILGA-Europe*¹⁰¹

The European Region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA-Europe) is a non-governmental umbrella organisation that represents its members, principally organisations of lesbian, gay, bisexual and transgender persons, at the European level.

*European Trade Union Confederation - ETUC*¹⁰²

The ETUC promotes the interests of working people at European level and to represent them in the EU institutions.

*Business Europe*¹⁰³

Former UNICE, Business Europe is the Confederation of European Business. Their members are the central national business federations of the 34 countries they represent.

*European Association of Craft, Small and Medium Size Enterprises - UEAPME*¹⁰⁴

UEAPME is the employer's organisation representing the interests of European crafts, trades and SMEs at EU level. This European SME umbrella organisation incorporates 85 member organisations consisting of national cross-sectorial SME federations, European branch federations and other associate members, which support the SME family.

Other European networks and think tanks include:

Black European Women's Council¹⁰⁵

Caritas Europa¹⁰⁶

CECOP European Confederation of Cooperatives and Worker-Owned Enterprises Active in Industry and Services¹⁰⁷

CEJI - A Jewish Contribution to an Inclusive Europe¹⁰⁸

COFACE - Confederation of family organisations in the European Union¹⁰⁹

Equality and Diversity Forum (UK NGO network)¹¹⁰

Eurochild - Promoting the Welfare and Rights of Children and Young People¹¹¹

Eurocities¹¹²

European Commission on Sexual Orientation Law¹¹³

Eurodiaconia¹¹⁴

European Federation for Street Children - EFSC¹¹⁵

¹⁰¹ <https://www.ilga-europe.org/>

¹⁰² <https://www.etuc.org/>

¹⁰³ <https://www.buinesseurop.eu/>

¹⁰⁴ <http://www.ueapme.com/>

¹⁰⁵ <http://blog.blackwomenineurope.com/tag/black-european-womens-council/>

¹⁰⁶ <http://www.caritas.eu/>

¹⁰⁷ <http://www.cecop.coop/>

¹⁰⁸ <http://www.ceji.org/>

¹⁰⁹ <http://www.coface-eu.org/about-2/what-is-coface-families-europe/>

¹¹⁰ <http://www.edf.org.uk/>

¹¹¹ <http://www.eurochild.org/>

¹¹² <http://www.eurocities.eu/>

¹¹³ <http://www.sexualorientationlaw.eu/>

¹¹⁴ <https://www.eurodiaconia.org/>

¹¹⁵ https://ec.europa.eu/anti-trafficking/eu-projects/european-federation-street-children_en

European Foundation Centre – EFC¹¹⁶
European Forum for Urban Security - EFUS¹¹⁷
European Microfinance Network - EMN¹¹⁸
European Migration Network - EMN¹¹⁹
European Network of Legal Experts in the Non-discrimination Field¹²⁰
FEANTSA - European Federation of national organisations working with the homeless¹²¹
ICARE - Internet Centre Anti-Racism Europe¹²²
IMISCOE International Migration, Integration and Social Cohesion¹²³
INTERIGHTS - The International Centre for the Legal Protection of Human Rights¹²⁴
ISCA - International Sport and Culture Association¹²⁵
Mental Health Europe - MHE¹²⁶
Migration Policy Group - MPG¹²⁷
PICUM - Platform for International Cooperation on Undocumented Migrants¹²⁸
Solidar - European Network of NGOs working together to advance social justice in Europe and World Wide¹²⁹
Transgender Europe - TGEU¹³⁰
WAVE - Women against Violence Europe (Feminist Network promoting Human Rights of Women and Children)¹³¹
Youth for Exchange and Understanding International.¹³²

All the above initiatives, although not specifically militating in the disability sector or dealing specifically with inclusion or independent living concepts, have, at one point or another, had to address the issue of inclusion needs and the importance of independent living for persons with disability.

Although the project in question has researched extensively in this field, the following European organisations – or international organisations which are particularly active in Europe - are by no means exhaustive and should not be considered to be the sole institutions operating in this sector. The project however notes that the enclosed list should incorporate the most active operators in this field which touch on a daily basis on the concepts of inclusion needs and the essential right of independent living for persons with disability:

¹¹⁶ <http://www.efc.be/>

¹¹⁷ <https://efus.eu/en/>

¹¹⁸ <https://www.european-microfinance.org/>

¹¹⁹ https://ec.europa.eu/home-affairs/what-we-do/networks/european_migration_network_en

¹²⁰ <https://www.humanconsultancy.com/projects/european-network-of-legal-experts-in-the-non-discrimination-field>

¹²¹ <http://www.feantsa.org/en>

¹²² <http://www.icare.to/abouticare.html>

¹²³ <https://www.imiscoe.org/>

¹²⁴ <http://www.forcedmigration.org/research-resources/organizations/international-centre-for-the-legal-protection-of>

¹²⁵ <http://www.isca-web.org/english/>

¹²⁶ <https://mhe-sme.org/>

¹²⁷ <http://www.migpolgroup.com/>

¹²⁸ <http://www.epim.info/picum-platform-for-international-cooperation-on-undocumented-migrants/>

¹²⁹ <http://www.solidar.org/>

¹³⁰ <https://tgeu.org/>

¹³¹ <https://www.wave-network.org/>

¹³² <http://www.equineturope.org/-EU-networks-and-platforms->

Global Alliance of Mental Illness Advocacy Networks-Europe.¹³³

GAMIAN-Europe was established in order to represent a coalition of patient organisations. This means an organization or concept in which the patient is truly the priority and is the central issue of healthcare debates within the EU.

This organisation strives to act as the voice for patients through advocacy, as well as inform the public about the truths regarding mental health and intellectual disability in order to remove stigma and negative discrimination which may be put on such patients. It is with this increase in awareness that such organizations hope that a greater priority may be given to those in need of special help. Moreover, this would also improve a patient's rights both as a person with disability as well as a human being. This means more cooperation with key groups such as academics and health professionals which allow the progression of these patients.

European Disability Forum.¹³⁴

The European Disability Forum is an independent NGO that defends the interests of 80 million Europeans with disabilities. They are a unique platform which brings together representative organisation of persons with disabilities from across Europe. They are run by persons with disabilities and their families.

EDF incorporates a strong, united voice of persons with disabilities in Europe and are considered to be one of the most important and influential lobby groups within the EU. EDF's objective is to achieve equal opportunities for all men, women and children with disabilities. It is deemed to be one of the most vociferous and leading European platform engaging with the European institutions on the issue of persons with disability.

EDF's mission is to ensure persons with disabilities' full inclusion in society and access to our human rights through our active involvement in policy development, implementation and monitoring of the CRPD in Europe, via EU structures.

EDF is committed to a strong and inclusive European Union, where the right to live, travel, work, study, vote or be elected is guaranteed to all citizens in the Union, and where women, men and children with disabilities enjoy these rights on an equal basis with others.¹³⁵

International Disability Alliance.¹³⁶

The International Disability Alliance (IDA) is an alliance of eight global and six regional organisations of persons with disabilities. It advocates at the UN for a more inclusive global environment for persons with disabilities and their organisations. The Convention on the Rights of Persons with Disabilities (CRPD) is IDA's touchstone. IDA is invested in ensuring that the 2030 Agenda and the Sustainable Development Goals are inclusive and in line with CRPD.

¹³³ <https://www.gamian.eu/>

¹³⁴ <http://www.edf-feph.org/>

¹³⁵ <http://www.edf-feph.org/our-values>

¹³⁶ <http://www.internationaldisabilityalliance.org/>

IDA supports organisations of persons with disabilities worldwide to take part in UN and international human rights processes, and use international accountability mechanisms.

With member organisations globally, IDA represents the estimated one billion people worldwide with disabilities. The European Disability Forum represents the European continent within the IDA.

The Disability Intergroup (European Parliament).¹³⁷

Closely linked with the EDF is the Disability Intergroup of the European Parliament. It is an informal grouping of Members of the European Parliament (MEPs) from all nationalities and most political groups who are interested in promoting the disability policy in their work at the European Parliament as well as at the national level.

The Disability Intergroup is one of the oldest Intergroups of the European Parliament: it was established in 1980. It is also one of the largest ones, with over 110 MEPs. The overall aim of the Disability Intergroup is to promote the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, in line with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The Intergroup has been a key ally in advocating for and advancing the rights of persons with disabilities in the Europe.

It also contributes to enabling participation of persons with disabilities in decisions that concern them. Disability Intergroup members organise debates with their colleagues and with other EU institutions, submit amendments, draft parliamentary questions and other parliamentary initiatives and participate as keynote speakers in European events on disability issues.

Throughout its years of existence, the Disability Intergroup has been instrumental in the adoption of legislation which is favourable to persons with disabilities in areas such as transport, employment, research, structural funds, accessibility and non-discrimination. The Disability Intergroup endeavours to hold a strong and fruitful dialogue with all persons with disabilities and their representative organisations. The European Disability Forum (EDF), as the umbrella organisation defending the interests of 80 million persons with disabilities in Europe, cooperates closely with the Disability Intergroup and act as its Secretariat.

European Network for Independent Living.¹³⁸

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination.

¹³⁷ <http://www.edf-feph.org/disability-intergroup-european-parliament>

¹³⁸ <http://enil.eu/>

ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for barrier-free environment, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible. ENIL's activities target European, national and local administrations, politicians, media, and the general society. ENIL works to strengthen the empowerment of disabled people mainly through providing resources for peer counselling and peer training. ENIL enhances the European disability network by providing the arena for the sharing of experience of services and in providing economical, logistics and technical expertise. This as well as by being a strong network of grassroots activists.

ENIL works directly with disabled individuals, organizations (mainly Centres of Independent Living), politicians, social agents, media, the business world and any individual or organization interested in learning about Independent Living history, values, principles and its practical application.

That which makes ENIL different from other disability-related European organizations is its make-up of strong grassroots guided by the social model approach; the dedication of us as members to promote, advocate and lobby for social change (empowerment of disabled people to take control over their lives); and the transferability of the Independent Living principles into applicable practices. ENIL represents a disability movement for human rights and social inclusion based on solidarity, peer support, de-institutionalization, democracy, self-representation, cross disability and self-determination.

Independent Living Institute.¹³⁹

In 1989, at the European Parliament in Strasbourg, over 80 persons with extensive disabilities participated in a 3-day conference on personal assistance and founded ENIL, the European Network on Independent Living. Two of the Independent Living grassroots organizations represented at the Strasbourg meeting, STIL, the Stockholm Cooperative for Independent Living, and GIL, the Gothenburg Independent Living coop, together founded the Institute on Independent Living 1993 (the name was changed to Independent Living Institute in May 2003) with the purpose of spreading the Independent Living philosophy and approach within Sweden and internationally.

The Independent Living Institute (ILI) is a policy development centre specializing in consumer-driven policies for disabled peoples' freedom of choice, self-determination, self-respect and dignity. The Institute's ultimate goal is to promote disabled people's personal and political power.

Towards this end, they provide information, training materials and develop solutions for services for persons with extensive disabilities in Sweden and internationally. They are experts in designing and implementing direct payment schemes for personal assistance, mainstream taxi and assistive technology.

¹³⁹ <https://www.independentliving.org/links/links-organisations-disabilities.html>

European Coalition for Community Living.¹⁴⁰

The European Coalition for Community Living (ECCL) is a Europe-wide crossdisability initiative working towards the social inclusion of people with disabilities by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalisation.

ECCL was founded in 2005 by ENIL, Autism Europe, the Centre for Policy Studies of the Central European University, the European Disability Forum, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative. As from the beginning of 2008, ECCL has been a project of the European Network on Independent Living (ENIL).

Inclusion Europe.¹⁴¹

Inclusion Europe is an association of people with intellectual disabilities and their families in Europe which was constituted in 1988. Inclusion Europe fights for equal rights and full inclusion of people with intellectual disabilities and their families in all aspects of life. As a European association it works in the many different areas which members have identified as important to them, including the exchange of knowledge across Europe, member support, networking, policy influencing and lobbying and other related initiatives.

Inclusion Europe is widely considered as a staunch lobbyist throughout EU institutions.

Inclusion International.¹⁴²

Inclusion International is the international network of people with intellectual disabilities and their families advocating for the human rights of people with intellectual disabilities worldwide. Together they agree on a Statement of Unity and are committed to progress towards inclusion International's vision.

Inclusion International has been committed to the promotion of these human rights for over fifty years and now represents over 200 member federations in 115 countries throughout five regions including the Middle East and North Africa, Europe, Africa, the Americas, and Asia Pacific. Naturally, Inclusion Europe mentioned above incorporates the European NGOs within Inclusion International. The latter, albeit focusing on international operations, are headquartered in London and thus regularly focus on European related issues.

European Intellectual Disability Research Network.¹⁴³

The European Intellectual Disability Research Network (IDRESNET) is a group of academics working together with support from the European Union Fifth Framework for Research and Development. IDRESNET includes colleagues from seven Universities: Universidad de Cádiz:

¹⁴⁰ <http://community-living.info/members/>

¹⁴¹ <http://inclusion-europe.eu/>

¹⁴² <http://inclusion-international.org/who-we-are/>

¹⁴³ <http://www.enil.eu/wp-content/uploads/2012/07/Intellectual-Disability-in-Europe.pdf>

J. Garcíalbañez, T. Magallanes, Ramon Novell, Miriam Poole, Prof Luis Salvador-Carulla, Universiteit Gent: Catherine Molleman, Prof Dr Geert Van Hove, Rijksuniversiteit Groningen: Prof Dr Carla Vlaskamp, Universität Siegen: Laurenz Aselmeier, Dr Johannes Schädler, Prof Dr Norbert Schwarte, Timo Wissel, University of Kent at Canterbury: Prof Jim Mansell, Dr Julie Beadle-Brown, Paul Cambridge, Dr Rachel Forrester-Jones, Aristotle University of Thessaloniki: Dr Susana Padelidu, Uppsala Universitet: Dr Kent Ericsson.

The network is coordinated by Prof Jim Mansell of the Tizard Centre at the University of Kent at Canterbury. IDRESNET presented an analysis of policy and services for people with intellectual disabilities in the IDRESNET countries, in which the underlying assumptions, structures and processes are explored from a comparative perspective. IDRESNET's studies are indeed a precursor to this project itself.

European Association of Service Providers for the Disabled. ¹⁴⁴

For EASPD, everything started with a road trip; a 2,500 km, 30 hour, all day, all night drive from northern Europe to attend a conference on the transition from education to employment for persons with disabilities in Portugal. *'This was how it was in those days for our sector: a relatively unstructured and amateurish approach to cooperation between service providers throughout Europe.'*¹⁴⁵

Following year-long discussions in 1995, five partners formally established EASPD in 1996. It continued to grow and opened up its membership basis to service providers coming from the 47 Council of Europe member countries, in addition to the sole European Union countries. EASPD – as the voice of over 12,000 service providers for persons with disabilities - works with the relevant European institutions to ensure that the logic behind the United Nations Charter for the Rights of Persons with Disability is fully implemented throughout Europe.

The Academic Network of European Disability experts (ANED).¹⁴⁶

The Academic Network of European Disability experts (ANED) was created by the European Commission in December 2007. The aim was to establish and maintain a pan-European academic network in the disability field that will support policy development in collaboration with the Commission's Disability Unit.

ANED builds upon the expertise of existing disability research centres, supported by national experts, thematic rapporteurs, and links to relevant networks in the disability policy field. Its philosophy and aims support the objectives of European disability policy towards the goal of full participation and equal opportunities for all disabled people.

In this manner, ANED provides a coordinating infrastructure of academic support for implementation of the European Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities.

¹⁴⁴ <http://www.easpd.eu/en>

¹⁴⁵ <http://www.easpd.eu/en/content/our-story>

¹⁴⁶ <http://www.disability-europe.net/about-us>

European Agency for Special Needs and Inclusive Education.¹⁴⁷

The European Agency for Special Needs and Inclusive Education is an independent organisation that acts as a platform for collaboration for its 30 member countries, working towards ensuring more inclusive education systems. The Agency's mission is to help member countries improve the quality and effectiveness of their inclusive provision for all learners.

All European countries are committed to working towards ensuring more inclusive education systems. They do so in different ways, depending on their past and current contexts and histories. Inclusive education systems are seen as a vital component within the wider aspiration of more socially inclusive societies that all countries align themselves with, both ethically and politically. The ultimate vision for inclusive education systems is to ensure that all learners of any age are provided with meaningful, high-quality educational opportunities in their local community, alongside their friends and peers.

The Agency has a mandate from its member countries to facilitate collaboration regarding country priorities that are in line with the European Council priorities as identified in the ET 2020 strategy¹⁴⁸ and in accordance with international agreements, such as the United Nations Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child. The Agency was established in 1996 as an initiative of the Danish Ministry of Education. The Agency Secretariat is based in Odense, Denmark and the Agency has an office in Brussels, Belgium.¹⁴⁹ Through its activities the Agency facilitates the collection, processing and transfer of European level and country specific information in the area of inclusive education, and it provides opportunities for sharing different types of knowledge and experiences.

European Platform for Rehabilitation.¹⁵⁰

The European Platform for Rehabilitation (EPR) was a network of European providers of rehabilitation services to people with disabilities and other disadvantaged groups. EPR members delivered services in the fields of vocational training and education, reintegration of service users into the open labour market and improvement of their employability, physical rehabilitation and social care.

It was first established in 1993 by rehabilitation centres in France, Germany, Italy and the Netherlands. Its Secretariat was located in Brussels, Belgium and operated a range of services in the areas of professional development, research and innovation and public affairs. EPR was also active in the field of quality of services, and developed its own quality system: EQUASS (European Quality Assurance for Social Services). EPR was a member of the Social Platform and had a seat at the EU's High Level Group on Disability¹⁵¹ as well as participatory status with the Council of Europe. EPR received structural funding under the European Commission

¹⁴⁷ <http://www.european-agency.org/about-us>

¹⁴⁸ Education and Training 2020 strategic framework:

http://europa.eu/legislation_summaries/education_training_youth/general_framework/ef0016_en.htm 149

<http://www.european-agency.org/about-us/contact-us>

¹⁵⁰ https://en.wikipedia.org/wiki/European_Platform_for_Rehabilitation

¹⁵¹ "The High Level Group on Disability". European Commission (ec.europa.eu)

Lifelong Learning Programme 2007–2013, and was involved in a number of projects funded by the European Commission.

Disabled Peoples' International Europe. ¹⁵²

DPI Europe is the European network of National Assemblies of Disabled People's Organizations (DPO's) who are members of the World Non-Governmental Organisation named Disabled Peoples' International. The latter was founded in Singapore in 1981 and has a network of National Assemblies in over 140 Countries. DPI Europe's Regional Development Office is based in Lamezia, Italy and the DPI World headquarters is based in Canada.

DPI Europe enjoys a coordinated network of 31 DPI National Assemblies from 31 European countries.

The European Social Network. ¹⁵³

The European Social Network (ESN) is the network for local public social services in Europe. ESN brings together people who plan, finance, research, manage, regulate and deliver local public social services, including health, social welfare, employment, education and housing.

It is a network of over 125 member organisations in 33 countries which comprise national associations of directors, departments of social welfare of government, regions, counties and municipalities, funding and regulatory agencies, universities and other research and development organisations. It believes that social services must protect and support vulnerable people, uphold their dignity and independence, pursue excellence and innovation in social work, listen to service users and respond to their needs, and promote solidarity with people and their communities. ESN is a non-profit charitable organisation, supported by the European Union Programme for Employment and Social Innovation "EaSI" (2014-2020).

International Disability and Development Consortium. ¹⁵⁴

The International Disability and Development Consortium is a global consortium of disability and development non-governmental organisations (NGOs), mainstream development NGOs and disabled people's organisations (DPOs) supporting disability and development work in more than 100 countries around the world.

The aim of IDDC is to promote inclusive development internationally, with a special focus on promoting the full and effective enjoyment of human rights by all persons with disabilities living in economically poor communities in lower and middle-income countries.

IDDC's main objectives are:

- To promote the inclusion of the disability dimension, as well as appropriate disability-specific approaches, in all development policy and practice.

¹⁵² <http://www.dpi-europe.org/>

¹⁵³ <http://www.esn-eu.org/who-we-are/index.html>

¹⁵⁴ <https://www.iddcconsortium.net/who-we-are>

- To improve the practice of the member organisations by collaborating and sharing experience about policy and practice.
- To support the exchange of information and knowledge about inclusive development, especially between people and organisations in economically poorer countries, by the wide distribution of information.

European Union of Supported Employment.¹⁵⁵

The European Union of Supported Employment (EUSE) was established in 1993 to facilitate the development of Supported Employment throughout Europe. Supported Employment assists people with significant disabilities (physical, intellectual, psychiatric, sensory and hidden) to access real employment opportunities, of their own choice, in an integrated setting with appropriate ongoing support to become economically and socially active in their own communities.

EUSE works to achieve this through the promotion of the Supported Employment model, the exchange of information and knowledge on good practice in Supported Employment and the development of model services. EUSE provides a platform for networking with other organisations and associations at European and worldwide level.

The main activities of the European Union of Supported Employment include:

- Organising the EUSE Conference, which is held bi-annually.
- Exchanging information via regular mail shots, and now, thanks to this project through newsletters, email and website (www.euse.org).
- Influencing European social and economic policy.
- Networking with other European Associations and working with worldwide organisations.
- Developing new National Associations – assisting and supporting organisations to establish their own National Associations
- Campaigning and lobbying for the rights of people with significant disabilities to access vocational training and employment.
- Researching and developing models of good practice, staff training, quality standards, self-advocacy, capacity building and legislation.
- Membership services and support for National Associations.

The World Association of Supported Employment.¹⁵⁶

WASE is a network of persons and organizations with the aim to promote supported employment all over the world.

WASE was constituted in 1995 and is since promoting supported employment. In 2003, with the help of the ILO, a special CD Rom and Handbook was produced for developing countries and organizations who are interested in introducing supported employment in their jurisdictions.

¹⁵⁵ <http://www.euse.org/content/supported-employment-toolkit/EUSE-Toolkit-2010.pdf>

¹⁵⁶ <http://www.wase.net/>

WASE is also looking at quality in supported employment performance and has designed quality criteria. A new initiative is a quality mark for employers/companies with proven records in employing persons with a disability through supported employment.

Gladnet.¹⁵⁷

The Global Applied Disability Research and Information Network (GLADNET) brings together research centres, universities, enterprises, government departments, trade unions, and organizations of and for persons with disabilities. Its common goal is to advance competitive employment and training opportunities for persons with disabilities.

GLADNET's objective is to promote disability policy and program reform with emphasis on integrated training and employment options for working age persons with disabilities. These objectives are achieved through collaborative applied research projects, and by the global exchange of information via the Internet.

GLADNET is taking a lead in making sure that the implications of the UNCRPD are made clear to those national and international agencies with responsibility for promoting the implementation of the Convention in the areas of employment and training. With the support of the ILO an on-line resource has been developed which provides access to a wide range of resources. GLADNET has also established a Thematic Group to monitor progress in the implementation of Articles 27, 28 and 32 worldwide.

¹⁵⁷ <http://gladnet.org/>

Legislation, DPOs and Disability-Oriented Organizations, Schools, and Agencies ¹⁵⁸

In order to establish how each country is attempting to provide support and growth for people with intellectual disability, one must analyse each member of the European Union in order to determine what available information is available regarding the related situation in the country in question and about institutions or organizations set up to provide for these patients.

Admittedly, this is a daunting task since there is no uniform methodology in assessing such support for persons with disability, especially intellectual disability from one country to another. Every EU country has its own distinct operators working in this field: some are state agencies, some are DPOs, some are NGOs, some are voluntary or charity registered service providers, some are registered limited liability companies and some states have varying degrees of public/private partnerships.

Additionally, not all service providers strategically promote their specific services in this field. Some do not market their services whatsoever, mostly due to the fact that they have a guaranteed beneficiary client list, mostly referred to them by a government body or parastatal agency. Most of the service providers in this specialised field project a generic overview of their services, without in-depth information regarding each and every service on offer. In the case of countries with competing service providers, this is all the more evident for obvious reasons.

This project will be constantly updating information related to each and every EU country throughout its three year project period in order to ensure that, by 2020, this report will have a comprehensive reporting of such practices throughout the European Union country members.

Since, by the end of this Erasmus+ project, the United Kingdom does not feature as a European Union member, data and case studies related to this country and jurisdiction will not be introduced in the mix being projected in the following research.

¹⁵⁸ For a categorized, albeit certainly not fully comprehensive list of these entities, please go to <https://www.widernet.org/portals/index.php?PortalID=65&PortalPageID=4558&view=public>

Austria.

The Academic Network of European Disability Experts (ANED) issued country report on Austria¹⁵⁹ on the 12th of July 2017. In this report, a number of factors need to be underlined.

Firstly, the *general lack of specific data*¹⁶⁰ on the living situation of persons with disabilities in Austria makes it hard to evaluate the overall situation as well as the effectiveness of programmes and measures. The evidence base is limited due to the fact that the data situation is quite incomplete. Definitions of 'disability' differ between data collection tools, legal frameworks and political practices (i.e. referring to different models of disability). Measures taken are often not seriously evaluated. E.g. the scarce data available on the effectiveness of the new rehabilitation benefit indicates distinct weaknesses of this new programme in the framework of EU2020 targets.

Secondly and intertwined with the first point, a main challenge in Austria still is to make persons with disabilities visible as a distinct 'target group' for policymaking – particularly in the field of employment, education, poverty reduction and social exclusion. There is a lack of disability mainstreaming in the Austrian National Reform Programme 2016 (NRP), where persons with disabilities are almost invisible.¹⁶¹ To ensure a sustainable inclusion, persons with disabilities need to be explicitly addressed in the NRP (and in the first place, addressed in the Commission's Country Report and Country-Specific Recommendations) – regarding employment, education and social inclusion. Measures (e.g. to combat unemployment among young people and older people or to ensure tertiary education for young persons with disabilities) should explicitly be tailored to support this (heterogeneous) group.

Thirdly, *federalism* in the Austrian political system complicates responsibilities in policymaking in the field of disability policy. This is obvious in the context of employment for persons with disabilities where responsibilities are split up depending on the severity of disability. Implementing policy measures which refer both to the federal and to the regional level means there is a need to clarify content-related competencies and financial responsibilities, in practice leading in many cases to stalemate.

The interweaving of these main three challenges for policymaking in the field of disability policy in Austria hinders sustainable and efficient change with regard to the situation of persons with disabilities in areas relevant to the EU2020 priorities. ESF funds are not used to tackle these well-known problems.

In general, the current omnipresent political and public debate about refugees and migrants superimposes sustainable debates about persons with disabilities in Austria – e.g. regarding labour market access, minimum income and the educational system.¹⁶² This has indeed a

¹⁵⁹ <https://www.disability-europe.net/country/austria>

¹⁶⁰ No new national data is available. A micro census that was carried out in 2015 is expected to be published at the end of 2016.

¹⁶¹ See section 4 of this report.

¹⁶² See section 5.1 on education of this report.

significant impact on persons with disabilities in Austria, as they even more fade from the political and societal spotlight.

According to a study published in December of 2010, the average density of psychotherapists was 1.73 per 10,000. This is approximately nine times higher than the density of psychiatrists. Such a figure suggests that mental illness and such issues as depression are more prevalent than intellectual disability.

Access to medical assistance is focused much more centrally in urbanized areas with higher income, resulting in a level of neglect to lower statuses caused by a socioeconomic imbalance.¹⁶³

Alarmingly, such a factor also affects the research related to suicide rates in Austria, with persons affected with mental health issues and intellectual disability registering an alarmingly high incident rate nationwide. Professional studies show that access to psychiatrists and psychotherapists is better in urbanized and privileged districts than in deprived regions, as mentioned above. On the other hand, the low availability of psychiatrists resulting from long waiting lists and the minimal reimbursement for psychotherapy from non-psychiatrists increase barriers to the professional mental health care needed by suicidal patients.

Poorer access to mental health professionals partly explains how socioeconomic conditions may influence suicide rates. A previous study noted an increasing gap between rural and urban suicide rates in Austria¹⁶⁴. In the beginning of the 1970s, urban regions experienced higher suicide rates than rural ones; however, this ratio changed by the mid-1980s, and the disparity between rural and urban suicides continues to grow, with suicide rates falling more notably in urban areas than in rural ones¹⁶⁵. Further studies should examine whether improvements in access to mental health care and socioeconomic changes in urban areas are in line with the greater reductions in urban suicide rates compared with rural rates.

Although social insurance expenditures for psychotherapy have grown in recent years in Austria, demand-planning authorities have recognized that the need for reimbursement of psychotherapy visits is far from met. Waiting periods of up to 30 weeks are common. Of a total of 1.4 million reimbursed visits for psychotherapy in 2007, 36% were only partially reimbursed - at approximately 30% of the cost per visit¹⁶⁶. Thus access to psychotherapy depends on patients' socioeconomic situation. Similarly, because only 20% of all psychiatrist practices in Austria are contracted with social insurance, waiting periods of up to three months are typical for a first appointment covered by social insurance¹⁶⁷.

¹⁶³ <https://www.psychotherapie.at/sites/default/files/files/studien/Studie-Availability-mental-health-services-providers-and-suicide-rates-in-Austria-Kapusta.pdf>

¹⁶⁴ Hirsch JK: A review of the literature on rural suicide: risk and protective factors, incidence, and prevention. *Crisis* 27:189–199, 2006

¹⁶⁵ Kapusta ND, Zorman A, Etzersdorfer E, et al: Rural-urban differences in Austrian suicides. *Social Psychiatry and Psychiatric Epidemiology* 43:311–318, 2008

¹⁶⁶ Provision of Psychotherapy and Psychopharmacotherapy 2007 [in German]. Vienna, Austrian Health Institute, 2009

¹⁶⁷ *Ibid.*

In 2015, the OECD published a report entitled 'Mental Health and Work: Austria'.¹⁶⁸ In this comprehensive report, the researchers noted that Austria needs to do more to help people with mental health problems find a job or stay in the workplace. A more comprehensive approach would help employees and firms alike: mental health issues are estimated to cost the Austrian economy around 3.6% of GDP every year in lost productivity, health care and out-of-work benefits.

Mental Health and Work: Austria states that about one in three people on sickness, unemployment or disability benefits report a mental health problem. The unemployment rate of people with mental illness is three times the overall rate and it is particularly high among older workers. The link between age, health and work suggests that in Austria age in combination with mental health problems is viewed as an acceptable reason for leaving the labour market prematurely. Accordingly, in the past two decades mental illness has emerged as the main factor in disability benefit claims.

Austria has a strong labour market but people with mental health problems have a high incidence of absence as well as significant performance problems. Their situation can be improved by health-insurance supported sickness management at the workplace and the introduction of a partial return-to-work option. Existing occupational health and fit2work services can play a bigger role in helping workers struggling with mental health problems stay in or return to their job.

The recent disability benefit reform is a major step in the right direction, as it aims to prevent premature labour market exit and helps people to stay in or return to the labour market. Nevertheless, its success will hinge on the extent to which people now entitled to either rehabilitation or retraining benefit will be supported by the responsible authorities. Without due support, the new benefits could easily become a dead end.

Health spending in Austria is high and health services in general are easily accessible. However, according to the report there is a lack of attention to mental health needs and insufficient funding for psychotherapy. Treating people with the aim of helping them get back to work is not widespread and there is no link between health and employment services. Other countries are experimenting successfully in this field. Such findings from this recent OECD report further underline previous findings mentioned earlier.

Change is also needed in other areas, notably the Austrian education system. High overall education spending does not sufficiently help youth with behavioural and mental health problems. More professional support is required both in and around schools. Youth and apprentice coaching should be expanded to reach the intended target groups and tackle drop out from upper-secondary education or vocational schools.

¹⁶⁸ <http://www.oecd.org/austria/mental-health-and-work-austria-9789264228047-en.htm>

Therefore, in this report, the OECD recommends that the Austrian authorities:

- Implement the 2013 disability benefit reform rigorously for workers of all ages and extend the reform to the entire labour force.¹⁶⁹
- Improve the resources and competences of the public employment service so that it can attend to clients who suffer from poor mental health.
- Make sickness benefit payments part of an active system to foster a quick or, where necessary, partial return to work.
- Further strengthen fit2work as an active support service that is easily accessible for workers as well as employers.
- Shift health resources to increase mental health care to adequate levels, especially in outpatient and primary care, child psychiatry, and rural areas.
- Reorient education resources to increase qualified professional support for teachers and students.

Mental health reform efforts in Austria have, therefore, since the 1970s, had considerable impact with regard to de-hospitalization and a move to community orientation of mental healthcare. A scientific survey carried in Austria with regards to Caring for Carers in Austria due to such a transition can also be browsed online.¹⁷⁰ However, the incentive structure of the fragmented and federalized financing system and the lack of coordination still pose serious obstacles to the full implementation of systems of integrated care with a flexible and person-orientated approach.¹⁷¹

These facts as well as inequalities between different regions and between mental health and health services in Austria are in line with what the US Department of Health and Human Services lists as main obstacles to recovery orientation of mental healthcare¹⁷² despite otherwise big differences between the two countries' health systems. The other notable constant as impediment to recovery across many different care systems and cultures are stigma and discrimination.

The fight for better mental healthcare and against stigma and discrimination in Austria profits from a 30-year tradition of a strong national family organization. The user movement is quite established and influential in some parts of Austria but not in others, and there is no national user organization. In recent years, the beginning of a shift from the traditional paternalistic medical culture towards a culture of partnership and empowerment clearly highlights the need for further developments in this direction. In Austria (as well as in Germany) the topics of power, empowerment and recovery in mental health carry some special and especially painful connotations because of the terrible crimes of psychiatry during the Third Reich. Thus, discussions about empowerment and recovery cannot be led or viewed without considering this context.¹⁷³

¹⁶⁹ <http://www.oecd.org/newsroom/austria-should-do-more-to-help-people-with-frequent-mental-health-problems.htm>

¹⁷⁰ <http://www.caringformentalhealth.org/region/austria>

¹⁷¹ Meise, U., Wancata, J. & Hinterhuber, H. (2008). Mental health care in Austria: History – developments – perspectives. *Neuropsychiatrie*, 22, 230–242.

¹⁷² Amering, M. & Schmolke, M. (2009). *Recovery in Mental Health. Reshaping Scientific and Clinical Responsibilities*. London: Wiley-Blackwell.

¹⁷³ <http://www.tandfonline.com/doi/full/10.3109/09540261.2012.655713>

Generally speaking however, estimations according to the EU indicate that the number of people with special needs constitute 10% of the total population. At a population of about 8.2 million Austrians, there would be about 800,000 to 850,000 disabled persons. In 2002, the "Eurostat" carried out an inquiry with the following result: 16.4% of the questioned persons in working age indicated in the EU to be concerned of "a long continuous health problem or a handicap". In Austria, only 12.8% indicated that. In the year 2007, 94.200 benefited disabled persons were registered at the social services department. As more awareness on the subject matter increased, every new year saw an increase in these numbers.

From the year 2000 (unemployment rate 5.8% = 194.300 people unemployed) onwards there was a continuous growth in the Austrian unemployment rate (general population) until the year 2005 (7.3% = 252.700 people unemployed). From that time on people regained work, which means that the number of unemployed people diminished in the year 2006 (239.200 unemployed people) as compared to 2005 by 5.3% and in 2007 (222.200) as compared to 2006 at 7.5%.

Sadly, the situation for people with special needs was the exact opposite: In the years 2006 and 2007 the unemployment rates rose. The reason for that growth was a statistical effect. Many unemployed people, who couldn't find work easily, were labelled as "people with special needs". This term made it possible for them to take part in special support programs. Since 2007 the unemployment rates for people with special needs decreased. The percentage of unemployed people with special needs as related to the population of unemployed people increased from 2003 onwards until 2005 and then increased again slightly. The unemployment rate for people with special needs – split in the type of disability- for the year 1999 was as follows: 88% bodily disabled, 15% mentally (psychical) disordered, 3% mentally disabled and 1% disability of senses.¹⁷⁴

The "Statistik Austria" published a statistical overview of expenditures and revenues of institutions for people with special needs. The expenditures as well as the revenues increased continuously (+110% every ten years from 1996). Generally speaking, costs rose at 9.2%, whereas the proceeds only increased at 7.6%. Austria's costs for people with special needs grew in the last years amongst other reasons because of a shift of responsibility of the social services departments. More than 4,000 persons with disabilities were detained in special institutions, of which 53.6% are male.

BABE (Bundesweites arbeitsmarktpolitisches Behindertenprogramm, which translates to the national labor market policy program for persons with special needs) was created by the federal social services department of Austria (Bundessozialamt) to support TRAVORS 6 disadvantaged people (among those people with special needs) and to help especially those, who can maintain a job at least for the medium term. The target groups for the BABE services are teenagers and young adults with learning disabilities, elderly people who are at risk to lose their jobs, people with mental impairments and, lastly, enterprises.

¹⁷⁴ General Insurance Act has changed - since 2014 access to permanent pension (Invaliditäts- und Berufsunfähigkeitspension) is limited to those born before 1964; all other persons with chronic diseases receive rehabilitation allowances from their medical insurance for a limited time period (up to 2 years) and are coached by rehabilitation counsellors/case managers. After this period, vocational re-assessment is foreseen.

An Austrian employer is legally obligated to employ 1 person with special needs per 25 other employees. The employers get financial support in form of exemption of taxes. If a company cannot find an appropriate job for a person with special needs, compensations have to be paid. This regulated number should guarantee a better integration into working life.

A so-called “representative of people with special needs” has to be elected by the work council if at least a minimum of 5 persons with special needs are working in that company. If the number of people with special needs exceeds 15, two “representatives of people with special needs” have to be elected.

They monitor the correct abidance by the laws, give an account of the perceived shortcomings and report them to the work council. They make proposals for further education and training and they point out the special needs concerning the workplaces of disabled persons.

The protection against dismissal is extended for people with special needs. Employers have to keep a term of four weeks when dismissing a benefited disabled person. A permission of the regional office of the social services department committee is required for a dismissal of a person with special needs. Without that permission the dismissal would be ineffective. Since 2001 an amendment made it possible to dismiss a person with special needs in the first 6 month without keeping a term of four weeks. This modification was invented to make an employment of a person with special needs more attractive and profitable for the companies. The employers are given enough time to see for themselves, what kind of job performance the person really delivers. Many general managers worry that they cannot dismiss a person with special needs even if this person falls short of their expectations.

Besides the possibility to get work in any company, there exist so-called “integrative companies” especially for people with special needs, who can’t find work at the general employment market because of the severity or particularity of their disability. These “integrative companies” are designated to support these persons in the working life and to serve them as a steppingstone back to the normal employment market.

These workshops were established to offer people with special needs the possibility to learn work techniques e.g. in industrial fabrication (wood, metal or plastic processing). The terms of admission for an integrative company consist of a hearing of an expert team. This expert team is made up of four representatives (a representative of the country “Behindertenhilfe”, of the Austrian Job Centre, of the social services departments and the general manager of the integrative company). The Integrative business is the primary place for requires to get work in such an institution.

The possibility of an employment therapy exists for persons whose work performance based on their handicap is so reduced that a full term employment is not reasonable. It is offered in special institutions and in care homes. Persons with disabilities are socially integrated – similar to a professional activity. By the help of expert care, meaningful and useful employment is provided. People with disabilities learn how to use their capacities and can develop further skills. The persons do not earn a regular salary, but they get pocket money. An expert team, consisting of a physician, a psychologist, a qualified social worker and an occupation adviser decide whether people fulfil the preconditions. The applications can be submitted directly to the

competent authority (the local district commission or the municipality).

Whether a job can be regarded as barrier-free (disability-friendly) is a question of ergonomics. The workplace should be fully accessible, which means that all office equipment and tools are accessible and in the right height or even vertically adjustable. If a company wants to modernise its equipment and make them fully accessible for people with special needs, several financial support programs can be requested at the regional service points of the federal social services department. Support is provided for the following categories:

- Creation of new barrier-free workplaces
- Adaption of existing rooms (e.g. sanitary rooms)
- Reconstruction of machines (e.g. computer) and arrangements (e.g. office room)
- Technical work aids (e.g. mobile reading-devices for visually disabled persons)
- Acquisition and restoration of work aids and education to the use of work aids

For disabled persons, all services of the AMS (Austrian labour market service) are available. The priority of the AMS is to integrate persons with special needs into the first labour market. Support is offered in form of education and occupation information over the consultation and care in search for a suitable job up to individually voted qualification supports or employment supports. Since 2007, there exist leading projects for the better integration of people with special needs into the labour market. These projects include educational programs as well as support measures.

The Employment of People with Disabilities Act (Behinderteneinstellungsgesetz) supports people with disabilities in the world of employment. Austrian citizens with a degree of disability of at least 50% can apply for an official decision (Bescheid) stating that they are disabled persons receiving special support.

Disabled persons receiving special support benefit from numerous advantages:

- Increased protection against redundancy/dismissal
Employers have to obtain the agreement of the Disabled Persons Committee before they can make a person redundant
- Occupational subsidies
The range of offers extends from financial benefits via technical working aids to special training courses
- Additional holidays
This is permitted insofar as it is provided for in the respective collective agreement, Employment regulations or company agreement
- Income tax allowance
Tax breaks can be applied for at the local tax office from a degree of disability of 25%.¹⁷⁵

¹⁷⁵ https://www.sozialministerium.at/siteEN/Labour_Disabilities/People_with_disabilities/

EU funding also plays a role in Austria on the subject matter. The ESF provides information regarding the European Union's main financial instrument for the improvement of the employment situation in the individual member states. One main target group of the ESF are people with special needs. Several support programs were piloted to advance the employment situation for people with special needs. These interventions include arrangements for a better integration of young disabled persons (education, training, job-coaching, mentoring), elderly persons with disabilities (maintaining of work, reintegration), people with severe functional impairments and also for enterprises. Together with national support programs these arrangements should stabilize and ameliorate the employment market for people with special needs.

In Austria, many different institutions offer courses of studies for working with people with special needs. There are secondary schools with a focus on social work and care of people with special needs. People can also attend extra occupational courses or pass further full-time education (3 years with a degree in professional care for people with disabilities). All these courses offer care-specific knowledge and skills in general support. The professional care workers support persons with special needs in everyday life and help them to develop further social skills. But specific courses for the work with people with disabilities in the sector "integration into working life" are still missing. There exist just two university studies of that kind (studies of education with a focus on social, familiar integration and integration into working life for people with disabilities).

Supported employment is a national mainstream programme in Austria. It began in 1992 with two pilot projects "Arbeitsassistenz", which provided individual support for persons with mental or physical disabilities. In 1994, this kind of service was incorporated in an amendment to the Austrian Disability Employment Act and the service was extended to a broader target group and made available nationwide. In 2011, a total of 45 different NGO service organisations ran 135 projects. Persons with chronic diseases may benefit from these services, although the effects have not been evaluated systematically. Adaptation of the working time is dependent on agreements between the employer and the person concerned and may also depend on collective agreements within the different industries or employment contract or 'Dienstrecht'. The employer has to be disposed to organize such adjustments but may get advice.¹⁷⁶

Additionally, there exists a special service for employers, who are not sure about the engagement of people with special needs. That special service is provided by the regional offices of the social services department of Austria. Employers can get answers to frequently asked questions about, for example, the following concerns: cost-benefit analysis, legal foundations, and support in establishing new specially equipped workplaces or optimal assignment of personnel with special needs.¹⁷⁷

¹⁷⁶ https://www.path-ways.eu/wp-content/uploads/country_report_at.pdf

¹⁷⁷ https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=100083_08
http://www.travors.eu/download_material/subhABOUT%20TRAVORS/ENglish%20site/backgroundreport_austria.pdf

On 24 July 2012 the National Action Plan on Disability 2012-2020 (NAP Disability) was adopted by the Ministerial Council. The NAP Disability is the federation's long-term strategy for the implementation of the UN Convention on Disability Rights and was included in the current government programme (2013-2018).

The NAP Disability contains 250 measures divided up into eight main focuses which have to be realised by 2020. The Ministry of Social Affairs formulated the measures of the NAP Disability in cooperation with all other ministries as the result of a participative process with civil society - above all with the organisations of people with disabilities - and with the social partners.¹⁷⁸

With regards to service providers in this field, Austria has a number of regional operators when compared to national operators. In order to give a practical example, one can note the following institution:

The IFS (Institut für Sozialdienste) SPAGAT is a practice which integrates processes regarding people with a disability's integration into normal living so that they may begin to form a part of a community in society. It is also a form of integration into employment as it provides necessary aid and seeks to assist in finding work in the open labour market.

The Institute for Social Services is an institution of voluntary welfare, in which professionally qualified social workers, psychologists, marriage counsellors, counsellors for people with disabilities, educators, doctors, psychotherapists, lawyers and interpreters work together.

They are politically independent, non-denominational and active in all regions of Vorarlberg (Austria). During the day, their employees at the counselling centres are also available at short notice for consultations and in crisis situations. Counselling sessions are free. In the case of long-term treatments and therapies, co-participation is agreed individually according to social criteria.

The target groups are indeed people with intellectual disabilities which are greatly in need of support and wish to integrate themselves into a workplace. This allows people who would be previously considered unemployable to freely choose between employment, either in sheltered workshops or in a general labour market. This has set a trend in the implementation of the UN CRPD and also provides the inclusion of such people with a greatly reduced cost.

Other Service Providers based in Austria can be gleaned from the following links.^{179 180 181 182 183 184 185 186}

¹⁷⁸ https://www.sozialministerium.at/siteEN/Labour_Disabilities/People_with_disabilities/

¹⁷⁹ www.eusetoolkit.eu/index.php/partners/1-dachverband-berufliche-integration-austria

¹⁸⁰ <http://www.easpd.eu/easy/node/302>

¹⁸¹ www.easpd.eu/sites/default/files/sites/default/files/.../annex_3._10_best_practices.pdf

¹⁸² <http://supportemployment.eu/>

¹⁸³ <https://www.fab.at/de/kontakt/fab-regional-standorte-projekte/locations/show/75.html>

¹⁸⁴ <http://www.oecd.org/employment/leed/37728993.pdf>

¹⁸⁵ <http://www.transition.net/index.php?m=partners&s=at>

¹⁸⁶ https://www.stepstone.at/5/ergebnisliste.html?gclid=Cj0KCQjw8YXXBRDXARIsAMzsQuX-ubJ7XyZsx82QJ8sqlMAoo0gTQw5fSfC3xJY7ZI4E3ujfweljuBQaArC1EALw_wcB&stf=freeText&ke=Support&ws=&loc_interest=2040&loc_physical=2470&cid=SEAdvert_Google_SEARCH_AT_1000000-IT_c_Job-Support_job%20%2Bsupport_RLd_Etald3-L1_-&s_kwcid=AL!524!3!263875355161!b!!g!!job%20+support&ef_id=V@pm8QAABQV3ujzT:2018042612_2143:s

Bulgaria

Rapid and ongoing transformations have taken place in Bulgaria over the last twenty five years, a process which was accelerated when the country acceded to the European Union in 2007, making it one of Europe's newest and easternmost Member States. In 2012, Bulgaria ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The country's ratification took place five years after the country's accession to the European Union.

Despite significant transformations in Bulgarian society, and some promising commitments to advancing the right of people with disabilities to live in the community, over 7,000 people with mental disabilities are still required to live in long-stay institutions. A slow pace of development of community-based services and little support to develop community networks means that large numbers of Bulgarians with mental disabilities continue to be segregated from society, and are more likely to be the victims of exploitation and abuse.¹⁸⁷

The social exclusion of people with mental disabilities reflects an old, paternalistic model of care and restriction, rather than rights and autonomy. This is clearly characterised through the system of guardianship which operates in the country, removing the legal recognition and right to choose for many people with mental disabilities. The Constitutional Court of Bulgaria recently decided not to declare guardianship unconstitutional,¹⁸⁸ again highlighting the need for legislative reform to bring the country into compliance with Article 12 of the CRPD.

Rhetorically, the Bulgarian Government has made numerous commitments to securing the right of people with mental disabilities to live independently in the community, adopting a number of national strategies on deinstitutionalisation since 2006. However, concrete action has been minimal and slow. Only a tiny number of people have moved out of large institutions into smaller protected homes or family-type centres. Even these models, which the Bulgarian government presents as community-based residential services, continue to reflect institutional models where people with disabilities are separated from the rest of society.¹⁸⁹

The level of investment into community-based services, which are vital in securing inclusion, are significantly lower than the large sums still spent on maintaining and establishing new institutions. Instead of using European Union structural funding to transition people with disabilities from institutions to the community, the Bulgarian government continues to invest in institutions. It is this basic choice of priorities which must change for the government to come into line with its obligations under Article 19 of the CRPD.

¹⁸⁷ Manfred Nowak, Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, 28 July 2008, para. 38

¹⁸⁸ The Constitutional Court of the Republic of Bulgaria, Constitutional case 10/2014, available in Bulgarian at <http://constcourt.bg/contentframe/contentid/2807>

¹⁸⁹ European Network on Independent Living – European Coalition for Community Living, Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living, 2013, 15.

Bulgaria has a major problem with institutional warehousing of people with mental disabilities, including abandonment of children in institutions. Although Bulgaria has ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) in 2012, the right to live in the community is still denied to people with mental disabilities due to the lack of community support services and the failure of successive governments to effectively and speedily implement de-institutionalisation plans. Placement in institutions results in severe restrictions of the rights of children to inclusive education, and the rights of all people with disabilities to live in the community, to have a family life and to participate in society. III- treatment, abuse and neglect continue in children's institutions despite international attention.

Although the Bulgarian government planned review and amendments of legislation to comply with the Convention, the initial 2013-2014 plan was not implemented and the next plan only extended the deadlines to 2020 thus postponing the legislative regulation and practical implementation of the rights of persons with disabilities in Bulgaria for unknown period.¹⁹⁰

Bulgarian law does not respect the right to legal capacity, with people under guardianship being deprived access to justice and political participation.¹⁹¹

In 2007, the Mental Disability Advocacy Centre¹⁹² brought a case to the European Committee on Social Rights challenging the complete lack of education of children in "Homes for Mentally Disabled Children". This involved approximately 3,000 children with intellectual disabilities. The Committee found that Bulgaria had violated its obligations under Article 17 of the Revised European Social Charter to provide an education to all children, and found a violation of the right to non-discrimination (Article E).¹⁹³

The case and the recommendations to the Bulgarian government following the judgment were widely used as arguments for changes in the law in the area of education - especially for children with disabilities. Now the law contains the right to equal access to education for all children, including children with disabilities.

Other cases pending before the European Court include cases related to a death in a psychiatric hospital of a person who was subjected to both chemical and physical restraints and the State's failure to investigate the death and cases related to involuntary detention in psychiatric institutions. As to cases pending before domestic courts and other judicial bodies, there is a challenge of a mayor's discriminatory decision to refuse to sign a contract for supported housing with owners due to their mental disability.

MDAC has also embarked on litigation to seek justice and compensation for past violations of the rights of children placed in the children's institution in Mogilino and Krushari and the physical

¹⁹⁰ <http://www.bghelsinki.org/en/news/press/single/delayed-reform-and-implementation-rights-persons-disabilities-bulgaria/>

¹⁹¹ <http://www.mdac.org/en/books/introduction-0>

¹⁹² <http://www.mdac.info/en/bulgaria>

¹⁹³ <https://issuu.com/bghelsinki/docs/2002-children-special-needs-1->

and emotional harm caused to them. Their litigation seeks legal recognition that the treatment children experienced in Mogilino and Krushari amounts to torture and ill-treatment and that the victims are entitled to appropriate remedies.¹⁹⁴

The collective complaint was declared admissible by the European Committee of Social Rights on 26 June 2007, and the ECSR issued its decision on the merits on 10 June 2008. In its decision, the European Committee of Social Rights found that there was a violation of Article 17(2) (right to education) alone and in conjunction with Article E (non-discrimination) of the Revised European Social Charter because children with moderate, severe and profound intellectual disabilities residing in “Homes for Mentally Disabled Children” do not have an effective right to education and this is due to disability-based discrimination.

The European Committee of Social Rights found a violation of Article 17 (2) of the Revised Charter for several reasons. Although it recognised the Bulgarian government’s efforts to respect the educational rights of children with disabilities living in institutions through adopting legislation and drafting action plans, the Committee highlighted deficient implementation of legislation and policies, and noted that there were inadequate standards for the right to education and equality of educational opportunities.

In its decision, the European Committee of Social Rights referred to the educational standards established by the United Nations Committee on Economic, Social and Cultural Rights, which considered that education must fulfil the criteria of availability, accessibility, acceptability and adaptability. The European Committee of Social Rights found that the Bulgarian educational standards were inadequate because mainstream educational institutions and curricula were not accessible in practice: only 2.8% of children with intellectual disabilities residing in institutions were integrated in mainstream primary schools, whereas integration should be the norm.

The European Committee of Social Rights found also that only 3.4% of the children attended special classes, which also shows that special education is neither accessible to children living in “Homes for Mentally Disabled Children”. Further, mainstream schools are not adapted to the needs of children with intellectual disabilities, teachers are not appropriately trained, nor are resources developed to cater to the educational needs of children with disabilities. Moreover, due to the absence of primary educational opportunities, children with disabilities are ineligible to enter secondary education

The Bulgarian government argued that the educational rights of children living in “Homes for Mentally Disabled Children” are being implemented progressively due to financial constraints. However, the European Committee of Social Rights rejected this argument, finding instead that the Bulgarian government has failed to fulfil the three criteria consistent with progressive realisation of rights, these three criteria being:

- (1) A reasonable timeframe
- (2) Measurable progress
- (3) Financing consistent with the maximum use of available resources

¹⁹⁴ http://www.crin.org/en/docs/ESCR_Bulgaria_MA.pdf

The European Committee of Social Rights observed that any progress has been very slow and has been limited to the adoption of legislation and policies which have been followed through with little or no practical implementation. In addition, the European Committee of Social Rights found that the Bulgarian government has failed to take simple measures such as disseminating information on existing legislation to "Homes for Mentally Disabled Children" or to primary schools. Nor has the government ensured that key staff of such Homes and educational institutions received training to equip them with the skills and knowledge to implement the laws and policies. The European Committee of Social Rights noted that such training could have taken place without much additional cost.

One must, however, note, that in these last two years, government agencies have focused more attention to psycho-social needs within the community.¹⁹⁵ The government's official position of the present situation shows a general trend towards coming to terms with the UN CRPD on these issues. Presently there are a number of social services that provide some support of the persons with disabilities.

With regards to personal assistance, two basic programmes are available for the persons with disabilities: the National Programme "Assistants to persons with disabilities" and the Project "Independent life".

The National programme is a year-round programme and it is implemented throughout the country. The programme is funded by the state budget but it contains too many restrictions that impede persons who need support to be included. People with disabilities can apply as users of the service, but the procedure for approval is too complex and contains many obstacles – for example – income criteria that have not been updated since 2009 and that do not comply with the economic and social processes in the country during this period.

The Ombudsman of the Republic of Bulgaria have sent many recommendations to the authorities for taking measures to improve the conditions and the access to the programme and in this way to guarantee the rights of the persons with disabilities and to implement the provisions of the Convention on the Rights of Persons with Disabilities.¹⁹⁶

The Project "Independent life" is funded by the Human Resources Development Operational Programme. The Project is a very significant part of the Bulgarian system for social support and a lot of persons who need personal assistance apply for it. The project and the provided budget cannot meet all the needs of the persons with disabilities but the established conditions for approval as user of the service are better than those in the National programme.

The challenge that the Ombudsman of the Republic of Bulgaria tried to tackle is the existing lack of openness and transparency of the rules for assessments of the needs of persons with disabilities. In order to guarantee the rights of the persons, the Ombudsman sent several recommendations to the authorities, including the Ministry of labour and social policy and the national association of municipalities in the Republic of Bulgaria, for actions to ensure the necessary information.

¹⁹⁵ <https://www.ncbi.nlm.nih.gov/pubmed/21670687>

¹⁹⁶ See the OHCHR report on disability issues in the Republic of Bulgaria; www.ohchr.org

There are some NGOs that accomplish some activities for providing personal assistance under various projects but their services are available only for a limited number of users, who live on the territory of the municipality where the headquarters of the NGO are located.¹⁹⁷

The positive features of the situation today are the ongoing process of deinstitutionalization and the development of new social services within community.

The shortcomings and the challenges are the insufficient capacity of the providers of the social services to meet the needs of all the persons with disabilities and the lack of enough social services in the small regions where many old people with disabilities, mostly living alone and hailing from the lower stratificational segments of society, live.

The Ombudsman has recommended that the state should take more measures to ensure conditions for the person with disabilities to enjoy independent living and to have access to a range of in-home, residential and other community support services, necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.

Currently the Bulgarian legislation provides the possibility to limit the legal capacity of the people with mental illnesses in two stages - limited and full guardianship. Because of the general nature of the interdiction, the citizens with mental disabilities suffer significantly larger than the necessary restrictions when exercising their rights. Positively speaking, this process is a main topic of many political and civil society discussions conducted in the country over the last few years.

On one hand, the reason for this is the case *Stanev v. Bulgaria*, App. No. 36760/06, and the decision of the Grand Chamber of the European Court of Human Rights. The decision has enormous significance for the rights of thousands of persons with psycho-social disabilities and intellectual disabilities not only in Bulgaria but throughout Europe.¹⁹⁸

In finding violations of Articles 3, 5.1, 5.4, 5.5, 6.1, and 13 of the European Convention on Human Rights, the Grand Chamber opened the possibility for persons in social care institutions to challenge both their deprivation of liberty and the inhumane and degrading conditions in institutions. Moreover, it reaffirmed its jurisprudence regarding the right of persons whose legal capacity has been restricted to have access to a court to challenge their loss of rights.¹⁹⁹

The decision along with the provisions of article 12 of the CRPD, ratified by the National Assembly of the Republic of Bulgaria and the lack of adequate reaction of the authorities prompted the Ombudsman to request the Constitutional Court to cancel the texts of the

¹⁹⁷ Ibid.

¹⁹⁸ https://www.coe.int/en/web/commissioner/country-monitoring/bulgaria-/asset_publisher/llCM6m5KhFKp/content/steps-forward-in-protecting-persons-with-disabilities-in-bulgaria?inheritRedirect=false&desktop=false

¹⁹⁹ <http://socialprotection-humanrights.org/legaldep/4211/>

Persons and Family Act, which regulate the limits of the legal capacity as contrary to the Constitution and art. 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD).²⁰⁰

Although the request was rejected, in its decision the Constitutional Court drew attention to the need for comprehensive reform in order to ensure the conformity of the legislation with article 12 of the CRPD. Subsequently, in 2015 the Ministry of Justice presented for public discussion a draft Law on individuals and support measures. Representatives of the Ombudsman participated in the working groups on the development of the texts of the bill and the Ombudsman supported its submission to the Parliament. After some period of public discussions, in 2016 the bill was approved by the Bulgarian Council of Ministers and submitted to Parliament.

The process for ensuring support to the deaf persons and people with intellectual disabilities has been initiated and some conditions are established in order to guarantee that these vulnerable people are able to fully enjoy all their rights and fundamental freedoms. For instance - Art. 4, para. 3 of Code of Civil Procedure states that where in the lawsuit a deaf or dumb person participates, an interpreter of the person shall be appointed.

Some actions have already been taken by the state for establishing common and official sign language. The position of the Ombudsman on this subject matter is that the process is still too slow and persons with disabilities meet difficulties to fully integrate in the society. The Ombudsman has also noted in his recommendations and in his Annual reports presented to the National Assembly that the social services in Bulgaria are still insufficient. Recurring problems pinpointed are the lack of funding, sustainability, flexibility and individual approach to the needs of the persons in question.²⁰¹

In June 2017, the Bulgarian Helsinki Committee sent its alternative report on the rights of persons with disabilities to the UN Committee on the Rights of Persons with Disabilities. Bulgaria has ratified the UN Convention on the Rights of Persons with Disabilities in January 2012. The first review of the implementation of the convention in Bulgaria was due in 2017- 2018 by the special body set up to control the national implementation – UN Committee on the Rights of Persons with Disabilities.

The main shortcomings discussed in the report are:

Bulgarian disability legislation is still far from the philosophy of the UN Convention as it mainly considers persons with disabilities as non-able and thus an object of social assistance schemes/benefits. A far more radical and holistic approach needs to be applied in the field of personal and social assistance, independent living and support in decision making, education and employment of persons with disabilities.

The medical model in assessment of disabilities is leading and is a basis for all rights and benefits in practice.

²⁰⁰ See the OHCHR report on disability issues in the Republic of Bulgaria; www.ohchr.org

²⁰¹ Ibid

Social assessment of the needs and capacities of the persons with disabilities is done in a formal and bureaucratic way.

Individually tailored services, assistance and allowances do not exist.

Public environment is largely inaccessible for persons with different kinds of disabilities.

Universal design is not adopted as a notion/definition and measures for its potential implementation are taken on EU funded projects basis sporadically.

For persons with disabilities in Bulgaria, the right to independent living is not respected. The majority of them live with their families and cannot choose and with whom to live. Access to community-based services is not guaranteed to all potential users and the quality of care provided in them is generally low, with a few exceptions. Users' opinions are not being sought and taken into account while the services are being developed, while they are functioning and when their quality is being evaluated.

The practice of unlawful seclusion and restraint of some residents (with intellectual disabilities or psycho-social problems) of institutions continues (both children and adults). Death cases and abuse cases in both institutions and residential community-based services are not investigated and prosecuted.

People with intellectual disabilities and psycho-social problems are often deprived of their legal capacity and placed under guardianship. This automatically deprives them of the right to be recognised as "persons" before the law. They do not receive any support for decision making and are not allowed to enter into legal commitments. A significant and positive step towards implementation of Art.12 of the CRPD is the elaboration of the draft Natural Persons and Support Measures Act which was adopted by the Council of Ministers in 2016 and was introduced for voting in the Parliament.

People with disabilities (especially those with intellectual disabilities and psycho-social problems) living in institutions have no access to any mechanisms of complaint before the courts, within the institutions where they live or before human rights institutions or organisations.

Social assistance is available only for very poor persons and families, only to those with permanent disabilities and is extremely insufficient to meet even their basic needs. Disability allowances are also extremely low and are received only by persons with permanent disabilities. Day care and consultation/rehabilitation services are provided in special centres and are not available for all persons with disabilities.

Although the number of children with disabilities in special schools has significantly decreased over the last ten years and over 14,000 such children are enrolled in mainstream schools every year, children with disabilities still cannot benefit of quality education as schools still lack expertise, accessibility, sufficient and qualified staff and funding to be adapted to their needs. Some children with complex needs, severe forms of disability or living in residential community-based services do not attend school at all. Vocational high school training for

children with disabilities is not developed and is largely unavailable.

Persons with disabilities (especially those with intellectual and psycho-social disabilities) are not provided with real opportunities for vocational training or employment on the open labour market. State funding and attention are mainly focused on specialized enterprises and the promotion employment measures (subsidized employment) on the open labour market which do not prove to be effective.²⁰²

While progress has been made in some aspects of support for people with intellectual disability in Bulgaria - largely prompted by the EU accession process as mentioned above - negligible changes have occurred in relation to the provision of early intervention for children with disabilities. EUMAP made specific recommendations that early intervention services should be made widely available throughout Bulgaria in order to maximise the potential of children with intellectual disabilities and facilitate their social inclusion to the fullest extent.²⁰³

Cognisant of the hard task faced by NGOs and other service providers due to the mentioned situation, one can cite a number of organisations which try hard to ameliorate the situation related to persons with mental disabilities or intellectual problems. For example, the Bulgarian Association for Persons with Intellectual Disabilities (BAPID)²⁰⁴ is a national network of parents' organizations which defends the right to dignified and independent life for persons with intellectual disabilities and their families.

They are advocates for national and local policy that respect the rights of people with intellectual disabilities and contributes to the building of the necessary supporting environment and inclusion in the society. BAPID also offers support for full involvement of persons with intellectual disabilities and their families in developing, monitoring and control over national, regional, and local policies, related to disabled persons. They support their members in realizing of their activities for people with intellectual disabilities and their families as providing information, expert and methodological consultations, financing and project implementation support.

BAPID is a member of the National Disability Integration Committee (with consultative functions to the Government) under the Council of Ministers and the National Disability Council, (consisting of similar nationally represented disability organizations) as well as a member of Inclusion Europe, the European Association of Societies of Persons with Intellectual Disability and their Families, Inclusion International and the European Association of Service Providers for Persons with Disabilities. Thus the organization has access to practical and theoretical experience of a working network of similar organizations on a transnational and international level.

²⁰² <http://www.bghelsinki.org/en/news/press/single/delayed-reform-and-implementation-rights-persons-disabilities-bulgaria/>

²⁰³ <https://frontline-ireland.com/intellectual-disability-services-in-bulgaria/>

²⁰⁴ <http://bapid.com/bapid/?lang=en>

BAPID, together with several other Bulgarian NGOs, has tried its level best to introduce programs and projects targeting the inclusion and independent living of the sector in question. One example of these programs would be 'Empowering People with Intellectual Disabilities'.²⁰⁵

In Bulgaria, as in many other countries, people with intellectual disabilities are still considered unable to make their own decisions and are thus placed under guardianship. Under the current legislation, people with intellectual disabilities are, instead of being given support to make their own decisions, being put under guardianship where someone else makes decisions for them. This puts persons with intellectual disabilities at risk of abuse, as the legal guardian may take all the decisions for and on behalf the person concerned, without in any way having to consult them.

The project 'Empowering People with Intellectual Disabilities' aims at demonstrating the practical feasibility of supported decision-making and thereby advocating for a change in legislation concerning the legal capacity of people with intellectual disabilities in accordance with Article 12 of the UNCRPD.

The type of decisions which are covered by the supported decision-making model developed during the project cover the following areas:

- Accommodation (for example the type of accommodation, location, whether to live alone or to share accommodation with others and with whom)
- Relationships and lifestyle (includes choosing who to spend the time with and doing what activities)
- Health issues (considering advice from medical professionals including making choices about treatment options)
- Financial decisions (how to manage, spend or save money)
- Contracts (providing necessary support to the person in order for them to understand the meaning and consequences of a contract)
- Specifically excluded from the supported decision making model developed during the project were decisions about marriage, voting and religion.

In the pilot project in the Bulgarian town of Vidin, networks of support have been established for 15 people with intellectual disabilities, with the assistance of a facilitator. Two cases have been successfully taken to court to remove guardianship measures imposed on two persons with disabilities.²⁰⁶

²⁰⁵ <http://www.right-to-decide.eu/2016/02/empower-people-with-intellectual-disabilities-bulgaria/>

²⁰⁶ Ibid.

Croatia

Croatia's social policy is not based on a coherent social investment approach, either at national, regional or local levels. Social policies remain largely passive, although the issue of active inclusion, including active inclusion in the labour market, has received greater attention in recent years. While all aspects of social policy remain a low political priority, those programmes which protect the rights of politically influential groups, notably war veterans and, to an extent, pensioners, tend to be prioritised at the expense of needs-based and evidence-based approaches.

There is little horizontal or vertical integration of policies, with little real co-ordination between different levels of government, or between governmental and non-governmental actors. Strategies tend to be developed separately for a series of so-called 'vulnerable groups' although most of these strategies are little more than wish lists with low implementation potential and, crucially, too few clear timelines, indicators, or budgets. In the context of fiscal consolidation required by Croatia's Excessive Debt Procedure, the idea of social policies as investment has remained underdeveloped and, often, long-standing or traditionally core social programmes which are compensatory in approach have tended to be better protected than more innovative social programmes which may have a stronger social investment component.²⁰⁷

Professor Natalia Lisak, PhD., from the Faculty of Education and Rehabilitation Sciences of the University of Zagreb, in a symposium held in April 2015, entitled Disability Studies in Post-Socialist Countries and organised by the European Social Work Research Association, highlighted the salient issues on the subject in question in Croatia.

She stated that many recent studies have shown that in the Republic of Croatia people with disabilities still face various types of barriers in the field of early intervention support, access to regular preschool and educational systems, access to the labour market and income maintenance and, ultimately the right to independent living and family life instead of institutional care.

In the Republic of Croatia the historical and political context which have shaped the current support system for people with disabilities as well as the theory and practice of the social work profession, was developed by the Soviet state policy. This is the reason why people with intellectual disabilities were considered as unable to enter paid employment and were put under the state institutional care.

Scholarship on disability in Croatia was developed in the 1960's when the High school for Defectology was established, as well as a High School for Social Work. Based on the medical model approach to rehabilitation²⁰⁸, disability policy has been based on rehabilitation and social care for people with physical, visual, hearing and intellectual impairments. The special

²⁰⁷ ec.europa.eu/social/BlobServlet?docId=13818&langId=en

²⁰⁸ Lisak, 2013

rehabilitation programs as well as centres were established across the country, where children and people with disabilities were placed to live. The biggest institutions were for people with mental and intellectual impairments, physical, visual and hearing impairments, children with chronic diseases as well as for children with poor family environment who have had some minor difficulties. In the discursive representations of disabled body are those of physically and war induced disabilities.

Based on an academic knowledge in the field of disability, the changes from the medical to the social model of disability started in the 1990's. Certain changes in providing support for persons with intellectual disabilities could be noted in the last thirty years through the implementation of new programs and by means of a new profile of experts engaged in support for educational inclusion. Six years ago, the Faculty of Education and Rehabilitation Sciences of the University of Zagreb introduced its doctoral degree program "Prevention Sciences and Disability Studies".

Since the 1990s, when state socialism collapsed and Croatia became an independent state, the focus of governmental policy was to develop community based public services for the vulnerable population such as children and people with disabilities and their families.²⁰⁹ Nevertheless, the process is slow and negatively influenced by the current economic crisis.

Organized support for people with intellectual disabilities is focused on community based support and family-centred approach. The aim is to integrate persons with disabilities into the local communities and to support the employment of people in the local area. The process of transformation of institutions started in 2011 and can be recognized through the establishment of the day centres and services and the community based supported housing which started to operate by newly established nongovernmental organisations.

The non-governmental organizations have an important role in this respect. Many important changes and public awareness to the quality of support for people with disabilities in Croatia were connected with the so-called process of NGO-ization.²¹⁰ NGOs have become very active in different daily activities for persons with disabilities. One of the NGOs that has an important role in this respect is the Association for Promoting Inclusion and the Self Advocacy Association established in the Republic of Croatia in the late 1990s and in the early 2000s.

The Association for Promoting Inclusion supports the development of a society in which people with intellectual disabilities have equal opportunities, their contributions are valued, and their human rights are respected. Based on these circumstances a certain number of persons with intellectual disability get the possibility to fight for their rights and to live independently in the community.

²⁰⁹ Lisak, 2013

²¹⁰ Završek, 2007

Nevertheless, recent reports have shown that there is still a gap between formal legislation and its implementation. The present situation is shaped by the legacy of the socialist tradition within the political system as well as the importance of the family and the family support system. There is a great importance given to the family support network which has a significant role in achieving the quality of life of people with disabilities and families in the country. Christian values and the impact of the Catholic Church organizations plays an important role as well.

The discriminative experiences include the lack of early intervention support for the disabled children, the lack of life-long support and a certain level of discrimination experienced by the health, social welfare and educational professionals.

Some families reported also about discrimination from the Catholic Church organizations that refused to enrol the disabled child into the kindergartens run by the church. The findings emphasize the role of the Catholic Church in empowering families but also show its discriminative angle which is based on the historic exclusion of the disabled from the church ceremonies. The Church was all for giving charity to the poor and the disabled, but has kept very rigid rules against the principles of diversity despite its normative principle of acceptance of every human being.

From a social work perspective it is very important to introduce transparency and availability of information about guaranteed rights in the existing support services of the social welfare system. This will serve to raise awareness of the acceptance of every person and respect for diversity in order to prevent rejection and exclusion of children with intellectual disabilities through institutionalization; to empower professionals for appropriate correspondence with parents of children with intellectual disability with full respect to the parents' perspective; to organize systematic support for social inclusion; to supervise professionals at the work place; to improve the quality of social service on local and regional levels; to organize systematic support for independent living in the community through organized housing and multidisciplinary team work and raising community awareness of children with disabilities and their families through social action.²¹¹

Government published a comprehensive National Strategy for Equalization of Opportunities for Persons with Disabilities 2007 – 2015. Its aims are evidently set in harmony with the UN CRPD and EU funds and state funds were reserved for nationwide programs on the subject in question.²¹²

However, more than 8,200 people with intellectual or psychosocial disabilities in Croatia remain in segregated institutions and psychiatric hospitals with little control over decisions that affect their lives. In 2014, the United Nations reviewed Croatia's efforts to put into effect the Convention on the Rights of Persons with Disabilities.

While the Croatian government has made some progress in protecting the rights of people with disabilities, the process of moving people out of institutions and into community-based living arrangements has been limited and slow, Human Rights Watch research found.²¹³ People

²¹¹ https://bib.irb.hr/datoteka/762228.Disability_Policy_in_Croatia_Lisak_Natalia.pdf

²¹² <https://dredf.org/legal-advocacy/international-disability-rights/resources/national-and-regional-strategic-plans-on-disability/>

²¹³ <https://www.hrw.org/news/2014/10/06/croatia-locked-and-neglected>

with certain disabilities are still legally deprived of their right to make decisions about their lives. The government's deinstitutionalization plan should include all state and private institutions where persons with disabilities live, and the government should revise the law on legal capacity so that all people with disabilities are allowed and encouraged to make their own decisions.

"People with disabilities have spent their whole lives locked up, deprived of things so many of us take for granted, like going to school and work, or deciding what time to wake up in the morning," said Emina Ćerimović, Koenig Fellow at Human Rights Watch. "The Croatian government needs to step up its efforts to develop community-based housing, care, and support so people with disabilities can lead the lives they choose."

Between April and August 2014, Human Rights Watch interviewed 87 people in three regions in Croatia, including people with intellectual and psychosocial disabilities and their families; staff of institutions; representatives of nongovernmental organizations, including groups for people with disabilities; government officials; and the Ombudswoman for people with disabilities. Human Rights Watch found that people in institutions experience a range of abuses including segregation from the community, verbal abuse, forced treatment, lack of privacy, and limited freedom of movement.

Eleven of 46 state institutions have begun the process of deinstitutionalization, and as of July 2014, 458 people with intellectual disabilities and 96 people with psychosocial disabilities have moved into the community.

However, more than 8,200 people with intellectual or psychosocial disabilities in all types of institutions in Croatia are still denied their right to live in the community.

The Croatian government's Plan on Deinstitutionalization and Transformation of Social Welfare Homes ("Master Plan"), adopted in 2011, excludes more than 1,800 people with intellectual or psychosocial disabilities who live in the 24 privately run but state-funded institutions. Moreover, the Master Plan does not cover the so-called family homes and foster families. Family homes, run by private individuals, accommodate up to 20 people with intellectual or psychosocial disabilities, while adults with disabilities are placed with foster families without their consent and with limited interaction with the community.

The Croatian government considers these categories non-institutionalized community living arrangements. However, Human Rights Watch research indicates that family homes are in fact small institutions and that foster homes where people are placed without their consent may amount to institutionalization, allowing people only limited interaction with the community.

People with psychosocial disabilities placed long-term, without their consent, in psychiatric hospitals are also not included in the Master Plan.

Roughly 18,000 people with intellectual or psychosocial disabilities are placed under guardianship in Croatia, and denied their legal capacity or the right to make decisions about basic rights, such as the right to marry and form a family, to sign an employment contract, or to hold property. A significant majority live under full guardianship, under which guardians – often nominated by the state – make all decisions for them.

In 2008, Croatia ratified the United Nations Convention on the Rights of Persons with Disabilities, the human rights treaty that requires governments to move away from institutionalization and guardianship and instead to provide opportunities for people with disabilities to live in the community and make decisions about their lives with assistance, if needed.²¹⁴

In addition, the Croatian social protection system creates disincentives for people with disabilities to work; for example, those who work full-time are ineligible for community-based housing. Lack of formal education and access to education, stigmatization, and discrimination also make it very difficult for people with disabilities to obtain employment.

People with disabilities confined in institutions have not only been deprived of the choice about where and how to live, but have very limited access to education, work, and health care. For instance, people in the institutions Human Rights Watch visited had very poor dental hygiene. Staff said residents had limited, if any, access to dental care.

Each person spends about six months preparing for life in the community. Staff work with them to identify their needs, strengths, life goals, and plans, including how, where, and with whom they want to live and what support they need. This individual planning also involves building daily life skills such as cooking, housekeeping, personal hygiene, and even social interaction. For this purpose, the home built a mock apartment where people learn how to cook, do dishes, and wash and iron their clothes. Once the residents move to community-based housing, institution staff provide regular support services based on the individual's needs, such as dealing with financial matters, helping with public transportation, and facilitating access to community health services.²¹⁵

While a national strategy for people with disabilities has been adopted, legislation remains inconsistent, implementation continues to be irregular, and a lack of coordination among the various responsible bodies leaves many people with intellectual disabilities without the support they need to fully engage in society. Education is for the most part segregated, as only children with mild intellectual disabilities are placed in mainstream schools; those in special schools often receive a substandard education that leaves them unprepared for employment or any form of independent living. Access to the employment market is equally limited for people with intellectual disabilities; services are not tailored to the needs of this population, and supported employment opportunities are offered only through NGOs that can reach only a tiny fraction of those who would benefit. Croatia should take advantage of this period where international attention and support is at its strongest to demonstrate a clear will to improve the situation of people with intellectual disabilities in all aspects of society.²¹⁶

Very limited support for the transition from education to employment is available to people with intellectual disabilities in Croatia. Several forms of vocational education are open to people with intellectual disabilities, some offering a diploma and others only a certificate, which is of

²¹⁴ Ibid.

²¹⁵ https://www.opensocietyfoundations.org/sites/default/files/croatia_2005_0.pdf

²¹⁶ http://undp.ivisa.com/upload/file/130/65078/FILENAME/WEB_engleska_verzija.pdf

very limited use on the employment market. People with intellectual disabilities are entitled to register at their local employment office upon completing their education, but studies suggest few actually do so, and therefore only a small number of people with intellectual disabilities take advantage of the services these employment offices provide. More intensive efforts on the part of the Ministry of the Economy, Labour, and Entrepreneurship to promote these services among people with intellectual disabilities could result in better access to the employment market.

Croatia's Constitution guarantees the right to work, and provides for special protection at work for people with disabilities. Legislation also provides for the right to professional rehabilitation, training for employment, for people with disabilities.

The Labour Law does explicitly prohibit discrimination in hiring and employment on the basis of physical or mental disability. Eligibility for social benefits is assessed by an expert body at the local centre for social welfare; concerns have been raised that these assessments vary greatly in quality and focus on incapacity, rather than taking into account an individual's potential. The Service for Professional Orientation conducts assessments to determine eligibility for vocational training programmes; this process has come under criticism as it places an undue emphasis on IQ, rather than on specific capacity to perform a given job. People under plenary guardianship often do not receive a separate assessment of their capacity to work, as the loss of full civil capacity is presumed to preclude any employment. Several different forms of social benefit are available to people with intellectual disabilities, but the administration of these benefits is problematic; in certain cases, parents have sought to have their children declared unqualified for work so the child retains eligibility for one type of benefit, for example, the family pension.

On the plus side, Croatia has adopted several employment incentive programmes, with specific provisions relating to people with disabilities. These measures have had some success in finding jobs for people with disabilities, and people with intellectual disabilities have found work through this programme, although there are no initiatives targeting the population with intellectual disabilities. The long-term success of these efforts remains unclear, as there are indications that retention of employees hired under these measures is poor beyond the period of State salary co-financing.

Quota requirements are in place for governmental bodies, and a penalty is applied to workplaces that do not meet hiring quotas for people with disabilities. These penalties are too low to be an effective means of enforcement, however. Very few people with intellectual disabilities have any form of employment. Exact figures on the number of people with intellectual disabilities who are unemployed are unreliable, as many people do not register as unemployed.²¹⁷

Supported employment is available only on an extremely limited basis in Croatia. One NGO, with international support, has developed a supported employment programme, and other organisations follow, but there is no robust Government support for such initiatives. Around 400

²¹⁷ Ibid.

people with disabilities work in sheltered workplaces, which are segregated and do not enhance inclusion. Although some of these workshops are intended to give participants the skills and training necessary to make the transition to work on the open market, few people are able to actually make the transition from sheltered employment to any other form of work.

The Association for Promoting Inclusion (API), for instance, is a non-governmental organization established in 1997 in Zagreb, Croatia. Its mission is to promote the development of a society in which people with intellectual disabilities have equal opportunities, their contributions are valued, and their human rights are respected. The focus of API's work has been to develop models of community-based services, such as supported housing and specialized foster family care, to enable children and adults with intellectual disabilities to move from large residential institutions to a life in the community.

API offers supported housing services to persons with intellectual disabilities in rented apartments. In 2000, API negotiated the recognition of supported housing as a social welfare service for persons with intellectual disabilities, and identified a loophole in the Social Welfare Law that enabled it to register its program as a residential institution offering services in the community. In 2003 the law was amended, and 'organized housing' was introduced as a new type of service. In 2008 the Ministry of Social Policy and Youth developed the regulatory mechanism for organized housing, and API has continued to provide services, including employment and volunteering activities.²¹⁸

The summation of the situation in Croatia can best be stated by quoting Predrag Bejaković from the Institute of Public Finance of Zagreb. He states that Croatia has to find and develop constitutional and legal arrangements for reducing social exclusion that best suit its own historical, social, cultural and economic situations, conditions and possibilities. Government could provide stable legal framework, social infrastructure and with the co-operation of its citizens establish the rule of law. Otherwise, socially excluded persons will suffer most from the lack of clear laws and the unwillingness of society to create social inclusion in blatant disrespect of the law. In order to make legislation work, political will and leadership commitment is vital. Just as important is the empowerment of citizens and their full participation in the political process. All partners hope to significantly improve the social picture of Croatia, hoping that their efforts will achieve expected results.²¹⁹

²¹⁸ <https://zeroproject.org/practice/association-for-promoting-inclusion-api-croatia/>

²¹⁹ <http://www.ijf.hr/eng/progress/long.pdf>

Cyprus

Ever since Cyprus took it upon itself to implement the UN CRPD and ensure that its laws and legislation positively affected the lives of persons with intellectual disabilities and mental health issues, an extensive upgrading exercise of upgrading or doing away with old archaic existing laws had to be executed.

Laws in Cyprus adopted several decades ago use terms to refer to persons with mental health problems that today are considered as pejorative and possibly even offensive. For example, the 1959 Mental Health Law in Cyprus, which has been repealed, included the terms ‘insane’, ‘lunatic’ and ‘idiot’.²²⁰

Another case in point was the Cypriot Law on Persons with Disability. This includes in its definition of disability “mental or psychological limitation permanently or for an indefinite duration which, considering the background and other personal data of the particular person, substantially reduces or excludes the ability of the person to perform one or more activities or functions that are considered normal or substantial for the quality of life”. The requirement that the limitation is permanent or of an indefinite duration and that it reduces or excludes the ability of the person to perform one or more activities or functions that are considered normal or substantial for the quality of life may be interpreted in a way that excludes mental health problems. At the same time, it leaves some leeway for courts to assess the situation in a given case, although to our knowledge such a case has not yet been brought in Cyprus.²²¹

Similar scenarios could also be seen with regards to laws and regulations covering employment issues and the furthering of opportunities for persons with disability in Cyprus.²²² The European Union Agency for Fundamental Human Rights positively noted that Cyprus ‘implemented different types of measures to bolster young people’s access to employment, education and training in 2015. Examples include...personalised guidance to any or all of the following: young persons with disabilities, parents, single parents, women, early school leavers, recent graduates and those in long-term unemployment. Cyprus also took action to counter discrimination based on disability.’²²³

Accordingly, the Cyprus IMM (Independent Monitoring Mechanism) was established according to article 33 (2) of the CRPD, as a result of a Council of Minister’s Decision dated 9 May 2012 which granted such competences to the Commissioner for Administration and Human Rights (Ombudsman). The mechanism was later named “Independent Authority for the Promotion of the Rights of Persons with Disabilities” (Ανεξάρτητη Αρχή Προώθησης Δικαιωμάτων Ατόμων με Αναπηρία) and this name is used since, at national level.

For this appointment, the Council of Ministers took into account the constantly expanding competences and functions of the Office of the Ombudsman in the area of combating

²²⁰ <http://fra.europa.eu/en/publication/2011/legal-protection-persons-mental-health-problems-under-non-discrimination-law>. Page 21.

²²¹ Ibid. Page 23.

²²² European Union Agency for Fundamental Rights, on the rights of persons with disabilities from published reports related to Cyprus fra.europa.eu. Page 63. February 2017, Vienna

²²³ Ibid. Page 65.

discrimination and human rights violations. The competences of the IMM cover the public as well as the private sector.²²⁴

The IMM report is clear in its reading of the Cypriot present state of affairs in this regard. Even though Action 1.1 of the NDAP called for the review of the legislation on “regulating the rights of persons with disabilities” with the aim of implementing state obligations under the CRPD, little has been done in this direction. This was largely owed to the lack of essential participation of persons with disabilities along with their representative organizations and the lack of systematic commitment and review mechanisms to this end. The non-uniform understanding of the CRPD amongst the Article 33 Mechanisms and the public authorities involved - especially with regards to its binding legal nature, the human rights model and the extent of the obligations arising thereunder - is quite worrying. Such procedure requires a clear strategy incorporating unambiguous criteria as to what is and what is not compatible with the CRPD (e.g. human rights indicators). Such a strategy should be adhered to in a consistent manner by all ministries and implicated authorities while at the same time being under close and constant supervision and coordination by designated authorities/bodies within the government.

Disappointingly, the developments that did take place after the ratification of the CRPD, did not or did not adequately take the CRPD into account. This is evident in the amendments completed or promoted but also in the statutory language used therein. Such developments include legal amendments completed or pending approval as well as the establishment of new policies/schemes, practices or even new decision-making bodies that do not have the CRPD as their core. An example of such a body is the establishment of a new ministerial committee. The ombudsman is on record as being concerned about the non-participation of representatives of persons with disabilities in the Committee and the potential overriding of the CRPD mechanisms/framework.²²⁵

More specifically, although the Law for Persons with Disabilities was amended twice after the ratification of the CRPD (in 2014 and in 2015), such amendments did not lead to the adoption of the CRPD’s concept of disability in substitution of the medical model definition and neither did they provide that denial of reasonable accommodation amounts to disability discrimination.

Another example concerns the ongoing amendment proposal of the Social Insurances Law which does not include any amendment on the current definition of disability. This definition fails to distinguish between impairment and disability and is particularly stigmatizing (“disability” signifies loss of health, strengths or the ability to enjoy life”).²²⁶

A further example would be the proposed legislation for the Homes for the Elderly and Persons with Disabilities or the Adult Centres Laws which was not based on CRPD standards and in particular, the standards of Article 19. An additional example is found in the pending amendment of the Laws for Radio and Television Stations which does not include proposals for strengthening compliance with the CRPD or for including prohibition of discrimination on the ground of disability within the rest of the prohibited discrimination grounds.

²²⁴ First State Report (SR) and National Disability Action Plan (NDAP): July 2013 and Reply to List of Issues (SRLol): December 2016.

²²⁵ Independent written contribution by the IMM to the UN Committee on the Rights of Persons with Disabilities, 2017.

²²⁶ Article 2.1 of the Law.

Lastly, there are concerns which need to be expressed with regard to the recently adopted Order for care (under the Minimum Guaranteed Income Law) in that, again, the notion of care was not approached under the guidance of the CRPD. The same can be said with regards to the IMM investigating complaints with regards to the implementation of the law on a quota system in employment in the public sector. The IMM made a series of recommendations concerning the assessment procedure and tools being used focusing on the aspect of personal and functional limitations and the non-assessment of environmental barriers.²²⁷

Thus, the independent IMM report mentioned above basically reiterates another study conducted in June 2015. Simoni Symeonidou penned a profoundly researched paper entitled 'Rights of People with Intellectual Disability in Cyprus: Policies and Practices Related to Greater Social and Educational Inclusion'. The paper focuses on the extent to which policies and practices concerning the education and independent living of people with intellectual disability in Cyprus allow for the full enjoyment of rights under Articles 19 and 24 of the UNCRPD.

Data was gathered through a systematic web search for documents of local, international, and European bodies, covering the period April 2007 to July 2014. Documents reviewed included annual reports, country reports, legislative documents, conference papers, and newspaper articles.

Findings show that the Republic of Cyprus has not taken significant measures to implement Articles 19 and 24 of the UNCRPD. Existing policies and practices greatly restrict people with intellectual disability from exercising their human rights and fail to promote social and educational inclusion. The study raises questions about the essential nature of policies and practices for people with intellectual disability that may inform the debate in other national contexts.²²⁸

The Project for the Implementation in Cyprus of a New System for Assessing Disability and Functioning was incorporated in the Operational Programme "Employment, Human Capital and Social Cohesion" 2007-2013, with a total budget for the entire period of implementation until June 2015 amounting to € 3.2 million.

The project is co - funded by the European Social Fund and national funds in a ratio of 70% and 30% respectively. The project is implemented by the Department for Social Inclusion of Persons with Disabilities under the Ministry of Labour, Welfare and Social Insurance. The aim of the project is to identify and assess, based on a systematic and scientifically justified methodology, the disability of an individual and, optionally, his or her functioning. It also aims to document suggestions for appropriate interventions that will support and enhance the person's social inclusion. By applying the scientific basis of the International Classification of Functioning, Disability and Health issued by the World Health Organization, and by using specially designed assessment protocols, the certification of disability is based on a more

²²⁷ Law for the Employment of Persons with Disabilities (Law 146(I)/2009).

²²⁸ <https://onlinelibrary.wiley.com/doi/abs/10.1111/jppi.12120>

scientific, reliable and objective basis, treating people with disabilities with respect and dignity, serving the public services with professionalism and upgrading the knowledge for all types of disability: motor, sensory, intellectual and mental.²²⁹

State initiatives promoting disability integration and independent living however, are hard to quantify, when it comes to actual benefits for persons with disability in Cyprus. Professor Bent Greve, from the University of Roskilde, Denmark, was entrusted with a report to be prepared for the Academic Network of European Disability experts (ANED). The report, entitled 'The labour market situation of disabled people in European countries and implementation of employment policies: a summary of evidence from country reports and research studies' singled out Cyprus, amongst other countries, as a state where reported data is not reliable or updated.²³⁰

This does not mean that the state was idle on the subject matter. Government funding, throughout this last decade, was also put aside in order to create an on-going series of initiatives with the voluntary sector, which the Cypriot authorities refer to as network projects. One such example out of many is a project organized by the Pan-Cyprian Volunteer Coordinative Council with the participation and the co-operation of all its member organizations.

It was targeted to empower vulnerable groups (currently or potentially exposed to discrimination) by mobilizing the voluntary sector, which is the main welfare provider and representative of these groups at policy making processes of the right of equal opportunities; to launch awareness raising/promotional activities to policy makers and the general public so as to respect and understand the benefits of diversity and present the valuable contribution of volunteers in promoting equal opportunities and to initiate promotional and other activities with a strong multiplier effect. Frequent such similar initiatives are executed every year throughout Cyprus.²³¹

As mentioned above, civil society voluntary organisations, NGOs and other organisations are essential in Cyprus in providing services for persons with mental and/or intellectual disability.²³² Several examples can be cited. However, services for the persons with mental disabilities are provided by "Nea Eleousa", the State Institution for people with severe mental disabilities and by four State Community Houses that operate in the Nicosia district.

"Nea Eleousa" was opened in September 1977 on a 24 hours basis and accommodates circa 30 adults and children with severe mental disabilities. The institution aims to:

- improve the patients' physical and mental abilities through a wide range of care services and treatments;
- assist and give respite to the patients' families from their everyday care;

²²⁹ [http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/A6FC55828DB3BE65C2257DCD00421701/\\$file/FLYER_english.pdf](http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/A6FC55828DB3BE65C2257DCD00421701/$file/FLYER_english.pdf)

²³⁰ <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.469.998&rep=rep1&type=pdf>

²³¹ [www.mjpo.gov.cy/mjpo/mjpo.nsf/.../\\$file/national%20strategy_english.doc](http://www.mjpo.gov.cy/mjpo/mjpo.nsf/.../$file/national%20strategy_english.doc)

²³² <http://infocyprus.com/citizen/social-welfare/disability-and-illness/mentally-disabled-persons>

- raise their households' standard of living by giving the family members the opportunity to enter into the labour market, thus increasing their income flow.²³³

Another good practice in this sector can be found in the Centre for the Vocational Rehabilitation of Persons with Disabilities. This centre operates under the Department for Social Inclusion of Persons with Disabilities and aims to design and implement vocational training programs and to co-ordinate or provide funding for programs that promote disabled people's employment, either in the open market or in sheltered workplaces.²³⁴

More importantly, the department is now working towards the development of a unified disability assessment plan, which is expected to facilitate disabled people's inclusion in different areas (society, education, employment). In parallel, the department continues to coordinate existing schemes targeting employers who wish to hire disabled people in their workplaces or disabled individuals who wish to establish their own business.

Home care services provided by Social Welfare Services are partially covered and are limited to the physical needs of the persons with disabilities rather than their social inclusion and their participation in society²³⁵. As a result, the majority of persons with disabilities in Cyprus are "trapped" in their homes with no real social life, while the State only gives inadequate financial assistance to adults with disabilities (approximately 85% of the persons with intellectual disability according to the annual report 2015 of the Committee for the Protection of the Rights of People with Mental Handicap).²³⁶

The necessary financial support provided by the public departments is given only as compensation for their disability mostly because of the lack of essential services that persons with disabilities need in order to live independently and to be included in the community. Independent living is still a great challenge in Cyprus, especially for persons with intellectual disabilities who, in some cases, against their declared will, live in institutions for elderly people or other residential institutions (10%).²³⁷ At the moment, the objective of deinstitutionalization is missing completely from all policies and legislation managed but also from the discussions held with the responsible authorities.²³⁸

With regards to inclusive education, Cyprus adopted new legislation in 1999 (L. 113(I)/99).²³⁹ The Law on Education and Training for Children with Special Needs (L. 113(I)/99) introduced the concept of integration in Cyprus, but until today the existing legislation legitimizes the establishment, further existence and formation of new special schools and special classroom environments in the mainstream schools.

²³³ <http://www.supportedemployment.eu/best-practice/24-cyprus>

²³⁴ http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/dsipd08_en/dsipd08_en?OpenDocument

²³⁵ Terms and Conditions of the Director of Social Welfare Services for provision of home care services, 2015.

²³⁶ Annual Report of the Committee for the Protection of the Rights of People with a Mental Handicap for the Year 2015.

²³⁷ Ibid.

²³⁸ <http://www.kysoa.org.cy/kysoa/userfiles/file/nomotheties/20160905%20Cyprus%20Alternative%20report.pdf>

²³⁹ Law on the Recognition of Cyprus Sign Language (L. 66(I)/2006 available at:

http://www.kysoa.org.cy/kysoa/userfiles/file/nomotheties/nomoi%20voulis/pdf/14_66_2006.pdf

There is no personalized approach to students and their preparation for developing individual skills, mobility skills and skills for their integration in the open labour market and in society in general. Furthermore, the teaching staff of mainstream schools does not yet receive appropriate training in disability matters. The teaching method that the Ministry of Education follows is not in line with the values of universal design for learning. As a result, children with disabilities are prevented from having equal opportunities in mainstream education. Moreover, some essential therapies such as physiotherapy, occupational therapy and speech therapy are provided only in special schools, so parents prefer that their children with an intellectual or other disability attend the special schools instead of regular ones.

Another very important issue is also the fact that no special education teachers are provided by the Ministry of Education and Culture to secondary mainstream schools. Children with disabilities are attending lessons outside their classroom, by teachers that mostly are not educated to teach children with disabilities.²⁴⁰

According to statistical data from the Ministry of Education and Culture for, five thousand one hundred eighty six (5.186) children with “special needs” were living in Cyprus. Three hundred forty three (343) of them were students between the ages of 3-21 who visited special schools and four hundred forty five (445) children were in the above-mentioned “special units” (seven hundred eighty eight (788) in total). Another one thousand and thirty-three (1033) students with disabilities were integrated in the primary school.

The remaining three thousand three hundred sixty five (3365) of the registered students with special needs were visiting different types of secondary classrooms. According to the above data 15.2% of children with special needs were in special schools and special units, in contrast to 19.92% who were taught in primary schools and 64.89% who were in the secondary education.²⁴¹

Persons with disabilities are much more often affected by unemployment than other people. According to the archives of the Pan-Cyprian Alliance for Disability, the percentage of severely disabled people who are excluded from the labour market reached 60% in 2011 and 80% in 2016. This partly results from the lack of job opportunities on the regular labour market and the Government policy to cancel any implementation of Incentive Schemes for employment of persons with disabilities or other appropriate measures in accordance with the CRPD.

Also, due to the economic crisis, employment opportunities for persons with disabilities are almost non-existent, either in the private or the public sector, where all vacant posts have been frozen, making the existing Quota System Law almost inactive.

²⁴⁰ <http://www.kysoa.org.cy/kysoa/userfiles/file/nomotheties/20160905%20Cyprus%20Alternative%20rep%20ort.pdf>

²⁴¹ Statistical data given in a meeting of the Thematic Technical Committee on Education and Vocational Training, by an Officer of the Cyprus Ministry of Education and Culture.

Despite the very high percentage of unemployment rate among severely disabled people, the Cypriot Government emphasized in par. 15 of the State Report the absence of “systematic mechanisms for the assessment of disability, functioning, vocational needs and abilities for employment of persons with disabilities as well as mechanisms to offer adequate motives for integration in the work force and in occupations on demand”, instead of including in the said measures very specific actions, not declarations of intentions, but vision and inspiration.

We have already noted that, due to the extensive austerity measures, with regards to the suspension of the procedures laid down in law for filling vacant positions, the abolition of a large number of positions, the freezing of recruitments in the public sector and the restriction of their rights in general, adopted by the government in 2012, hundreds of vacant persons with disabilities were competing or might have competed are not any more available to apply to the public sector.

Consequently, law and procedures for recruiting persons with disabilities were cancelled restricting in this way the right to work and being included as active members in the society (articles 27 & 19 of the CRPD).

The organizations of persons with disabilities expressed in various opportunities their disappointment about the way of implementation of the above legislation²⁴², resulting in excluding persons with disabilities from the labour market, contrary to the goals of the law. The most important violation of the human rights perspectives of persons with disabilities, is the assessment of candidates for the different vacancies to the broaden public services sector, using a tool which is based on the medical approach, giving priority to the criterion of functionality. The principle of reasonable accommodation is totally ignored mainly by the Public Education Service Commission, which is responsible for taking the final decision of recruiting persons with disabilities in the education service, leading to the rejection of the applicants from that service.

Disability NGOs were, however unanimous in lauding successful measures for persons with disabilities, such as the schemes of subsidizing the employment of persons with disabilities under the axis "Enlargement of the Labour Market and Social Cohesion" included in the Organizational Programming Period of 2007 – 2013.²⁴³ The same can be said for a new Incentive Scheme for the Employment of Persons with Disabilities in the Private Sector and the introduction of the Supported Employment Scheme.²⁴⁴ Some 300 persons, mainly with intellectual disabilities, are supported in the latter scheme.²⁴⁵

One of the most important actions included in the national disability action plan was the requirement of establishing a framework (which had to be implemented until 2015 with no required expenditure) that would set up and operate on suitable structures and services for

²⁴² L. 146(I)/2009

²⁴³ See par. 214 of the State Report.

²⁴⁴ This has been running since 1994.

²⁴⁵ <http://www.kysoa.org.cy/kysoa/userfiles/file/nomotheties/20160905%20Cyprus%20Alternative%20rep%20ort.pdf>

independent living of persons with severe disabilities, including the provision of appropriate support services where necessary (par. 21 of NDAP).²⁴⁶

Unfortunately, minimal or next to no progress was made in this respect. The NDAP fails to address the urgent need for the adoption of effective deinstitutionalization legislation and policies. At the moment, the objective of deinstitutionalization is missing completely from all policies and legislation managed but also from the discussions held with the responsible authorities, being the departments of the Ministry of Labour, Welfare and Social Insurance, especially the Social Welfare Services and the Department for Social Inclusion of Persons with Disabilities but also the Mental Health Services that fall under the competence of the Ministry of Health.

The only initiative in this direction related to the deinstitutionalization of 8 persons with severe intellectual disabilities and behavioural disorders, hospitalized for years in “Athalassa Psychiatric Hospital”, the main mental health facility in Cyprus.²⁴⁷

These persons are now placed in two small housing units and receive care under the competence of the Department for Social Inclusion of Persons with Disabilities. This was an action decided in 2010. However, it was implemented in 2016 and the procedure followed raises significant concerns such as: whether a deinstitutionalization procedure was put in place or whether the persons deinstitutionalized were the “easier” cases.

In other words, there is no evidence to suggest that any measures were taken in order to achieve deinstitutionalization other than the recognition that persons with disabilities needing less support could be removed from psychiatric facilities. There is evidence suggesting that the initial plan was that more persons were to be deinstitutionalized, however, there is nothing to explain why this objective has, with time, been abandoned.

Finally, there are concerns as to what are the future plans to be applied, regarding those already “deinstitutionalized” and whether the acts taken are in the direction of achieving real autonomy and social inclusion or simply perpetuate institutionalization in a different environment.

Independent living remains a great challenge for all persons with disabilities. Although it is directly related to the right of self-determination, homes in the community are used as emergency solutions when families cannot meet the person’s care needs hence, the introduction in institutions or care homes is clearly not a matter of choice for persons with disabilities, especially persons with intellectual or mental disabilities.

²⁴⁶ National Disability Action Plan available at:
http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/dsipd08_en/dsipd08_en?OpenDocument

²⁴⁷ Ibid. Par. 23.

Only 3% of persons with intellectual disabilities live in houses in the community.²⁴⁸ Consequently there are many people with disabilities in Cyprus who are not free to choose their place of residence, type of housing and/or type of support. They have to deal with serious barriers in the exercise of their right to self-determination for a number of reasons. Among such reasons is the fact that in certain cases, the cost of the provision of care, assistance and support in institutions will more easily be covered as opposed to the cost occurring during home care.

²⁴⁸ Annual Report of The Committee for the Protection of the Rights of People with a Mental Handicap for the Year 2015.

Czech Republic

The Czech government ratified the UN Convention on the Rights of Persons with Disabilities in 2009, designating the Public Defender of Rights (Ombudsperson's office) as the "National Preventive Mechanism", the body responsible for visiting all facilities in which people may be deprived of their liberty.

This ratification signalled its commitment to moving towards recognition of the dignity, autonomy and liberty of everyone with disabilities – including those with mental health issues, dementias and intellectual disabilities. Ratifying these treaties, however, has not substantially reduced overall levels of coercion within psychiatric institutions, a point which has also been reported by the Public Defender of Rights. We will be discussing psychiatric institutions further down.

According to the official governmental ministries and agencies²⁴⁹, people with disabilities receive a higher degree of protection in the labour market. The main tools and services utilised are as follows:

Vocational Rehabilitation - continuous activity aimed at acquiring and maintaining suitable employment for a person with a disability, provided and financed, upon application, by the Labour Office. In cooperation with a person with a disability, the Labour Office will compile an individual plan for vocational rehabilitation.

Training for a job - initial training of an individual with a disability for a suitable job based upon an agreement with the Labour Office. The training for a job may be performed with an assistant's support. The training lasts for a maximum of 24 months.

Specialised retraining courses - performed under identical conditions as other retraining.

Sheltered employment - a sheltered work position is a position created by an employer for an individual with a disability based upon a written agreement with the Labour Office. A sheltered work position must be maintained for at least 2 years from the day specified in the agreement.

The Labour Office may award an employer a contribution towards the creation of a sheltered work position and a sheltered workshop. An employer who provided training for disabled individuals may receive full costs of such training for disabled individuals, from the Labour Office. An employer who employs more than 50 per cent of his staff as persons with disabilities, out of the total number of employees, is entitled to a financial or tax relief contribution.

Employers who employ more than 25 people are required to employ individuals with disabilities to the proportion of 4 percent out of the total number of employees. The methods of

²⁴⁹ <https://www.mpsv.cz/en/1612>

meeting this obligation, that is employment relationship, acquisition of products and services or penalty payments to the state budget, are considered to be equivalent and may be mutually combined.²⁵⁰

In a country which spends a mere 0.26% GDP on mental health service provision,²⁵¹ moving to a community-based mental health provision remains low on the government's set of priorities, partly because of a lack of political will, and partly because of a lack of investment.

In 2012, the UN Committee against Torture noted that the high level of psychiatric coercion reflected a failure by the Czech government to adopt mental health reforms, expressing concern at "reports of frequent placement of persons with intellectual or psychosocial disabilities in social, medical and psychiatric institutions without their informed and free consent". Reforms had been slow and piecemeal, the Committee found, causing concern to be raised about "the continued use of cage-beds, despite the prohibition in law, and of net-beds as well as the use of other restraint measures such as bed strapping, manacles, and solitary confinement, often in unhygienic conditions and with physical neglect".

"In addition, the "absence of investigations into the ill-treatment and deaths of institutionalized persons confined to cage and net-beds, including suicides" was a matter of particular concern highlighted by the Committee.

On 30th June 2014, the Mental Disability Advocacy Centre published "Cage beds and coercion in Czech psychiatric institutions" which exposed the continuing use of cage beds and other highly coercive practices in Czech psychiatric institutions. Based on human rights monitoring missions conducted in 2013, the report found that there has been little progress in respect for the human rights of people with mental health issues in Czech psychiatric facilities, with high levels of use of strapping, chemical restraint and isolation in the context of chronic underfunding.²⁵²

The Mental Disability Advocacy Centre has been very active in the Czech Republic, mostly by means of its partner NGO the League of Human Rights (an NGO based in Brno, Czech Republic).²⁵³ They have been jointly working to advance the rights of children and adults with intellectual and psycho-social disabilities.

Amongst the most active NGOs in the Czech Republic, one finds Inclusion Czech Republic²⁵⁴ (SPMP CR). It is a nationwide non-profit organization defending the rights and interests of people with intellectual disabilities and their families. Its membership organizations are located in all the regions and principal towns of the Czech Republic. The organisation provides educational activities for children and adults with intellectual disabilities, as well as for people who live or work with them.

²⁵⁰ Ibid.

²⁵¹ The average in the EU is 2%.

²⁵² <http://www.mdac.info/en/Czech-Republic>

²⁵³ <http://llp.cz/>

²⁵⁴ <http://inclusion-international.org/czech-republic/>

They provide different kinds of social services and sheltered workshops. Inclusion Czech Republic lobbies for the implementation of the UN Convention on the Rights of Persons with Disabilities, comments on relevant laws and supports the deinstitutionalisation. They transpose important information into easy-to-read tools and support the development of the self-advocacy movement.

Other NGOs also organise Community Living Arrangements as a good practice example of community inclusion projects in the Czech Republic. One of the NGOs in question is RYTMUS.²⁵⁵ These projects are based on providing a social service for people with disabilities who left institutional care after decades of years. Their main goal is to ensure that people will be included into the community through employment, a positive social role (e.g. like volunteers in their community) and social relationships with people in neighbourhood.

The key activities of these projects are those of using person centred planning; providing support in decision making and the strengthening of civil rights; and providing support in the development of skills for inclusive living in the community.²⁵⁶

Although injections from civil society organisations are essential, the main responsibility of reforms related to the subject matter rests wholly on the state. The National Reform Programme (NRP) of the Czech Republic of 2016 does not directly refer to disability in strategic targets – employment, education, fighting poverty and social inclusion. The NRP only provides general information on measures taken to tackle issue of early school leavers from vulnerable groups such as Roma and children with disabilities.²⁵⁷

However, this Strategy shows the direction which addressing social exclusion should take. It promotes socially responsible values related to combating social exclusion, highlights the shortcomings in the search for solutions to social exclusion and encourages the spread of the principle of social inclusion mainstreaming at all levels of government. At a time when certain parts of the CR experience social tensions, which is, inter alia, a direct consequence of social exclusion, it is essential to show the political and moral will to deal with the new situation not only by introducing specific measures, but also by building a social discourse which will lead to the strengthening of social cohesion. Therefore, the document also aims to contribute to the creation of such a social climate with conditions for policies aimed at weakening or slowing down social exclusion.²⁵⁸

The strategy also gives one the possibility of exercising a comparison of national employment trends for disabled and non-disabled women and men, compared with the EU2020 headline indicator for the EU as a whole, shows progress registered in this field:²⁵⁹

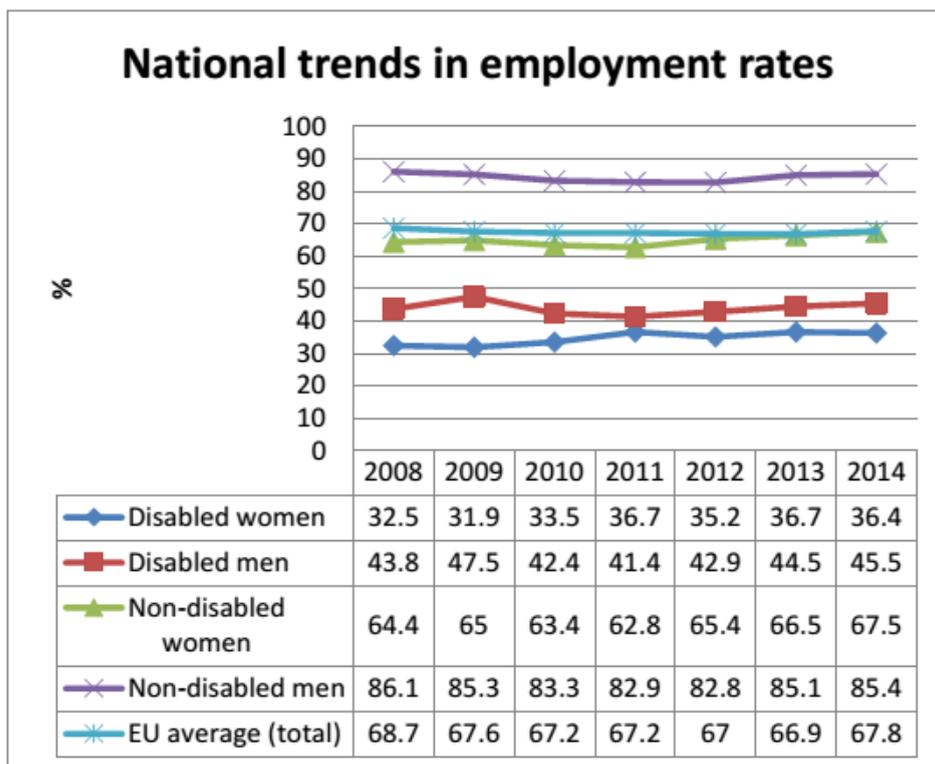
²⁵⁵ <http://www.rytmus.org/>

²⁵⁶ http://www.personcentredplanning.eu/images/OnlineKnowledgeCenter/Multiplication_Course/365-steps-for-Mcu-Czech-Republic-draft-web.pdf

²⁵⁷ The National Reform Programme of the Czech Republic 2015, p. 43 http://www.vlada.cz/assets/evropske-zalezitosti/aktualne/NPR-2015_EN.pdf

²⁵⁸ https://www.mpsv.cz/files/clanky/19478/Strategie_EN.pdf Page 7.

²⁵⁹ EUSILC UDB 2014 – version 2 of August 2016 (and preceding UDBs).



The data on employment gives an overview of employment rates in EU28 and the Czech Republic. The employment rate (no disability) in the Czech Republic is slightly higher than the EU average (72.5%). In contrast, the employment rate of disabled men and disabled women in the Czech Republic is estimated as much lower than the EU28 average. This difference between employment rates - disability national average and EU disability average - is more than 10 percentage points for those reporting moderate levels of impairment

With regards to where persons with disabilities are employed, there are only statistical data available on new work places in sheltered workshops. Similarly, there is no overall data on fulfilment of the disability employment quota.

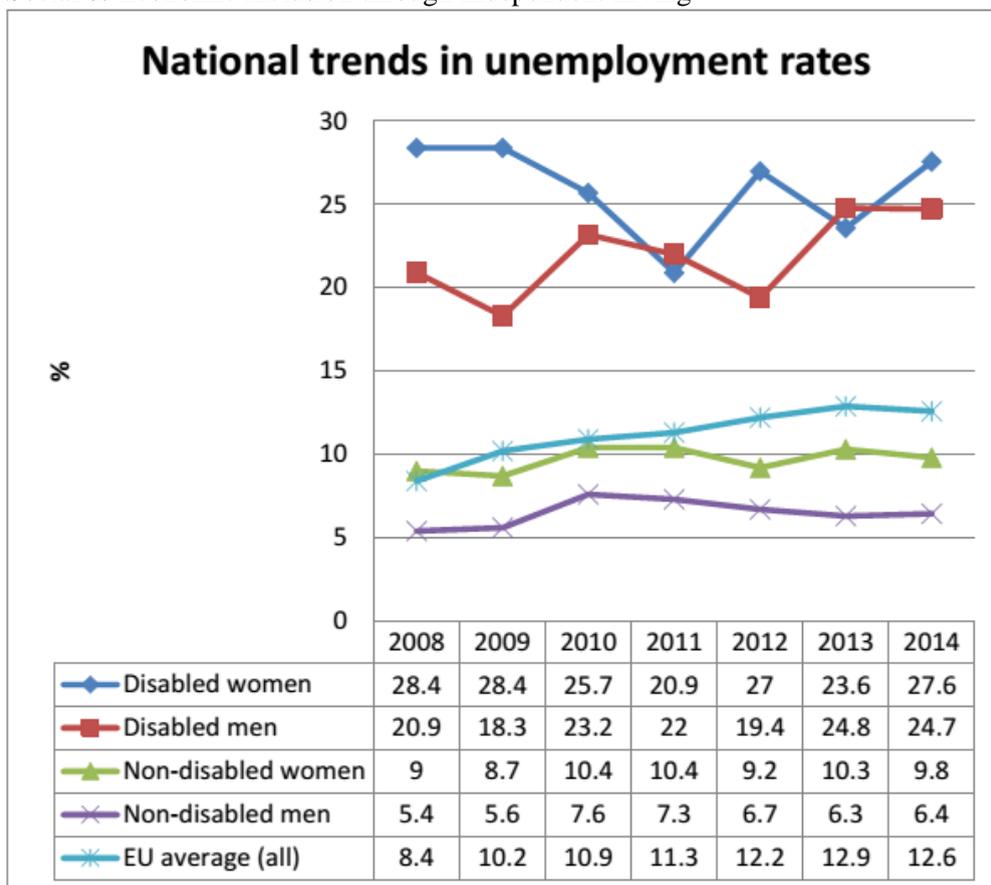
This is also the situation reported by the Czech Republic to the UN CRPD, and compared by ANED in 2014. Older statistics on economic activity were referred to in the Czech CRPD report, based on the VŠPO 07.²⁶⁰ These statistics conclude that ‘the most economically active group of persons with disabilities represents persons aged 45 – 59 years’ and that ‘in the group of economically active persons with disabilities, four fifths are employed and one fifth self-employed’.²⁶¹ It is assumed this refers to employment rather than activity.

Similarly, when one notes unemployment trends, the same situation arises, the Czech Republic lags behind the EU average when it comes to persons with disability:²⁶²

²⁶⁰ Sample Survey of Persons with Disabilities 2007.

²⁶¹ EUSILC UDB 2014 – version 2 of August 2016, Page 89.

²⁶² Ibid.



However, in the above data, there are fewer than 50 observations in the sample of people aged 16-24 who declare impairment/limitations. The Academic Network of European Disability Experts (ANED) suggests that these data should be treated with caution.²⁶³

With regard to national trends in disability employment rates there has been only a small growth in employment rates during years 2008-2014. This trend is similar for disabled men and disabled women, as it is for the general population.

The national average unemployment rate of non-disabled men is about one half lower than for non-disabled men in EU. However, a different pattern can be found between the unemployment rate of disabled women in the Czech Republic (almost 25%) and unemployment rate of disabled women in EU (19%). The national average unemployment rate regarding disabled women is even higher in the Czech Republic compared to same category in EU average

The same can be said with regards to statistics on education. These were also referred to in the Czech report to the UN CRPD, based on the VŠPO 07.²⁶⁴ The conclusions are as follows:

²⁶³ <https://www.disability-europe.net/country/czech-republic>

²⁶⁴ Sample Survey of Persons with Disabilities 2007.

'The education level of persons with disabilities is lower compared to the total population of the Czech Republic. In the group of persons with disabilities over the age of 15, the majority is constituted by persons with primary education'.²⁶⁵

Looking at the situation in tertiary education from a disability perspective, some differences between the Czech Republic and the EU average can be found. In the Czech Republic there remains a significantly lower proportion of young disabled people who have completed tertiary education compared to the EU28 average. In the EU, the percentage of people aged 30-34 with disability completing tertiary education was steadily increasing. In the Czech Republic the proportion of young people with disability completing tertiary education did not significantly change and remains lower than the EU28 average.²⁶⁶

With regards to social exclusion, the numbers show that the EU SILC data provides indicators of the key risks for people with disabilities – household risks of low work intensity, risks of low income, and material deprivation. The national averages of household poverty risk for both age cohorts of “disabled” has been lower in the Czech Republic than the EU average across the years since 2010. However, a growing trend can be seen in the national risk of household poverty or social exclusion for the disability group aged 16-64 (2010 – 26.7%, 2014 – 33.3%).²⁶⁷

Lastly, the National Plan shows a trend of “moving employees with disabilities to sheltered labour market” (employers with more than 50% of employed persons with disabilities). This trend can be also be seen as one of the major forceful measures of the state in this regard.

This trend is evident particularly from the period of 2006 onwards. In 2006, the total number of employed persons with disabilities employed in working places with more than 50% of employed persons with disabilities was about 19 %, in 2010 it was already 27%. The aim of employment policy and support for people with disabilities in the labour market should be primarily to employ such persons on the open labour market among the majority population.

The National Report Programme 2015 refers to the Youth Guarantee Implementation Programme which was finalized in April 2014. It has become a key strategic document of the Czech Republic for the support of young people in the labour market. However, the Youth Guarantee Implementation Programme states that document excludes economically inactive persons including disabled people.

Therefore, for employment of persons with disabilities in the Czech Republic two recommendations are universally formulated, both by the EU structures and by civil society. First of all, to conduct an overall evaluation of the current system of employment support, including assessment of impacts of related support systems (social, fiscal). This also includes

²⁶⁵ Ibid. Page 89.

²⁶⁶ Ibid.

²⁶⁷ Government Board of People with Disabilities 2015. Zaměstnávání osob se zdravotním postižením na ministerstvech a v ostatních ústředních orgánech státní správy v roce 2015.

a proper evaluation of some of the archaic sheltered employment schemes presently being executed which sound more like exclusion and exploitation instead of inclusivity and job inclusion. Secondly, to pay attention to career guidance, which increases the opportunities for employment of graduates with disabilities including technical and vocational and technical guidance. These factors are both in need of an overhaul in this country.²⁶⁸

Poverty and social exclusion are very closely related to unemployment, in particular its long-term kind. Almost half (46.7% in 2012) of unemployed persons are at risk of poverty. Ensuring equal access to employment for all groups of the Czech population is a prerequisite for combating social exclusion, especially in the productive part of the population.

Promoting employment of disadvantaged groups is important both in order to ensure adequate income and prevent the risk of poverty for socially excluded persons or persons at risk of social exclusion, and also to facilitate social integration of this group of the Czech population, as having a job is not only an essential source of income, but also an important social value.

Conversely, long-term or repeated unemployment contributes to an increase in material and social deprivation and increased risk of social exclusion, trapping the socially excluded individuals in welfare benefit dependency. Long-term or repeated unemployment makes it difficult to participate in social relations, may lead to social isolation, exclusion from social relationships, loss of support from the community and thus a lack of opportunities for education and employment. Long-term and repeated unemployment in the CR is primarily associated with low qualifications, disability and discrimination by employers – in particular against ethnic groups, women with small children and persons aged 50 and over.

The long-term unemployed lose their working habits, which leads to a further decrease in their chance to succeed in the labour market. There is an increased risk of intergenerational transmission of these negative aspects of unemployment and other negative social phenomena.²⁶⁹

²⁶⁸ <https://www.disability-europe.net/country/czech-republic>

²⁶⁹ https://www.mpsv.cz/files/clanky/19478/Strategie_EN.pdf .Page23

Denmark

In Denmark, the legislation on special education offers solutions to persons with disabilities in different manners. In most cases, the pupil remains in a mainstream school class and receives special education in one or more subjects as a supplement to general teaching. A pupil may receive special education that replaces participation in regular education in one or more subjects. Alternatively, they may be taught in a special class, either in mainstream or special school settings. Finally, the pupil may attend either a mainstream school class or a special class and be taught in both types of classes. Special classes exist for pupils with, for example, intellectual disabilities, dyslexia, visual impairment, hearing impairment, and physical disabilities.

Parents, including parents of children with special needs, have the right to enrol their child in a *Folkeskole* of their choice within the municipality of their residence or within other municipalities. This includes schools specialising in special needs education within the municipality of residence or within other municipalities. The free choice of school is, however, limited in the sense that the chosen school should be able to offer relevant support for the child with special needs and must be capable to accommodate them.

As early as during the last year of primary education (sixth grade), individual pupil plans are developed in the form of ideas about what should happen after compulsory education or the voluntary tenth grade following compulsory education.

This transition plan is drafted partly on the basis of the so-called *Uddannelsesbogen* (Educational Record) and the *Uddannelsesplanen* (Educational Plan). This latter presents a kind of portfolio, which is created in the sixth grade and contains summaries of individual dialogues between the counsellor and the pupil on topics such as when and where the educational programme will be completed, aims of the programme and how best to achieve progress.

The Educational Record contains necessary documentation about the counselling process and the pupil's choices during this process. The course of choosing a youth educational programme or employment after schooling is also reflected in the Educational Record. The Educational Record deals with issues such as the pupil's strengths, interests, expectations for the future and requirements for development. The pupil's efforts during a certain time span may also be stated as intermediate aims in the Educational Record.

The pupil's wishes and expectations, as stated in the Educational Record, are not binding for their future choices. They are meant to serve as guidelines for defining important issues in relation to the transition from school to further education or employment.

On the basis of the Educational Record, the pupil will prepare an Educational Plan in the ninth grade. This may be repeated in the tenth grade. The Plan will show the pupil's aims and objectives in relation to further education or employment. The reason why it could be drafted again during the tenth grade is that compulsory education finishes after the ninth grade.

To strengthen pupils' abilities to choose a programme for further education or employment, educational, vocational and labour market relations are taught as a subject during the last years of schooling. Furthermore, all pupils are offered vocational training. Young people with special educational needs are offered a more comprehensive vocational training programme than others, and they might also be offered a work-training programme of longer duration during their last years of schooling. This will be arranged either for two whole days per week, in which case the pupil will attend school for the remaining three days, or it can be for five afternoons per week, so that the pupil attends school each day from 8 am to 12 pm approximately. The pupil will receive non-tariff based remuneration, i.e. a so-called financial reward for participating in the work-training programme. This kind of work training is known in several European countries as the 'dual system'.²⁷⁰

The Danish Act on Secondary Education of Youth with Special Needs No. 564 of 6 June 2007 provides young people having mental or intellectual disabilities or people with special needs, who are not able to complete mainstream education, a right to a three-year youth education after primary and lower secondary education, which can be attended from 16 until 25 years of age. Youth education starts with a process of up to 12 weeks that uncovers the person's wishes and opportunities for future training and employment, and consists of three years of training following a person-centred curriculum which is based on the young person's qualifications, maturity and interests, and which is planned together with the young person, the parents and youth guidance experts. Comprising a minimum of 840 hours annually, it can take place in different kinds of schools or in the form of work experiences, with the aim of getting a job, living a more independent life and reducing care needs. It can be adjusted each year and is completed with a certificate. Meanwhile the Ministry of Children and Education is the overall coordinator, the municipalities are responsible for awareness raising and for bearing the costs of the education, transport and special assistance needed.²⁷¹

As one can note, the Danish educational system is theoretically endowed with the necessary tools to ensure that persons with disability are streamlined in an inclusive manner throughout their educational foray, thus making them ready for job inclusion. The same goes for the social services structures of the Danish government. In the government's paper entitled 'Social Policy in Denmark' which was published in 2015, the latter states that the key initiatives targeted at particular groups include persons with physical and mental disabilities, socially excluded groups and groups at risk of social exclusion as well as some of the initiatives targeted at mentally ill people and alcohol and drug addicts.²⁷²

²⁷⁰ <https://zeroproject.org/policy/denmark/>

²⁷¹ Department of Education: <http://www.uvm.dk/Aktuelt/~/UVM-DK/Content/News/Udd/Erhvervs/2014/Feb/140224-Ambitioes-erhvervsuddannelsesreform-paa-plads>.

An overview: <http://www.3byggetilbud.dk/erhvervsuddannelsesreform/>.

²⁷² <http://www.oim.dk/media/14947/social-policy-in-denmark.pdf> Page 7.

Thus, the Danish disability policy is based on three principles:

- The principle of equal treatment of and equal status for disabled people
- The sector responsibility principle, implying that the person responsible for the sector is also responsible for ensuring that the area is accessible to disabled people
- The compensation principle implying that people with reduced functional capacity should be compensated for the consequences hereof.

Local authorities and regions provide free advisory and counselling services with the purpose of creating favourable living and development conditions for disabled people. When local authority advisory services are insufficient, the disabled person is referred to regional special advisory services or other special advisory services.

The local authority provides support for the necessary extra costs connected with maintaining a person with permanently reduced functional capacity, when the impairment is of a character which severely affects daily life and requires significant supportive measures. The extra costs must be a direct result of the reduced functional capacity.

Personal help and care services to people who are unable to carry out these tasks themselves are also given because their physical or mental functional capacity is permanently reduced.

The aim of the Citizen-controlled Personal Assistance (BPA) scheme is to provide a flexible form of help for disabled persons with a substantia need of help. Citizen-controlled personal assistance is a subsidy which covers the cost of employing care assistants to provide the necessary help. To become eligible, a person must have severely and permanently reduced physical or mental functional capabilities.

The local authority offers substitute or respite care to parents, spouses or other close relatives who care for a person with reduced functional capacity. Notwithstanding, a disabled person below the age of 65 is entitled to 15 hours of attendance per month in order to be accompanied to activities outside the home he or she wishes to attend. The object of the attendance scheme is to help normalise and integrate persons who cannot get about on their own due to significantly and permanently reduced functional capacity.

Local government also provides support towards aids and consumer durables when such devices may considerably relieve the reduced functional capacity and/or enable the disabled person to fulfil a job. Car purchasing schemes and home adaptation schemes are also available. Special labour market and rehabilitation offers, including supported employment and sheltered employment are also offered.

With regards to independent living, the guiding principle in the disability policy is that the needs of the individual, and not the type of accommodation, decide what assistance should be provided. Consequently, accommodation and services are separated, and disabled people live independently.

Under Danish housing legislation, specially designed housing may be built which is adapted to the needs of dependent elderly people and people with disabilities. Residents in such housing are tenants and subject to the Rent Act as regards notice to quit and other rights and obligations. However, this does not apply to residents in housing created under the Social Services Act. The local authority may offer temporary stays in residential accommodation. These could take the form of respite care, physical rehabilitation or weekend stays. It could also be in preparation for living independently. The municipality is responsible for providing the necessary number of habitations in long-term residential accommodation for persons needing extensive help with ordinary daily functions, care or treatment, and whose needs cannot be covered in any other way. The municipality is also responsible for providing the necessary number of places for temporary stays for training related to the preparation for living more independently. The objective is to improve the individual's skills through socio-educational activities and treatment.²⁷³

Additionally, two sets of rules provide parents with an opportunity for financial assistance in connection with children's disabilities. The first initiative is referred to as the Reimbursement of Extra Costs to Parents with Disabled Children. With this scheme, the local authority pays the parents' extra costs related to care for a disabled child in the home. The extra costs must be incurred as a result of the child's disability.

Secondly, one notes the Lost Wages Scheme. The local authority also grants assistance to cover wages lost while the parents at home are caring for a child with severely and permanently reduced physical or mental functional capability or an impairing chronic or long-term illness.²⁷⁴

Volunteer-based social work plays an important role in the social area in Denmark. The public sector has the primary responsibility for children, youth and adults with social problems, but voluntary social organisations can often contribute in the effort to help socially vulnerable people and families for example. Central government aid to the voluntary social sector is provided from different programmes, partly as basic grants, partly as project grants. Besides the basic grants and project grants, a range of temporary programmes with specific objectives are also available. Section 18 in the Act on Social Services requires local authorities to cooperate with the voluntary social organisations and societies and to financially support voluntary social work. The Volunteer Centre in Denmark was established in 1992 aiming to offer a wider range of services to the voluntary organisations.

The Centre is a self-governing institution and an independent unit with its own supervisory board under the Ministry of Social Affairs and Integration. The Centre offers advisory and counselling services, courses and consultancy to the voluntary social organisations and groups. The Council for Social Volunteering was set up in 2008. The Council advises the Minister for Social Affairs and Integration and the Parliament on the voluntary sector's role and work in

²⁷³ <http://www.oim.dk/media/14947/social-policy-in-denmark.pdf> Page 17

²⁷⁴ <http://www.oim.dk/media/14947/social-policy-in-denmark.pdf> Page 14.

relation to social challenges. The aim of the Council is to contribute to public debate on the voluntary sector's roles in developing the welfare society and to advise the Minister for Social Affairs and Integration on innovative welfare policy initiatives that the voluntary sector can be part of.²⁷⁵

For instance, the Disabled People's Organisations Denmark²⁷⁶ (DPOD) is a Danish umbrella organisation with 33 member organisations. DPOD is strongly committed to engaging in efforts that serve to promote and protect the rights of persons with disabilities in developing countries. In close collaboration with its member organisations DPOD supports the development of vibrant, representative and inclusive disability movements that are able to advance the implementation of the CRPD and hold governments and other duty bearers effectively to account.

This is done in cooperation with Danida (the Danish Development Agency) who backs the activities through a Framework Agreement administered by DPOD and a Disability Fund managed by DPOD from which its Danish member organisations can obtain Danida funding for their respective development interventions.²⁷⁷

In 2015, author Freja Marie Gaare Larsen published 'The Gold Indicators' on behalf of the Danish Institute for Human Rights. The institute is the national human rights institution of Denmark, accredited as an A-status National Human Rights Institution by the International Coordinating Committee of National Human Rights Institutions. Since 2011, the Danish Institute for Human Rights has been appointed as the independent mechanism for monitoring, promoting, and protecting the implementation of the CRPD in Denmark in accordance with Article 33(2) of the CRPD.²⁷⁸

Overall, this report gives glowing references to the execution of the subject in question in Denmark. However, the CRPD requires that the labour market be made inclusive for persons with disabilities. In Denmark, however, only about 50% of persons with disabilities are employed, compared to nearly 80% of persons without disabilities. For people with both disabilities and reduced work capacity, the proportion of those employed was only 25%. This should be compared to Sweden, where the employment rate for persons with disabilities and reduced work capacity is 50%. Furthermore, it should be noted that in Denmark, women with disabilities also have a lower employment rate than men with disabilities.

15-20 years ago, a number of laws were implemented to strengthen the employment of people with disabilities, including flex job²⁷⁹ from 1998 and the Act on Compensation for Disabled People in Employment²⁸⁰ from 2002. These laws still apply with minor changes. A number of projects were also launched in order to strengthen the employment of people with disabilities,

²⁷⁵ <http://www.oim.dk/media/14947/social-policy-in-denmark.pdf> Page 11.

²⁷⁶ <https://iddcconsortium.net/who-we-are/members/full-members/dpod>

²⁷⁷ <https://www.european-agency.org/country-information/denmark/national-overview/complete-national-overview>

²⁷⁸ <https://www.humanrights.dk/>

²⁷⁹ LBK no 1342 of 21/11/2016 <https://www.retsinformation.dk/forms/r0710.aspx?id=184891>

²⁸⁰ LBK no 727 of 07/07/2009, <https://www.retsinformation.dk/forms/r0710.aspx?id=125905>.

and to follow the effects of the effort, it was supplemented with a research on the effects. Since 2002 the employment of people with disabilities has been surveyed in regular reports from SFI - The Danish National Centre for Social Research.²⁸¹

Most of the persons with disability are employed on ordinary terms, but a growing part is employed on special terms. This proportion has been growing steadily from 8.8 per cent in 2002 over 18.1 per cent in 2008 to nearly 30 per cent in 2017. The growth before 2008 was a little faster than it was after 2008. The majority, 80 per cent, of the persons that are employed on special terms are in flexi jobs. 10 percent are in sheltered jobs that are agreed between the social partners, and the rest are distributed over different schemes with few percentages in each. More than 15 per cent of the persons with disabilities in employment have some sort of aid, which may be a special computer, reduced time or other things which may be necessary to keep the job.²⁸²

The courts have also begun to impose obligations on employers to provide facilities to meet the specific needs of their employees with disabilities, based on the Act on Non-discrimination. However, the point of departure under other general legislation and under the collective labour agreements is still that the employer can dismiss an employee because of reduced work capacity and that employers have relatively few obligations to employees who have reduced work capacity due to disability.

Therefore, it should be indicated in the general legislation on the labour market that reduced work capacity does not comprise lawful grounds for dismissal if it stems from a disability, and that the employer is required to provide reasonable accommodation to assist the person with a disability in carrying out his or her work. The Government's Disability Policy Action Plan 2013, unfortunately, does not appear to focus on this issue.²⁸³

In June 2017, a press statement from Social Progress Imperative issued in Washington, found that Denmark beats out 127 other countries by making exceptional social and environmental progress across all dimensions of the 2017 Social Progress Index. Not far behind, its Nordic neighbours—Finland, Iceland, Norway and Sweden—also demonstrate strong social progress performance.

New research, released today by the Social Progress Imperative in collaboration with Michael E. Porter of Harvard Business School and Scott Stern of MIT, shows these countries excel at meeting basic human needs, at providing a foundation for wellbeing with basic education and environmental protection, and at creating opportunities for all citizens to make personal choices and reach their potential. Distinct from simply making residents happy, the Social Progress Index recognizes these countries for having produced the greatest social and environmental outcomes through effective policy making, inclusive programs and bold investment in social progress.

Yet, analysis by Social Progress Imperative also reveals Denmark along with other advanced nations have hardly made much progress in the past four years. "Denmark has long been

²⁸¹ <http://www.sfi.dk/projekter/handicap-og-beskaeftigelse-2002-2016-11385/>.

²⁸² <https://www.disability-europe.net/country/denmark>

²⁸³ <https://www.humanrights.dk/activities/our-work-denmark/disability/10-greatest-challenges>

heralded for its successful welfare policies and quality of life. While not surprising, its strong performance on the 2017 Social Progress Index is impressive and will serve for others as a model of what works in social progress,” Social Progress Imperative CEO Michael Green said. “Still, even the country at the top of the charts can improve and strive for more inclusive growth.”

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These hugely successful strides in these fields by this country have been pledged by the authorities all throughout the country. For example, Copenhagen had, as its declared goal, to become the most inclusive metropolis in Europe by the year 2015. While the measures for determining this might be unclear and the success of the goal thus hard to establish, the goal itself speaks of the importance put on creating a city with room for diversity. Consequently, diversity-related considerations are incorporated explicitly into municipal policies and documents as well as into the daily work of municipal employees.

In the context of a small and rather homogenous country like Denmark with a fairly recent history of immigration, a 2015 EU funded report shows how Copenhagen stands out as a pioneering municipality and a role-model for other municipalities with respect to diversity. Copenhagen is thus an interesting case to study with respect to its approach to diversity.²⁸⁵

The report also brings to light that in recent years, a change has taken place away from targeting the diversity efforts through specific, isolated projects towards mainstreaming the diversity effort of Copenhagen municipality. The previous project-based approach had undesirable consequences e.g. projects overlapping and working against each other.

Furthermore, making diversity-related efforts part of the everyday work of all municipal employees is seen as ensuring better opportunities for success. These reasons for focusing on mainstreaming are valid and meaningful, and both the municipal and the NGO interviewees support the idea. However, mainstreaming can have negative implications.

First, it makes it very complicated to extract the resources devoted to diversity within the municipality. An attempt has been made by the estimation of the costs spent through the municipal inclusion and integration policy. However, these are estimates and relate only to one specific policy. Consequently, determining the total expenditure on diversity efforts and identifying potential cuts to these become difficult. Whether or not this is currently an implication is not possible to establish in this report; however it is a definite risk either now or in the future.

Second, while there might be good and valid reasons for mainstreaming diversity-related efforts, an inherent risk is that such efforts are not realised or that they vary between administrations as they depend to a high degree on the individual municipal employees and the extent to which they focus on diversity in their everyday work. It can be hard to establish the extent of such an everyday effort when it is not conducted as separate projects.

²⁸⁴ http://www.socialprogressimperative.org/wp-content/uploads/2017/06/English-News-Release_Nordic-Leaders.pdf

²⁸⁵ <https://sbi.dk/Assets/Urban-Policies-on-Diversity-in-Copenhagen-Denmark/urban-policies-on-diversity-in-copenhagen-denmark.pdf>

As a consequence, success criteria for the diversity-related efforts have to be considered in depth. The report highlights the difficulties of the Copenhagen Municipality of ensuring and enabling the implementation of diversity policies.

Third, another complicating aspect is that some challenges are harder to solve than others, meaning that in some fields, the impact of efforts and resources will be much bigger than in others, regardless of the equal amount of work put into them. Furthermore, some challenges are more sensitive than others. Mainstreaming could lead to a deflection away from such potentially sensitive discussions, whether the intention of the municipality or not.

Diversity in the city meaning a variety of differences also entails differences of opinion, of culture, of life styles, etc. This poses challenges to mutual tolerance, communication and understanding, as Copenhagen policies show. Additionally, diversity also entails differences in social, cognitive, economic and cultural resources in the population, posing challenges regarding the social and material living standards of some of the city's citizens. For instance, policies focus on increasing access to the labour market for the long-term unemployed, including persons with disability.

Furthermore, focus of Copenhagen diversity policies are often on the most marginalised and deprived citizens of ethnic minority background, entailing challenges of both social and economic resources, and of inclusion and cultural integration. Thus, in spite of the positive municipal discourses on diversity and the celebration of the diverse city, the variety of differences within the population necessitates that policies address the challenges and problems arising from this diversity. However, despite these challenges, Copenhagen municipality has chosen a more positive and pragmatic approach compared with the national approach, thereby embracing the diverse population of the capital.

The emphasis put on creating a good living environment in all Copenhagen neighbourhoods is in itself a positive goal. Area-based urban regeneration plays a central role in this. However, the implications of area-based urban regeneration can be gentrification: when a neighbourhood becomes more attractive, it attracts more well-off inhabitants. As such, ensuring a more mixed resident composition of the deprived neighbourhoods is an explicit goal. However, while such measures might solve problems for neighbourhoods, they do not necessarily change the situation of those in a socio-economically weak position who no longer finds housing in the regenerated areas and the areas subject to flexible allocation rules. Problems might be dispersed rather than solved. There is a fine balance between the notion of good living situations for all Copenhageners and gentrification.

In this way, diversity can be converted into a policy vehicle justifying gentrification as a consequence of mixing policies. The neighbourhood initiatives are coupled with social and employment-related initiatives, aiming to ensure the basis for socio-economically good living conditions for all Copenhageners. However, it remains unclear whether there will still be room in Copenhagen as a whole and in the regenerated areas specifically for those who cannot be lifted socio-economically. This is made all the more relevant by the high cost of building, which makes it unfeasible to build cheap social housing: if old neighbourhoods are renewed with more expensive and more sought-after housing units as a consequence, and if building new and cheap social housing is not possible, then where are the low-income households to live?

This begs the question: is there a limit to room for diversity? The change in focus from integration to inclusion carries with it promises of visions of and aspiration for change. It highlights the differences between Copenhagen and the national level. However, there are

grounds for questioning the actual realisation of this change and thus the real life implications. There seems to be at least some way to go in realising the change both rhetorically and in the municipal approach. It is clear, however, that diversity-related issues will continue to be high on the agenda in the coming years. The launch in 2014 of the first actual municipal strategy for equality of treatment is a key part in this.²⁸⁶

²⁸⁶ Andersen, H.T., V. Blach, R. Skovgaard Nielsen & A. Winther Beckman (2014), Assessment of Urban Policies on Diversity in Copenhagen. Copenhagen: Danish Building Research Institute, Aalborg University.

Estonia

For people with intellectual disabilities in Estonia, access to inclusive education and to any kind of employment remains highly limited.²⁸⁷ Attitudes towards people with intellectual disabilities have improved over the last decade and the EU accession process has encouraged positive changes in terms of legislation and policy. However, Estonia does not have comprehensive anti-discrimination legislation. While the number of children with intellectual disabilities in the education system is increasing, most of these children are not able to receive education in an integrated environment. Most young people with intellectual disabilities do not receive the education or vocational training they need to later access employment, and the vast majority of people with intellectual disabilities has no employment or work of any kind, so these people are reliant on social benefits. To date, the Government has not adequately addressed the specific needs of people with intellectual disabilities in the labour market.

Without the consent of the guardian, a person whose legal capacity has been removed cannot sign a contract, including an employment contract. Adults with intellectual disabilities whose active legal capacity has been restricted in certain areas retain the right to work and to sign an employment contract, but their guardians must give their consent for the ward to be employed. If the active legal capacity of adults with intellectual disabilities is restricted in all areas – a condition equivalent to plenary guardianship – they lose the right to vote but can still work with the consent of a guardian.

Even when it comes to employment opportunities within government entities, none of the state organisations saw a need to mention in job advertisements that disabled people were welcome to apply; there is still no cohesive action plan or programme for recruiting employees or trainees with disabilities. The European Foundation for the Improvement of Living and Working Conditions²⁸⁸ found, after research, that some organisations said this was because they did not need such programmes, others that they did not know how to develop them. Only one ministry had paid special attention to disabled people while developing a new human resources strategy. None of the organisations had any recruitment targets for people with disabilities even though the government has announced that public sector organisations will hire 1,000 people with disabilities.²⁸⁹

In Estonia, access to early intervention services is very limited, and intellectual disability is usually not diagnosed before the age of seven. This means that children with intellectual disabilities (and their families) do not receive the support they need for successful integration into a mainstream school. The assessments carried out by the Counselling Committees are multidisciplinary and involve parents or guardians. Based on their assessment of a child's level of intellectual disabilities, the Committees recommend a type of school for the child. They also recommend the type of class the child should be enrolled in – there are special classes for children with differing levels of intellectual disabilities – and the most appropriate curriculum

²⁸⁷ https://www.opensocietyfoundations.org/sites/default/files/estonia_2005_0.pdf

²⁸⁸ <https://www.eurofound.europa.eu/>

²⁸⁹ <https://www.eurofound.europa.eu/observatories/eurwork/articles/working-conditions-labour-market/estonia-improving-work-opportunities-for-people-with-disabilities>

he or she should follow. However, the parents or guardian of a child with intellectual disabilities must give their agreement for their child to be placed in a special school or a special class. Today, most parents want their child with intellectual disabilities to attend a mainstream school.

Special, separate curricula are available for children with mild intellectual disabilities or moderate or severe intellectual disabilities. Children with severe and profound intellectual disabilities are educated in special “nursing” classes. Children with intellectual disabilities in mainstream classes can also follow an individual education plan. However, although this option is increasingly popular, many students with intellectual disabilities are not yet provided with the support they need to follow an individual education plan, mainly because mainstream schools lack the necessary specialists and support system. Teachers do receive training on working with children with special needs as part of their education, but research suggests that more instruction and support for teachers is needed.

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The main legal framework has largely remained the same and is stipulated in the Constitution²⁹⁰ and more specifically in the Education Act.²⁹¹ In 2010 every type of education (general, vocational and hobby-based) needed to establish the national standards. In the Education Act responsibility for keeping track of disabled people among students and their relevant needs was laid upon local governments (§ 7.2.11).

The Education Act was complemented by a special Act on Adults Education Act²⁹² in 2015, which regulates the life-long learning issues. In 2013 the standard for vocational education was adopted,²⁹³ in addition to the Standard for Higher Education (adopted in 2009).²⁹⁴ The organisation of formal education is governed by the Basic Schools and Upper Secondary Schools Act,²⁹⁵ Vocational Educational Institutions Act, Institutions of Professional Higher Education Act, Universities Act and Private Schools Act.

The Basic Schools and Upper Secondary Schools Act in § 2 (4) and division 4 specifically draw attention to the needs of disabled people, mentioning the need to adjust teaching materials as well as evaluation of learning outcomes for them. Basic Schools and Upper

²⁹⁰ <https://www.riigiteataja.ee/en/eli/521052015001/consolide>.

²⁹¹ <https://www.riigiteataja.ee/en/eli/ee/506012016003/consolide>.

²⁹² <https://www.riigiteataja.ee/en/eli/529062015007/consolide>.

²⁹³ <https://www.riigiteataja.ee/akt/116072016008>.

²⁹⁴ <https://www.riigiteataja.ee/akt/123082016006>.

²⁹⁵ <https://www.riigiteataja.ee/en/eli/ee/530102013042/consolide/current>.

Secondary Schools Act §51 stipulates at these educational levels for specific educational needs the limits for class sizes: in some cases the size cannot exceed 4 persons and in most cases 12 persons per class. The Decree No. 76²⁹⁶ of the Research and Education Minister stipulates pupils with which kind of disorders can be accommodated in small classes. Similar small classes are also applicable at the vocational educational institutions.²⁹⁷

The Education Act adopted in 2010 foresaw the need to bring the curricula of the disabled people in compliance with new recommendations and for that these classes had a transitional period until September 2011 (§ 47 and 93). The transition period also concerned the compliance with new recommendations for class sizes for different educational needs. The Act stipulated the main principle that education of students with special needs need to be organised in inclusive schools § 47 (1). In 2016 a decree was adopted which regulates the grants for the benefit of students with special educational needs in basic schools from European structural funds during 2014-2020.²⁹⁸ These are mainly foreseen for investments to modernise the

Although Estonia recognises certain principles of inclusive education in law and policy, in practice, most children with intellectual disabilities still do not have the opportunity to receive an education in a mainstream setting. The trend with students with special educational needs has been their increased integration into normal schools (mainly through organising of special classes), which has meant the reduction of specialised schools.²⁹⁹ Almost half of the students with special educational needs have had a possibility to rely on support schemes and almost all of the students with the need of care or coping problems with everyday life have used the prolonged education measure. However, more than 11% of those who are categorised as with more severe (or multiple) special educational needs have not used any measure in the schools.³⁰⁰

Estonia does not have a quota system for the employment of people with disabilities. The primary way in which the Government encourages the employment of people who are “less competitive on the labour market”, including people with disabilities, is through tax concessions and active employment measures.³⁰¹

However, these measures were not specifically designed for people with disabilities, and they do not meet the specialised needs of people with intellectual disabilities. In particular, the amount of the subsidies are too low to cover the costs of a job coach, and aids, such as instructions in simplified language, are not included under provisions for workplace modification. Generally, awareness of these measures is very low, and in some cases funding for subsidies is not actually available. Very few people with intellectual disabilities have any kind of work or employment; in fact, only about 12 per cent of people with disabilities are in employment. Official data on the employment situation of people with disabilities is not

²⁹⁶ <https://www.riigiteataja.ee/akt/129122010088>.

²⁹⁷ <https://www.riigiteataja.ee/akt/115052014004>.

²⁹⁸ <https://www.riigiteataja.ee/akt/125062016053>.

²⁹⁹ Kallaste E. (2016). Report on inclusion of students with special educational needs and the measures supporting them in Estonia 2010-2014. Centar, Tartu <http://hdl.handle.net/10062/55400>.

³⁰⁰ <http://hdl.handle.net/10062/55400>.

³⁰¹ <https://www.eesti.ee/en/disabled-people/disabled-persons-at-work/rights-of-disabled-persons-at-work/>

disaggregated by type of disability. The data also systematically underestimates the total number of people with disabilities who are in the workforce or unemployed, because the figures do not include people with mild disabilities. Furthermore, many people with intellectual disabilities do not register as unemployed, and so they cannot benefit from employment services.

The Unemployment Insurance Fund provides advice and training to employers who are willing to employ or who have already employed persons with disabilities but need knowledge and guidance to support such employees. Such advice and training may address for example any of the following topics:³⁰²

- overview about types and nature of different disabilities and chronic illnesses
- part-time, flexible, adjusted and disability-friendly working environment
- availability of information for hard – of - hearing, deaf, visually impaired and blind people and people with learning disabilities
- communicating in a job interview and preparing for recruitment
- advising and training the people around an employee with disabilities, like co-workers, support persons and supervisors
- handling emergency situations

Wage subsidy may be granted to an employer who employs an unemployed person with decreased working ability and

- who has been registered as unemployed for at least six consecutive months or
- has worked under protected employment conditions immediately before entering the open labour market.

Wage subsidy is paid for up to 12 months. In the case of a fixed-term contract with the duration of at least six months, the wage subsidy is paid during a period that is equal to half the duration of the employment relationship, with a maximum of 12 months. Wage subsidy is calculated as 50% of the wage or salary, but not more than the minimum wage (470 EUR per month in 2017).^{303 304}

The Unemployment Insurance Fund may also pay compensation for training costs to an employer if the employee:

- is unable, due to a disability or their state of health, to continue previous work and after completing retraining or ongoing training the employer offers him/her a new job; or
- before starting work the employee had been registered as unemployed for at least 12 months and now needs to develop their working knowledge and skills.

³⁰² Estonian Unemployment Insurance Fund (<https://www.tootukassa.ee/eng/content/work-ability-reforms/advising-and-training>).

³⁰³ Labour Market Services and Benefits Act §18 (<https://www.riigiteataja.ee/en/eli/511012017005/consolide>).

³⁰⁴ Estonian Unemployment Insurance Fund (<https://www.tootukassa.ee/eng/content/work-ability-reforms/wage-subsidy>).

The Fund can also compensate to the employer any additional training costs of an employee with decreased working ability which stem from the disability or state of health of the employee. Mainly the latter concerns sign language interpretation costs³⁰⁵

Social tax compensation for a person with decreased working ability is paid to an employer who employs an employee with decreased working ability.³⁰⁶ The compensation covers the amount of social tax calculated from the minimum wage. Social tax on amount of remuneration exceeding the minimum wage is the liability of the employer. To be eligible for social tax compensation the following conditions shall be met:

- the employer shall be a company, non-profit association, foundation or sole proprietor;
- the employee shall be assessed as having partial or no working ability (or at least 40% permanent incapacity for work under the old assessment);
- the employee is working for the employer under an employment contract. (No other types of contract, e.g. contract for services, authorisation agreement or any other contracts under the law of obligations give entitlement to social tax compensation).

In addition, several labour market services are available for persons with decreased working ability:³⁰⁷

- assistance in job interviews
- peer support
- working with a support person
- work rehabilitation
- assistive work equipment
- commuting benefits
- travel cost compensation for an accompanying person - support for continuation of employment
- protected employment

Supported employment services are the most important way in which people with intellectual disabilities can access employment on the open market. However, in Estonia, there is no legal framework for supported employment as it is commonly understood, though a definition does appear in a Ministry of Social Affairs regulation.

One small project to encourage the employment of people with intellectual disabilities, through use of employment subsidies, was carried out by the Tallinn City Board of Disabled People. The Estonian Mentally Disabled People Support Organization (EVPIT) also provides vocational counselling for adults with intellectual disabilities living in Tallinn. However, there is an urgent need for the Government to encourage the establishment of supported employment

³⁰⁵ Estonian Unemployment Insurance Fund (<https://www.tootukassa.ee/eng/content/work-ability-reforms/compensation-employees-training-costs>).

³⁰⁶ Estonian Unemployment Insurance Fund (<https://www.tootukassa.ee/eng/content/work-ability-reforms/social-tax-compensation-person-decreased-working-ability>).

³⁰⁷ Labour Market Services and Benefits Act §§20–23 (<https://www.riigiteataja.ee/en/eli/511012017005/consolide>). 1

services for people with intellectual disabilities. In addition to inadequate State funding and inadequate support services, an important barrier for people with intellectual disabilities who wish to enter the workforce is their lack of preparedness for seeking employment – in particular their lack of vocational training.

Peer support is provided by an individual with a similar disability or illness with the aim to support the client in coping with their disability or illness, to boost their motivation and self-confidence and to prepare for job seeking and working life or keeping a job. Peer support is generally provided for a maximum of 10 academic hours, but the provision may be extended if there is a justified need.³⁰⁸

Working with a support person is a service where the support person provides help and guidance upon starting work.³⁰⁹ The support persons offer guidance and help to overcome difficulties when starting in a new job, communicating with other staff or understanding the work duties. However, the support person will perform actual work duties on behalf of the employee. The Unemployment Insurance Fund pays an hourly fee to the support person. The provision of this service is limited to 1,000 hours over the course of a year and may be provided to employees with employment contract of unlimited duration or a fixed-term contract with the duration of at least 6 months. To provide the service the Estonian Unemployment Insurance Fund enters into contracts under public law with support persons.³¹⁰

Rehabilitation service is a social service provided to improve the ability of persons to cope independently, their social integration and employment or commencement of employment in Estonia. In the case of persons who are unable to work due to age, disability or special needs regarding mental health, rehabilitation service is provided to support their ability to live independently and reduce the care burden of their family members. Children's rehabilitation service is aimed at ensuring equal development opportunities at the time of attaining working age. In the course of rehabilitation services, the ability to live independently, personal potential for employment and the need for external assistance are assessed, and suggestions are made for adjusting the (home) surroundings, for obtaining and using assistive devices. A rehabilitation team comprises at least five specialists of different areas (physiotherapist, occupational therapist, speech therapist, nurse, social worker and psychologist).

The rehabilitation service provided by the government today includes: Rehabilitation assessment and development of an individualized rehabilitation plan (valid for a term of 6 months up to 3 years); Guidance in the implementation of the plan; evaluation of results Provision of services to a disabled person and his/her family by the different specialists of a rehabilitation team (list of services includes 17 services); Accommodation if services are provided in inpatient rehabilitation facilities; Refunding of travel costs if a person must travel outside of the municipality of residence for receiving rehabilitation services or the provider of rehabilitation service travels to the person in question.³¹¹

³⁰⁸ Regulation No 57 of the Minister of Social Protection and the Minister of Health and Labour from 27.03.2015 on the provision of labour market services to the target group of work ability reform

³⁰⁹ Labour Market Services and Benefits Act §23
(<https://www.riigiteataja.ee/en/eli/511012017005/consolide>).

³¹⁰ <https://www.disability-europe.net/country/estonia>

³¹¹ http://www.travors.eu/download_material/subhABOUT%20TRAVORS/ENGLISH%20SITE/backgroundreport_estonia.pdf

Although many people with disabilities manage, under favorable conditions, in the open labour market, there are lots of others who need a safe working environment or to go through the different stages of workability before entering the open labour market. For the time being, alternative working arrangements can only be developed under the projects financed from the European Social Fund.³¹²

The monthly disability allowance for a person of working age is paid with the aim to partly compensate for the additional disability-related expenses. The benefit floor has been set as 65% and the benefit ceiling 210% of the social benefit rate a month. In 2016 and 2017 the rate of social benefit has been 25.57 EUR per month. Accordingly, the disability allowance for a person of working age has been not less than 16.62 EUR and not more than 53.70 EUR per month. Up to 1 July 2016 the actual rate paid was discretionary, to be determined by the National Social Insurance Board depending on the disability-related expenses. From 1 July 2016 onwards, the National Social Insurance Board is gradually applying new principles for determining the rate of allowance and the disability allowance will be paid based on the degree of disability, area of impairment and taking into account the function with the highest degree of impairment.

Persons with disabilities of working age may additionally receive three types of disability-related allowances:

- study allowance, which is paid to non-working students of secondary school, vocational school or institutions of higher education, to compensate for additional disability-related expenses for obtaining education. This allowance is paid at the rate of 6.39– 25.57 EUR per month based on actually incurred documented expenses.
- further education allowance, which is paid to working persons with disabilities to compensate for the costs of work-related training courses or university education based on actually incurred expenses, but not more than 613.68 EUR over the period of 3 years.
- disabled parent allowance, which is paid to one of the disabled parents (or a single disabled parent), if raising a child up to 16 years of age (up to 19 in case of schooling) at the rate of 19.18 EUR per month.

Up to 1 January 2016, working persons with disabilities were also granted a specific work allowance to partly compensate for the additional disability-related expenses. The allowance was paid based on actually incurred documented expenses, with the ceiling of 255.70 EUR over a three-year period. In connection with the 'work ability reform' no new granting of this allowance is made from 1 January 2016. However, persons who were granted work allowance before 1 January 2016 receive their allowance until the granting deadline.

The 'work ability reform' will transform former work-incapacity pensions into working ability allowances as from 1 January 2017.³¹³ Principally, the reform will affect all working age persons with disabilities. However, in practical terms the benefits for the former recipients of work-incapacity pension whose loss of work capacity was determined for a term until the general

³¹² Ibid.

³¹³ <https://www.riigiteataja.ee/en/eli/502042015015/consolide>.

pension age, remain unaffected and their benefits are retained until attaining the pension age. Similarly, the benefits for recipients of work-incapacity pension whose work incapacity percentage was determined before 1 January 2017 for a fixed term, will continue to receive the benefit in previous amount until the end of this term. All newly granted working ability allowances are based on the new assessment method, new eligibility criteria, payment rates and conditions.

The new assessment method entails a significant paradigm shift. Previously, the assessment measured loss of work capacity in percentages based on the degree of impairment. The new working ability assessment focuses on the remaining abilities. In practical terms, the new assessment method still takes into account the state of health and restrictions on activity and participation, while including an assessment of physical and mental abilities.

The personal scope of working ability allowance scheme includes Estonian citizens residing in Estonia, aliens residing in Estonia on the basis of a residence permit or right of residence and persons enjoying international protection staying in Estonia or asylum seekers staying in Estonia with the right to work in Estonia. Eligible to working ability allowance are persons from 16 years of age to pension age, if the working ability assessment has established that they have partial or no working ability. This means that compared to the previous assessment of work capacity in percentages there will be effectively now just three categories: full working ability, partial working ability or no working ability.

In contrast to the former work-incapacity pension, which was partly based on contribution record of the beneficiary, the working ability allowance is paid at flat rates:

- for a person with partial working ability – 57% of the daily rate;
- for a person with no working ability – 100% of the daily rate.

This means that the working ability allowances have no link to the previous contribution record of the beneficiary.

In 2017 the daily rate of the working ability allowance is 11.82 euros. Accordingly, the monthly allowance for persons with partial working ability is 202.1 euros and for persons with no working ability 354.6 euros.

A working ability allowance is not paid to recipients of a state pension or certain other state allowances (allowance of a rescue worker waiting for old-age pension, prosecutors' work ability allowance or spouse allowance on the basis of the Foreign Service Act or the Public Service Act).

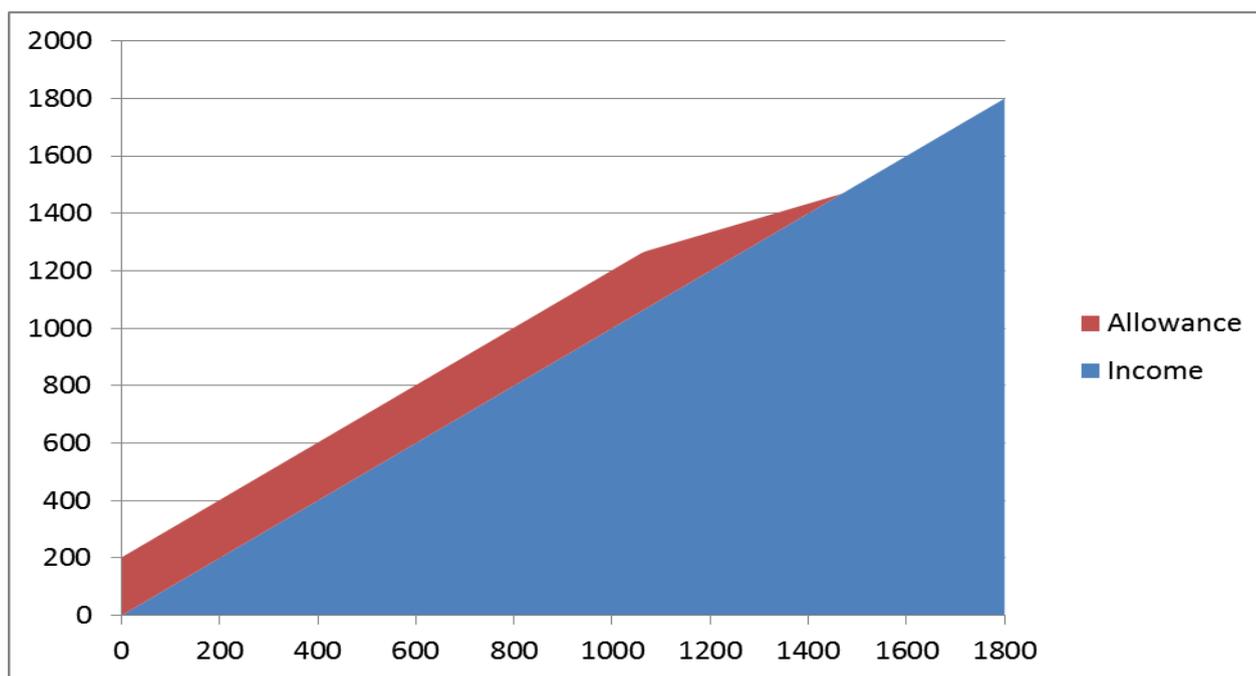
Transformation of work-incapacity pensions into working ability allowances is accompanied with an administrative change. While the former work-incapacity pensions were part of the state pension insurance scheme and administrated by the National Social Insurance Board, the new working ability allowances are administrated by the Unemployment Insurance Fund and accordingly integrated with labour market policy measures.

Recipients of working ability allowance with no income from work or other prescribed sources (unemployment insurance benefit, parental benefit, benefit for temporary incapacity for work and sickness benefit paid by employer) receive the full allowance. The allowance remains unaffected if the recipient enters work or receives above mentioned social security benefits, provided the monthly income from work or from such social security benefits is not more than 90 times the daily rate (in 2017 this is 1063.80 EUR).

If the income of a person with partial or no work ability during the calendar month preceding the payment of work ability allowance exceeds 90 times the daily rate in force, the amount of his or her allowance shall be recalculated by reducing his or her allowance for the month of payment of work ability allowance by an amount which is half of the difference between his or her income and 90 times the daily rate.

As 1063.80 EUR is in the range of the average salary, the full working ability allowance is also paid to persons earning up to the level of an average salary. With incomes above this level, the allowance will gradually decline. The allowance is discontinued if the person's monthly income reaches 1468 EUR in case of partial working ability or 1773 EUR in case of no working ability.

The above described scheme of accumulation of work income and working ability allowance avoids a classical benefit trap.



Accumulation of partial working ability allowance with income from work and certain social security benefits (2017)

However, compared to the pre-reform situation where it was possible to accumulate work-incapacity pension with earnings from work without restrictions, the new rules have introduced some limits on such accumulation.³¹⁴

³¹⁴ <https://www.disability-europe.net/country/estonia>

The Commissioner responsible for the rights of persons with disabilities in Estonia made a number of recommendations, valid for both public and private sector employers, designed to improve work opportunities for people with disabilities. Six of the suggestions were made in 2013, including the need to draw up action plans for recruitment, improve accessibility to facilities and information, adjust the work environment, and provide flexible working.

The European Foundation for the Improvement of Living and Working Conditions mentioned earlier found that the organisations questioned did not know how many employees with a disability were working for them; this was because this information was seen as health data and therefore personal, meaning the employer had no right to access it. The Commissioner's seventh recommendation was that these organisations should collect anonymous personal information (such as disability or religion) on employees and job applicants. However, the study did not provide any guidelines on how to do this.

Moreover, the Access For All initiative was launched in September 2015 with the aim of motivating business owners and organisations to improve accessibility to their facilities, services and information. Those that do will be entitled to display an official badge or logo indicating that their facilities are accessible to all people.

The initiative, developed in cooperation with the Commissioner and civil society organisations, acknowledges that adaptation is a process and that even small steps are valued. Therefore, the Access for All badge will be supplemented with similar formal recognition for organisations that have developed dedicated access for people in wheelchairs or for those with vision, hearing or learning disabilities. However, the quality standards and actual accessibility will not be monitored or inspected for compliance; the scheme is based on organisations acting in good faith. By December, 18 organisations had joined the initiative, including educational institutions, state enterprises, public sector organisations, restaurants and shops.³¹⁵

It is therefore evident that a precondition for independent living, and working, of people with disabilities in Estonia is good education, i.e. education for all irrespective of the severity or extent of a disability.

Estonia proceeds from the assumption that each disabled child is capable of learning and acquiring education, but the challenge is to find a suitable mode of study for each learner. Basic education is compulsory in Estonia, but it is essential to pay particular attention to further study opportunities. It is education that determines the ability to cope and work for people with disabilities.

However, work is important not only in terms of earnings; it is equally important in terms of social networks and self-esteem accompanying employment. Young people with disabilities can acquire vocational education both in ordinary vocational schools and the Astangu Vocational Rehabilitation Centre.³¹⁶

³¹⁵ <http://www.vordoigusvolinik.ee/siiasaab/>

³¹⁶ <http://eng.astangu.ee/>

On the one hand, the motivation of people with disabilities to find work is very low. There are several reasons for that: health condition, lack of suitable work, opinion that employers do not want to hire disabled persons. On the other hand, also employers hold a negative attitude that disabled persons pose more problems at work than normal people do. Such an attitude may arise from unawareness, which in turn may cause fear of persons with disabilities.³¹⁷

Hence, the consultants of the Estonian Labour Market Board³¹⁸ and representatives of disabled people's organisations continue to play a key role in reducing negative trends related to the issues in question. The consultants of the Labour Market Board can help raise the qualifications of disabled persons and in this way improve their competitiveness and help them get a suitable job. Changing attitudes means continuous information.

The survey on coping and needs of the disabled³¹⁹ revealed that a disabled person would like to work in an office or another workplace with the daily working time being less than 8 hours. Flexible modes of employment have been used little so far. In certain areas such as information technology or services, flexible working is easier to arrange. In other cases flexible work arrangements call for longer discussions with the employer.

On the basis of the government or EU funded projects, these can claim that upon employing people with disabilities, employers have agreed to arranging working hours, working conditions (e.g. standing work has been reorganised into sitting work) and work duties (easier tasks have been assigned if appropriate). The use of flexible modes of employment among employers saw even more adaptations under the programmes "Increase in the supply of qualified workforce 2007-2013" and "Improvement of the quality of working life 2007-2008".

In conclusion, although many people with disabilities manage, under favourable conditions, in the open labour market, there are lots of others who need a safe working environment or to go through the different stages of workability before entering the open labour market. For the time being, alternative working arrangements can only be developed under the projects financed from the European Social Fund. Similarly, the restructuring of the rehabilitation system began already in 2005 within the framework of the project "Access to employment of the disabled through case-by-case rehabilitation" (PITRA) when the bottlenecks in the provision of rehabilitation services were mapped, process-based descriptions of rehabilitation services were developed and a new scheme for the provision of rehabilitation services was designed.

Within the framework of a follow-up project "Access to employment of the disabled through the modification of the rehabilitation system" (PITRA 2), the following measures were developed – principles for the implementation of a new rehabilitation system, policies and documentation for preliminary evaluation, criteria for the assessment of the need for rehabilitation services; guidelines for the implementation of the main stages of the rehabilitation process (evaluation of needs and resources, target-setting, planning of activities,

³¹⁷ http://www.travors.eu/download_material/subhABOUT%20TRAVORS/ENGLISH%20SITE/backgroundreport_estonia.pdf

³¹⁸ http://www.ilo.org/dyn/ilossi/ssimain.viewScheme?p_lang=en&p_scheme_id=2537&p_geoaid=233 319 Estonian Ministry of Social Affairs, 2006

interventions and evaluation of efficiency) and for the design of rehabilitation intervention programmes; the mechanism for funding rehabilitation on a needs basis – and their applicability is tested.

The need for an in-service training programme for rehabilitation service providers consistent with the new system has become evident in order to:

- Enable rehabilitation specialists to develop a harmonized understanding of the concept and goals of rehabilitation;
- Further cooperation between the medical, social and employment sectors and
- To promote employment-centred approach in rehabilitation.³²⁰

³²⁰ http://www.travors.eu/download_material/subhABOUT%20TRAVORS/ENGLISH%20SITE/backgroundreport_estonia.pdf

Finland

The Finnish Basic Education Act (1998/ 628)³²¹ defines the framework for quality on learning in basic education. It offers the foundation for inclusivity for persons with disability outside the basic family unit. The Basic Education Act does not distinguish disabled students from other students. However, special-needs support consists of special-needs education and other support provided under this Act. Special-needs education is provided, allowing for the pupil's interests and the facilities for providing the education, in conjunction with other instruction or partly or totally in a special-needs classroom or some other appropriate facility. Since the 1st of January 2015 the legislation has set an obligation to participate in one-year long pre-school education.³²²

The Act on Vocational Basic Education and the Non-Discrimination act (2014/1325) together define the obligations of educational institutes to provide special training and arrangements for disabled students.^{323 324} Vocational basic education was reformed in 2015.³²⁵ This has caused some drawbacks on smaller units in rural areas of Finland and cancelations of some guiding and training programs for vocational education of disabled students.³²⁶

Upper secondary education is provided equally for disabled people regarding the Non-Discrimination Act (2014/1325). However, upper secondary education institutions are not obligated to offer any special education. Only the adaptations of environment are required.

There is a well-established apprenticeship program in Finland and it has been a part of Youth guarantee program since 2013. The very idea is to combine practical training to working conditions for young people having difficulties learn theory based knowledge and skills. The training schemes are defined by demand and supply of employers and employees. Work requiring formal higher education is unlikely. The funding for the schemes come from local employment offices or apprenticeship centres with whom the contract is made. Some specific centres are specialized for disabled people, especially for mildly and moderately disabled young.

Finnish companies may have financial aid for training for each apprentice and increased support for young with working related incapacities. In specific cases, rehabilitation allowance with apprenticeship is possible when the aim is to maintain work ability.³²⁷

³²¹ Finlex: Basic Education Act (1998/ 628)

<http://www.finlex.fi/en/laki/kaannokset/1998/en19980628.pdf>.

³²² Finlex: Act on reforming Basic Education Act (2014/1040)

<http://www.finlex.fi/fi/laki/alkup/2014/20141040>.

³²³ Finlex: Act on vocational basic education (1998/630)

<http://www.finlex.fi/fi/laki/ajantasa/1998/19980630>.

³²⁴ Finlex: Non-discrimination Act (2014/1325)

<http://www.finlex.fi/fi/laki/kaannokset/2014/en20141325.pdf>.

³²⁵ Finlex: Act on reforming vocational basic education (2015/246)

<http://www.finlex.fi/fi/laki/alkup/2015/20150246>.

³²⁶ The Ministry of Education and Culture (2016). *Selvitys vaikeimmin vammaisten erityisopetuksen tarpeesta ja koulutuksen saatavuudesta ammatillisessa peruskoulutuksessa*. Owlgroup. [Report on severely disabled needs and accessibility for vocational basic education].

³²⁷ Kela: Rehabilitation Allowance. <http://www.kela.fi/web/en/rehabilitation-allowance>

According to reports on apprenticeship programs, it can be positively said that most of the programs with increased compensation, which are used to support disabled young, have been carried out very well.³²⁸ However, there are still shortcomings to improve regarding bureaucracy, law and employers' attitudes.³²⁹ In practice employers are unlikely to hire disabled people during economic recession. Some disabled young have been employed but the overall success has been moderate under the Youth Guarantee Program.³³⁰ This can be seen in the overall unemployment rates, which indicate no significant change over time.³³¹

The Ministry of Health and Social Affairs has accomplished its latest policy program to support disabled people's working. Program "Osku" (2013–2015) was aimed for people with partial work ability and it tested a new approach to increase employability of disabled people. The programme has ended and the results are in a phase of consideration and implementation.

Government's spearhead program OTE³³² (2016-2018) continues testing the best practices for people with partial work ability with several projects. The program is emphasizing people who are able to work and it reflects a change of policy towards active social policy of disability. The aim was to ease the service processes of different agencies. The basic idea was to combine all services together in order to have seamless service package for disabled people: employment service, education, rehabilitation, health and social services, working place arrangements and social security. Thus, all of these agencies are responsible of their own area of help as they would normally, but work ability coordinator helps the disabled person to manage between these services.

The services for people with partial work ability concern all who have been diagnosed with any sort of disability, injury or illness.³³³ The very idea is to establish lasting practices. Overall, the legislation processes do consider disabled people or people with partial work ability regarding the public message, but the practices are not yet meeting the policy. For example, physical rehabilitation and rehabilitative work are implemented out of actual working life, which creates a gap between the service and labour market.³³⁴

³²⁸ Pastila-Eklund, Mari (2015) Oppisopimuskoulutusta koskevien selvitysten tuloksia. Ministry of Education and Culture, presentation 3.June.2015. [Results of reports on apprenticeship programs] http://www.oph.fi/download/168077_oppisopimusselvitysten_tuloksia_03062015.pdf.

³²⁹ Irjala, Marja (2014) Tuettu oppisopimuskoulutus – erityisryhmille mahdollisuus työelämän yhdenvertaisuuteen. Master's thesis, University of Tampere. [Compensated Apprenticeship – a chance for equal working life for special groups].

³³⁰ Ervamaa, Suvi (2014). Kohti onnistunutta nuorisotakuuta?: Nuorten ja ammattilaisten näkemyksiä nuorisotakuun toteutuksesta ja kehittämisestä. [Towards successful youth guarantee? Young people's and experts' point of views on implementation and development of youth guarantee]. Allianssi ry, Helsinki.

³³¹ ANED (2016). EU2020 disability report: Finland.

³³² The Ministry of Health and Social Affairs. Official website <http://stm.fi/hankeet/osatyokykyisyys>.

³³³ Nevala, Nina & Turunen, Jarno & Tiainen, Raija & Mattila-Wiro, Päivi (2015). Osatyökykyiset työssä –toimintamallin (Osku) toteutuminen ja hyödyt erilaisissa ympäristöissä. The Ministry of Health and Social Affairs. STM raportteja ja muistioita 48. [The Implementation and Benefits of Partial Work Ability Scheme in Different Environments] <http://julkaisut.valtioneuvosto.fi/handle/10024/74728>.

³³⁴ <https://www.disability-europe.net/country/finland>

The most promising practices consider the changes in law supporting people with partial work ability. The policy is underlining flexibility of the social security system rather than individual workplace arrangements such as working hours, patterns or location. Since 2015 it has been possible that a rehabilitee can have access to rehabilitation benefit on the days he/she is working only part-time alongside rehabilitation. This helps linking rehabilitation and working life. Since 2014 it is easier to access occupational rehabilitation, which is taking into account person's whole life situation. Extending working life is supported by extended part-sickness benefit (120 days).³³⁵ Support for people with partial work ability illustrates the policy to make work possible for disabled people, as well.

However, the main problem has been that Finnish working culture does not support part-time work solutions well enough. There are not well-established practices, for example, work trainers (people who mediate work services for a disabled people) to help disabled people and employers to tailor individual working arrangements. The social security system is not considering returning back to working life by increasing working hours gradually with better working ability. Moreover, the systems of rehabilitation and returning back to working life are separate from actual labour market. Disability pensioners' incentive traps are also one dimension of this problem, as working may not be profitable enough because of the reductions in the pension.³³⁶ A positive practise has been a project Muutos (change), which is studying occupational rehabilitation supporting employment in 2015-2019, for example effective services for people with musculoskeletal disorders in order to support their working careers.³³⁷

Through a Government Decree on Benefits Related to Public Employment Service (1346/2002) the employer has a right to apply for a benefit for arranging the working conditions in order to enable an employment of a disabled person. The municipality is responsible to provide the benefit and it can be applied via Employment Service.

Adaptations can cover necessary arrangements and new equipment to reduce the disadvantage in working conditions or hiring another employee to assist the disabled employee. Workplace adaptations are always means-tested considering the degree of person's impairment, the working conditions and employer's economic situation. The employer is expected to share the expenses modestly. The adaptations do not consider regular ergonomic solutions. The benefit is limited to 4,000 euros per person regarding adaptations and 20 euros per hour for maximum 18 months in a case of a personal employed assistant.

The Social Insurance Institution of Finland³³⁸ provides assistive devices needed to enable employment. Such devices include for example video magnifiers, braille displays or other computer equipment. The main adaptations at workplaces concern working times, ergonomics and the employee's own work planning. The employer may receive subsidies for these

³³⁵ The Ministry of Health and Social Affairs. Osatyökykyisten työllistymistä edistävät lainsäädännölliset muutokset. [Acts Supporting Working of People with Partial Work Ability] <http://stm.fi/osatyokykyiset/osatyokykyiset/lainsaadanto>.

³³⁶ <https://www.disability-europe.net/country/finland>

³³⁷ Kela: Muutos –hanke. [Project Muutos]. <http://www.kela.fi/muutos-hanke>.

³³⁸ <http://www.kela.fi/web/en>

adaptations. Assistive devices for work are available from The Social Insurance Institute of Finland (Kela). According to law, the benefits are rights, not obligations, meaning they are provided if the employer applies those with mutual understanding with the disabled employee.^{339 340 341}

When it comes to sheltered employment strategies, in Finland municipal organizations, foundations and civic associations organize sheltered workshops, which is normally referred to as work training or personal coaching. In addition, social firms have operated as employers of disabled people or people with partial work ability (1351/2003).³⁴² Social firms may hire disabled people with subsidised wages. Thankfully, there has been plans to discontinue the practice because of low success. Social firms have speculated to have problems with competing with other firms causing low establishment rates and difficulties to employ people with weak labour market status.^{343 344} In general, Finnish policy has rather limited practise in the carrying out of “sheltered workshops” which include only disabled employees or trainees.

In 2015, 93 percent of municipalities had work training services. The work training services had 25,000 participants of which 14,700 were under 29-year-old. The basic idea is to learn through training and working. The work trainings are meant to strengthen both young people’s (under 29 years of age) and adult’s employability and social and life skills.

Young people, including disabled young adults, are guided to work training via employment service, social service and educational institutions. Most of the participants are completing rehabilitative work or work trials. Some receive subsidized wage and some complete internships of educational programs.³⁴⁵ Subsidized wage is always means-tested support for the employer to hire a person with difficulties to find a job. Means-test primarily considers the unemployed person’s capability to find a suitable work contract regardless if it is granted for the employer.

Disability can be considered as a disadvantage for employment and, thus, a criterion for wage subsidy. Subsidised wage is beneficial so that the organization that hires the disabled person will have compensations for the salary costs from Employment Service. The costs are paid afterwards, not in advance. Compensation cannot be more than 50 percent of the salary. Employment Service assess individually how well wage subsidy supports one’s employment

³³⁹ Finlex. Government Decree on Benefits Related to Public Employment Service (916/2012) <http://www.finlex.fi/fi/laki/ajantasa/2012/20120916>.

³⁴⁰ Employment Service. Benefit for Workplace Adaptations http://tepalvelut.fi/te/fi/tyonantajalle/loyda_tyontekija/tukea_rekrytointiin/tyoolosuhteiden_jarjestelyt_uki/index.html.

³⁴¹ Kela. Assistive Devices http://www.kela.fi/web/en/vocational-rehabilitation-_assistive-devices.

³⁴² Finlex. Law on Social Firms (1351/2003) <http://www.finlex.fi/fi/laki/ajantasa/2003/20031351>.

³⁴³ Grönberg, Ville & Kostilainen, Harri (2012). Sosiaalisten yritysten tila ja tulevaisuus: Yhteisnen yritys-hanke ja loppuraportti. The Ministry of Economic Affairs and Employment <https://tem.fi/documents/1410877/3342347/Sosiaalisten+yritysten+tila+ja+tulevaisuus+12032012.pdf>.

³⁴⁴ YLE News (2014). Sosiaaliset yritykset saattavat jäädä pian historiaan. [Social firms may be history soon] <https://yle.fi/uutiset/3-7602897>.

³⁴⁵ National Workshop Association. Työpajatoiminta Suomessa. [Workshop Activities in Finland] <http://www.tpy.fi/tyopajatoiminta-suomessa/>.

and professional competence. Employment Service also decides the amount and duration of the subsidy.³⁴⁶

Work training is regulated in youth law (1285/2016). According to the law, the purpose of work trainings is that young people have better opportunities to access education or complete educational program or access open labour market. Moreover, the purpose is to improve life skills and societal activity. A work training centre (a sheltered workshop) drafts a training plan for the young person. Workshops must monitor their effectiveness.³⁴⁷ Work training is targeted for both young people and adults and it does not distinguish disabled people from other people by law regarding non-discrimination. In practice, the special needs of disabled people are considered more or less depending on the workshop.

The Rehabilitation Work Act (189/2001)³⁴⁸ is applied for the people who participate in work training. Obligations to participate in activation plan and rehabilitative work are regulated in unemployment security law (1290/2002)³⁴⁹ and in social assistance law (1412/1997).³⁵⁰ Dismissal leads to sanctions because work training is part of an individual activation plan and active labour market policy for unemployed.

There are no juridical obstacles for joining trade unions. Trade unions decide themselves on their members. Work training participants' health fall under the scope of the law on safe working conditions (738/2002).³⁵¹ A municipality must assure the participant according to law on safe working conditions. However, they do not have access to occupational health services. Most of the workshops practice regular meetings and final assessments with the participants, which helps consultation and receiving information.³⁵² Discrimination is taken into account by Non-discrimination Act (1325/2014).³⁵³

In practice severely, disabled people having pension may encounter some difficulties when competing on the resources of employment service with other long-term unemployed. In addition, most of intellectually disabled young are participating in work and day activities, which are separate from work training services. These activities are sheltered and remunerated with tax-free compensation, which is maximum 12 euro.³⁵⁴ A major problem of work training and activities are that they have weak transition rates to the labour market.

³⁴⁶ TE services: Pay subsidy http://www.te-services.fi/te/en/employers/find_an_employee/support_recruitment/pay_subsidy/index.html.

³⁴⁷ Finlex. Youth law (1285/2016) <http://www.finlex.fi/fi/laki/alkup/2016/20161285>.

³⁴⁸ Finlex. Law on Rehabilitative Work (189/2001) <https://www.finlex.fi/fi/laki/ajantasa/2001/20010189#L3P10>.

³⁴⁹ Finlex. Law on Unemployment Security (1290/2002) <http://www.finlex.fi/fi/laki/ajantasa/2002/20021290>.

³⁵⁰ Finlex. Law on Social Assistance (1412/1997) <http://www.finlex.fi/fi/laki/ajantasa/1997/19971412>.

³⁵¹ Finlex. Law on Safe Working Conditions (738/2002) <https://www.finlex.fi/fi/laki/ajantasa/2002/20020738>.

³⁵² Ministry of Education and Culture (2016). Työpajatoiminta 2015. Opetus- ja kulttuuriministeriön julkaisuja 2016:26 <http://www.minedu.fi/export/sites/default/OPM/Nuorisoliitteet/okm26.pdf>.

³⁵³ Finlex. Non-discrimination Act (1325/2014) <http://www.finlex.fi/fi/laki/kaannokset/2014/en20141325.pdf>.

³⁵⁴ <https://www.disability-europe.net/country/finland>.

The Finnish Association on Intellectual and Developmental Disabilities (FAIDD)³⁵⁵ regards community employment as a drawback that should be overthrown or turned into a temporary arrangement, always aimed at normally paid employment. A majority of adults with intellectual disabilities are on pension. Without any employment background, the pensions are small and the income of most of the people with intellectual disabilities is low. The minimum monthly amount of pension is now 743.38 euros. According to a recent study, households with an intellectually disabled family member regard themselves clearly poorer compared to other households. The basic income of people with intellectual disabilities needs to be increased by raising the minimum amount of pension and developing opportunities to enter paid employment. Additionally, the government is planning a linear model in order to match disability pension with earned income, which could allow higher income for disabled people and encourage them to work. This would also increase incentives to work regardless disability pension. Earned income would decrease disability pension gradually without a major cut in pension. There is no significant evidence supporting this policy. It remains to be seen whether benefit traps will decrease for real.

When it comes to accessible housing conditions in Finland, one should note that the constructor or the client (e.g. municipality) is ultimately responsible for the successful realization of accessibility requirements. Constructors have ultimate responsibility to control the fulfilment of accessibility and the property owners have the constant responsibility to supervise the realization of current regulations. In communal areas and housing, accessibility requirements are less strict than in public buildings. In practice buildings having at least three floors are required to have accessible communal yards, entrances and corridors. Accessibility requirements are not very comprehensive in Finland and constructors and property owners can/could implement better accessibility than the regulations require.³⁵⁶

In January 2010 the Finnish Government issued a resolution on a program to organize housing and related services for people with intellectual disabilities. The goal was to provide persons with intellectual disabilities individual housing solutions in regular housing environments and to reinforce their inclusion and equal treatment in the community and society.

The program was aimed at producing about 1,500 homes for persons with intellectual disabilities moving from institutions and about 2,000 homes for grown-up persons moving out of their childhood homes. Once fully implemented, the program will reduce the number of places in institutions, from 2,000 long-term places of the year 2010 to about 500 places by the end of 2015. The goal is to ensure that no one lives in an institution after the year 2020. Through this resolution, the Government committed itself to continue the structural reform of the services for persons with intellectual disabilities and to develop services that enable people with the most severe disabilities to live in the local community.³⁵⁷

³⁵⁵ https://en.wikipedia.org/wiki/Finnish_Association_on_Intellectual_and_Developmental_Disabilities

³⁵⁶ Accessibility Centre ESKE. Finnish Association of People with Physical Disabilities. 9 August 2017.

³⁵⁷ www.ohchr.org/Documents/Issues/Disability/.../NHRI/NHRIFinland_ENG.docx

The Finnish State promotes construction, renovation and acquisition of housing for persons with disabilities by granting various subsidies (interest subsidies, guarantees and grants) to local authorities, other public sector organisations and private non-profit organisations. Granting of these subsidies is based on national legislation and decisions of the competent authority, The Housing Finance and Development Centre of Finland.

Regardless of the legislation and precise regulations, accessibility has still many practical problems in Finland. For example, people lack knowledge of the law and the realization of accessibility in practice can be only mediocre.³⁵⁸ The government and municipalities have supported constructors to build lifts within older buildings. Otherwise, they need to fund the necessary changes themselves.

However, there are some promising practices in Finland. For example, there is a web based information centre and a portal³⁵⁹ and education for different parties, especially constructors. The information is provided as much for civil actors as for constructors and real estate owners. The centre of accessibility of People with Physical Disabilities (ESKE) provides lectures and paid consultation for constructors.³⁶⁰

The state also created a monitoring mechanism. The Regional State Administrative Agency³⁶¹ is the regional steering, licensing and oversight authority in the social welfare sector. The aim of the Agency's work is to ensure that high-quality social welfare services are provided for all citizens. The Agency directs and supervises both municipal and private social welfare services and works for the best interests of the residents in its area together with the municipalities and other local and regional actors. The Agency also provides advice in case of serious shortcomings or deficiencies in the availability or quality of the services or if a client has been treated inappropriately.

The Agency's actions in the field of social welfare services are informed by the legislation, and the agency works closely with the Ministry of Social Affairs and Health, the National Supervisory Authority for Welfare and Health (Valvira)³⁶² and other actors.

Valvira is Finland's national supervising authority on social welfare and it cooperates with six regional administrative agencies that have primary responsibility on supervising social care in their own region. All six agencies have similar duties in healthcare and social welfare but they differ in actual geographical scope of jurisdiction.³⁶³

³⁵⁸ Säkjärvi, Maija (2008). Uutta tuulta esteettömyyteen: Invalidiliiton Esteettömyysprojektin ulkoisen arvioinnin loppuraportti. Sosiaalikehitys Oy. [Fresh Breeze for Accessibility: Final Report on External Assessment of Project Accessibility for People with Mobility Disabilities <http://www.esteeton.fi/files/attachments/esteeton/loppuraportti.pdf>.

³⁵⁹ <http://www.esteeton.fi/portal/fi/>.

³⁶⁰ https://vanin-yhdistysavain-fi-bin.directo.fi/@Bin/6f23af3573d67558b5216243023cfc89/1525661653/application/pdf/400594/ESKE%20yleisesite%20A5%20_ENGLANTI.pdf

³⁶¹ https://en.wikipedia.org/wiki/Regional_State_Administrative_Agency

³⁶² <http://www.valvira.fi/web/en>

³⁶³ http://www.valvira.fi/web/en/social_welfare

Valvira handles welfare-related supervisory cases when they are of nationwide importance and matters of principle; other complaints are handled by the six agencies. Valvira's decisions will act as a precedent that set an example for the Regional Administrative Agencies which they can then follow when processing similar cases³⁶⁴

To conclude, there are reported to be around 47,000 disabled people in the public labour market. Their impairments are:

- physical disabilities (35 %)
- mental health disorders (23 %)
- respiratory diseases (10 %)
- others (32 %)

Only 20 % of disabled people have a paid job compared with a rate for the whole population of about 70 %.³⁶⁵ This situation has been static for many years. Disabled peoples' gross incomes are 2/3 lower than that for the whole population. More specifically, in 2005, 22 % of disabled people lived in poverty.³⁶⁶

The truth of the matter is that professional research shows that about 30 000 disabled persons could be employed in open labour markets. 6000 of them could be in full-time jobs and the rest of them in part-time jobs.³⁶⁷ The report suggests companionship policy programmes; social policy reforms to identify risks i.e. to pre-empt risks; different kinds of contracts of employment and consideration of a conventional contract of employment as not a norm. A new policy of taxation, deeper social risk analysis, strengthening adult education and life-long learning, better connections between rehabilitation activities and the realities of working life, more multidisciplinary research and follow-up by other EU countries are further recommendations of these reports.³⁶⁸

Finnish labour policy is undeveloped in sense of employment of disabled people. The ethos and practice of welfare is based on the idea that disabled people do not have to be at work and the welfare state attempts to compensate this matter with the disability pension. Two policy developments should be considered:

- Consideration of sanctions if enterprises do not employ disabled people
- Better public support for the employment of disabled people.

³⁶⁴ <http://www.valvira.fi/web/en/-/valvira-has-published-its-annual-review-2017-promotion-of-self-monitoring-continues>

³⁶⁵ https://kuntoutusportti.fi/files/attachments/k_paivat_2012/40_kp_teittinen.pdf

³⁶⁶ Parrukoski, Sanna & Karjalainen, Jouko: Tietoja vammaisten työllisyydestä ja toimeentulosta. Helsinki: Terveysten ja hyvinvoinnin laitos, 2009. [Knowledge on employment and livelihood of disabled people] <http://www.koyhyyskirjoitukset.org/alustuksia/20092/Tilastoja%20vammaisten%20k%F6yhyydest%E4.doc>

³⁶⁷ Vuorela, Mika (2008): Työtä haluaville uusia mahdollisuuksia työhön. Selvityshenkilö Mika Vuorelan selvitys. Työ- ja elinkeinoministeriö 10.3.2008. [New job possibilities for people who want to work] http://www.tem.fi/files/18750/Vuorela_loppurap_ortti.pdf

³⁶⁸ Suikkanen, Asko (2009): Selvitys välityömarkkinoista. Sosiaali- ja terveysministeriö. [Report of intermediate labour markets] http://www.stm.fi/c/document_library/get_file?folderId=41254&name=DLFE-4806.pdf

Thus, notwithstanding its successes, there is a need to basic research on disabled people's employment in Finland. Only a few surveys or statistical analysis have been done, and these are not included in the strong Finnish tradition of the sociology of work. These recommendations should be taken up together with the development of legislation and statistics.³⁶⁹

In March 2018, Finland has published, for the first time, a National Action Plan on the UN Convention on the Rights of Persons with Disabilities. The Action Plan will implement the UN Convention that entered into force in summer 2016. The aim is to strengthen the rights of persons with disabilities and to improve their opportunities for participation.

The objective of the Action Plan is to raise awareness of the rights of persons with disabilities and to take account of their rights in all activities in the different administrative branches and in society at large. Accessibility, availability and participation are essential when implementing the rights of persons with disabilities.

Everyone is entitled to basic and human rights. However, there are groups of people who cannot use these rights until particular attention is paid to the implementation of these rights and special measures are carried out to secure the rights. Persons with disabilities is one such group. Therefore, we need the UN Convention on the Rights of Persons with Disabilities as well as national actions. This is what Pirkko Mattila,³⁷⁰ Minister of Social Affairs and Health, stated at the publication launch of the National Action Plan on the UN Convention on 13 March.

The Action Plan contains 82 measures that the ministries are committed to implement. Part of the measures will be implemented during the current Government's term of office. Some measures take a longer time to carry out.

'There is much room for improvement in the implementation of the rights of persons with disabilities.'

According to a survey conducted in the autumn of 2017, persons with disabilities felt, as a rule, that their rights are secured relatively poorly. The right to work was considered as the objective that was achieved least well. An adequate standard of living and social protection emerged in the survey as the primary issues to be rectified.

- Work and an adequate income are in a key position when we think about the opportunities of people with disabilities to live independently and to participate. It is very important that working should always be economically profitable. We must remove people's fear that their income will weaken if they start to work, said Minister Mattila.
- Safeguarding employment for people with partial work capacity is one of the Government's goals, and it is being carried out by the key project Career opportunities for people with partial work ability. The key project is constructing, among many other measures, a linear model to combine pension and earned income, Minister Mattila continued.

³⁶⁹ https://kuntoutusportti.fi/files/attachments/k_paivat_2012/40_kp_teittinen.pdf

³⁷⁰ https://en.wikipedia.org/wiki/Pirkko_Mattila

- Services are also part of social protection. The Social Welfare Act, and particularly the Disability Services Act, secure that persons with disabilities receive assistance in their everyday lives. The services will be further developed as part of the ongoing reform of regional government and health and social services.

A key principle of the Convention on the Rights of Persons with Disabilities involves the inclusion of persons with disabilities in decision-making that concerns them. The Advisory Board for the Rights of Persons with Disabilities (VANE)³⁷¹ was responsible for drawing up the National Action Plan, and the Advisory Board will also coordinate the national implementation of the UN Convention on the Rights of Persons with Disabilities. The Advisory Board includes representatives of disability organisations, labour market organisations and the ministries with key significance to the rights of persons with disabilities.

Disability organisations and persons with disabilities were heard, as agreed, when drawing up the Action Plan. They provided important information on how the matters relating to the UN Convention on the Rights of Persons with Disabilities should be primarily promoted.³⁷²

³⁷¹ <http://vane.to/en/vane>

³⁷² http://stm.fi/en/artikkeli/-/asset_publisher/suomen-ensimmainen-yk-n-vammaissopimuksen-toimintaohjelma-vahvistaa-vammaisten-henkiloiden-oikeuksia

France

As a preliminary comment, it should be observed that disabled employees who carry out their professional activity in a normal working environment are considered as full-fledged employees and thus benefit from the same rights as any employee. Moreover, and in any event, an employee is never obliged to disclose his/her disability situation to his/her employer.

However, disabled employees constitute a particularly fragile population which has been the subject of great attention with a view to ensuring their professional integration within the workplace. In particular, any company with more than 20 employees is under an obligation to employ disabled persons for up to 6% of its workforce (although this obligation may also be complied with through the payment of a specific contribution). Similarly, French employment law makes provisions for specific measures with the goal of granting additional rights and protection to disabled employees (such as reinforced medical follow-up, doubling of the notice period in certain situations of dismissal, etc.).

Still, one of the strongest means of protecting disabled workers lies in the general principle of non-discrimination which prohibits any employer from treating an employee differently on the basis of certain grounds including, inter alia, the employee's health situation and disability. However, this principle still allows for differences of treatment provided that such differences are justified by an essential and direct professional requirement, as long as the objective is legitimate and the requirement is proportional. French employment law also specifies that differences of treatment based on the employee's incapacity or unfitness recognized by the occupational health physician are not considered to constitute discrimination as long as such differences are objective, necessary and appropriate.

In addition to the general principle of non-discrimination, the Labour code provides that the employer must take measures, appropriate to the needs of a given situation, in order to enable disabled employees to:

- have access to, or retain employment corresponding to their qualification, and to participate or advance in such employment
- receive appropriate training adapted to their needs.

These measures concern in particular the adaptation of equipment and tools as well as work stations (including the necessary support and individual equipment for the concerned employees), and access to the workplace. Similarly, any disabled employee may, upon request, benefit from individualised working hour arrangements. Nevertheless, the employer is considered as being discharged from this obligation if it would create a disproportionate burden on the business. In this respect, public subsidies that may be granted to the employer in relation to the employment of disabled persons will be taken into account for the purpose of assessing the extent of such burden.

The underlying logic of such provisions is that, in order to ensure compliance with the principle of equal treatment for persons with disabilities, reasonable adjustment should be made within the workplace. Therefore, these positive measures adopted by the employer to promote the equality of treatment for those persons are regarded by law as not being acts of discrimination.

On the contrary, the Labour code states that it is the simple fact that an employer refuses to take appropriate measures which could constitute discrimination.

In this context, any employer which does not comply with such obligations and thus discriminates against an employee on the basis of his/her disability faces the same sanctions as any other type of discrimination, i.e. in particular criminal sanctions (up to 3 years' imprisonment and a fine of 45,000€ for an individual and 225,000€ for a legal entity) as well as the nullity of any decision made in violation of such principle.³⁷³

But before analysing the employment trends and opportunities for persons with disability in France, it is essential to note the main educational legislation which purports to ensure inclusivity and provide the main foundations for independent living. In the law n° 2005-102 of 11th February 2005 for equal rights and opportunities,³⁷⁴ participation and citizenship of disabled persons forms the basic legal framework for equality of learning opportunities. Its art.19 introduced Art L. 112-1³⁷⁵ into the code of Education from which the public service provides schooling, professional training or tertiary education to disabled children, teenagers and adults and the State provides human and financial resources which are required for schooling of disabled children, teenagers and adults in an ordinary environment in its skills domains. France has been progressively engaging into an inclusive policy.

In accordance with the 2005 law³⁷⁶ a personal plan for schooling (Plan personnalisé de scolarisation, PPS) is elaborated in order to organise the child's schooling and the guidance procedures and means. It implies the cooperation of a multidisciplinary team around the child's or adolescent's project, including pedagogical, educative, social, psychological, medical and paramedical actions.

If needed, children can be schooled in a specialised institute, part-time or full-time where they are taught by specialised teachers in teaching units (Unité d'enseignement, UE).³⁷⁷ If necessary a distance education can be organised with the support of a teacher coming to the child's home.

But mainstream schooling is a priority (art 112-2). Inclusion in ordinary schools can be organised either individually, with specific support of the mainstream teacher, adapted pedagogical situations and material, and/or the guidance of a school aid, depending on the child's specific needs, or through an inclusion scheme dealt by a specialized teacher in charge of organising some of the teaching inside a special class and of supporting inclusion into mainstream classes.

³⁷³ <https://www.globalworkplaceinsider.com/2014/10/disability-what-protection-from-discrimination-do-disabled-employees-have-in-france/>

³⁷⁴ <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT00000809647&dateTexte=20170809>.

³⁷⁵ <https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006071191&idArticle=LEGIARTI000006524373>.

³⁷⁶ art L 112-2

<https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006071191&idArticle=LEGIARTI000006524375&dateTexte=&categorieLien=cid>

³⁷⁷ Order of 2d April 2009.

Whatever the schooling modality, disabled children can benefit from the support of a specialised education and care service, SESSAD (service d'éducation spéciale et de soins à domicile).

A law n° 2013-595 of school reworking was voted in 2013.³⁷⁸ It introduced the concept of school inclusion which implies disabled children being in the mainstream classroom with adapted teaching and it reinforced cooperation between ordinary schools and specialized institutions whose frame was defined in the code of education.³⁷⁹ Teachers as well as other education personal now benefit from a training concerning disability.

Taking into consideration the variety of pupils and disabled children in particular has been introduced into the initial training of teachers.³⁸⁰ In fact the proportion of disabled children is higher in the primary schools than in the secondary schools³⁸¹ and is increasing in secondary schools. In 2013 a circular³⁸² organised modules at a national scale into the vocational training of teachers for the year 2013-2014 on five topics related to the schooling of disabled children in schools, one of which specifically concerned secondary schools, professional upper secondary schools in particular. One of the modules was tackling the pathway to the labour market for adolescents suffering from intellectual and mental disabilities and the role of ULIS inclusion schemes in it.

The school aid employment (school life assistant contracts, subsidised school life contracts) is currently being replaced by the profession of educational and social aid and in 2016 the school aids' qualifications were settled as well as a corresponding Diploma.³⁸³ The qualified job of persons accompanying disabled pupils was created in 2014 and has been co-existing with subsidised 1-year contracts.

From 2014, after 2 3-year contracts, the former school life assistants can get a permanent contract. The 1-year contracts employing unqualified school life assistants are being converted into qualified 3-year contracts which can drive to a permanent contract after 2 3-year contracts. The persons being employed through a subsidised contract now benefit from a 120-hour training. During the school year 2015-2016, there were 70 000 persons as a whole (25 000 full-time) employed to accompany disabled children in ordinary schools, 122 000 pupils were benefiting from their support, 83 000 individually, 39 000 in small groups.³⁸⁴

³⁷⁸ <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000027677984>.

³⁷⁹ Article L351-1-1.

³⁸⁰ Decree of 27th August 2013,

<https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000027905257&categorieLien=id>.

³⁸¹ DEPP-RERS-2016, http://www.education.gouv.fr/cid57096/reperes-et-references-statistiques.html#Données_publicues.

³⁸² Circular n° 2013-122, 27-8-2013,

https://www.education.gouv.fr/pid25535/bulletin_officiel.html?cid_bo=73298.

³⁸³ Decree n°2016-74 of 29th January 2016,

<https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000031941461&categorieLien=id>, order of the 29 the January 2016,

<https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000031941478>.

³⁸⁴ <http://www.education.gouv.fr/cid207/la-scolarisation-des-eleves-en-situation-de-handicap.html>.

In September 2015 all the inclusion schemes located in ordinary schools are qualified as ULIS³⁸⁵ (Unité locales d'inclusion scolaire, local inclusion units), aimed at supporting inclusive education rather than segregating disabled students. ULIS schemes exist in elementary schools, junior high schools, senior high-schools and technical colleges.

The 2013 law puts emphasis on the schooling of deaf children thanks to adapted schemes organised in a school at the scale of an administrative department. These schemes consist in a set of resources³⁸⁶ organised at the scale of a geographic zone composed of primary and secondary schools, necessarily including general and professional education secondary schools and aiming at supporting the pupil's inclusion into ordinary schools.

Inclusion also organises itself around the externalisation of specialised teaching units from the socio-medical sector.³⁸⁷ In respect of the "feuille de route" guidelines were written aiming at externalising 100 units and drove to the writing of specifications³⁸⁸ in 2015. The externalisation of specialised teaching units consists in part³⁸⁹ or all of a teaching unit having a class and being taught in an ordinary school part-time³⁹⁰ through a cooperation between the professionals of both establishments. It also has to favour inclusion of disabled children or adolescents into ordinary classes with the support of a medico-educative professional. In 2016 103 units had already been externalised.³⁹¹

Also in the scope of the "autism plan 2013-2017" 110 preschool units had been created in 2016.³⁹² Each school is now supposed to organise the reception and the guidance of disabled children in the scope of its project.³⁹³

Measures described in the scope of the 2016 NRP aiming at adapting schooling and training in secondary schools and universities to companies' needs follow on from the 2013 law. They pass by the improvement of the acquisition of basic fundamental competences by all the children and adolescents and by the preparation and the progressivity of orientation. Measures toward inclusion are being reinforced in those ways.

In the scope of the reform of secondary education aimed at improving the children's and adolescents' pathways, in a circular³⁹⁴ dated 2016 the French government announced the

³⁸⁵ Circular n° 2015-129, 21st August 2015 B.O. n° 31 of 27th August 2015, http://www.education.gouv.fr/pid285/bulletin_officiel.html?cid_bo=91826.

³⁸⁶ Teachers mastering the sign language, spoken completed language coders.

³⁸⁷ <http://social-sante.gouv.fr/grands-dossiers/conference-nationale-du-handicap-cnh/article/conference-nationale-du-handicap-cnh-2014>.

³⁸⁸ Instruction no DGCS/3B/2016/207 of 23rd June 2016, http://social-sante.gouv.fr/fichiers/bo/2016/16-08/ste_20160008_0000_p000.pdf.

³⁸⁹ Minimum 6 children.

³⁹⁰ Minimum 12 hours,

³⁹¹ <http://www.education.gouv.fr/cid102157/conference-nationale-du-handicap-2016-un-point-d-etape-positif-pour-l-ecole-inclusive.html>.

³⁹² <http://solidarites-sante.gouv.fr/affaires-sociales/handicap/l-autisme/le-plan-autisme-2013-2017/>.

³⁹³ <http://eduscol.education.fr/cid47660/le-droit-a-l-ecole-pour-tous.html>.

³⁹⁴ Circular n° 2016-058, 13-4-2016, http://www.education.gouv.fr/pid285/bulletin_officiel.html?cid_bo=100720.

reinforcement of the means of SEGPA,³⁹⁵ which are special classes in ordinary secondary schools intended to students with high learning difficulties or with disabilities aimed at supporting the acquisition of the common fundamental competences before the orientation toward professional training which should be progressive. At the same time SEGPA classes have evolved to be more embedded in secondary schools as it was foreseen in a 2015 circular concerning these schemes in particular.³⁹⁶

In the 2015 circular it had been decided that the SEGPA students should have class both inside the SEGPA classes and in ordinary classes and that shared projects should be developed as well as cooperation between specialised teachers and others. The 2016 circular also announced the reinforcement of the means of EREAs³⁹⁷ which are part of the upper secondary teaching and which aim at enabling students with high learning difficulties or disabilities to build their orientations and their professional projects. A 2017 circular³⁹⁸ was also recalling the importance of adapted upper secondary schools. Both EREAs and professional upper secondary schools offer adapted teaching in addition to professional training as well as a specific pedagogical and educative guidance in the scope of a boarding school. The accommodation consists in adjusting pedagogical situations, training materials, teaching tools, paces of learning, pedagogical approaches and teaching styles.

One of the objectives of the 2016 National Conference was to improve the access to apprenticeship of disabled secondary-schools pupils. Concerning schemes specifically intended to disabled students the functioning of ULIS which had been redefined in 2015 takes into account the specific adaptations in the scope of the “future pathway”.

As for students whose studies are supported through an ULIS scheme in professional upper secondary schools, a circular dated 2010³⁹⁹ had given the possibility to collaborate with specialised settings offering professional training or with a CFA. The 2016 circular insists on the importance of the preparation of the orientation for ULIS students which must be planned in the student’s personal schooling project and supported by collaborations with education inspectors in charge of technical teaching as well as with medical teams who take into account the student’s possibilities. In case an orientation toward professional education is forecasted it should be prepared through internships and possibly through agreements with SEGPA schemes and specialised settings aiming at proposing a large variety of pre-professional experience.

The planning of and preparation for the orientation is particularly important in a national context where most disabled learners enrolled in upper secondary education are enrolled in vocational courses which provide lower post- secondary enrolment opportunities than general education.

³⁹⁵ Sections d’enseignement général et professionnel adapté (adapted general and professional teaching sections).

³⁹⁶ Circular n° 2015-176, 28th octobre 2015.

³⁹⁷ Etablissement régionaux d’enseignements adaptés (Regional adapted education schools).

³⁹⁸ Circular n° 2017-045 of 9th March 2017 about the starting of the school year,
http://www.education.gouv.fr/pid285/bulletin_officiel.html?cid_bo=113978.

³⁹⁹ Circular n° 2010-088 of 18th June 2010,
<http://www.education.gouv.fr/cid52478/mene1015813c.html>.

Disabled learners have the opportunity to discover work life in adapted companies.

As far as upper secondary ULIS students are concerned, the 2015 circular explains that they should be monitored in the building of their tertiary education project and prepared for the specific studying conditions of university. A circular dated 8th August 2016⁴⁰⁰ added that disabled students benefited from the same supports as the other upper secondary students.

For the year 2016-2017, the vocational training of teachers⁴⁰¹ organised at a national scale concentrated on the specific needs of pupils and students; one theme was targeting inclusion and another one disabled upper secondary students and professional training in particular.

Following the National disability conference of November 2014, the Ministry for social affairs and for health announced that end 2014, 77% of the French universities were engaged in the elaboration of directing schemes concerning disability and 10% already have adopted them. In its 2016 balance sheet it reports that 25 universities had adopted it. Financial supports are being developed to support universities in guidance of disabled students.

In tertiary education, accessibility to digital services and pedagogical accessibility is being strengthened.

All these measures go along with the legal and policy frameworks providing equality of learning opportunity for young people in France. For example the reinforcement of inclusion schemes aiming at supporting the acquisition of the common fundamental competences and improving the orientation of disabled young people corresponds to a necessity regarding the fact that their number is far insufficient to enable all the young people to have the same opportunities to benefit from these devices at a secondary level.

Discrimination is defined in article 225-1 of the Penal code⁴⁰² as a “distinction” made between persons on the basis of characteristics amount which disability is mentioned. The law of 11 February 2005 sets the legal frame of the equality of rights for disabled people, among which the right to education and vocational training.

Differentiation in the scope of accommodation of learning or working conditions does not constitute any discrimination; it is part of the compensation of the consequences of disability which a right by law as mentioned in the 2005 law. In 2011 the organic law n° 2011-333 of 29th March 2011 dealing with the “Right Defender”⁴⁰³ as well as decrees⁴⁰⁴ gave rise to the inclusion of an administrative authority into the French Constitution in order to fight against discrimina-

⁴⁰⁰ Circular n° 2016-117 , 8-8-2016,
http://www.education.gouv.fr/pid285/bulletin_officiel.html?cid_bo=105511.

⁴⁰¹ Circular n° 2016-119, 25th August 2016,
http://www.education.gouv.fr/pid285/bulletin_officiel.html?cid_bo=105526.

⁴⁰² https://www.legifrance.gouv.fr/affichCodeArticle.do;jsessionid=85C61C0D69B05DFA9604AC36DACF7A73.tpdila09v_1?idArticle=LEGIARTI000033461473&cidTexte=LEGITEXT000006070719&categorieLien=id&dateTexte.

⁴⁰³ <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000023781167&categorieLien=id>.

⁴⁰⁴ Decree n° 2011-905 of 29 juillet 2011 dealing with the organisation and the working of the services of the Right defender <https://www.legifrance.gouv.fr/eli/decret/2011/7/29/JUSC1113861D/jo/texte>.

tion.⁴⁰⁵ It was called “The Rights defender” (Le Défenseur des droits) It represents the ombudsman’s function and is in charge of defending people who have been victims of discrimination in general, even in front of a court if necessary. It published reports on the inequalities of rights disabled people and their families were used to being faced with. Disability and health were the main reasons for discrimination for which people referred to the Right defender in 2014.

In the scope of UN Convention on the Rights of Persons with Disabilities (CRPD) the “Right defender” was appointed by the French government as the organization in charge of the promotion, protection and monitoring of its application, in cooperation with the National council for disabled persons. As such it helps disabled people in knowing and defending their rights.⁴⁰⁶ People who are victims of discrimination in any aspect of their lives can refer to The Right Defender and get help in front of a court.

As far as education is concerned, the equality of rights implies that all the people have a right to education which is a fundamental right. It implies an obligation of guarantee of this right by the State, and of providing school, vocational or tertiary education to disabled children by the public service, teenagers and adults as mentioned in the 2005 law⁴⁰⁷ and in the education code. Non-discrimination implies that disability can’t constitute the reason for being refused education, be it beyond compulsory schooling age.

Young disabled people in vocational skills programmes are not specifically covered by disability discrimination legislation beyond compulsory school age. There is a positive discrimination (compensation) in favour of apprenticeship and specific financial support from Agefiph in favour of vocational training in general.

Inclusion schemes such as ULIS, SEGPA and EREAs as they are being developed, especially at a secondary level, and reinforced, as well as the externalisation of specialised education units into mainstream schools constitute a promising practice enabling the acquisition of common fundamental competences and offering a basis for professional insertion and inclusion.

The development of ULIS schemes in upper secondary level schools is a promising practice to prevent disabled young people from early school leaving due to the previous insufficiency of adapted education and training offers.

Support to disabled people’s vocational training makes it possible for employers to get familiar with disabled persons’ abilities and to disabled people to get the qualifications required to convert their abilities into professional competences and get a job.

⁴⁰⁵ <https://www.defenseurdesdroits.fr/>.

⁴⁰⁶ Guide « La Convention relative aux droits des personnes handicapées, Comprendre et mobiliser la Convention pour défendre les droits des personnes handicapées » Decembre 2016, http://www.cfhe.org/upload/CIDPH/supports%20pedagogiques/04_%20Guide%20Comprendre%20et%20mobiliser%20la%20CIDPH.pdf.

⁴⁰⁷ Article L112-1 of the education code.

Disabled people can work in an ordinary environment as regards their working right, in an ordinary company, in an adapted company, or in a home work distribution centre (Centre de distribution de travail à domicile, CDTD),⁴⁰⁸ or they can work in a specialised workshop (Etablissement et service d'aide par le travail, ESAT).⁴⁰⁹ They are oriented by the commission for the rights and the autonomy of disabled persons (CDAPH)⁴¹⁰ and can be recruited through public employment agencies (Pôle emploi and Cap emploi).

Public-Private service providers are also active in the country, with NGOs and other foundations offering a number of services in this field. One such example is L'Arche⁴¹¹ homes and programs. It operates according to a not-for-profit "community model" which is distinct from "client-centred", medical, or social service models of care. The main aims of this service provider are the following:

- people with disabilities, and those who assist them, live together in homes and apartments, sharing life with one another and building community as responsible adults.
- everyone is believed to have the capacity to grow and to mature into adulthood, and to make a contribution to society, regardless of the physical or intellectual limitations with which they may be living; and
- the important goals of achieving personal growth and maturing socially as an adult are things which are understood to be nurtured most effectively within the context of a community whose policies and practices support and promote, among other things:
 - The development of long-term, mutual, interdependent relationships;
 - The maintenance of a stable, life-giving home environment;
 - The training and ongoing formation of those who provide assistance to community members with disabilities; and
 - Cooperation with outside professional care providers.

According to the Labour Code⁴¹² in France companies which have been employing more than 20 persons for at least 3 years legally have the duty to employ at least 6 % of disabled persons. However there are some alternatives to the employment of disabled persons which were extended by a law in 2015⁴¹³ such as the settlement of an annual program in favour of disabled workers which must plan recruitment measures, internship opportunities, especially for disabled young people under 16 in the scope of the discovering of pathways to the labour market, subcontracting with adapted companies, specialised workshops or independent disabled workers.⁴¹⁴

⁴⁰⁸ <https://travail-emploi.gouv.fr/emploi/insertion-dans-l-emploi/recrutement-et-handicap/article/handicap-et-emploi-les-entreprises-adaptees-les-centres-de-distribution-de>, Article L5213-13 L5213-19 of the Labour Code, <https://www.legifrance.gouv.fr/affichCode.do?idSectionTA=LEGISCTA000006195890&cidTexte=LEGI TEXT000006072050>.

⁴⁰⁹ Article L344-1 to L344-7 of the Labour Code, see section 2.5.

⁴¹⁰ Commission des droits et de l'autonomie des personnes handicapées.

⁴¹¹ <https://en.wikipedia.org/wiki/L%27Arche>

⁴¹² Articles R5212-1 to R5212-31 of the Labour Code.

⁴¹³ Law n°015-990 6th August 2015.

⁴¹⁴ <https://travailleur-handicape.ooreka.fr/comprendre/emploi-handicape>.

Companies not fulfilling their duty have to pay for a tax which is collected by Agefiph. Agefiph is an organisation which was created in 1987 following the law driving to the 6 % quota. It was in charge of the administration of the contributions paid by companies not fulfilling the quota which was converted into a fund for the professional insertion of disabled persons. In 2011 and 2013, following the budget law n° 2010-1657 of 29th December 2010 for 2011⁴¹⁵ and a decree,⁴¹⁶ its competences were extended by the Government, including the funding and the settlement of professional training for unemployed disabled people. It is administrated by representatives of employers, employees and disabled people. The tax paid by companies which do not comply with their duty of employment enables to fund and support consulting services, training activities, monitoring in companies, inclusion, job keeping and accommodation in favour of disabled persons.

The taxes paid by public employers not complying with their quotas are collected and administrated by FIPHPF (fonds pour l'insertion des personnes handicapées dans la fonction publique), which was created in 2006 by decree.⁴¹⁷

Agefiph and FIPHPF support and cooperate with Cap emploi⁴¹⁸ which is a national network of employment agencies in charge of diagnostic, orientation and guidance services to disabled⁴¹⁹ people registered as job seekers and to employers wishing to employ disabled persons.

Cap emploi⁴²⁰ helps disabled people in defining their professional project, analysing their training needs, defining their training projects and looking for financing resources, supports them and give them advice in their job seeking, selects job offers, puts job seekers into relation with employers, provides employment follow-up and information about job keeping. It is also in charge of informing, advising and supporting companies wishing to recruit disabled people by helping them elaborating and settling their recruitment projects, seeking candidates, accompanying them in applying for financial helps and making the insertion of the disabled person into the company easier. It is the actor of the compatibility between the labour market and the competences of disabled people.

Like any unemployed person, disabled persons can benefit from a human support from the government employment agency to look for a job.

In their job seeking disabled people benefit from specific internet interfaces between themselves and employers (for example HandiCV,⁴²¹ hanploi.com). Like any unemployed

⁴¹⁵ [https://www.legifrance.gouv.fr/affichTexte.do?](https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000023314376&categorieLien=id)

[cidTexte=JORFTEXT000023314376&categorieLien=id.](https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000023314376&categorieLien=id)

⁴¹⁶ Decree n° 2012-1354 of 4th December 2012,

[https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000026728887&dateTexte=&categorieLien=id.](https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000026728887&dateTexte=&categorieLien=id)

⁴¹⁷ [www.legifrance.gouv.fr/affichTexte.do?](http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000814863&dateTexte=&categorieLien=id)

[cidTexte=JORFTEXT000000814863&dateTexte=&categorieLien=id.](http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000814863&dateTexte=&categorieLien=id)

⁴¹⁸ [http://www.capemploi.com/.](http://www.capemploi.com/)

⁴¹⁹ Cap emploi is the Agency supporting disabled job seekers whereas Pôle emploi is the national agency in charge of registering and supporting every job seeker in his/her job search.

⁴²⁰ [http://www.capemploi.com/personnes-handicapees/handicaps-3.php.](http://www.capemploi.com/personnes-handicapees/handicaps-3.php)

⁴²¹ [http://www.handi-cv.com/.](http://www.handi-cv.com/)

people, disabled people can also benefit from a financial help and from a network of accommodation possibilities to travel for interviews.

From the employer's side wishing to recruit an employee there mustn't be any positive or negative segregation in the selection process. During the selection interview the disability situation of the candidate should be mentioned only in case the recruitment of the person would imply some specific adaptations of the working conditions.

As far as training activities are concerned, in accordance with the 2005 law disabled people have access to training as any other person,⁴²² with possible adaptations.⁴²³ As explained further there are also training schemes that are exclusively reserved to disabled people. First of all as any worker, disabled people benefit from the personal activity account⁴²⁴ which makes it possible to have an access to vocational training in function of the cumulated working time. As for disabled persons who are not working, they have access to work/study training as explained in section 1 like any young person and can benefit from specific accommodation.

Apart from these schemes which address all the people, with possible accommodation concerning disabled people, two types of qualifying training can be proposed specifically to disabled people:

- Conversion training, which is a training organised in a professional conversion school, driving to a diploma, and providing medial, social and professional guidance to the disabled person (for example, training for interviews);
- Conversion internship⁴²⁵ inside a conversion centre which drives to a professional qualification or to a diploma.

The conversion internship is intended to people who have become unfit because of his/her disability. They can also be offered a professional conversion contract aiming at making it possible for them to get re-accustomed to their former jobs and to adapt their working conditions.

These training sessions are funded by Agefiph and the regions. Another possibility is to be employed in the scope of a fixed-term contract which includes a conversion training and during which neither the employer nor the employee can stop the contract. If required, the disabled person can benefit from a pre-orientation internship.⁴²⁶

Different schemes exist to support the inclusion of disabled people into the open labour market. At the end of a training (apprentice ship / professionalising) contract, incentives aim at encouraging companies to employ disabled persons at the end of the training (see section 1.3).

⁴²² Art 112-1 of the Education Code.

⁴²³ Art 112-2 of the Education Code, Article L114-1-1 of the social action and family Code

⁴²⁴ <https://ec.europa.eu/epale/en/content/personal-activity-account-comes-force-france>.

⁴²⁵ <https://www.service-public.fr/particuliers/vosdroits/F211>.

⁴²⁶ <http://www.handipole.org/spip.php?article764>.

Disabled unemployed people who meet particular difficulties in accessing the labour market can benefit from a subsidised contract (contrat unique d'insertion, CUI) in the market sector (CUI-CIE, contrat initiative emploi) or the non-market sector (CUI-CAE, contrat d'accompagnement à l'emploi) like any unemployed person meeting such difficulties.

This contract is aimed at introducing people into the labour market. In the scope of a contract in the non-market sector, the employer has the duty to plan vocational training and validation of acquired experience actions. In both cases the employee can benefit from training sessions.

As a derogation the duration of a CUI which is normally limited at 2 years can be extended to 5 years when a disabled person is employed thanks to such a contract. The financial support from the State is the same one for everybody. In case the contract includes a qualification, Agefiph pays for a part of the pedagogical expenses which can reach 80 % and the complement can be funded by the region.

As far as young unqualified people are concerned, they can apply for a "job for the future" ("emploi d'avenir").⁴²⁷ It does not necessarily drive to any diploma and it is supposed to be offered in sectors with a social or environmental utility, or with a high potential of opportunities of employment or of development of new activities. In addition to the financial help from the government, Agefiph provides a 10300 € additional financial support for a 3-year contract.

Agefiph also provides financial incentives to companies employing disabled people far from the labour market, that is to say disabled persons over 45, or coming from a specialised medical institute, an ESAT, a conversion centre or an adapted company, or not having worked for more than 6 months during the last 12 months, or having worked in the recruiting company for at least 6 months during the last 12 months, in the scope of a contract whose duration is at least of 12 months.⁴²⁸

Every disabled person can benefit from the employment guidance scheme (dispositif de l'emploi accompagné)⁴²⁹ aimed at making it possible for disabled people to get or to keep a job. It consists in medico-social support and in a support to professional insertion, taking the form of an evaluation of the disabled person's situation, professional project and competences, the elaboration of a professional project in favour of an insertion into the ordinary environment, support in job-seeking, a follow-up of the person at work in order to secure his/her professional path by facilitating his/her access to training and to competences balance-sheets, propositions of accommodations of work conditions.

The disposal is decided by the CDAPH in accordance with the disabled person. The guidance is provided by an organisation which may be a social or medico-social service or establishment

⁴²⁷ <http://travail-emploi.gouv.fr/emploi/insertion-dans-l-emploi/contrats-aides/article/les-emplois-davenir>.

⁴²⁸ <https://www.agefiph.fr/Personne-handicapee/Acces-a-l-emploi-et-integration/Aide-a-l-insertion-professionnelle>.

⁴²⁹ <http://travail-emploi.gouv.fr/emploi/insertion-dans-l-emploi/recrutement-et-handicap/article/le-dispositif-de-l-emploi-accompagne>.

target by article L 312-1 of the code for social action and family.⁴³⁰ It can also be solicited by the employer in order to prevent difficulties, adapt the working conditions, and anticipate the employee's path in the company.

Companies employing a disabled person who was previously employed in an Esat can also benefit from a human support funded by Agefiph.⁴³¹

Due to the severity of the disability leading to a possible productivity gap compared with normal conditions and in adapted conditions, a company employing a disabled person can get some financial compensation in the scope of the process of recognising the severity of the disability (Reconnaissance de la Lourdeur du Handicap).⁴³² It can take the form of a modulation of the contribution due to Agefiph or of a support for the employment of disabled person (Aide à l'emploi des travailleurs handicapés, AETH)⁴³³ forecasted by the Labour code.⁴³⁴

In the scope of the law on work, modernisation of social dialogue incentives to collective negotiation about disability in companies were decided, among which the possibility to sign an agreement with the government which plans the recruitments as well as actions in favour of the inclusion of disabled people.⁴³⁵

In the scope of France's engagement into supporting self-employment Agefiph promotes self-employment of disabled people.

Good examples of communication toward employers about the employment of disabled people are being developed.⁴³⁶

Disabled people working in ordinary companies get the same salaries as the other persons who do or would do the same jobs.⁴³⁷ It is fixed in the same conditions as with any other employee. If needed the employer can apply for a financial compensation in the scope of the process of recognising the severity of the disability (Reconnaissance de la Lourdeur du Handicap, see section 2.1).

⁴³⁰ <https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006074069&idArticle=LEGIARTI000020892821>.

⁴³¹ <https://www.agefiph.fr/Entreprise/Recrutement-et-integration/Aide-au-suivi-post-insertion-d-une-personne-handicapee-sortant-d-Etablissement-et-services-d-aide-par-le-travail-Esat>.

⁴³² <https://www.agefiph.fr/Professionnel/Reconnaissance-de-la-lourdeur-du-handicap>.

⁴³³ Article R5213-40 of the Labour Code.

⁴³⁴ Article L 5213-11

<https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006072050&idArticle=LEGIARTI000006903710&dateTexte=&categorieLien=cid>.

⁴³⁵ Dynamiser la négociation collective handicap, Ministère du travail, de l'emploi, de la formation professionnelle et du dialogue social, Ministère des affaires social et de la santé, 4 février 2016, http://travail-emploi.gouv.fr/IMG/pdf/feuille_de_route_dynamiser_la_negociation_collective_handicap-2.pdf.

⁴³⁶ See for example <http://www.ladapt.net/travailler-en-esat.html>.

⁴³⁷ Article L5213-7 of the Labour Code, <https://www.legifrance.gouv.fr/affichCodeArticle.do?idArticle=LEGIARTI000006903705&cidTexte=LEGITEXT000006072050>.

Employees who work in an adapted company or at home are classical employees as regards working rights. As such, they are supposed to get a salary which can't be under the minimum guaranteed wage. In case the adapted company or the home work distribution centre has signed an objectives agreement with the State and they employ a person whose application came from a public employment agency or from a specialised placement organisation or in case the disability of an employee implies a reduction of his/her efficiency, they get some financial support from the State amounting to 80 % of the brut minimum wage.

Employees working in a specialised workshop do not have any work contract but a contract of support and help by work (contrat de soutien et d'aide par le travail)⁴³⁸ and get a pay which is variable according to their productivities and which is situated between 55 % and 110 % of the minimum guaranteed salary.⁴³⁹ In addition in the scope of the Code for social action and family,⁴⁴⁰ the workshop can allocate a profit-sharing⁴⁴¹ to the disabled workers. This is calculated on the bases of the gross profit surplus.

Most of the time disabled persons get the allowance for disabled persons which they can cumulate with their salaries (not including the profit sharing in the calculation of the right to the benefit) in the limit of the gross minimum wage. The salary is maximum 50 % funded by the State and minimum 5 % by the ESAT itself.⁴⁴²

The valid reasons for a lay-off of a disabled person are the same ones as for any person. Disability is not a valid reason for a lay-off whereas unfitness constitutes one. The classical lay-off procedure applies to a disabled person. However he benefits from a notice which is twice the one of other employees in the same situation in the limit of 3 months, except any more favourable existing agreement. The financial compensation is calculated on the basis of common right.

Disabled people are oriented to sheltered workshops when the CDAPH has noticed that his/her abilities do not enable him/her to work in an ordinary company nor in an adapted company or a CDTD nor as independent worker.⁴⁴³ The whole sheltered sector is composed by ESATs⁴⁴⁴ whose creation is decided at an administrative department scale.

⁴³⁸ Annex 3-9 of the Labour Code,

<https://www.legifrance.gouv.fr/affichCodeArticle.do?idArticle=LEGIARTI000019325306&cidTexte=LEGITEXT000006074069>.

⁴³⁹ Article R243-5 of the Code for social action and family,

<https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006074069&idArticle=LEGIARTI000006905768>.

⁴⁴⁰ Art R.314-5.

⁴⁴¹ Article R. 314-5 of Code for social action and family.

⁴⁴² Article R243-6 of the Code for social action and family,

<https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006074069&idArticle=LEGIARTI000006905771>.

⁴⁴³ Ministry for Work, <http://travail-emploi.gouv.fr/droit-du-travail/contrats-et-carriere/travailleurs-en-situation-d-handicap/article/les-etablissements-ou-services-d-aide-par-le-travail>.

⁴⁴⁴ https://www.agefiph.fr/Entreprise/Dossiers-pratiques/Sous-traiter-aux-secteurs-protège-et-adapte-quels-avantages#ss_article_f.

The préfet who is, as a representative of the Prime Minister and all the ministers, in a position of public authority, and who implements the government policy and controls the regional authorities' actions at a department scale, decides on the number of places. ESATs can be public or private or a mix of both. They employ management staff as well as social workers thanks to an operating budget funded by the State.

Disabled people are offered professional activities as well as socio-medical and educational support in ESATs. Normally the disabled person must be over 20 years but as an exception, adolescents aged 16 can be admitted in an ESAT. In addition, they must have a work capacity under 1/3 of the one of a valid person or need medical, educational, social and/or psychological support.⁴⁴⁵

Once an orientation has been decided by the CDAPH, there is a trial period whose duration is generally 6 months. Disabled people can also be received for periods of in-work situations in the scope of the evaluation of their compensation needs and of their orientation by the CDAPH.

According to the Work Ministry,⁴⁴⁶ disabled workers who are employed in a sheltered workshop are not employees. They don't have a classical work contract and the money they get does not constitute salaries. The person and the workshop are linked by a support and help contract by working⁴⁴⁷ which mentions the rights and obligations of each party. The ones of the workshop take on professional, medical and educational aspects.

It is impossible to lay-off a disabled person working in an ESAT. Common working rights apply concerning health and security. The person benefits from paid holidays (2,5 days per worked month + 3 mobile days). In addition he/she benefits from holidays for training and from the possibility to get qualifications through the validation of professional experience like any employee. The maximum duration of work is 35 hours per week as for any employee.

An ESAT's worker can be put at the service of an ordinary company or establishment by a contract between the ESAT and the company if it favours the fulfilment and the employment abilities of the person.

Disabled persons who work in an ESAT and plan to work in an ordinary environment can benefit from the employment guidance disposal. A person working in an ESAT can move to an ordinary company. In this case it is possible for the disabled employee to continue to benefit from the socio-medical support of the ESAT in the scope of a contract between the employer, the ESAT and possibly a social life guidance service (Service d'accompagnement à la vie sociale, SAVS⁴⁴⁸) for a maximum duration of 1 year which can be renewed. In case the contract with the ordinary company is broken he can come back to the ESAT.

⁴⁴⁵ <https://www.service-public.fr/particuliers/vosdroits/F1654>.

⁴⁴⁶ <https://travail-emploi.gouv.fr/droit-du-travail/contrats-et-carriere/travailleurs-en-situation-d-handicap/article/les-etablissements-ou-services-d-aide-par-le-travail>.

⁴⁴⁷ In case of a period of in-work situation, a convention is signed between the disabled person and the ESAT.

⁴⁴⁸ Service in charge of taking part in the life project of the disabled person as defined in the scope of the compensation of disability, Article L.114-1-1 of the Code social action and family.

As the disabled people working in ESATs don not have any work contract, they are not allowed to unionise.

The number of persons who get the disability benefit has increased of 2.1 % in 2015 to amount to 1 028 800 in December 2015. Part of this increase is due to the evolution (+ 5 %) of the category of beneficiaries whose incapacity ranges between 50 and 79 %. They represent around 40 % of the total beneficiaries. The number of persons who stand to benefit and who have an incapacity over 80 % has been stable (+0.2% annually).⁴⁴⁹

There are no data about the number of them being out of work and its evolution but the fact that unemployment has continues to increase among disabled people in 2016 drives to think that the number of out of work beneficiaries has increased.

The possibility to partly cumulate benefits with incomes is a good factor of motivation. It is a good way of making work pay. Disabled people can benefit from the two levers offered by the calculation of the amounts of both of the AAH and the in-work benefit.

The fact a person can try for a job or go for a training period without definitely losing his/her out-of-work benefits prevents from “benefit traps”, which is a good way of securing people.

With regards to housing accessibility, the accessibility rules and requirements concern only newly built buildings except in the cases of rehabilitations, that is to say newly built communal buildings, newly built houses aimed at being sold or rented and refurbished communal buildings in certain circumstances.

It concerns moving inside and outside the building, the parking, the apartments, the lifts, communal parts and their equipment.

The Minister for construction sets by decree the obligations with which the houses and accommodation must comply. The accommodation which are targeted are the ones proper to ensure their accessibility as well as the ones of the outside surrounding areas concerning outside movements, car parking, inside and outside circulation, minimal and maximal inside characteristics of houses in relation with the number of floors it contains, making it possible for a disabled person to occupy them as well as their equipment and collective premises. Applicable decrees detailing technical rules can be found on the site of the Minister for ecology and solidarity and of the Ministry for territories cohesion.⁴⁵⁰

Newly built individual houses (aimed at being sold or rented) also have to respect the rules of accessibility.⁴⁵¹ They concern outside circulation, the house itself and the possible parking.⁴⁵² In case of a communal group of individual houses these rules also apply to communal parts and equipment.

⁴⁴⁹ <https://informations.handicap.fr/art-profils-beneficiaires-aah-51-8904.php>.

⁴⁵⁰ <https://www.accessibilite-batiment.fr/>. Ex. Doors must be at least 90 cm wide, with a 83 cm passage space.

⁴⁵¹ Art. R*111-18-4 CCH, www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006074096&idArticle=LEGIARTI000006895909&dateTexte=&categorieLien=cid.

⁴⁵² Art. R. 111-18-5 CCH, <https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006074096&idArticle=LEGIARTI000006895911>.

If a disabled person wants to have communal parts adapted to his needs it is necessary that the owners' assembly agrees on them.⁴⁵³ It is possible to resort to a tribunal if needed.⁴⁵⁴ The works can be paid either by the assembly of the owners or by part of the owners with the financial support of Anah (Agence National de l'Habitat, national agency for housing)⁴⁵⁵ which is a public organization placed under the supervision of the Ministries in charge of territories cohesion, of public action and of public accounts providing financial support to the improvement of existing housing.

- In order to fund the accessibility of communal areas there are benefits⁴⁵⁶ consisting in subventions allocated by the national Agency for Housing⁴⁵⁷ to disabled owners and to their landlords who make accessibility adaptations to existing buildings. It is possible to apply directly as an owner, individually or in a group of owners (but independently from the owner's association). It is means-tested and every applicant must comply with the eligibility criteria. In this case the amount of the help is calculated as a proportion of the works the applicant has to support. Owners associations can also apply if they meet difficulties. The financial support can reach 50 % of the net⁴⁵⁸ amount of the works in the limit of 10,000 Euros.
- Anah also provides financial support to fund the accessibility of private apartments. It is means-tested and can reach 50 % of the amount of the works in the limit of 10,000 Euros.
- The 2005-102 law of 11 February 2005 created the Disability Compensation Benefit (Prestation de compensation du handicap / PCH),⁴⁵⁹ a personalised non-contributory, non means-testing, not subject to taxation individual budget meant to compensate for additional living costs in terms of human assistance, technical aids, adaptation of home, vehicle and extra - costs for transportation, animal assistance, and exceptional expenses. The PCH is granted to persons whose disability generates, permanently or for a foreseeable period of one year minimum, an absolute difficulty to perform at least one basic Activity of Daily Living (ADL) or severe difficulty in performing at least two basic ADLs out of a list of 19 ADLs in the following 5 different domains among which the adaptation of home. Depending on the person's income and of the amount of the work cost, the support covers part or all the expenses in a limit of 10,000 Euros per period of 10 years.

⁴⁵³ art. 24 de la loi n°65-557 du 10 juillet 1965.

⁴⁵⁴ art. 30 de la loi n°65-557 du 10 juillet 1965.

⁴⁵⁵ <http://www.anah.fr>.

⁴⁵⁶ <https://vos-droits.apf.asso.fr/files/Fichespratiques/FichespratiquesMAJFevrier2014/2h-%20Financement%20am%C3%A9nagement%20logement%20Janvier%202014-MIS%20EN%20LIGNE%2002%2006%202014.pdf>.

⁴⁵⁷ <http://www.anah.fr/proprietaires/proprietaires-occupants/adapter-votre-logement-a-votre-handicap/>.

⁴⁵⁸ Before VAT.

⁴⁵⁹ <https://vos-droits.apf.asso.fr/files/Fichespratiques/FichespratiquesMAJFevrier2014/2j-%20Prestation%20de%20compensation%20Janvier%202014-MIS%20EN%20LIGNE%2002%2006%202014.pdf> and <https://www.service-public.fr/particuliers/vosdroits/F14202>.

- There is also a tax credit⁴⁶⁰ to incite owners, be they the disabled person or his/her landlords to invest in housing accessibility which can reach 25% of the amount of the investment. The list of eligible equipment is settled by the general direction of public finances.⁴⁶¹ The works must be made by the company providing the equipment. Works done until the 31th December 2017 are eligible. The limit of the eligible expenses for each period of 5 years amounts to €5,000 for a person living alone, €10,000 for a couple and there is an additional eligible expense of €400 per dependent person. It applies to existing buildings but also to new ones. Works in communal areas are eligible to the tax credit in proportion of the works supported by the beneficiary of the credit.⁴⁶²
- There are also specific VAT rates for accessibility works. For example elevators and showers made especially for disabled people⁴⁶³ as well as refurbishment works contributing to accessibility of social housing are subject to 5,5 % VAT rate.⁴⁶⁴ As for existing apartments or houses which were built at least 2 years before, works not eligible to the 5,5 % VAT rate are eligible to a 10 % rate.⁴⁶⁵ It applies to private and communal areas.⁴⁶⁶
- Disabled persons who acquire a new apartment/house (which meets accessibility requirements) or who acquire an apartment in which they plan to do significant works can be allowed a 0 % credit.⁴⁶⁷ As an exception disabled people do not have to comply with the obligation according to which one must have been a renter during the two preceding years.
- Disabled owners and tenants who worked or are retired, depending on the possibilities offered by the sector in which they were working and like any other person, can also fund adaptation works thanks to low rate (1%) home loans without any income condition. It is limited at 50 % of the amount of the works and 9 600 Euros (+ 16 000 Euros in case a physical impairment). Under income conditions the part of the investment which can be covered by this low rate loan can be higher (60%).

Finally, it would be pertinent to analyse the research paper written by Louis Bertrand, Vincent Caradec and Jean-Sébastien Eideliman concerning the issues surrounding the “recognition of the quality of disabled workers” in France.⁴⁶⁸

⁴⁶⁰ <https://www.service-public.fr/particuliers/vosdroits/F10752>.

⁴⁶¹ <http://bofip.impots.gouv.fr/bofip/ext/pdf/createPdfWithAnnexePermalien/BOI-ANNX-000048-20150624.pdf?doc=5894-PGP&identifiant=BOI-ANNX-000048-20150624>.

⁴⁶² <http://bofip.impots.gouv.fr/bofip/4734-PGP.html?identifiant=BOI-IR-RICI-290-10-20150624>.

⁴⁶³ Article 278-0 bis,

<https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006069577&idArticle=LEGIARTI000031776596>.

⁴⁶⁴ Article 278, section of the general taxation code, paragraph IV-1-2°

<https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006069577&idArticle=LEGIARTI000020892735&dateTexte>.

⁴⁶⁵ <https://www.service-public.fr/professionnels-entreprises/vosdroits/F23568>.

⁴⁶⁶ <https://www.service-public.fr/professionnels-entreprises/vosdroits/F23568>.

⁴⁶⁷ <https://www.service-public.fr/particuliers/vosdroits/F10871>.

⁴⁶⁸ Situating disability. The recognition of “disabled workers” in France. ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap: Volume 8, Issue 4.

Perspectives on these issues were researched from both applicants' and decision-makers' points of view. While the latter strive to make "disabled workers" into a sub-category of disabled persons, applicants' positions are often more ambivalent. In speaking of their experience, many of them use the notion of "situation of disability", a term quite common in current French debates about disability that was not retained in the French law of 2005: even if they are bothered by a functional difficulty in certain professional situations, many still do not think of themselves as disabled persons.

To understand these differences, the authors propose returning to the foundations of French employment policy in favour of disabled persons and exploring the variety of issues that dominate claims to recognition, without forgetting the essential interface role played by professionals in the field of disability. Their analysis is based on a field study on both sides of the counter at Departmental houses of people with disabilities, with people working in the institutions and those requesting recognition of the quality of disabled worker.

In May 2018, an official complaint against France was lodged at the Council of Europe by two European associations in collaboration with 5 French Advocacy NGOs, in an effort to uphold the human rights of persons with disabilities. The complaint asserts that France is breaching the legal obligations it committed to in the European Social Charter and the UN Convention on the Rights of Persons with Disabilities. The collective complaint addresses failures by the French state, such as:

Lack of equal and effective access to social support services

Not only are many persons with disabilities not able to access support services, but France is effectively using the concept of freedom of movement to exile people. Today France is not providing the right for all persons with disabilities to live with their families and in their communities: in December 2015, 5385 adults and 1451 children were placed in social services and institutions in Belgium. In some cases, they were relocated more than 200 kilometres away from their families.⁴⁶⁹

Lack of equal and effective access to healthcare

There is a lack of coordination between the French social and health services, and certain healthcare services are not accessible. This means that some persons are not able to access essential health services.

Lack of equal and effective access to housing

The lack of accessible and adequate housing prevents persons with disabilities from accessing housing. It creates long waiting lists: sometimes more than 15 years.

Lack of essential support to independent living

Adequate support and personal assistance solutions for people with disabilities are often missing. This makes it impossible for them to work, live and participate independently in society.

⁴⁶⁹ Rapport d'information fait au nom de la commission des affaires sociales sur la prise en charge des personnes handicapées en dehors du territoire français, page 20.

Failure in its duty to protect families

Lack of support for persons with disabilities is affecting family members, as they need to be in charge of the support themselves, with consequences on their health and well-being. Other families see their loved ones placed in institutions far away from their homes.

Failure in its duty to protect work-life balance

Lack of support for persons with disabilities is affecting family members, as they need to be in charge of the support themselves. When families are obliged to support their relatives with disabilities, this can lead to lack of job security as, in some cases, family members need to reduce their working hours or to stop working.

These failures to uphold the rights of persons with disabilities and their families often put them in a very difficult position. The situation is all the more worrying as the bilateral agreements between Belgium and France highlight how freedom of movement can be used to undermine the rights of persons with disabilities to live independently in the community. They are exiled in a different country, away from their families, without it being a choice. France is also violating the commitments it took when joining the European Social Charter and the UN Convention on the Rights of Persons with Disabilities.⁴⁷⁰

⁴⁷⁰ <http://edf-feph.org/newsroom/news/organisations-representing-persons-disabilities-lodge-complaint-against-france>

Germany

German law (*Grundgesetz*) forbids discrimination on the basis of physical or mental disability. The Social Welfare Code IX (SGBIX), which came in to force in April 2001, is based on the idea of equal opportunities and participation rather than merely welfare. It focuses on rehabilitation and access for disabled people and stipulates levels of support depending on measurement of the degree of disability.⁴⁷¹

The German Disability Report (Teilhabebericht) of 2016 underlined the significance of better education and academic qualification as they affect chances of participation as well as opportunities to be employed. As a group, people with disabilities face considerable problems regarding the transition from school to work. In most cases, a smooth transition from school to in-firm training cannot be achieved as people with disabilities are less commonly offered an apprenticeship position. This applies especially to adolescents and young adults who lack academic qualifications or whose level of qualification is low, which is often the case for people with disabilities. People that graduated from special schools, mostly lacking a regular school leaving certificate, are at a disadvantage. Despite the lack of representative data, initial evaluative studies indicate that even equally qualified people with disabilities are discriminated against when competing for an apprenticeship training position. Employers consider them less capable than non-disabled competitors. (BMAS 2016a)⁴⁷²

Inclusive education/school attendance has been advanced and legal changes have been made in Germany. Still, for people with disabilities the transition into vocational training and the regular labour market is associated with considerable obstacles. People with learning disabilities, in particular, still do not receive sufficient education or school leaving certificates, and their transition to vocational training or to the regular labour market is very limited. Thus, they are highly segregated in education and work. However, other young people with disabilities are also still disadvantaged regarding school qualifications, vocational training and tertiary education.⁴⁷³ On the part of the government, several programmes have been launched, aimed at the transition from school to work or at students to doctoral students. Their effectiveness is still debatable.⁴⁷⁴

The new National Action Plan 2.0⁴⁷⁵ offers several programmes to promote participation of people with disabilities in employment and the workforce and also within the scope of professional orientation. The latter is essential during the transition from school to work. The federal government is promoting and assisting people with all kinds of disabilities in occupational orientation through the "Initiative Inklusion", which was started in 2011. This programme is funded by the compensation fund, which is financed by those companies that have not hired the legally required number of employees with disabilities.

⁴⁷¹ <https://smartexpat.com/germany/how-to-guides/health/disability-support/people-with-disabilities>

⁴⁷² BMAS = Federal Ministry for Work and Social Affairs.

⁴⁷³ BMAS 2016 a

⁴⁷⁴ <https://www.disability-europe.net/country/germany>

⁴⁷⁵ BMAS 2016 b

Through legal reforms, concrete measures for orientation and employment transitions are funded by the compensation fund on a national basis, in addition to the activities of the Bundesländer.⁴⁷⁶

Supported employment (assistierte Beschäftigung) was established in an attempt to provide access to the regular labour market for people with disabilities that have been employed in what are known as 'sheltered workshops' thus far. For many employees with disabilities, sheltered workshops became a long-term place of work in a segregated labour market, although this is contradictory to the provisions of the Social Code Book 9⁴⁷⁷ which defines employment in sheltered workshops as temporary.

Furthermore, the substantial reforms of disability rights through the Participation Law (Bundesteilhabegesetz) suggest that the 'work budget' (Buget für Arbeit) is an additional opportunity to promote disabled people's participation in the regular labour market. The particular organisation and efficiency of this new instrument for participation in working life remains to be seen as the law became legally binding in January 2017.

Precedents and decisions of the Social Court will provide initial findings in order to evaluate and optimise the policy packages regarding vocational training that are stressed in the National Action Plan 2.0. At the same time, the German government is aiming to develop and establish new concepts, as well as funding projects through the compensation fund. 50 concepts/projects shall be funded by the end of 2018. The National Action Plan 2.0 refers to various programmes and pilot projects, which focus on inclusion and participation in matters of work and occupation.⁴⁷⁸

One example is the promotion of integration projects by the Federal Ministry of Labour and Social Affairs, which will create additional jobs in integration enterprises and is funded by the compensation fund. At the same time, employers are being made aware of vocational training and employment by "Initiative Inklusion". In this context, essential economic actors are, among others, assigned to make employers aware of the workforce potential and the capability of people with disabilities. Here, campaigns such as 'Inclusion works!' (Inklusion gelingt!) and projects such as 'Inclusive Economy' ("Wirtschaft inklusiv") are being implemented.

Furthermore, the number of disabled people as students or doctoral candidates in tertiary education is increasing.⁴⁷⁹ This can be traced back to an increase in inclusive education, the reduction of barriers at universities, and targeted counselling and support for students / doctoral candidates. Measures that support students, doctoral candidates and scientists with disabilities and measures that support inclusion at universities are now intensified and should be extended in order to achieve sustainability.

⁴⁷⁶ BMAS, NAP II, 2016

⁴⁷⁷ SGB IX, §§39ff.

⁴⁷⁸ Vereinte Nationen CRPD (2015): Ausschuss für die Rechte von Menschen mit Behinderungen. Abschließende Bemerkung über den ersten Staatenbericht Deutschlands [Online]. Verfügbar unter: http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/UN-Dokumente/CRPD_Abschliessende_Bemerkungen_ueber_den_ersten_Staatenbericht_Deutschlands_ENTWURF.pdf [19.05.2017].

⁴⁷⁹ BMAS 2016 a

The National Action Plan 2.0 covers specific policies to promote participation in working life for various subgroups of people with disabilities, as well as policy measures to raise and create awareness of various actors and systems within the economy and the labour market.

Ultimately, it focuses not only on the regular labour market, but also on the special institutions for occupational orientation and qualification of people with disabilities mentioned at the beginning and the evaluation of policy measures. These are characterised by a processual nature and continuous enhancement of policy measures for people with disabilities.

In the last 7 years progress has been made towards more social inclusion of people with disabilities, especially by increasing inclusion in mainstream schools, by increasing the number of students, and by promoting doctoral students through special programmes. Discrimination and disadvantages particularly persist when it comes to school leavers of special schools, who often do not obtain regular school leaving certificates.

71% of the pupils that attend a special school do not obtain a Certificate of Secondary Education.⁴⁸⁰ At the same time, becoming disabled at a young age seems to go together with discrimination as this group of people faces persistent obstacles with the educational system and obtain a lower level of education.

This can affect the transition from school to work, as well as participation in working life later on.⁴⁸¹ The field of higher education also shows that the number of people obtaining an advanced technical college entrance qualification or a higher education entrance qualification increased by 11%, whereas the number of people with disabilities that obtained these certificates increased only by 5% in the same period.⁴⁸² Further efforts are needed to counteract discrimination against people with disabilities in the field of education and vocational training.

In the context of the separated systems mentioned above – offered by the “Berufsbildungswerk” (vocational training centre) and sheltered workshops – it is possible to receive training sponsored by the Federal Agency of Employment. In this regard, the two-year training cannot be classified as qualifying training; it merely leads to a recommendation for specific areas of activity within the sheltered workshop or for cooperating integration companies.⁴⁸³

Generally, it is impossible to integrate into the first labour market in this way. In addition to regular training that can also be gained on the regular labour market, the vocational training centre includes training for specific semi-skilled/unskilled jobs for people with disabilities whose performance capabilities exceed the requirements of the sheltered workshops but are too limited to complete regular training.

⁴⁸⁰ BAMS 2016 a

⁴⁸¹ Ibid.

⁴⁸² BAMS 2016 a

⁴⁸³ <https://www.disability-europe.net/country/germany>

These training courses have the theoretical potential to include more disabled people in the general labour market, but as they are specific and not on the same level as regular training they can also lead to a long-term exclusion. If possible, dual training within companies in the regular labour market would be preferred and is supported by initiatives such as those mentioned above; intensified attempts are made to include more disabled persons in the mainstream apprenticeship schemes. Nevertheless, in view of generally declining numbers of regular professional training opportunities and due to prejudices and a persistently low level of educational qualification, it is likely that young disabled people will still have problems prevailing against competitors without disabilities on the apprenticeship market.

To improve the effectiveness of measures, numerous projects are supported by the compensation fund and named within the National Action Plan 2.0.⁴⁸⁴ At the same time, on a social law level there are efforts to create incentives, e.g. subsidies for employers that employ and train disabled people, as well as financial support for adapting workplaces to the disabled person's needs.⁴⁸⁵ In this way, the disabled person receives various benefits.⁴⁸⁶ Additionally, in the context of professional training, subsidies and awards can be granted in order to, for example, reduce examination fees and minimise additional costs that arise due to the employment of a severely disabled person.⁴⁸⁷

Even though both professional orientation and professional training for disabled people are regulated by law, and thus in this context individual needs are considered on a legal-normative level, there was a decline of around 40% in the conclusion of new training contracts in professions for disabled people in 2014 compared to 2007.⁴⁸⁸

Finally, it remains to be said that even though there are numerous measures provided by the federal government, in the context of professional orientation and professional training people with learning disabilities are still discriminated against to a very high extent, with hardly any access to the first labour market. It is currently difficult to estimate how far this will change as a result of the adoption of the new "Bundesteilhabegesetz" and the "Budget für Arbeit"⁴⁸⁹ that will be established in this context. Due to the fact that this target group is frequently segregated in school, training and professional life from childhood, projects and measures that focus on inclusion in the regular labour market have to be intensified even more, in order not to let the burden of such services and other related services fall on the civil society service providers and/or public-private partnerships.

Notwithstanding the above, there is a great deal of support available to disabled people (*behinderter Menschen*) in Germany, from general counselling to specific institutions such as:

⁴⁸⁴ BMAS 2016 b

⁴⁸⁵ BIH-Integrationsämter

⁴⁸⁶ Benefits such as a training pension according to § 122 SGB III, transitional payment according to §§ 119ff. SGB III or subsidies for working aids, as well as accompanying assistance, such as compensation for disadvantages.

⁴⁸⁷ BMAS 2016 b

⁴⁸⁸ BMAS, 2016 a

⁴⁸⁹ Federal Participation Law and Work Budget respectively.

- Advice centres
- Early support centres for children (Frühförderung)
- Integrated kindergartens
- Special kindergartens (Sonderkindergarten or Förderkindergarten)
- Special Schools (Sonderschulen)
- Special professional schools (Berufsschulen), for instance for deaf pupils
- Apprenticeships for visually impaired and deaf people (Ausbildungsplaetze)
- Employment integration support
- Care and accommodation grants for disabled people
- Workshops for disabled people (Werkstätten für behinderte Menschen)
- Transport services (*Fahrdienste*)

These institutions and services are delivered mostly by private charity organisations (such as Caritas, Diakonisches Werk, self-help groups, parent associations) or, where no private service is available, through the public sector.⁴⁹⁰

One such example is the Lebenshilfe, which sees itself as a self-help association, parents, professional and carrier association for people with intellectual disabilities and their families. It was founded in 1958 in Germany at the federal level by concerned parents and professionals as a federal association.

The objective of Lebenshilfe⁴⁹¹ is the well-being of people with mental disability and their families. It is committed to ensuring that disabled people can live as normally and independently as possible from childhood to a high age and that they are given the aids and support they need to do so. It represents the interests of people with mental disability and their family members, rejects discrimination and social exclusion and campaigns for acceptance, respect and recognition. Lebenshilfe wishes to show that mental disability is an expression of human life, which by no means depreciates the value of life. The sentence nobody may be discriminated against for their disability, which is part of the constitution, must become reality in all areas of life. Lebenshilfe provides information, advice and further education for people with mental disabilities, their relatives and for employees of disabled peoples' support agencies.

It runs more than 3,200 facilities and mobile or out-patient services throughout Germany to promote people with mental disabilities and to support their relatives, for instance: early learning offices; family-relieving services; kindergartens and schools; workshops for disabled people; residences and leisure offers for its beneficiaries. As such, Lebenshilfe represents the rights of people with mental disabilities and their families with the legislator and authorities, and advises on expert and legal questions. Many services, such as their "Simple Language" (Leichte Sprache) internet portal, are directly targeted to people with mental disabilities.

Let us now dwell a bit on the subject of access to the open labour market. In the first National Disability Action Plan for the implementation of the CRPD, published in 2011, the German government committed itself to inclusion as a long-term objective. Participation of persons with

⁴⁹⁰ <https://smartexpat.com/germany/how-to-guides/health/disability-support/people-with-disabilities>

⁴⁹¹ <https://www.lebenshilfe.de/de/andere-sprachen/en/index.php>

disabilities in working life was identified as a priority. In the new National Disability Action Plan presented in 2016,⁴⁹² the government explained that it was aiming to heighten efforts to achieve professional integration into the regular labour market for disabled people (according to Art. 27 CRPD) and to bindingly determine these aims within the coalition agreement of the next legislative period.

Every disabled person should, according to his/her individual capabilities and through services and support appropriate to his/her needs, be enabled to participate in professional life as much as possible. Measures focus particularly on the following areas: support for and awareness among employers, professional orientation, placement into professional training and employment and the establishment of employment opportunities outside of sheltered workshops.⁴⁹³

With regards to NAP 2.0 in the scope of the “Initiative Inclusion”, in future such professional orientation will be additionally financed by the compensation fund, and thus by funds provided by the federal government.⁴⁹⁴ The supported employment services introduced in 2009 aim to increase the chances of inclusion in the regular labour market after professional orientation. This measure is especially aimed at disabled people in the area of sheltered workshops.

Additionally, since 2015/16, integration projects are being supported and developed to a greater extent. Furthermore, new employment opportunities are to be developed by means of the work budget. Besides expanding employment opportunities (including by financing numerous jobs and projects through the compensation fund), placement by governmental institutions is to be improved. Employment services are designed to place disabled people that are seeking work into appropriate mainstream training programmes or employment. In the course of a support measure for the integration and counselling of severely disabled people provided by the federal government, employment services work with further institutions and offices to develop strategies for improved integration of disabled people in training and employment.⁴⁹⁵

At the same time, there are sanctions for the non-employment of disabled people depending on the company size or the number of employees. These sanctions have to be paid annually. The exact amount is regulated.⁴⁹⁶ These measures are financed within the framework of the social laws by the relevant service providers that are defined within the respective Social Code Book.⁴⁹⁷ On the level of national legislation, services for participation in working life are subsumed under occupational rehabilitation. The responsibility for financing these measures lies, in most cases, with the Federal Labour Office, as well as with the integration offices that are located there.

⁴⁹² NAP 2.0

⁴⁹³ BMAS, 16 b, 25

⁴⁹⁴ BMAS 2016 b

⁴⁹⁵ BMAS, 16 b, 26

⁴⁹⁶ § 77 “Ausgleichsabgabe” = compensatory levy.

⁴⁹⁷ Social Code Book IX, <http://www.sozialgesetzbuch-sgb.de/sgbix/77.html>.

In terms of specific needs of disabled people, further potential support services are provided. These cover, for instance, support for adapting workplaces to the disabled person's needs. This support includes work-related aids or technical utilities that can be applied by employees and employers.⁴⁹⁸ Additionally, there are different models of work assistance that can be utilised. There are three ways to organise and manage the assistance:

- a) Autonomously
- b) As a service model (special services fulfil assistance services)
- c) As a mix of a) and b).

Funding can also be provided by a personal budget or as a contribution in kind by a relevant service provider.⁴⁹⁹ However, the use of these services is associated with enormous bureaucratic effort. In general, due to the individualisation of services this becomes the burden of the persons concerned.⁵⁰⁰

Essentially, supported employment can be subsumed as a measure for participating in professional life. It aims to give access to appropriate and suitable insurable employment for disabled people with special needs. This measure is legally embedded and includes not only individual company-based qualification but also vocational support in accordance with the applicant's needs.⁵⁰¹

It is by far more effective than sheltered employment on a national scale. In Germany, around 700 sheltered workshops with more than 2,700 establishments are in existence. By the end of 2014 a total of 264,842 people were working in sheltered workshops: 20% more than in 2007.⁵⁰² The increase in the number of people working in sheltered workshops was explained by the increasing percentage of employees older than 50 and the increase in people with a psychological diagnosis in sheltered workshops.⁵⁰³ Besides the general sheltered workshops there are an additional 23 specific workshops for over 6,000 blind employees, but these are defined as part of the general labour market.⁵⁰⁴

Work in sheltered workshops is portrayed by the social law as a protective form of participation in working life, but in reality it is highly separated from the work environment of non-disabled people. According to the Social Code Book,⁵⁰⁵ people that cannot be integrated into the general employment market due to the form or severity of their disability have the right to participate in sheltered workshops for disabled people.

Standard labour law does not apply to sheltered workshops as the sheltered workshops are seen as a mixture of rehabilitation institutions and economic companies. People who work in

⁴⁹⁸ REHADAT 2015.

⁴⁹⁹ betanet 2016 § 17.

⁵⁰⁰ AKTION MENSCH 2012

⁵⁰¹ § 38a SGB IX

⁵⁰² BMAS 2016 a, 192

⁵⁰³ BMAS 2016 a, 193

⁵⁰⁴ Ibid.

⁵⁰⁵ § 136 SGB IX

sheltered workshops are not defined as employees and they do not have a contract of employment, but a sheltered workshop contract. The regulations of labour law, e.g. in regard to termination, do not apply to them. Termination by the company is virtually impossible, or only possible to a very limited extent.⁵⁰⁶

The new Work Budget aims to support free choice of workplace inside or outside of the sheltered workshops, but thus far there is little evidence of it being applied frequently (only some Bundesländer have started to implement it). Theoretically, due to the ratification of the UNCRPD, the state is obligated to regularly provide evidence as to whether a transition from sheltered workshops into the general labour market or integrative companies has been possible; furthermore, there is a statutory obligation for sheltered workshops to aim for the integration of their employees into the general labour market, but there is no evidence that this is consistently met. It may also conflict with the economic interests of the (for-profit) companies organising sheltered workshops.

Outside the sheltered employment environment, however, severely disabled employees have the right to workplace adaptations based on the needs of the employee.⁵⁰⁷ This includes technical adaptations and barrier-free conditions throughout the whole workplace. Furthermore, it can include a change to another workplace or working time organisation, as well as personal assistance.⁵⁰⁸ The obligation of the employer to arrange suitable working conditions for employees with disabilities is covered by the social law. The employer is supported financially and organisationally by the integration office/public agency.

With regards to accessible housing, Section 8 paragraph 1 of the Disability Equality Act stipulates at national level that public buildings have to be accessible; this obligation applies to new buildings as well as to reconstructions of public buildings on a large scale and to buildings rented by the government.⁵⁰⁹

All 16 Bundesländer (Federal States) have similar laws and regulations on accessibility in buildings that are open to the public.⁵¹⁰ The regulations are limited to public buildings and the public sphere, and do not concern the private sector.

⁵⁰⁶ Schumacher, 2016, <https://www.disability-europe.net/country/germany>

⁵⁰⁷ https://www.gesetze-im-internet.de/sgb_9/___81.html

⁵⁰⁸ Social Code Book §81 Abs. 4, Satz 4-5

⁵⁰⁹ Gesetz zur Gleichstellung behinderter Menschen – Behindertengleichstellungsgesetz, BGG, http://bundesrecht.juris.de/bgg/___8.html

⁵¹⁰ See, for example, Section 4 Disability Equality Act of North Rhine-Westphalia

https://recht.nrw.de/lmi/owa/br_bes_text?anw_nr=2&gld_nr=2&ugl_nr=201&bes_id=5216&menu=1&sg=0&aufgehoben=N&keyword=bgg#det190771 and Section 55 Building Regulation of North Rhine-Westphalia

https://recht.nrw.de/lmi/owa/br_bes_text?anw_nr=2&gld_nr=2&ugl_nr=232&bes_id=4883&aufgehoben=N&menu=1&sg=0#det241837.

In December 2016 the Federal Government published a new version of guidelines for accessible housing and construction. These guidelines provide information on standards and technical means for public buildings and areas in the public sphere, but are also intended to encourage the whole sector of architects and planners to pay more attention to accessible construction.⁵¹¹

Common standards for the accessible construction of houses/flats, entrances and nearby surroundings are regulated in DIN-Norm 18040-2.⁵¹² These standards recognise the needs of persons with different disabilities and those of children and the elderly.⁵¹³ For the private sector there is no obligation to comply with these standards.

The newly revised Disability Equality Act strengthens the state obligation and the activities of public actors in terms of providing best-practice house building in such a way that all persons with motor, visual, auditory and cognitive disabilities have access to and orientation in the public sphere. There are also plans to conduct evaluations of the current situation.⁵¹⁴ According to the current disability report, concrete conceptualisations for accessible housing are not defined. This is described as a hindrance to improved data and stocktaking of the current situation.⁵¹⁵ Social organisations put forward the criticism that the government has not determined concrete time frames for full accessibility in all public buildings. Furthermore, they state that the private sector is still almost totally excluded and not bound by the obligations to provide free access and housing for all.⁵¹⁶

Another problem concerning free choice of housing and living arrangements has to be mentioned here. On the one hand, free choice of living arrangements and the transition from residential home care to private households is being strengthened by new laws and policies in Germany.

However, on the other hand, this could be weakened by some regulations of the new “Bundesteilhabegesetz”, especially by the higher cost reservation “Mehrkostenvorbehalt”. The new Bundesteilhabegesetz (National participation law) regulates that persons with disabilities can be forced into residential home care and/or pooling of benefits/assistance when the private and individual solutions are more expensive and/or not perceived to be reasonable.⁵¹⁷

When it comes to ensuring that legislation in favour of persons with disability is enforced, Germany has seen its own share of zealous civil society lobbying. For years people with disabilities in Germany have called for legislation to provide them with better benefits and opportunities in life and work. On Thursday 1st December 2016, the German parliament

⁵¹¹ Bundesministerium für Umwelt, Naturschutz, Bau und Reaktorsicherheit: Leitfaden Barrierefreies Bauen, Berlin 2016

⁵¹² Barrierefreies Bauen – Planungsgrundlagen – Teil 2: Wohnungen

⁵¹³ <http://www.barrierefrei-bauen.de/text/149/de/din-18040-2:-wohnungen.html>

⁵¹⁴ Ibid., p. 5.

⁵¹⁵ BMAS 2016: 261

⁵¹⁶ Sozialverband Deutschland 2016

⁵¹⁷ Deutsches Institut für Menschenrechte 2016

passed such a reform, some positive repercussions of which has been noted above - but is it enough?⁵¹⁸ News reports featuring various reactions from various strata of German society project the fact that our notes on the relevant German situation above are indeed the sentiment felt across the nation.⁵¹⁹

The German parliament (Bundestag) passed comprehensive reform legislation to expand rights for the 7.6 million people who live with severe disabilities. The 400-page legislation includes such measures as simplifying the application process for disability benefits, and allowing benefit recipients to save more of their own money.

Before the reforms, a disabled person was only allowed to save up to €2,600 of their personal wealth if they wanted to receive social assistance, and the income of their partner was also taken into consideration - which CDU politician Karl Schiewerling said was essentially a “marriage ban”.⁵²⁰

Under the new reforms, partners' incomes will not be part of the calculation, and the amount that benefits recipients may save will now be raised to €27,600, and to €50,000 by 2020. Still, opposition parties and the Social Democrats say there should be no consideration of assets.

The reform was brought about after UN officials criticized access for and inclusion of disabled citizens in the education system and labour market.⁵²¹

A spokesperson from the Federal Employment Agency stated that only about 16 percent of people with severe disabilities are part of the regular labour market. Another 4 percent are self-employed or are part of the so-called secondary labour market, such as being part of a job creation programme.

One reason for this is that many employers still do not fulfil the statutory quota: companies with more than 20 employees are supposed to fill at least 5 percent of their positions with people with disabilities.

The reform is also supposed to improve working conditions for disabled people. In special workshops that employ disabled people - currently 300,000 people with disabilities are employed in such shops - there will be gender equality officers to help protect against violence and attacks. It will also be easier for people to switch from such workshops into the regular job market. The reform also encourages the hiring of disabled people by providing a subsidy for up to 75 percent of wages when businesses employ someone with a disability.

⁵¹⁸ <https://www.thelocal.de/20161202/at-last-germany-pushes-reform-for-disability-rights>

⁵¹⁹ <http://www.dw.com/en/activists-angry-as-germany-passes-contentious-disability-law/a-36606791>

⁵²⁰ https://de.wikipedia.org/wiki/Karl_Schiewerling

⁵²¹ <https://www.thelocal.de/20150327/germany-seeks-to-improve-disabled-rights>

“There will be fewer obstacles, and it will make more things possible,” said Social Affairs Minister Andrea Nahles, calling the reform a “systemic change”.⁵²² The German branch of Catholic charity Caritas praised the new legislation, calling it “modern participation rights”. “This is an important step,” said Caritas Germany president Peter Neher in a statement. “During the intensive exchange within the parliamentary process, many improvements were achieved for the sake of the affected people.”⁵²³

But the new reform has also been met with criticism from opposition parties as well as disability rights activists, who say it does not go far enough. “Despite positive signs, the law remains below the original aims,” wrote the Sozialverband Deutschland (Social Community Germany), which campaigns for disability rights, in a statement. “Among the unresolved areas of improvement are the regulations relating to the self-determination of disabled people. This is still inadequate.”

In particular the group points to a system where benefits may sometimes be “pooled” among recipients. “This does not change the possibility that disabled people may be forced into a home if the costs of living at home are too high,” said Die Linke (Left Party) politician Dietmar Bartsch to broadcaster MDR.⁵²⁴ “It creates the possibility that people are forced to share their assistance aid with others and prevents people from having self-determination and participation in society. It restricts the rights of disabled people because the government wants to save costs.”⁵²⁵

There is also one important subject matter which needs to be stated when analysing inclusivity and independent living in Germany. It is indeed a very delicate subject which still evokes past horrors, but it needs to be stated:

Among the 11 million non-combatants killed by Nazis during World War II⁵²⁶, an estimated 300,000 were people with disabilities who were euthanized.⁵²⁷ Six decades later, German companies are still dealing with the implications of that past horror.

One sign is the widespread lack of compliance with quotas for employment of the disabled. Any German company with more than 20 employees is required to fill at least 5% of its jobs with workers who are “severely disabled,” meaning more than 50% disabled, whether physically or psychologically. (The degree of disability is determined by medical and legal guidelines.) These employees have the right to special perks, and government subsidies are available to employers to make sure the employees get the tools and accommodations they need.

⁵²² https://de.wikipedia.org/wiki/Andrea_Nahles

⁵²³ https://de.wikipedia.org/wiki/Peter_Neher

⁵²⁴ <https://www.mdr.de/nachrichten/politik/inland/bundestag-beschliesst-bundesteilhabegesetz-100.html>

⁵²⁵ <https://www.thelocal.de/20161202/at-last-germany-pushes-reform-for-disability-rights>

⁵²⁶ <http://www.nybooks.com/articles/2011/03/10/hitler-vs-stalin-who-killed-more/>

⁵²⁷ <http://dsq-sds.org/article/view/692/869>

But according to a new report from the Centre for Talent Innovation,⁵²⁸ “a cultural tendency toward keeping such information private, perhaps rooted in Nazi policies that targeted people with disabilities in the run-up to World War II, make meeting the government quota quite difficult.”⁵²⁹

Rather than push for more disclosure from employees, say the report’s authors, “virtually all” companies simply pay the government fines. That money—roughly €105 to €260 per month⁵³⁰ for every position that ought to be filled by someone who is severely disabled—is redirected to employment programs and to making public spaces accessible. A disability activist interviewed by the German media outlet DW has called this common practice buying your way out of law abidance.⁵³¹

In a few important ways, the report’s portrait of Germany suggests that the country’s culture around disabilities in the workplace is less progressive than that of the US. The study found that 55% of German workers with disabilities have endured insults at work, and 33% say they have felt avoided at the office, compared to 31%, and 20%, respectively, in the US.

In Germany, 45% of the study’s sample population agreed that they don’t share their health status with their colleagues because it’s “none of my colleagues’ business.” In the US, only 33% agreed with that statement. And, among the survey respondents who identified themselves as being disabled, 49% in Germany (vs 29% in the US) “say they downplay or avoid drawing attention to aspects of their identities by avoiding mentioning their lives outside of work,” the report notes.

The report also cited an unnamed journalist at a global media company, who spoke of a form of discrimination that sadly still feels universal: “I disclose when I need to, not because I want to,” he said. “It’s perceived as a weakness and abnormality, so one does not openly run around and tell everybody.”⁵³²

Notwithstanding the above, government social handouts and inclusivity initiatives to persons with disability made a positive mark on the British respected newspaper The Guardian, who gave a glowing report on Germany in an article which analysed ‘which are the best countries in the world to live in if you are unemployed or disabled?’ in April 2015, even before the passing of the above legislation.⁵³³

The same situation vis-à-vis the German inclusivity model can be also noted with regards to a specialised research report, entitled ‘Integration of People with Disabilities at Work’ undertaken by Flora Koch Davidovich for, interestingly enough, The Knesset Research and Information Center of Jerusalem.⁵³⁴

⁵²⁸ http://www.talentinnovation.org/_private/assets/DisabilitiesInclusion_PressRelease.pdf

⁵²⁹ http://www.talentinnovation.org/_private/assets/DisabilitiesInclusion_KeyFindings-CTI.pdf

⁵³⁰ <https://www.internationallawoffice.com/Newsletters/Employment-Benefits/Germany/CMS-Hasche-Sigle/Federal-Labour-Court-rules-on-severe-disability>

⁵³¹ <http://www.dw.com/en/germany-makes-headway-integrating-disabled-people/a-17267162>

⁵³² <https://work.qz.com/1110806/german-attitudes-about-disability-disclosure-in-the-workplace-are-shaped-by-a-nazi-past/>

⁵³³ <https://www.theguardian.com/politics/2015/apr/15/which-best-countries-live-unemployed-disabled-benefits>

⁵³⁴ <https://knesset.gov.il/mmm/data/pdf/me02640.pdf>

Greece

The key features related to the community support system in Greece for persons with disability are financial empowerment through disability benefits and pensions (the earliest intervention), and the provision of state-funded community-based or short-term residential rehabilitation services.⁵³⁵ Local support started to appear in the form of small pilot projects with Help at Home in 1997⁵³⁶, and developed through local social services departments and networks of support centres across the country only after 2003⁵³⁷.

The late development of community-based support, which includes information, counselling, training, after-care rehabilitation and home help services, means that these services are not yet fully activated, despite increased investment by the state in comparison with state funding of institutions over the last decade⁵³⁸.

The Inspection Body of Health and Social Services reported in 2006 that key tasks in various local social services departments have not been carried out, due to lack of staff, while support centres for people with disability have not fully developed training and independent living programs due to lack of policy on internal regulation. Importantly, there is lack of data on the population using social services and on local needs, as well as a lack of evaluation of the effectiveness of services even though regional authorities⁵³⁹, as well as the National Observatory of Disabled People⁵⁴⁰ and the Institute for Social Protection and Solidarity⁵⁴¹ are legally responsible for this.

The omission is a significant barrier in planning effective services from the point of view of the users of services. There are moreover problems inherent in the system of assessment and service provision, which impede individually tailored and self-directed support. This is most evident in relation to home help programs, the “de-institutionalisation” benefit, and provision of assistive equipment. All of these have a direct impact on daily life activities at home. Common shortcomings are: eligibility criteria are based on diagnosis (a medical model) rather than support needs; access and use depend on available resources (except for the benefit) and they are inadequate in terms of the nature, amount and range of support they offer.

Overall, Greece generally lags behind in comparison with many European countries in developing independent living schemes based on principles of choice and control over one’s support. There has been a move towards community services but self-directed support is completely absent from discourse in policy and future strategies. Implementation would require a wholesale restructuring of the current system of assessment and provision, moving from the medical model to one that took self-defined support needs into account.⁵⁴²

⁵³⁵ Law 2072/1992

⁵³⁶ Law 5814/1997

⁵³⁷ Law 3106/2003

⁵³⁸ Social Budget, 2008

⁵³⁹ Law 3329/2005

⁵⁴⁰ Law 3106/2003

⁵⁴¹ Law 3370/2005

⁵⁴² <https://www.disability-europe.net/downloads/368-el-8-aned-2009-task-5-request-07-template-approved-final-03-july-to-publish-in-layout-to-ec>

Disability benefits were legislated separately for different impairments, starting in chronological order with benefits for blind people⁵⁴³, people with hearing impairment⁵⁴⁴, people with paraplegia and tetraplegia⁵⁴⁵, people with learning disability⁵⁴⁶ and people with cerebral palsy⁵⁴⁷.

In 1989, a Ministerial Decision made benefits available to all other categories of disability not already covered, and who were regarded as being over 67% disabled. It is worth noting that all benefits, except those given to blind people, require that recipients do not stay in welfare state-funded institutions for longer than 3 months. In 1998, important modifications were made to the benefit given to people with paraplegia and tetraplegia⁵⁴⁸, in that support from a third person was included. Eligibility was extended to people with 67% disability, people with paraplegia or tetraplegia or similar, caused by any impairment to nervous and muscular system (previously restricted to paralysis), to people with amputation on any limb (previously restricted to people with double amputation), people with myasthenia and multiple sclerosis, as well as to family members in instances where the entitled person lacked legal capacity.

An additional modification made was that only half the amount of the benefit was given to people living in institutional settings. Disability pensions are legislated for by different social security bodies, who have differing eligibility criteria, mainly in terms of insured working days. Disability pensions of the social security body for private sector employees under the Ministry of Employment and Social Protection are coordinated on the basis of Law 612/1977 and 1902/1990, those of the agricultural social security body under N.2458/1997, and those of public sector employees under Law 2227/1994 and 3620 /2007, which entitles people with disability to a full pension if they have completed 15 years of work.

In 2004, Law 3232 (applicable to all main social security bodies under Ministry of Employment and Social Protection) allowed early retirement for mothers and spouses of people with disability with 80% or over, after 25 working years, regardless of age. The law also established that people with severe disability are entitled to their parent's pension after their death. ⁵⁴⁹

Other measures⁵⁵⁰ that can be argued to indirectly assist community living through financial relief are:

- Housing loan benefit (1 year)⁵⁵¹
- Rent benefit (1 year)⁵⁵²
- Housing adaptations (only for houses older than 20 years old)⁵⁵³

⁵⁴³ Law 1904/1951

⁵⁴⁴ Ministerial Decision D3b/423/1973

⁵⁴⁵ Ministerial Decision 115750/3006/1981

⁵⁴⁶ Ministerial Decision C4/1930/1982

⁵⁴⁷ Ministerial Decision C4a/1434/1984

⁵⁴⁸ Law 2646/1998

⁵⁴⁹ Academic Network of Disability experts (ANED) – VT/2007/005

⁵⁵⁰ All measures apply to persons assessed with 67% disability or over.

⁵⁵¹ Law 2736/1999

⁵⁵² 2 Law 1849/1989 (Official Journal of Government 113A) and Ministerial Decision 2000 number 50262

⁵⁵³ Law 2224/94 and N.2736/99

- Revenue Tax relief: all three applicable for disability pensioners only⁵⁵⁴
- Motor tax relief⁵⁵⁵
- Free travel within city (buses, underground) and 50% reductions for coach and train travel⁵⁵⁶
- Social Tourism funding⁵⁵⁷
- Free access to cultural sites⁵⁵⁸

Naturally, as the years progressed, more initiatives were introduced by the authorities in order to positively discriminate in favour of persons with disability. The above, however, are noted by most experts in the field as the basic foundation stones of legislation in Greece which directly affect persons with disabilities.⁵⁵⁹

Christos Zervas, in a study entitled *Is Greece an Inclusive Country?*⁵⁶⁰ tries to assess how much Greece has progressed in this sector. He notes that it seems that Greece has a solid legislation in its arsenal. As stated above, from the early seventies, when the first 43 special secondary schools were established, until the latest “Special education and training people with disabilities or special educational needs” law of 2008, brave steps towards inclusion have been taken.

The compulsory nature of “Special education and Training” (EAE) as an integral part of obligatory and free education, was fully adopted. Furthermore, the state committed itself that all citizens with any kind of disability will have equal opportunities for full-time complicity in the society. Moreover, it promises a chance for independent living, financial and economic self-sufficiency and staking their claims for inclusive education.

In general, Greece’s policy (and legislation) follows the trend of the European continent. It is true that Greece has ratified the international declarations of UNICEF, UNESCO and WHO. Nevertheless, essays from UNICEF and UNESCO inexorably pinpoint the major problems at implementation stage.

UNICEF points out a variety of weaknesses about the present policy around the country. To begin with, it discusses the low level of projected funds. It states that the child protection allowance is a pittance every two months for each child. In addition, the annual lump sum for the family is also not in any manner adequate and never confirmed for its proper use, due to inadequately staffed social services. Another example is that families face specific problems in fostering and protection of their children. If the parents are mentally ill, the mentioned policies are omitted.⁵⁶¹

On the other hand, Greek society is considered quite stiff towards families of children with special needs, even nowadays. Greeks do not feel comfortable yet with anything that seems unknown. There have been some efforts from the government and media in the opposite

⁵⁵⁴ Law 2238/1994 (Official Journal of Government 151A) and Law 3522/2006 (O.J.G 276A)

⁵⁵⁵ Law 490/1976 (O.J.G. 331A) and Law 3156/2003 (O.J.G. 157 A)

⁵⁵⁶ Law 2072/1992 (O.J.G 125/A)

⁵⁵⁷ Law 2224/1994

⁵⁵⁸ Ministerial Decision E/22240, 2003 (O.J.G. 1705/B)

⁵⁵⁹ <http://enil.eu/news/independent-living-in-greece/>

⁵⁶⁰ <https://www.thinkinclusive.us/is-greece-an-inclusive-country/>

⁵⁶¹ Ibid.

direction, but still most people are reluctant. Children with sensory disabilities are a good example.

Deaf pupils in Greece are trying to be identified and associated only with each other. They know that without the Greek Sign Language they cannot communicate. In reality, few people are trained to use this language. Therefore, these children make their own separate and small community. They have their own culture. Even some parents need an interpreter to understand their children.⁵⁶²

As far as learning disabilities, a story from a small county city of Greece shows exactly what was described above: A family had a son who had a severe type of dyslexia. It affected him as if he had an intellectual disability. Anyone could see and understand he had many challenges. The parents knew it as well, but the advice received from the local society forced the father to send his son to a typical kindergarten which was not equipped to handle his learning differences. Some of the family's relatives tried to explain to the father what a better alternative for his son would be, but he ignored them. Only when the teachers insisted too much, the student went to a "special needs" kindergarten. The teachers were well aware that the student was bullied by his peers. The little boy was totally brushed aside. He was not given the opportunity to participate in any activity.

Theoretically, Greece should be able to provide a lot for children with special needs. Nevertheless, the reality is different. The economic crisis in Greece has had a major impact on the sector. The biggest psychological public hospital of Athens, named "Aiginiteio", remained without psychologists. All of them were fired because of the low budget momentum, which is offered to hospitals. It functioned only with volunteer work.

The economic crisis hard hitting disability initiatives in Greece is also noted and underlined by the European Network on Independent Living.⁵⁶³ In this report by Stelios Kypouropoulos, a shocking statement should be noted in this study:

"...during the last few years, there is a limitation depending on one's income in order to have that service, and another term is that one must have an unemployed member in his family, so that through this service the unemployed member of his family could have the chance to find a job since the "Assistance at home" assist the old or the disabled person. Of course that service is not enough to promote Independent Living or social inclusion. As I mentioned above, there are no official records but since there is no alternative to institutional care, mostly disabled adults whose parents are either old or unable to assist them anymore or dead tend to be institutionalized.

Furthermore, when those adults have low income they cannot hire personal assistance services. Also people with intellectual disabilities are institutionalized even in childhood because of the lack of state's support. The truth is that a Greek disabled individual can only survive with the daily support of his/her parents or siblings."⁵⁶⁴

⁵⁶² Ibid.

⁵⁶³ <http://enil.eu/news/independent-living-in-greece/>

⁵⁶⁴ Ibid.

The Office of the Commissioner of Human Rights of the United Nations also mentions the same situations when commenting on Greece in this sector:

"I find it particularly troubling that the European Commission has been insisting that Greece should close psychiatric hospitals before the end of 2015 while at the same time prescribing budget cuts to precisely those community-based services that could have replaced the institutional ones," said Jan Jařab in his final press conference on 1 April 2015. Of course, our Office is in favor of moving from institutional to community-based services, in line with article 19 of the Convention on Rights of Persons with Disabilities (CRPD), which speaks of independent living and inclusion in the community. But the community-based alternatives must be well prepared and of high quality - it is unthinkable to both close hospitals and cut community-based services, basically leaving the most vulnerable persons in the streets."⁵⁶⁵

Such problems were gradually all the more compounded with the influx of migrants into Greece, which naturally included persons with disabilities. In February 2018, over sixty experts attended a roundtable session in Athens to support a new model of alternative care for unaccompanied children and children with disability in Greece. The experts stressed the importance of Supported Independent Living (SIL) for older unaccompanied children as a model of care that would provide adolescents with housing, supported supervision and access to a range of protection services.

"Through the dialogue and exchange of experiences and best practices we will be able to improve relevant legislation and better approach this alternative care model following its adaptation to the Greek reality and current socio-economic conditions in the country," the Prosecutor General of the Supreme Court of Greece, Xenia Dimitriou, stressed in her opening address at the two-day conference.

"The question is not whether, but rather how to adopt the Supported Independent Living as a model of care in Greece, and how soon it can be implemented," added Dimitriou at the landmark 29-30 January gathering, which was co-hosted by the Supreme Court Public Prosecutor's Office and the National Centre for Social Solidarity (EKKA), with the support of UNICEF and UNHCR, the UN Refugee Agency, and with technical input from the inter-agency Alternative Care Task Force.⁵⁶⁶

When it comes to educational opportunities leading to independent living for persons with disability in Greece, one notes that the central administration agency of the state education system is the Ministry of Education, Research and Religious Affairs, which also oversees evaluation and support services for pupils with disability and/or special educational needs (SEN). The administration of education is allocated to the general authorities of the aforementioned Ministry, which in turn is distributed to specific authorities, e.g. the General Directorate of Studies in Primary and Secondary Education which is divided into separate offices, such as Administrations of Primary Education, Special Education, etc.

⁵⁶⁵ <http://europe.ohchr.org/EN/Stories/Pages/Greece2015.aspx>

⁵⁶⁶ <http://www.unhcr.org/gr/en/5711-roundtable-supported-independent-living-unaccompanied-children.html>

A number of public services report directly to the Ministry and contribute in fulfilling its functions. These include the Institute of Educational Policy (IEP)⁵⁶⁷.

The schools are directly administrated by the local authorities of education, with the Directors of Education co-ordinating and supervising the schools in their responsibility area. In addition, the Regional Education Directorates oversee the implementation of the national educational policy at regional level.

As mentioned above, the 'Myschool' nationwide database supports the everyday activities of pre-primary, primary and secondary schools (both mainstream and special) and their interaction with the Greek Ministry of Education. It is the main tool for staff administration, learner administration, classes, grades and everyday school activity.

The Greek State recognises disability as part of human being and as a complex social and political phenomenon. It undertakes to ensure equal participation in society, independent living and economic autonomy for people with disabilities and people with SEN, as well as full consolidation of their rights to education and social and professional inclusion. In this context, a great number of laws and decrees issued by the Ministry of Education, Research and Religious Affairs provide options for the best way of educating people with disability and/or SEN.

Law 3699/2008 introduced the provision of compulsory education for pupils with disability and/or SEN as an integral part of free public education.

Article 3 of the aforementioned law defines pupils with disability and/or SEN as those who have significant difficulties in learning for the whole or some period of their school life, because of sensory, intellectual, cognitive or developmental problems, or mental health or neuropsychological disorders that affect the process of their school adjustment and learning. Learners with any of the following are considered to have disability and/or SEN:

- Intellectual disability
- Vision and hearing sensory disabilities
- Physical disabilities
- Chronic non-curable diseases
- Speech disorders
- Specific learning difficulties (dyslexia, dyscalculia, etc.)
- Attention deficit hyperactivity disorder
- Pervasive developmental disorders (autism spectrum)
- Mental health disabilities
- Multiple disabilities.

Low achievers and learners with learning disabilities that derive from external factors, such as linguistic or cultural particularities, are not considered to have disability and/or SEN. Pupils with complex cognitive, emotional and social difficulties, delinquent behaviour because of abuse, parental neglect and abandonment or domestic violence, and pupils with one or more special intellectual skills and talents are considered to have SEN.

⁵⁶⁷ Created in 2011 by Law 3966

To ensure equity and quality education, pupils with disability and/or SEN receive education with priority in mainstream classes with or without support. If they have severe difficulties, they attend special schools. More specifically, pupils with disability and/or SEN are educated in the following settings:

1. In a mainstream class:

- For pupils with mild learning difficulties, supported by the class teacher, who co-operates on a case-by-case basis with the Diagnostic Assessment and Support Centres (KEDDYs) and mainstream and special education school advisors.
- With individualised parallel support co-education, provided by a special education teacher. This type of education is provided to pupils who can, with the appropriate individual support, follow the classroom curriculum and to pupils with more severe SEN when there is no other special education setting (special school, inclusive class) in their local area or when parallel support becomes necessary—based on the KEDDY's report – because of the pupil's SEN.
- By the inclusion teacher who may support one or more pupils in the class in co-operation with the class teacher.⁵⁶⁸ The inclusion teacher may also support the pupils in a separate room (inclusive class), taking their SEN into account with the aim of their future inclusion in the mainstream class. Inclusive classes provide two types of educational programmes:
 - common and specialised programme up to 15 hours per week;
 - specialised team or personalised programme of extended time – table for learners with more severe SEN.

Pupils with disability and/or SEN (apart from specific learning difficulties) are distributed in the classes of the same grade so that no more than one (1) attends the same class. If this is not possible, then the number of pupils in the class may be reduced to three (3) less than the maximum allowed. The number of pupils with specific learning difficulties attending a mainstream class cannot exceed four (4). If this is not possible and no inclusive class is in operation in the school, then the number of pupils in the class may be reduced by three (3).⁵⁶⁹

2. In special schools when pupils have severe difficulties in attending mainstream or inclusive classes. According to Law 4386/2016 (Article 82), special and mainstream schools can implement co-education programmes to promote inclusion and equal opportunities in education, to develop the cognitive, learning, emotional and social skills of pupils with disability and/or SEN and to develop mainstream pupils' awareness of human rights issues, diversity, respect and human dignity.
3. In schools or departments operating as autonomous units or annexes of other schools in hospitals, rehabilitation centres, disciplinary institutions for juveniles, or chronic disease institutions, provided that the pupils with disability and SEN live within.
4. Tuition at home, when pupils cannot attend school because of short- or long-term health problems.

⁵⁶⁸ Law 4368/2016, article 82

⁵⁶⁹ Law 4452/2017, Article 11

After assessing pupils' special educational needs, the KEDDYs suggest the proper school setting for each pupil. For all pupils with disability and SEN, Individual Education Plans are planned by the KEDDYs and implemented by the special needs teacher in co-operation with the special education school advisor. The pupil's parents or guardians can take part in planning the Individual Education Plan. Special schools also provide intervention programmes, like occupational therapy, speech therapy, physiotherapy and other services that ensure equal treatment, evaluation and pedagogical and psychological support for the pupils. KEDDYs may also provide such services.⁵⁷⁰

Law 3699/2008 (GG 199 A/2008) mentions that systematic interventions during pre-primary age are provided by local special school units, through the development of early intervention classes.⁵⁷¹ According to this law, early intervention classes will operate within special kindergartens to support children up to the age of seven (7).⁵⁷² KEDDYs are officially responsible for the preparation and support of early intervention programmes⁵⁷³.

Diagnostic Educational Evaluation and Support Committees (EDEAYs) operating in mainstream schools are also responsible for developing similar programmes in co-operation with the local paediatric services and Medical-Pedagogical Centres (IPDs). They also organise training programmes for parents with pupils up to the age of six (6) in co-operation with the municipality services.

Inter-ministerial co-operations (Ministry of Education, Ministry of Health and Ministry of Labour) are expected to promote the implementation of early intervention programmes.

More recently, the establishment of a new and more effective skills forecasting mechanism is foreseen to bridge the gap between vocational education and training (VET) and the labour market⁵⁷⁴. The body responsible for skills forecasting (EIEAD), in co-operation with the co-ordination committee, supports the State in developing VET curricula in line with labour market needs. Law 4115/2016 has made amendments to 3699/2008. Moreover, it introduced an apprenticeship system for learners with disabilities.

As far as the transition from secondary to tertiary education is concerned, a very important role is played by the Diagnostic Assessment and Support Centres (KEDDYs), the Career and Counselling Centres (KESYP)⁵⁷⁵ and the Counselling Service Offices for Youth.

Improved transitions between different education levels for all learners and between education/training and the labour market are among the priorities of the Greek educational system, as stated in the recent Action Plan for Education (2017–2020). Moreover, the priorities of the educational system include the modernisation of the operation of the KEDDYs. The main aim of these initiatives, which are currently under consideration, is to improve educational and career guidance across all phases of inclusive education.

⁵⁷⁰ <https://www.european-agency.org/country-information/greece/legislation-and-policy>

⁵⁷¹ article 2, paragraph 6c

⁵⁷² Article 8, paragraph 1a

⁵⁷³ No. C6/4494/01 (GG 1503 B)

⁵⁷⁴ Articles 85 and 86 of Law 4368/2016

⁵⁷⁵ Ministerial Decree 2316/10-08-2012

Law 3879/2010⁵⁷⁶ introduced 'Educational Priority Zones' (ZEPs), another measure that has been implemented since 2010 by the Ministry of Education, and is believed to contribute positively to combating segregation and its consequent effects in certain schools. It includes provisions for strategic planning to consider socio-economic barriers to learning. The general aim behind the implementation of ZEPs is to promote the equitable inclusion in the education system (especially in primary and secondary education) of learners from areas with low educational and socio-economic indicators, high school drop-out rates and low access to higher education.

In May 2012, Greece ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁵⁷⁷. As part of its commitments under Articles 7 and 24 of the UNCRPD, the Greek Government is committed to inclusive education for children and young people with disabilities, progressive removal of barriers to learning, and participation in mainstream schools.

The 2016 report on 'The State of the Children in Greece', by the Hellenic National Committee for UNICEF, provides important information related to the institutional framework for the rights and protection of children with disabilities at the national level.⁵⁷⁸

Law 4368/21.02.2016⁵⁷⁹ promotes inclusive education. It stresses:

- the need to educate all learners in a mainstream class along with their non-disabled peers;
- the need for collaboration between general teachers and inclusive class teachers;
- the need to implement differentiated instruction in mainstream settings;
- the need to implement co-education programmes for learners from mainstream and special schools.

Presidential Decree no. 72877/D3/17.10.2016 makes further provisions for close co-operation between special and mainstream schools. It has several objectives, including preparing a smooth transition from special to mainstream school settings for some learners with disabilities.⁵⁸⁰

There have been a series of policy measures introduced for modernising vocational training and enhancing transition to the labour market, mostly planned under the National Youth Guarantee initiative (2014)⁵⁸¹ with some policies recently enacted (February 2017) targeting mainly mainstream training structures.

⁵⁷⁶ Article 26 sections 1a and 1b (GG 163 A/2010)

⁵⁷⁷ Law 4074/2012

⁵⁷⁸ <https://www.unicef.gr/uploads/filemanager/PDF/2016/children-in-greece-2016-eng.pdf>

⁵⁷⁹ Article 82

⁵⁸⁰ <https://www.european-agency.org/country-information/greece/legislation-and-policy>

⁵⁸¹ Greek Youth Guarantee Implementation Plan May 2014

<http://ec.europa.eu/social/main.jsp?catId=1161&langId=en&intPageId=3337>.

Reforms in secondary vocational education were first foreseen in Law 4186/2013⁵⁸² introducing the "apprenticeship class" as a fourth optional year of study at Vocational Senior High schools (EPAL), as well as Vocational Training Schools (SEK) for secondary education graduates offering traineeship in a business on the third (final) year of study.⁵⁸³

The same legislation included regulations for the restructuring of special vocational educational units (secondary level), and the attainment of vocational rights upon completion of 5 grades of special vocational high school (level 2b vocational rights) and 4 grades of special vocational senior high school (level 3). It is worth noting that this is equal to the level of vocational rights/ qualification gained at completion of the respective mainstream structures, entailing however 2 more years of attendance. Apprenticeship schemes are not however as explicitly included in the study cycle as in mainstream education, but rather briefly referred to as "practice through special school cooperatives" (Law 4186/2013 Art.28, par.1a).

Furthermore, graduates from special primary education can alternatively enrol at the Workshops for Special Vocational Education and Training, which involve six years of study, and vocational rights at 2a level. The last year of study includes work practice over at least two trimesters, while "where this is not possible, then this is supported by the school cooperative"⁵⁸⁴.

The Ministerial Decision 26381/ 20 February 2017⁵⁸⁵ enacted the apprenticeship scheme for EPAL and SEK, introducing in parallel a Quality Framework of educational programs of Vocational Education and Training. Art 2 par 3 specifies that programs should aim at "approaching and evaluating knowledge through a variety of alternative means, so that they can offer opportunities for learning and development to all learners, according to their particular traits (such as learner's profile, cultural background, special needs or/and disabilities, etc.)". An additional ministerial decision⁵⁸⁶ enacted previous legislative commitments for broadening access to technical tertiary education for vocational education graduates (such as Tourist Studies, or Military School), but also to higher education at 1% of available places in any university department.⁵⁸⁷

Equality Law 3304/2005⁵⁸⁸, Art 8 par 2, safeguards non-discrimination on the grounds of disability for all kinds and levels of vocational education and training, including apprenticeship schemes. In this respect all measures outlined above apply equally to disabled students included in mainstream vocational education and training, while the providers bear the responsibility for

⁵⁸² Law 4186/2013 Restructuring of Secondary Education and other regulations <http://www.synigoros-solidarity.gr/solidarity/assets/uploads/2015/11/N-4186-2013.pdf>.

⁵⁸³ Greek Youth Guarantee Implementation Plan 2014 (p. 25).

⁵⁸⁴ Law 4186/2013 Art.28, par 1c

⁵⁸⁵ Ministry of Education (FEK 490,491/20-2-1) https://www.minedu.gov.gr/publications/docs2017/kya_mathiteias.pdf.

⁵⁸⁶ Ministerial Decision (545/22-2-2017) Access of Graduates of EPAL to Higher Education http://www.minedu.gov.gr/publications/docs2017/%CE%95%CE%A0%CE%91%CE%9B_%CE%A4%CE%95%CE%99_%CE%A0%CE%91%CE%9D%CE%95%CE%A0.pdf.

⁵⁸⁷ Following national examinations on two main subjects (Greek language and maths), plus any special class that may be required by a specific department (e.g. music, art, foreign language).

⁵⁸⁸ Equality Law 3304/2005 <http://www.ypakp.gr/uploads/files/2538.pdf>.

ensuring accessibility and reasonable adjustments as necessary. Nevertheless, state guidance as to implementing accessibility in that context has not been specified, while any legally binding requirements tend to be limited to physical accessibility.

Further measures specific to disability include the abolition of the previously held discretion of universities to decide on which cases an impairment is considered as an obstacle to studying a specific subject (Article 7 N. 4283/2014).⁵⁸⁹ Finally, recent legislation (L.4283/2014; Art.82)⁵⁹⁰ focusing on inclusive education may also be seen as a positive development towards increasing access of disabled pupils and youth to mainstream education and vocational training.

Firstly, primary special education is restructured similar to mainstream primary education in terms of grades.⁵⁹¹ Secondly, inclusion classes available for disabled pupils within mainstream schools are strengthened in number and scope,⁵⁹² seen as promoting equal opportunities and skills development, differentiated learning, accessible learning material as well as raising disability awareness in the wider school environment.

Apprenticeship schemes (Law 4186/2013) launched in February 2017⁵⁹³ targeted 519 graduates of Vocational Senior High Schools (NEET and up to 24) across 27 educational units in Attika. The scheme includes 28 hours of working practice weekly plus one day of classes over a nine-month period. Participants are paid at 75% of minimum wage and are fully insured, including pension scheme and health insurance.

Similarly, there has been a call for proposals for implementing apprenticeship schemes at the final year of SEK (Vocational Training Schools) as well as at the second study year at IEK (private sector vocational training centres).⁵⁹⁴

Such schemes are in principle available to young disabled people graduating from mainstream vocational high schools, or attending further vocational training (SEK or IEK).⁵⁹⁵

Nevertheless, available state guidance as to accessibility has been so far limited to physical accessibility, excluding adaptations necessary in other aspects, such as communication and information, or learning environments, for different types of impairments. For instance, with regards to private sector education, a circular of the Ministry of Education in April 2013 included

⁵⁸⁹ Law 4283/2014 Establishment of the council for National Educational Policy Art. 7 Enabling access to higher education for persons with disabilities <https://www.taxheaven.gr/laws/law/index/law/631>.

⁵⁹⁰ Law 4368/2016 Measures for the acceleration of governmental work Art 82. Regulation of Special Education

<https://www.taxheaven.gr/laws/view/index/law/4368/year/2016/article/82/hl/%CF%80%CE%B5%CF%81%CE%B9%CE%B2%CE%AC%CE%BB%CE%BB%CE%BF%CE%BD/>

⁵⁹¹ (Law 4368/2016) Modification of article 4 Presidential Decree 603/1982.

⁵⁹² (Law 4368/2016) Addition to article 8 Law 3699/2008 (main law on special education).

⁵⁹³ Ministry of Education (FEK 490,491/20-2-1)

https://www.minedu.gov.gr/publications/docs2017/kya_mathiteias.pdf.

⁵⁹⁴ <https://www.espa.gr/el/Pages/ProclamationsFS.aspx?item=3353>. Please note that according to the Youth Guarantee Implementation Plan (2014; p. 25, footnote 13): Vocational Training Schools (SEKs) will replace existing O.A.E.D.'s Vocational Schools (EPAS) starting from the 2016-2017 school year

⁵⁹⁵ Also noting that as apprenticeship schemes are funded under ESIF 2014-2020, the Conditionality for non-discrimination on the grounds of disability and accessibility should also apply (EU Regulations (1303/2013).

accessibility requirements (according to national Design Guidelines and Standards) among the conditions for renewing licenses of private educational establishments with a capacity of more than 75 students per teaching hour at all levels of educations and across the board of life-long learning.⁵⁹⁶ While for public buildings hosting education and training services the New Urban Planning Regulations 2012 apply. (Please see also Section 4).

On the other hand, those announced schemes exclude young disabled people attending special vocational senior high schools. It is worth noting that the same legislation establishing apprenticeship schemes in mainstream vocational education, acknowledged that the same curriculum should apply equally for Special Education, while any required adjustments specific to disability / special educational needs are to be specified separately by the Special Education Directorate of the Ministry of Education (Law 4186/2013; Art.28, par.2a). Please note there has not been yet a ministerial decision regarding the specification of “work practice” through special school cooperatives as foreseen for special vocational education.

Furthermore, actions for acquiring work experience, such as the Training Voucher planned to cover 15,000 young unemployed 18-24, and integrated intervention actions for 8,000 young people (NRP 2016 p. 48), have not targeted young disabled people so far in the new programming period (2014-2020), in terms of including disability among priority social criteria in the ranking process of candidates.⁵⁹⁷ More importantly, there is insufficient safeguarding of their participation both in terms of including accessible workplaces as part of eligibility criteria of private employers selected for the program, as well as lack of specified procedures to follow if an employer rejects a disabled candidate proposed.⁵⁹⁸

Last but not least, vocational training is available to young people (14-25 years old) with intellectual disabilities graduates of primary education at the “Protypi Viotechniki Monada Lakkias”⁵⁹⁹ in Thessaloniki, operating as a public non-formal special vocational training unit of the Man Power Employment Organisation (OAED) since 1985. There are currently 170 students enrolled, who receive further a daily educational benefit at 3 € per day.

One also notes that existing schemes for supporting employment for disabled people in Greece is mostly focus on enabling access to placements through disability specific schemes, while limited policies exist to ensure accessibility of workplaces and protection of employment rights, reinforcing obstacles in entering the labour market.

A renewed legislative framework for the employment of disabled people in the public sector (L. 4440/2016)⁶⁰⁰ set the mandatory employment quota scheme for those assessed with 50% impairment level at 10%, whilst including 5% quota for parents, spouses or siblings of a person

⁵⁹⁶ Ministerial Decision 182167/IA/2013 - FEK 3087/B/4-12-2013 <https://www.e-nomothesia.gr/kat-ekpaideuse/idiotike-ekpaideuse-phrontisteria/ya-182167-ia-2013.html>.

⁵⁹⁷ See for instance Call for Voucher Training/ Work experience acquisition Program (18-24) <http://vouchernews.gr/index.php/programmatavoucher/prosexws/neo-voucher-18-24-2015>.

⁵⁹⁸ See Public Call to Providers for the OAED Work experience Acquisition Program for 10,000 unemployed aged 18-24 and the OAED Implementation Guide.

⁵⁹⁹ Original name retained in English Documents- free translation: Exemplar Craft/Manufacturing Unit

⁶⁰⁰ Law 4440/2016 (art 25) <http://www.esaea.gr/pressoffice/announcements/3244-se-fek-o-n-4440-2016-dikaiosi-ton-agonon-toy-anapirikoy-kinimatos?tmpl=component>.

with impairment level at least 67%, in all regular or contracted staff vacancies procured and managed by the independent recruiting council for the public sector (ASEP). This recruitment process is particularly maintained in EU/National funded schemes of employment

The social economy legislative framework first set up in 2011 and recently updated with law 4430/2016,⁶⁰¹ allowed for the establishment of Social Cooperatives for Social Inclusion, where the recruitment of people belonging to the specific vulnerable group supported is mandatory at 30% of all staff.

Existing Social Cooperatives in the field of mental health, first established by Law 2716/99, are included in that category under the new Law (4430/2016). These cooperatives of limited liability developed from sheltered workshops in the field of mental health, and as social enterprises can be active in any industrial sector, and are eligible for national and EU funds.

Mainstream ALPs running currently involve public work programmes, which are planned to target 23,000 unemployed in total (NRP 2016 p. 47),⁶⁰² with disability being included and given priority in the selection process of beneficiaries (social criteria points system).⁶⁰³

With regards to disability targeted ALPs, the NRP 2016 makes reference to the operation of local schemes for the social inclusion of vulnerable groups, actions mostly involving career counselling and training schemes. In the previous programming period, the project was implemented from 2012 to 2015 through 128 Development Partnerships (DPs) across Greece with 11,908 beneficiaries.⁶⁰⁴

There is a service for “Special Social Groups” running within the Organisation for Public Human Resources Development (OAED) which is responsible for the promotion, design and implementation of programmes and actions targeted at the inclusion of disabled people in the labour market (established under law 2643/1998). There are six centres for promoting employment of vulnerable groups excluded from the labour market. In particular, the service provides psychosocial support and career orientation advice and encourages disabled people to enter mainstream programmes of employment and vocational training,⁶⁰⁵ such as Training Vouchers, Wage subsidy programs, Public Work schemes, or Social Enterprising.

Finally, one notes a positive development in legislation actively supporting employment of disabled people involves Art. 13 Law 4331/2015⁶⁰⁶ which secures continuity of disability welfare benefits provision whilst participating in ALP programs, including Social Entrepreneurship and Vocational Training schemes.

⁶⁰¹ Law 4430/2016 Social Economy and development of relevant agencies <http://www.esaea.gr/legal-framework/laws/3156-nomos-4430-2016-koinoniki-kai-allileggya-oikonomia-kai-anaptyxi-ton-foreon-tis-kai-alles-diataxeis>.

⁶⁰² http://ec.europa.eu/europe2020/pdf/csr2016/nrp2016_greece_en.pdf.

⁶⁰³ See for instance first call for 2,500 placements in first reception and asylum services not including disability criteria for selection of candidates <http://www.esfhellas.gr/el/Pages/ProclamationsFS.aspx?item=4097>.

⁶⁰⁴ <https://www.disability-europe.net/country/greece>

⁶⁰⁵ <http://www.oaed.gr/dioiketike-organose-diarthrose-tou-oaed>.

⁶⁰⁶ Law 4331/2015 enactment <http://esaea.gr/legal-framework/circulars/2719-30-09-2015-gnostopoiisi-diataxeon-toy-n-4331-2015>.

Flexible work arrangements are defined in Law 2846/2010,⁶⁰⁷ however, these are mainstream laws and there are no specific regulations or provisions around disability. Relevant regulations include the possibility of turning a contract to part time after one year of full time employment, with the possibility of returning to full time, and importantly working from home is legislated as a contract of employment for the first time. Legislation allows for turning a regular service contract to distance employment, foreseeing a period of adjustment, while in all cases the employer bears the cost incurred under working from home (e.g. ICT).

Particular measures in support of disabled employees apply in relation to annual leave and reduced working hours for the public sector only. More specifically, under the law 2683/1999 (Art 50 par3)⁶⁰⁸ parents of children who require periodical hospitalisation have 22 days of special paid leave, while employees with at least 50% level of impairment have six additional days to their regular annual leave.

Furthermore, public sector employees who are blind, paraplegic-tetraplegic or have children with impairment level over 67%, as well as spouses of people with 100% impairment, are entitled to reduced work schedule by one hour daily (Law 2527/1997 Art. 16, par 4).⁶⁰⁹

There is no established mechanism for providing ongoing funding support for workplace adaptations. There had been relevant provision in the past as part of an ALP scheme (2010-2012) covering 50 workplace adaptations up to 90% of the cost (e.g. ramps, accessible toilets, accessible work-tables, etc.), which has not been replicated since.⁶¹⁰

There is no employment protection in sheltered workshops, because they are not acknowledged as work places.

With regards to Social Enterprises of limited liability established in the field of mental health, i.e. fully acknowledged legal entities/ workplaces in the non-profit Social Economy sector⁶¹¹, the same protection levels apply as any other form of employment. More specifically, the relevant law makes explicit reference to that under Art.17 par.8, where it is stated that “all rights and duties that derive from employment and insurance legislation apply equally” in Social Enterprises. Additionally, a key protection measure for disabled employees working in Social Enterprises is that they can retain any social or disability related benefit or pension⁶¹².

The New Building Regulations (L. 4067/2012) defines accessibility as “the characteristic of environment, which allows all persons—without discrimination on the basis of gender, age and other traits such as bodily stature, strength, perception, ethnicity, to have access to it, meaning to

⁶⁰⁷ Law 3846/2010 Work safety Guarantees and other regulations
http://www.ggka.gr/aytoapasxoloumenoi/LAW_3846_10.pdf.

⁶⁰⁸ Law 2683/1999 Ratification of Public Sector Code of Employment
http://www.elinyae.gr/el/lib_file_upload/a19_1999.1118124927823.pdf.

⁶⁰⁹ Law 2527/1997 http://www.elinyae.gr/el/item_details.jsp?cat_id=155&item_id=4664.

⁶¹⁰ <https://www.disability-europe.net/country/greece>

⁶¹¹ Law 4430/2016

⁶¹² Art. 13 L4331/2015

access autonomously, with safety and comfort and use the infrastructure, but also the services (conventional and electronic) and the good provided in the particular environment.” (Art. 2 par.71)⁶¹³

We now briefly turn to housing. Although there is no distinct term of “accessible housing” the above definition applies for instance in requirements for ensuring accessible communal areas in apartments buildings as much as in gaining construction permission for a new building.

Law 4030/2011⁶¹⁴ regulating construction approval and licensing, makes reference to the prerequisite of submitting “an accessibility study for people with disabilities as and where necessary” (Art.3 par 2b), while a circular in 2012⁶¹⁵ clarified further the scope and content of that accessibility study which is mandatory for any construction under the New Building Regulations (2012).

The regulations apply to all types of buildings, both in the public and private sector, except for the case of single private houses (Article 26 par. 1). It is mandatory however to ensure accessibility regulations in apartment buildings, both in communal areas and in terms of ensuring easy adaptation of apartments for disabled people.

According to the New Building Regulations (L. 4067/2012), new buildings must ensure horizontal and vertical access in all common spaces, as well as permit easy adaptation of housing units for potential use of people with disabilities. (Art.26 par.2) There is no relevant prerequisite for existing buildings or renovation work.

Furthermore, the law introduces the right of disabled residents to make adaptations for ensuring access to common spaces within housing buildings, against any other regulation (e.g. housing contract) (Article 27 par. 2) and without a construction license (Article 4 par. 3), as long as the infrastructure of the building is not affected, and they cover the expenses.⁶¹⁶

⁶¹³ New Building Regulations (L. 4067/2012) http://www.hellenicparliament.gr/Nomothetiko-Ergo/Anazitisi-Nomothetikou-Ergou?law_id=3dc4f0f3-36b8-4431-92d2-4ade78c39705.

⁶¹⁴ Law 4030/2011 New Constructions Approval and Licensing Regulations <http://www.ypeka.gr/LinkClick.aspx?fileticket=gR8bg8dcdcA%3D&tabid=37>.

⁶¹⁵ Ministry of Environment Circular 29467/2012 Clarifications for the submission of the accessibility study for PwD- which must be included in studies submitted in applying the New Building Regulations (L. 4067/2012)

<http://www.ypeka.gr/LinkClick.aspx?fileticket=OmeV9k%2FRXs0%3D&tabid=777>.

⁶¹⁶ <https://www.disability-europe.net/country/greece>

Hungary

Hungary has a comprehensive disability policy⁶¹⁷, the National Programme on Disability Affairs (National Disability Programme), which also addresses access to education and employment. The programme incorporates current international standards targeting the social inclusion of people with disabilities, and its aims are comprehensive and highly relevant to people with intellectual disabilities. However, there has been no independent evaluation of the programme's impact to date, and the implementation of the programme's goals has been slow. Most foreseen projects have not yet been realised although progress in certain aspects can be noted. The "interventions" section states that the services of supported housing must be developed and the range of basic social services (e.g. day-care) needs to be enlarged. The programme does not assign any deadline, responsibility or funding, these are detailed in the Action Plan.⁶¹⁸

The Action Plan contains 80 specific measures in the most important fields that affect the everyday life of persons with disabilities, and specifies relevant deadlines, required financial funds and the persons responsible.⁶¹⁹

The Action Plan sets a number of objectives (assigning a responsible body/authority and deadline) for the next cycle of the DI process.

- A professional coordination centre must be established with the aim of providing professional, methodological support for the institutions involved in DI.⁶²⁰
- Based on the experience of previous years, the legislative environment of the DI and supported housing needs to be reviewed with regard to children with disabilities.⁶²¹
- A project should be launched to implement a person-centred, actual transition of social residential institutions and the development of related services.⁶²²
- Legislative measures should be made in order to expand and develop the infrastructure of basic social services for people with disabilities, in particular day care facilities.⁶²³
- Review the training of social professionals who support the independent living of people with disabilities and, if necessary, modify or develop new training requirements for these professionals.⁶²⁴
- Continue the modernization of the temporary and rehabilitation facilities for people with disabilities and psychosocial disabilities.⁶²⁵
- The support infrastructure needs to be improved, with the provision of new and maintained vehicles. The capacity of the support services/ basic social services should be increased, the national coverage of the service should be ensured.⁶²⁶

⁶¹⁷ https://www.opensocietyfoundations.org/sites/default/files/hungary_0.pdf

⁶¹⁸ National Disability Programme 7.2. point.

⁶¹⁹ 2nd and 3rd Periodic Report on Hungary, 2018 CRPD_C_HUN_2-3_6961_E), Question No. 3.

⁶²⁰ Action Plan of the National Disability Programme for 2015-2018 (Government Resolution 1653/2015. (IX. 14.) 7.3 points.

⁶²¹ Ibid 7.4 points.

⁶²² Ibid 7.5 points.

⁶²³ Ibid 5.4 points.

⁶²⁴ Ibid 5.5 points.

⁶²⁵ Ibid 5.8 points.

⁶²⁶ Ibid 5.9 points.

There has also been a positive change in the legal background of the development of supported housing (as a part of community-based services) since 2013. However, legislation is still lacking a consistent framework based on the principles of independent living and social inclusion. Current legislation of supported housing is not clearly distinguished from other residential regulations; thus, the same rules apply to supported housing as to large institutions. The current financing system is not based on individual needs.⁶²⁷

Hungary has been implementing strategies of the transition from existing large-scale institutional care to community-based support (deinstitutionalisation (DI)). The National Disability Programme (2015-2025)⁶²⁸ states that the DI process should be continued according to the Deinstitutionalisation Strategy focusing on the preparation, information and support of the persons and institutions involved in the transition. Also, an important direction is the promotion of supported housing.⁶²⁹

Services based on complex needs assessment: In supported housing the service provider is obliged to provide 9 service elements based on a complex needs' assessment of the service user, if required. These service elements are: supervision, meals, care, skills development, counselling, pedagogical assistance, special education assistance, transportation, household assistance. These services must be separated from the operation of housing.⁶³⁰

In the period between 2012–2015, in the framework of the Social Infrastructure Operational Programme, (transition from institutional care to community-based service – social institutions component) one notes 672 new supported housing places which were created from a total amount of aid of 5.6 billion Hungarian Forints (HUF).⁶³¹ In this period six large residential institutions went through the process of full transformation.⁶³²

In short, one can underline the governing structures and plans concerning the transition from institutional care to community-based living as being set out by means of the following:

- i. Partnership Agreement for Hungary, 2014-2020;⁶³³
- ii. Human Resources Development Operational Programme Hungary 2014-2020 (HDOP);

⁶³⁴

⁶²⁷ Adrienn Gazsi (2018) Legal inconsistency examination I., Equal Opportunities of Persons with Disabilities Non-profit Ltd. (FSZK), Budapest, 8-9.p.

⁶²⁸ National Disability Programme (2015-2025) (English version).

http://www.kormany.hu/download/c/e4/60000/NDP_2015-2025.pdf

⁶²⁹ Decision 15/2015 (of 07.04.) OGY of the National Assembly on the National Disability Programme (2015–2025), 7. point.

⁶³⁰ Social and Family Affairs Decree No. 1/2000 (I. 7.) on Professional Tasks and Conditions for Operation of Institutions Providing Personal Care 2. § I) point.

⁶³¹ TIOP-3.4.1.A-11/1 (<https://www.palyazat.gov.hu/doc/3342>) Social Infrastructure Operational Programme 2007-2013: (<https://www.palyazat.gov.hu/download.php?objectId=44027>); Official public access to supported projects: (https://www.palyazat.gov.hu/tamogatott_projektkereso)

⁶³² 2nd and 3rd Periodic Report on Hungary, (2018 CRPD_C_HUN_2-3_6961_E) Question No. 24, 180 point.

⁶³³ Partnership Agreement for Hungary, Available at: https://ec.europa.eu/info/publications/partnership-agreement-hungary-2014-20_hu

⁶³⁴ Human Resources Development Operational Programme Hungary (EFOP) <https://www.palyazat.gov.hu/node/56578>

- iii. Competitive Central-Hungary Operational Programme Hungary 2014-2020 (CCHOP); ⁶³⁵
- iv. Deinstitutionalisation Strategy for 2017–2036; ⁶³⁶
- v. National Disability Programme 2015–2025; ⁶³⁷
- vi. Action Plan of the National Disability Programme for 2015-2018. ⁶³⁸

When it comes to interaction with civil society, the Hungarian authorities have implemented a number of initiatives on this front. Act 131 of 2010 on social participation in the drafting of legislation enshrines the obligation to give NGOs and representative organisations of persons with disabilities an opportunity to express their opinions. In addition, persons with disabilities can participate in the decision-making processes that affect them via several forums. To monitor the implementation of human rights, in 2012 the Government established the Human Rights Working Group with the purpose of conducting consultations with NGOs.⁶³⁹

In 2015, new mechanisms were included in the processes of consultation and decision preparation. In addition to the National Disability Council, ⁶⁴⁰ the Social Policy Council, ⁶⁴¹ Expert Group ⁶⁴² and the Inter-ministerial Committee on Disability ⁶⁴³ were set up, while the National Committee for the Coordination of Deinstitutionalization (IFKKOT) was established in 2011 and reformed in 2017. ⁶⁴⁴

The IFKKOT monitors the submission and implementation of tenders for institutions in the DI process. The IFKKOT enjoys a wide range of rights in the DI process. In June 2017 the IFKKOT established a Subcommittee to monitor the operation of those high-capacity residential institutions for persons with disabilities where deinstitutionalization has not yet commenced. ⁶⁴⁵

We have already referred to the National Disability Council (OFT). ⁶⁴⁶ This was established in 2013. The council comments on drafts, makes recommendations and conducts advisory activities for the Hungarian Government in questions regarding persons with disabilities. Through this role they are involved in the design, planning and evaluation of the DI.

⁶³⁵ Competitive Central-Hungary Operational Programme Hungary (VEKOP) Available at:

https://ec.europa.eu/regional_policy/en/atlas/programmes/2014-2020/hungary/2014hu16m2op002

⁶³⁶ Deinstitutionalisation Strategy, Government Resolution 1023/2017. (I. 24.) was issued in January 2017 on the long-term vision for 2017–2036 concerning the replacement of capacities at social institutions offering care and nursing to people with disabilities.

⁶³⁷ Decision 15/2015 (of 07.04.) OGY of the National Assembly on the National Disability Programme 2015–2025.

⁶³⁸ Government Resolution 1653/2015. (IX. 14.) available at (Hungarian):

<https://net.jogtar.hu/jogszabaly?docid=A15H1653.KOR&getdoc=1>

⁶³⁹ More details: 2nd and 3rd Periodic Report on Hungary, 2018 (CRPD_C_HUN_2-3_6961_E), Question No. 2.

⁶⁴⁰ 2nd and 3rd Periodic Report on Hungary, 2018 (CRPD_C_HUN_2-3_6961_E).

⁶⁴¹ Council, Appendix INT_CRPD_ADR_HUN_31034_E 2/3.

⁶⁴² 2nd and 3rd Periodic Report on Hungary Appendix INT_CRPD_ADR_HUN_31034_E 2/4.

⁶⁴³ FTB, Appendix INT_CRPD_ADR_HUN_31034_E 2/5.

⁶⁴⁴ IFKKOT, Appendix INT_CRPD_ADR_HUN_31034_E 2/6.

⁶⁴⁵ 2nd and 3rd Periodic Report on Hungary, 2018 (CRPD_C_HUN_2-3_6961_E), Appendix (INT_CRPD_ADR_HUN_31034_E).

⁶⁴⁶ Government Decree 1330/2013. (VI. 13.) on the National Disability Council.

Initiatives in this sphere of government interaction has, however, faced criticism from European Disability institutions. 647 648

In January 2017, the Hungarian Government published a Call for Proposals on Human Resources Development Operational Programme 2.2.2 – 17. Conversion of institutional supply to community-based services – replacing institutional places (EFOP-2.2.2.-17). The aim of the programme was to close down institutions housing large numbers of people with disabilities, to increase their inclusion in the community, and provide individualised support, so that they can live independently. Institutions providing social care services for more than 50 people were encouraged to apply for grants funded by the European Regional Development Fund, worth 23.7 billion HUF (approximately 76 million EUR).

Analysis of the winners' applications showed that the projects, which affect 2,430 people, fail to comply with EU regulations on the use of EU funding, its policies on social inclusion and the Fundamental Rights Charter. The building of almost 200 mini-institutions envisaged under the funded projects breaches the European guidelines on deinstitutionalisation, and obligations under the UN Convention on the Rights of Persons with Disabilities (CRPD), as well as national law.

Many of the group homes which will be built, will be located away from cities in sparsely inhabited rural settlements, thus further ostracising people with disabilities. Many of the settlements chosen lack public services, have aging communities and declining populations. (For example: Bodonhely – 287 inhabitants, Sopronnémeti – 297 inhabitants, Tormásliget – 292 inhabitants, and Fülöpösdaróc – 320 inhabitants).

As it had been pointed out by the Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ), some group homes will be built on flood plains (Táplánszentkereszt); on inaccessible, industrial zones (Barcs); swampy-reedy areas (Somogyvár), or near a sewage disposal plant (Kéthely).

In many cases, group homes will be built within the grounds of current large institutions or in the immediate proximity of them (e.g. Táplánszentkereszt, Vésztő, Drávatamási, Kálmáncs, Szabás, Szombathely).

Residents of the newly built homes will be transported by minibuses to so-called Service Centres which will, in many cases, be established in the area of the former large institutions or in some cases inside of them. People will still eat and be cared for as previously, in an institutional setting.

The new residential homes will function as mini-institutions, denying people their independence: they won't be able to decide where and with whom they live, choose their careers, or make choices about their daily routine. Thus, the EU project aimed at eradicating institutions will ultimately result in the creation of 189 new mini-institutions. ⁶⁴⁹

⁶⁴⁷ <https://validity.ngo/wp-content/uploads/2018/02/DI-in-Hungary-FAQ-23.02.2018-1.pdf>

⁶⁴⁸ <http://politicalcritique.org/cee/hungary/2017/silent-horror-hungary-disabled/>

⁶⁴⁹ <https://enil.eu/news/hungarian-government-must-suspend-redesign-deinstitutionalisation-projects-affecting-2500-people-disabilities/>

On April 18, 2017, Pablo Gorondi, Budapest correspondent for the Associated Press, reported that the Mental Disability Advocacy Center (MDAC), after visiting Topház Otthon (Top House Home) in Göd, 30 km from Budapest, a state-run institution for people with mental and physical disabilities, called for the closure of the institution. They uncovered signs of ill-treatment and malnutrition in the run-down facilities of the institution that houses 220 children and adults. Steven Allen, the group's campaign director, said that "the conditions, abusive practice and evidence of violence ... are the result of systematic failings in law, policy and regulation and a lack of effective and independent monitoring."⁶⁵⁰

The report also pointed out that, according to the Central Statistical Office, there are some 25,000 people in Hungary with intellectual disabilities and mental health issues who have been placed in state institutions. The Hungarian government estimates that it would take 19 years to move these people to smaller homes. In addition to Gorondi, Nick Thorpe of BBC also filed a report about the "shocking conditions" found in the "home," although he attached the opinion of an official of the Office of the Commissioner for Equal Rights who claims that "Topház is an extreme case."⁶⁵¹

Hungary's Public Education Act is the main legislation governing public education, including special education. The 2003 amendments to the act introduce an explicit prohibition on discrimination on the ground of disability, defined as "lack or impediment of abilities". The Public Education Act includes special provisions on "children with special educational needs", including children with intellectual disabilities, but it does not take an unequivocal stand in favour of inclusive education. It states that parents or guardians can only request enrolment of their child at a specific school if the school has the necessary capacity, including staff and funding, for the type of education required. In practice, many school directors cite lack of capacity when refusing admission to students with intellectual disabilities. This means that most parents are prevented from enrolling their child with intellectual disabilities at a mainstream school. The Education Ombudsman receives a significant number of complaints, from parents of children with intellectual disabilities, concerning inadequate resources and services for the education of their children.

In Hungary, the early intervention network is inadequate, and, throughout the country, many children with intellectual disabilities of pre-school age cannot access early intervention services. Professional Committees are the primary providers of early intervention services, but because the committees are overburdened and do not always have sufficient capacity, a few NGOs try to fill in this gap in services. These NGOs receive State funding for provision of such services. Children receive early intervention services upon the recommendation of the Professional Committees. However, due to a lack of information, most parents are unaware of available early intervention services until after their children have finished kindergarten, when such services are much less effective.⁶⁵²

⁶⁵⁰ <https://hungarianspectrum.org/2017/05/06/the-hungarian-government-and-transparency-the-case-of-the-mentally-disabled/>

⁶⁵¹ Ibid.

⁶⁵² https://www.opensocietyfoundations.org/uploads/4c40da60-382e-4aaf-9e01-206ad39fc2a3/hungary_0.pdf

The Hungarian education system segregates children with intellectual disabilities. The diagnosed level of intellectual disabilities determines the quality of education a child is to receive, and, in effect, there is a two-tier system of special education.

Physical, sensorial, mental disabilities and speech deficiencies are stated by professional committees at county and national levels. National expert committees are committees investigating vision, hearing and speech and learning abilities.

There are expert/rehabilitation committees both in the capital and on county level; these consist of a teacher of special education as the leader, a therapeutic teacher, a psychiatrist and a specialist physician. They hand down an opinion on the child investigated, the child is placed based on their advice in kindergarten or school, and they also give suggestions on any special requirements concerning the education and teaching of the child. Placement of children in special classes and their integration into the classes of the mainstream schools is decided by the expert committees. According to the law on equal opportunities, parents of pupils needing special education have a voice concerning the attendance of their children in different institutions.

There are educational counselling services in all of the districts of the capital and in larger cities of the country. These are responsible for discovering any disabilities a child may have, they provide diagnosis and manage the behavioural, educational and teaching problems of 3-18 year old children and youngsters growing up in families. This service functions on an ambulatory basis. The advice after establishing the diagnosis is based primarily on concerns related to the further tasks of the teachers and the parents.⁶⁵³

In Hungary, few children with intellectual disabilities are schooled at home. Home schooling takes two forms: either special educators visit children in their homes, or students make regular visits to the supervisory special school, usually that nearest to the student's home. The Public Education Act provides for a system of travelling special educators, but it does not identify a source of funding for the system. Therefore, home-schooling and special educational services are generally not available to children with special educational needs living in more rural areas of the country.

In Hungary in the early 1990s several schools involved in innovation, sought ways for modernising their institutional practice and for becoming an institution that focuses on individuals. It was at that time that alternative schools with reformed pedagogical attitudes were founded. These schools placed the learner and not the teaching material into the centre of their educational philosophy, they broke with the rigidity of uniformity, of expectations being the same for each pupil and developing individual skills. Similarly to some mainstream general schools they developed their own pedagogical systems in their own way.⁶⁵⁴

We have no comprehensive research data on how inclusive assessment is carried out in public education institutions in Hungary. Therefore based on data from research and analyses of

⁶⁵³ <https://www.european-agency.org/sites/default/files/hungary-indexed-report.doc>

⁶⁵⁴ <http://mek.oszk.hu/09700/09751/09751.pdf>

pedagogical programmes we present the assessment practice of the host institutions that officially undertake to educate pupils with special education needs. Among them there are alternative schools, innovative general schools and secondary schools. In these institutions the procedure of inclusive assessment is defined in the pedagogical programmes and in practice, assessment by grades is replaced by assessment in report form.

While analysing best practices it is always the most characteristic institutional practice that is presented.⁶⁵⁵

In Hungary, approximately 60 percent of students with intellectual disabilities continue their studies at the secondary level, although the number of students with intellectual disabilities at the secondary level is reported to be slowly increasing. Segregation of students with intellectual disabilities in special vocational schools remains pronounced, and primarily students with mild intellectual disabilities have the opportunity to attend mainstream vocational schools. In the 2002–2003 school year, only 555 students with intellectual disabilities attended mainstream vocational secondary schools.⁶⁵⁶

The Hungarian Constitution guarantees the right to work, the right to freely choose a job or profession and the right to equal compensation for equal work without discrimination, but it does not specifically address the employment of people with disabilities. However, the Equal Treatment Act guarantees equal treatment in employment for people with disabilities, and the Disabled Persons Act establishes that, if people with disabilities cannot secure employment on the open market, sheltered workplaces must employ them. The Joint Decree on People with Altered Working Capacity regulates the rehabilitation process, occupational rehabilitation services, and State financial compensation for lost income due to altered working capacity. It also regulates eligibility for State subsidies for employers who employ people with disabilities.

People with intellectual disabilities are heavily dependent on social welfare benefits. Most adults with intellectual disabilities do not have the required work experience to access unemployment benefits or the invalidity pension. People with mild or moderate intellectual disabilities mainly receive various social benefits that depend on a number of factors, such as age and number of years employed. Some people in this group with the required work experience receive invalidity pensions. Adults with severe and profound intellectual disabilities are eligible for disability support, which they retain even if they secure employment. People who are under the age of 25, have 100 percent altered working capacity, and do not already receive a pension, are eligible for the invalidity benefit. Given the limited and unstable employment possibilities presently available to people with intellectual disabilities, and the limited access to employment services, social welfare benefits are a steady and stable source of support. These benefits tend to act as a disincentive to employment. Presently, most unemployed people with intellectual disabilities do not register at the local offices of the National Employment Service and, therefore, they cannot access available employment services or rehabilitation services. This is mainly due to a lack of awareness of their rights and of available services. Furthermore, the staff at the labour offices is not trained to deal with the special needs

⁶⁵⁵ Ibid

⁶⁵⁶ Ibid

of people with intellectual disabilities, and, in any case, they cannot meet the current demand for individualised services. As a result, labour offices mainly rely on cooperation with non-governmental rehabilitation and employment service providers.⁶⁵⁷

The main Government policy on the employment of people with disabilities is described in the National Disability Programme. The programme contains a number of goals that are highly relevant to promoting the employment of people with intellectual disabilities. Most importantly, it aims to restructure the sheltered employment system, including its legislative framework and system of financing. Another objective is to improve employment services for people with disabilities. This has led to the establishment of Rehabilitation Information Centres (RICs), which are located at county labour offices and are tasked with providing comprehensive support services for people with disabilities seeking employment. However, as with other areas, the implementation of the National Disability Programme's objectives on employment has not been adequately monitored, and many foreseen projects are still at an early stage of implementation.⁶⁵⁸

Although supported employment offers the best opportunities for the social inclusion of people with intellectual disabilities, at present, most people with intellectual disabilities who are able to access employment do so in sheltered workplaces. These workplaces generally do not adequately prepare people with intellectual disabilities for employment on the open labour market. Sheltered workplaces can be social employment centres or target organisations, both of which offer very low salaries for employees with disabilities. Social employment centres are mainly municipally maintained small-scale workshops that provide work opportunities of a limited variety, such as producing textiles and industrial paper.

From a political science point of view and at the macro level persons with disabilities and their organizations have become one of the strongest pressure and lobby groups. This strength, however, is not reflected in the employment ratio. In terms of employment policy, a large number of people with disabilities remains in disadvantaged positions. This situation is determined by three strong influential factors:⁶⁵⁹

i) Starting point

Hungary started from a deep level at the time of the regime change. Both the attitudes towards disability and the practices, as well as the level of resource allocations were rather low. Thus, no spectacular results or high standards could be reached during the past three decades including the last years since Hungary has joined the European Union. An employment related example is the creation of accessibility.

⁶⁵⁷ Könczei, György – Róbert Komáromi – Roland Keszi – Lilla Vicsek 2002. Employment of persons with disabilities and altered working ability using a database of TOP 200 companies. (Abridged version). The National Employment Public Foundation Public Benefit Company for Employment Promotion (OFA Kht).

⁶⁵⁸ Nagy, Zita Éva – Zsolt Pál 2008. Legal and Social Situation of People Living with Altered Working Capacities and Disability in Hungary and in International Perspective. Revita Foundation, Debrecen (Unpublished research report, in Hungarian)

⁶⁵⁹ Könczei, 2007

Before the political regime change, accessibility was only important for persons with disabilities, their service providers and for a handful of disability studies researchers. It was part of neither the dominant approach nor budget calculations. This is the reason why Hungary lags so terribly behind, and the status quo cannot be reversed in a decade or two despite the introduction of strict rules on making public buildings fully accessible (Act No. XXVI of 1998).

ii) Dependence on the budget.

The measures of the separate decision making levels that are supposed to promote employment for people with disabilities are highly budget-dependent and highly differentiated according to micro, mezzo and macro levels. It has been observed that in periods of budget cuts disability issues lose even their partial priority. During these times the power of the lobby is not even enough to retrieve its old resources, let alone going to fight for new ones – especially not at the level of the local self-government.

iii) Need for paradigm shift

As opposed to the medical (rehabilitation) model the social model has not gained strong enough momentum, therefore persons with disabilities and their organizations are not in control of the scarce resources. A too large portion of these resources trickles away in the system and a substantially smaller portion reaches people with disabilities.⁶⁶⁰

⁶⁶⁰ https://www.academia.edu/2062494/Report_on_the_employment_of_disabled_people_in_European_countries_-_Hungary

Ireland

According to the 2011 Census, 595,355 people reported having a disability in Census 2011 which is equivalent to 13% of the population of Ireland. However, the National Disability Survey (2006), which uses a broader definition of disability and chronic illness, recorded a disability rate of 18%, comparable to other developed countries. As one would expect, disability is age-related and increases sharply with age. Three out of every five people aged over sixty years has at least one chronic condition.

Living with a disability poses many complex challenges. In 2005, people with disabilities in Ireland had an employment rate of 32%, according to the OECD (2010). In 2011, following a period of challenging economic conditions, the employment rate for people with disabilities had fallen to less than 30%.⁶⁶¹

More recently, an NDA commissioned analysis of data compiled under the Quarterly National Household Surveys 2010-2015 concerning employment transitions of people with disabilities shows that in the 20-59 age group, 31% of people with a disability are in paid employment, compared to 71% of those without a disability.⁶⁶²

People with disabilities are also more likely to work part-time if they are in employment.⁶⁶³ Among those at work, one-third of people with a disability are working part-time, compared to one-fifth of people without a disability. The chances of exiting employment are twice as high for someone with a disability compared to an otherwise identical individual without a disability. While those aged 20-24 are most likely to move into employment, those over the age of 45 with a disability have a considerably reduced opportunity of entering employment if not currently at work. All this being said, nearly half of all those with a disability in Ireland are either at work or are interested in work (NDA, forthcoming).

People with disabilities are more likely to live alone and 42% live in a jobless household, putting them at high risk of poverty. Overall, people with disabilities experience high levels of consistent poverty.⁶⁶⁴ Families where the head of the household was not at work due to illness or disability, with the exception of students, had the lowest average annual disposable income in 2014. This was €24,914 compared to €54,430 for those at work. This represents a 21% drop since 2009 compared to a 7% drop for those at work. People with disabilities have poorer educational participation and outcomes, thereby further reducing economic prospects (NDA). For instance, just 24.5% of people with a disability have completed third-level education, compared to 38.7% of the general population (Census 2011 figures). In 2010, 50% of people with a disability had not completed full second-level education, compared with 22% without a

⁶⁶¹ Since 2004 the unemployment rate for people with disabilities rose from 8% to 22% in 2010 (Watson et al, 2013) D.Watson, G Kingston, F. McGinnity (2013), Disability in the Irish Labour Market: Evidence from the QHNS Equality Model 2010.

⁶⁶² <http://www.justice.ie/en/JELR/dept-justice-ndi-inclusion-strategy-booklet.pdf/Files/dept-justice-ndi-inclusion-strategy-booklet.pdf>

⁶⁶³ F.McGinnity, H. Russell, D. Watson, (2014) winners or losers? The equality impact of the great Recession in Ireland. Equality & Authority & ESRI, P.35. SIL 2015, Cited Social Inclusion Monitor 2015, DSP.

⁶⁶⁴ SIL 2015, cited in Social Inclusion Monitor 2015, DSP

disability. In fact, among people with disabilities generally, 43% have not progressed beyond primary education. This compares with 19% of all adults. About a third of people with disabilities have been found to leave education before they intended to, because of their disability or illness.

In conjunction with the policy of mainstreaming, a number of other significant developments in the Irish policy landscape were also deemed relevant to improving the lives of people with disabilities, and these are reflected in the actions contained in the Strategy. The Comprehensive Employment Strategy for People with Disabilities was aimed at improving employment participation and outcomes for people with disabilities. The Transforming Lives programme was dedicated to improving the delivery of health and social care services to people with disabilities, arising out of the Value for Money and Policy Review of Disability Services in Ireland (2012), based on enshrining the principles of self-determination and autonomy in all service provision for those with disabilities. The Department of Health's report, *A Vision for Change* takes a similar approach for persons with mental health difficulties.⁶⁶⁵

These and other developments sit against the backdrop of the CRPD which Ireland was the last country in the EU to ratify, even though a number of issues mentioned within the CRPD were indeed implemented months and, in some cases, years before ratification was actually sorted out.

The previous National Disability Strategy ran from 2013 to 2015, a period of time when the severest of economic and fiscal conditions applied, which frustrated implementation of the Strategy. We now have an opportunity - and an obligation - to make up the lost ground against a backdrop of renewed economic growth, and to ensure that we address the real needs of persons with disabilities.⁶⁶⁶

Development of the new Strategy began in 2015 when the Department of Justice and Equality, together with the NDA and the Interdepartmental Group, launched a consultation process in order to provide interested parties with the opportunity to make recommendations in proposed key areas such as service provision, accommodation, health, employment, transport and education. The consultations took the form of a three-stage process as follows:

Phase One – This phase commenced in mid-2015, and was an open call to people with disabilities, their families and disability organisations to respond to a suggested list of policy areas to be covered in the Strategy. The themes agreed for inclusion in the Strategy were:

- Education;
- Employment;
- Health and well-being;
- Person-centred disability services;
- Housing;
- Transport and accessible places;
- Equality and choice; and
- Joined-up services.

⁶⁶⁵ <http://www.justice.ie/en/JELR/dept-justice-ndi-inclusion-strategy-booklet.pdf/Files/dept-justice-ndi-inclusion-strategy-booklet.pdf>

⁶⁶⁶ <https://www.esri.ie/publications/disability-and-social-inclusion-in-ireland>

Phase Two – The aim of this phase was the identification and agreement of specific objectives under each of the themes identified in phase one. A provisional set of objectives was prepared by the NDA and again, people with disabilities, their families and the Disability Sector were invited to give an input on the priority objectives they would like to see achieved in the next four years. This stage of the consultation, which took place at the end of 2015 involved several regional meetings and an opportunity to send in written comments or to comment on-line.

Phase Three (September 2016 – December 2016) focused on identifying precise and measurable actions and timescales for achievement of each of the objectives that emerged from phase two. Following this phase, a draft proposal for a revised Strategy was prepared by senior officials, in collaboration with the DSG and was submitted to Government for approval on 30 May 2017.

The NDISSG comprises key government departments, the NDA, and the DSG. The Group is chaired by the Minister of State, and the Department of Justice and Equality provides secretariat functions to the group. The NDA is an independent statutory body with responsibility for providing information and advice to the Minister of State, and to assist him in the coordination of national policy.⁶⁶⁷ The DSG comprises an independent chair, individuals with lived experience of disabilities and representatives of the key disability umbrella bodies, including:

- Centre for Independent Living;
- Disability Federation of Ireland;
- Federation of Voluntary Bodies;
- Mental Health Reform;
- AsIAm Autism Spectrum;
- Brothers of Charity Services;
- Cheshire Ireland;
- Deaf Hear;
- Inclusion Ireland;
- Irish Association of Supported Employment; and
- National Council for the Blind Services.

Civil society and its interaction with the needs for persons with intellectual disability is quite extensively organised in Ireland. Voluntary organisations and service providers have managed to create a number of services which indeed give a positive impact on the inclusivity of persons with intellectual disabilities within societies. Moreover, a number of Irish experts running such organisations within their own country have been in a position to be elected to the highest echelons of European platforms promoting the disability sector, including the European Disability Forum.⁶⁶⁸ Such positions give huge benefits, including networking and good practice monitoring to the Irish activists in question. The list of voluntary organisations and service providers is extensive but, for the purpose of this report, one might mention a few examples:

⁶⁶⁷ <http://www.socialinclusion.ie/PromotingSocialInclusionForPeopleWithDisabilities.html>

⁶⁶⁸ <http://www.edf-feph.org/>

Intellectual disability signifies a significantly reduced ability to understand new or complex information, learn new skills or cope independently. Supporting and enabling children and adults with intellectual disabilities is a key focus at CareWorld. CareWorld aims to empower people and develop opportunities to enable their participation in the community as equal citizens.

Dignity and independence are key themes here at CareWorld. All of their care workers are sensitive to the possible risk factors for the client being aware of the multiplicity of physical and other challenges that may accompany intellectual disability. They understand that issues such as dental health, sensory impairment, nutrition, osteoporosis and exercise are all extremely important factors to people with an intellectual disability.

They are active members of Inclusion Ireland, Ireland's umbrella organisation for individuals and groups living and working with intellectual disability.⁶⁶⁹

Inclusion Ireland⁶⁷⁰ provides a central forum for its members to identify priorities and formulate nationally agreed policies to present to government, statutory bodies, other relevant groups as well as the general public. Inclusion Ireland campaigns for changes in services and legislation that will improve the quality of life and participation of people with an intellectual disability in Irish Society. In addition to this central role, Inclusion Ireland:

- Promotes Advocacy for people with an intellectual disability, particularly self-advocacy;
- Provides an information and advice service by phone, post and through its website;
- Publishes information leaflets/booklets;
- Publishes a quarterly newsletter;
- Organises seminars and conferences on intellectual disability;
- Gives information & training talks to a range of groups;
- Represents the intellectual disability sector in Ireland at an international level by its membership of Inclusion International & Inclusion Europe;
- Promotes research into intellectual disability.

Enable Ireland⁶⁷¹ provides services to children and adults with disabilities and their families from 40 locations in 14 counties. Covering childhood to adulthood their expert teams work with the individual and their family on a plan for each life stage.

When one focuses on the concept of social inclusion in Ireland, and within an Irish context, efforts toward social inclusion are best understood against both the historical and contemporary backdrop of disability services. Historically, the state took an arms-length approach to health and social services and ceded substantial control to the religious and voluntary sector.⁶⁷² Today a mixed economy of provision operates and services for children

⁶⁶⁹ <http://www.careworld.ie/intellectual-disability-support-services/>

⁶⁷⁰ <http://www.inclusionireland.ie/>

⁶⁷¹ <http://www.enableireland.ie/>

⁶⁷² Adshead & Millar, 2003; Harvey, 2007

and older people have seen a substantial shift toward private sector involvement, while the disability sector remains dominated by state funded voluntary providers⁶⁷³ which account for 90% of specialist intellectual disability services.⁶⁷⁴

Nonetheless, commissioning is increasingly favoured as a framework for service provision and it is likely that market mechanisms and/or private sector involvement will soon feature within the disability sector.⁶⁷⁵ Certainly, during the recent recessionary period where a moratorium on recruitment was imposed, agency staffing through private recruitment services became common within the disability sector.⁶⁷⁶ Moreover, in 2011, a major reform programme for disability services was initiated - Time to move on from congregated settings - A strategy for community inclusion.⁶⁷⁷ This sought to move individuals with disabilities from congregated settings into the community, with congregated settings those where ten or more individuals lived together.

This policy also included a move away from sheltered employment to open employment and was then quickly followed by the Value for money and policy review of disability services in Ireland⁶⁷⁸ and New Directions.⁶⁷⁹ This latter strategy envisages the utilisation of community supports to facilitate choice and inclusion, and reflected the wishes of individuals with disabilities for more involvement with communities, to build circles of friends.⁶⁸⁰ At the same time however, 'overall funding for disability services was reduced by €159.4 million between 2008 and 2015'.⁶⁸¹

Furthermore, the extent to which communities are receptive to such changes remains uncertain. The National Disability Authority (NDA) examines public attitudes to people with disabilities through regular surveys. Surveys in 2001 and 2006 showed improving public attitudes, though those with intellectual or learning disabilities were more likely to report negative attitudes than those with other types of disabilities (NDA, 2006). More worryingly, the 2011 survey found that attitudes had taken a negative turn (NDA, 2011).

Underpinned by the New Directions strategy, over 25,000 adults are provided with interventions to promote social inclusion in day services and staff have a particular remit to promote and facilitate social inclusion.⁶⁸² This entails accessing and drawing upon the supports available in the community and most often includes participation in educational opportunities, sport and recreational activities, social events and local partnership projects. Staff advocate and facilitate access, as well as planning, co-ordinating and supporting participation.⁶⁸³ Nonetheless, supports can be of varied quality and intensity, particularly amongst auxiliary staff who tend to prioritise direct care tasks.⁶⁸⁴

⁶⁷³ Mulkeen, 2016

⁶⁷⁴ National Disability Authority, 2010

⁶⁷⁵ Power, 2017

⁶⁷⁶ Cantwell & Power, 2016

⁶⁷⁷ Health Service Executive (HSE), 2011 ⁶⁷⁸ Department of Health, 2012

⁶⁷⁹ HSE, 2012

⁶⁸⁰ Abbott & McConkey, 2006

⁶⁸¹ Dolan, 2016

⁶⁸² HSE, 2012

⁶⁸³ Ibid

⁶⁸⁴ McConkey & Collins, 2010

Finally, the ultimate litmus test is best observed by the actual numbers and statistics themselves. However disability is measured, the proportion of Irish people with a disability who are in work is significantly lower than for the rest of the community (see the below table).

All three sources of data show significantly lower participation rates of people with disabilities than their non-disabled counterparts.⁶⁸⁵

Work participation rates People with disabilities⁶⁸⁶

Age group	Census 2002	QNHS 2004	QNHS 2004	LIS 2000
	%	%	%	%
15-24	23.2	36.3	39.8	n.a.
25-34	36.6	55.6	49.3	n.a.
35-44	31.3	50.2	49.3	n.a.
45-54	25.4	41.7	38.3	n.a.
55-64	15.5	27.0	24.5	n.a.
15-64	23.2	40.4	37.1	44.3
No disability:				
15-64	63.3	65.1	69.5	71.7
Gap	40.1	25.0	32.4	27.4

The differences in employment rates between these sets of figures may reflect that the QNHS and LIS cast their net wider than the Census and brought in a higher proportion of people under the "disabled" category. It is possible that some of the extra people included through using wider definitions of long-term illness and disability may have had milder levels of disability than the average. We know that substantial minorities of those included as "disabled" in these two surveys reported that their long-term illness or disability did not restrict everyday activities or the type or amount of work they could do.⁶⁸⁷

People whose disability does not limit their activities are more likely to be in work. So it is not surprising to see a narrower gap than in the Census between these surveys' employment rates for disabled and non-disabled people.

The next Table shows the percentage gap in employment rates in each age group between people with disabilities and the rest of the population, using the Census figures. Apart from teenagers, most of whom are still in school rather than at work, there is a large jobs gap in each age group and for both men and women.

⁶⁸⁵ The figures in 2004 for the numbers of disabled people in work and for the proportion of people with disabilities in the population were virtually the same as recorded in the 2002 QNHS. With a higher underlying population, a constant level of employment resulted in a slightly lower employment rate.

⁶⁸⁶ These figures from the Census and Living in Ireland Survey use Principal Economic Status and those from the QNHS use the ILO definition of employment.

⁶⁸⁷ About a quarter of those in the Living in Ireland Survey who reported a chronic illness or disability said this did not hamper their daily activities. About a third of those who reported long-term illness or disability in the Quarterly National Household Survey said this did not limit the type or amount of work they could do.

Percentage gap in employment rates of people with disabilities ⁶⁸⁸

Age	Men	Women
15-19	7.0	2.1
20-24	31.1	25.8
25-34	45.7	40.8
35-44	49.1	37.7
45-54	53.9	35.9
55-64	49.2	22.2

The great majority of people with disabilities who are not at work describe themselves as economically inactive rather than as looking for work. The largest single group are those saying they are "unable to work due to sickness or disability". Only 13% of disabled men and 6% of disabled women who are not working describe themselves as unemployed.

**How disabled people not in work describe their status ⁶⁸⁹
(age group 20-64)**

	Men	Women
	%	%
Unable to work due to sickness/disability	69	54
Retired	9	5
Home duties	2	29
Student	3	3
Unemployed or looking for first job	13	6
All non-employed	100	100

Men are more likely than women to be receiving long-term social welfare payments in connection with their disability. When we compare the number of people shown as disabled in the Census with the number of people claiming welfare payments for long-term conditions or occupational injuries, it seems about 84% of men but just 60% of women with a long-term condition would get a disability welfare payment. ⁶⁹⁰

⁶⁸⁸ Source: Census 2002, Principal Economic Status "at work"

⁶⁸⁹ Ibid.

⁶⁹⁰ Including those on Disability Allowance, Invalidity Pension, Blind Pension and Occupational Injuries payments, but excluding people on Disability Benefit which covers short term sickness absences and where only half of recipients are long-term claimants.

Research has established clear links between the employment rates of disabled people in Ireland and how restrictive their disability is. This research was conducted by the ESRI for the Equality Authority, and used statistical techniques to establish what effect the degree of restriction had on employment rates, when the influence of factors such as age, education, family status and region are stripped out (Gannon and Nolan, 2004).⁶⁹¹ The study used the data from the QNHS of 2002 and the LIS for 2000. Although these two sources measure the restrictions imposed by disability somewhat differently, the results are very similar whichever definition is used.⁶⁹²

The next Table shows how the severity of disability impacts on the likelihood of having a job.

**Percentage reduction in labour force participation rate of people with disabilities,
by extent of restriction or hampering⁶⁹³**
(correcting for age, education, family status, region)

Degree of restriction or hampering	Men		Women	
	QNHS	LIS	QNHS	LIS
	%	%	%	%
Considerable/Severe	66	61	42	52
Some	12	29	14	22
None	1	1	3	7

There is clearly a strong link between how severely restrictive the disability or chronic illness is, and the rate of employment. Both sources of data show that men who are severely restricted in work or living activities have employment rates that are about 60 percentage points lower than people who are not disabled. People who come into the "some restriction/hampering" category also have lower employment rates than their non-disabled counterparts, although here the size of the gap is much lower.

This ESRI research also showed that where people reported no restriction arising from their disability, then there were no statistically significant differences in whether they were working compared to people without a disability. So, leaving aside the part of the jobs gap for this group that can be explained by differences in age or education levels, any other apparent jobs gap is simply due to the random element that comes from a sample survey.

⁶⁹¹ This study analysed the microdata from the QNHS and the Living in Ireland Survey using a statistical technique called a probit. This technique related the probability of being employed if you had a disability to the probability of being employed if you had no disability, and analysed separately the impact of severe, moderate and non-restricting disabilities. This technique made corrections for such differences as in the age composition and education level of people with disabilities compared to non-disabled people. The intention was to isolate the influence of the severity of limits on work or life activities on the likelihood of having a job.

⁶⁹² The QNHS asked about restrictions on the amount of work someone could do, the Living in Ireland Survey about whether people were hampered in their daily activities.

⁶⁹³ Source: Gannon and Nolan, tables 6.1, 6.2, 6.3, 6.4

Italy

In the face of a weakening macroeconomic outlook, tackling Italy's macroeconomic imbalances is indeed the biggest challenge to social inclusion. In particular, reducing the country's high public debt ratio requires stability-oriented macroeconomic and fiscal policies to go together with more and better targeted investments and ambitious structural reforms to lift its sluggish productivity and potential growth. These endeavours are also key to market confidence.⁶⁹⁴

As a matter of priority, reviving the momentum for reform is needed to ensure sound public finances, more effective public administration and justice, a more efficient educational system and labour market, a friendlier business environment and a more resilient banking sector.⁶⁹⁵

After solid real GDP growth of 1.6 % in 2017, economic activity slowed down. Exports growth, a main contributor to previous GDP expansion weakened, while household consumption was subdued. The investment recovery remains uneven but is losing momentum overall. This is also partly due to domestic policy uncertainty, negatively affecting business confidence and the real economy through higher risk premia. Real GDP grew by 1.0 % in 2018 and is expected to decelerate sizeably in 2019 amid high uncertainty about domestic policies and the global outlook before picking up in 2020.

The uneven and gradual improvement of the labour market continued in 2018. The number of people in employment reached a record high by mid-2018. However, the employment rate remained well below the EU average, particularly for women and young people. Regional employment gaps also remain substantial. Over the past two years, job growth has been driven by temporary contracts. The unemployment rate has been declining at a slow pace also due to rising participation in the labour market. However, youth and long-term unemployment remain very high.

Poverty risk and income inequality remain high. In 2017, the share of people at risk of poverty or social exclusion (AROPE) declined to 28.9 % from 30.0 % in 2016. However, it remains well above both pre-crisis levels (25.5 % in 2008) and the EU average (22.4 %). Children, especially with a migrant background, are particularly at risk of poverty or social exclusion (32.1 % in 2017 down from 33.2 % in 2016). Moreover, poverty in urban areas is increasing. Income inequality in Italy is above the EU average.⁶⁹⁶

⁶⁹⁴ https://ec.europa.eu/info/sites/info/files/file_import/2019-european-semester-country-report-italy_en.pdf

⁶⁹⁵ The above report assesses Italy's economy in light of the Commission's Annual Growth Survey published on 21 November 2018. The Commission calls on the Member States to implement reforms to make the EU economy more productive, resilient and inclusive. Member States should focus their efforts on the virtuous triangle of economic policy: delivering high-quality investment, focusing reforms efforts on productivity growth, inclusiveness and institutional quality and ensuring macroeconomic stability and sound public finance. The Commission also published the Alert Mechanism Report that initiated the eighth round of the macroeconomic imbalance procedure. It found that Italy warranted an in-depth review.

⁶⁹⁶ Income quintile share ratio (S80/S20), stood at 5.9 in 2017, against the EU average of 5.1. The Gini index stood at 32.7 in 2017 against 30.3 on average in the EU. The higher the coefficient is, the less equal is the income distribution.

While the Italian income tax system is among the most progressive in the EU, the redistributive role of social transfers is weak. The impact of social transfers (excluding pensions) on poverty and inequality reduction was one of the lowest in the EU in 2017. Social spending is strongly biased towards old-age pensions, which largely depend on income. The distribution of wealth remains relatively even in Italy, due to high rates of home ownership.⁶⁹⁷

The provision and coordination of social services remains underdeveloped. Besides efforts to improve early childhood education and childcare, Italian authorities embraced an active inclusion approach, when the REI was introduced in 2018 (i.e. linking employment services with income support). According to the 2019 budget law, funds for dependent persons, persons with severe disabilities without family support and for family caregivers will be increased. However, people with disabilities and other disadvantaged groups in many cases do not receive adequate support as home and community-based care as well as long-term care services face challenges in terms of funding, access and quality.⁶⁹⁸

During this transition period which we are focusing on, a new government took office in Italy in June 2018 with the goals of jumpstarting growth, fostering social inclusion, and securing financial stability. To achieve these goals, the country needed a comprehensive reform package, alongside modest and balanced fiscal consolidation. This is indeed what the IMF advised in its annual review of the economy. Rishi Goyal, the head of the IMF team for Italy, was quoted as stating the following:

'The authorities' intentions to lift growth and social inclusion are welcome, as real incomes per person are still at the levels of two decades ago, living standards of the middle-aged and young have eroded, and emigration of Italian citizens is near a five-decade high. They have recently reformed the insolvency regime and are seeking to raise public investment and improve the business climate. These are needed initiatives.

The government is also partially reversing past pension reforms by easing early retirement rules and introducing a new "citizenship income program." On pensions, we are concerned that this would raise the number of pensioners, add to an already high pension bill, and lower labour force participation and potential growth.

*The new citizenship income program is aimed at alleviating poverty and facilitating integration of beneficiaries into the labour market. Italy needs a modern social safety net targeted at the poor. We are concerned, however, that the level of benefits provided is very high when compared to international good practice. This could discourage participation in the formal workforce and increase welfare dependency.'*⁶⁹⁹

As one can note from the above, the eradication or the targeting of poverty in Italy is indeed a priority with regards to a collective policy of social inclusion. This also inevitably affects

⁶⁹⁷ https://ec.europa.eu/info/sites/info/files/file_import/2019-european-semester-country-report-italy_en.pdf pg. 43

⁶⁹⁸ European Commission 2018b, p. 40

⁶⁹⁹ <https://www.imf.org/en/News/Articles/2019/02/05/na020619-italy-toward-growth-social-inclusion-and-sustainability>

persons with disabilities due to their being quite low on the level of available governmental funding due to the slow and limited performance of government revenue. At this point, one should note that after the ratification of the UN Convention on the Rights of Persons with Disabilities in 2009, the Italian Ministry of Social Affairs established the National Observatory on the Condition of Persons with Disabilities (CRPD) with the participation of the associations and federations of disabled people. Four working groups were also established consisting of local authorities, research centres, universities and businesses, which did not necessarily agree on different issues.

There was only one target: to elaborate a two-year Action Plan with seven lines of action for implementation in all the regions of the country. This Action Plan was implemented by a decree in December 2013. Line 3 in particular refers to Article 19 of the CRPD, and is entitled: "Policies, services and organizational models for Independent Living and inclusion in the society".

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Italy is still, however, centred on bureaucratic practices and dubious interpretations of regulations that considerably limit the real fulfilment of the rights that are recognised by law. In practice, disabled persons receive different types of social services and "indirect" assistance, depending on which of the twenty regions they live in. The regions of Valle d'Aosta, Piedmont, Veneto, Friuli Venezia Giulia, Tuscany, Emilia Romagna, Marche, Abruzzo and Sardinia have regulations and specific resolutions that arrange for financing of personalized support under one's own management and in "indirect" form. In the rest of the regions, there are only municipal regulations. In the region of Molise, for the first time in history in Italy, on 19 November 2010 a regional law specifically on Independent Living was endorsed, which provided for a small initial fund of €400,000 (it is the smallest region in Italy, with a population of about 320,000 inhabitants). For many years since its enactment, this law has not been implemented nor financed. The struggle to keep good practices alive has now been relocated from the local regions to the Government.

The Ministry of Social Affairs, based on the requests of the associations and officials during the National Conference in Bologna at the end of 2013, decided to promote an "experiment on Independent Living", with a new decree that provides for financing of €3.2 million to be split among the regions, with the aim to implement the national guidelines. For 2015, the financing increased to €10 million in order to expand the experiment; the scarceness of the amount is evident and is in line with the budgetary cuts that have been made in the past years.

From the analysis of the regions' spending, it is worrying that the scarce available resources are directed towards intermediary subjects supplying services, unclear variables of costs, home automation, transport, public institutions and so on. Only a small part of the funds are really directed to the persons with disabilities and almost nothing to training and empowerment, which are the essential principles indicated by that Action Plan. Problems have thus been created in the way funding is spent in some regions where there had been efficient paths towards Independent Living for over a decade. Added to this, there is the new decree

⁷⁰⁰ <https://enil.eu/news/independent-living-in-italy/>

introducing income supervision, aiming at participation of disabled people in covering the costs of taking part in social life. This, if applied in the wrong way, will limit the actual time disabled people can be expected to live in their own home and the realization of the project of inclusion.

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So what were the outcomes of such a social injection on the part of the authorities? Let us start with the recent review of Italy by the Committee on the Rights of Persons with Disabilities (CRPD Committee). After the review process started at the beginning of 2016, with the Italian Government's Official Report, the information from civil society, the List of Issues, and the constructive dialogue between Italy and the Committee that took place in Geneva on 24 and 25 August, the CRPD Committee published its Concluding Observations on 31 August 2016.⁷⁰²

The Committee's Concluding Observations strongly criticize the Italian government on numerous Articles of the CRPD and on their lack of implementation. Specifically, the most critical aspects are relative to Articles 1, 2, 3, 4, 5, 6, 7, 8, 9; 11, 12, 13, 14; 16, 17; 19, 21, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33.⁷⁰³

The only positive aspect that the Committee noted was the following:

*"The Committee notes with appreciation the decision on the National Disability Action Plan in 2010 and the ratification of the Council of Europe Convention on preventing and combating violence against women and domestic violence – the Istanbul Convention – in 2013. It commends the State party which has, for the last 3 decades, been striving to implement its inclusive education system free of segregation."*⁷⁰⁴

As regards Article 19 and the concept of living independently in the community, the Committee expressed their severe concern regarding Italy's policies:

"The Committee is deeply concerned about the trend to re-institutionalise persons with disabilities and that funds are not being reallocated from institutions towards promoting and ensuring independent living for all persons with disabilities within their community. The Committee further notes with concern the gendered consequences of the current policies where women are "forced" to remain within the family as caregivers of their peers with disabilities instead of being employed in the labour market.

*The Committee recommends: a) implementing safeguards to retain the right to autonomous independent living across all regions; and, b) redirect resources from institutionalisation to community-based services and increase budget support to enable persons with disabilities to live independently across the country and have equal access to services including personal assistance."*⁷⁰⁵

⁷⁰¹ Ibid.

⁷⁰² https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/SessionDetails1.aspx?SessionID=1052

⁷⁰³ A typical example:

<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#33>

⁷⁰⁴ https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/SessionDetails1.aspx?SessionID=1052

⁷⁰⁵ Ibid.

Not only are the funds directed to independent living very low and insufficient, but also the Parliament has recently approved a new law that incentivizes disabled people without family support to move into small institutions or even transform their houses into small group homes and transfer the management to third parties (e.g. foundations, cooperatives and other intermediaries). This is telling for two reasons. Firstly, because it becomes evident that Italian policies take for granted that it should be the families to fully or almost fully assist their disabled members up to an advanced age of their parents or up to their death. It is also telling because it shows that the main alternative for disabled persons is a life in small institutions, which are significantly funded by this law, instead of having a possibility and choice to live where, how and with whom they decide, with adequate funding.⁷⁰⁶

Just a few days after the publishing of the Concluding Observations, on 16-17 September 2016, the National Conference on Disability took part in Florence, organized by the Ministry of Labour and Social Affairs. Very sadly, no mention was made of the CRPD Committee's review and there was no evidence of the Italian Government taking it seriously. On the contrary, the Ministry presented the so-called Biennial Plan of Action, avoiding to mention the fact that the previous Biennial Plan of Action has not to-date been implemented. The question that naturally comes to one's mind is: If the government has not respected and not put in practice the previous Plan of Action, what will happen to the new one? Is it destined to be another declaration of nice intentions that will just remain in the archives of the Conference and of the governmental decrees?

As for the concept of independent living, the organizers of the Conference did not take seriously the CRPD Committee's recommendations and almost ignored this topic.

What is missing in Italy, to begin with, is statistical data that adequately shows the amount of funds dedicated to institutions and to living independently in the community. The other fact that becomes evident, also noted by the CRPD Committee, is that there is not a general disability policy in Italy but each Region decides different things, resulting in discrimination among Italian citizens around the country and also in the impossibility to move to a different Region without losing the acquired personal assistance. This is due to the modification to the Italian Constitution a few years ago, handing down to the Regions the jurisdiction on social affairs.

What is thus highly needed is a norm that recognizes independent living as a human right and not as a mere social affairs matter. A human right that should be decided on by the central State, for all citizens.⁷⁰⁷

⁷⁰⁶ <https://enil.eu/news/does-italy-care-about-independent-living/>

⁷⁰⁷ Ibid.

But what about statistics and numbers related to the subject in question? In 2015, there were 270 505 residents with disabilities or who were categorised as 'non-self-sufficient' (non-auto-sufficienti)⁷⁰⁸ in residential care facilities providing both social and health care services.⁷⁰⁹

Of those, 262 691 (97.11 %) were in institutional care, while 7 479 (2.76 %) were in community - based facilities.⁷¹⁰

Among the residents, 2 839 were children,⁷¹¹ 1 818 were males (64.04 %), and 1 021 were females (35.96 %); 2 162 were in institutional care (76.15 %), with 669 in community-based facilities (23.56 %); 49 046 were adults between 18 and 64⁷¹² with disabilities or psychiatric conditions; 29 214 were males (59.56 %), and 19 832 were females (40.44 %); 45 791 were in institutional care (93.36 %), and 3 207 were in community-based facilities (6.54 %).

A total of 218 620 residents were adults aged 65 and over; ⁷¹³ 214 738 were in institutional care (98.22 %), with 3 603 in community-based facilities (1.65 %).

In the residential care facilities providing both social and health care services, there were 69 065 elderly non-self-sufficient residents out of a total of 287 685 residents; there were 74 444 males (25.8 %) and 213 241 females (74.12 %). No differentiation is made between older people with age-acquired or pre-existing disabilities.

The sequence of official data generated by the Istituto Nazionale di Statistica (ISTAT, the Italian National Institute of Statistics) on residential care facilities that provided both social and health care services stopped in 2015. In October 2017, ISTAT announced the start of a new annual survey.⁷¹⁴

ISTAT data analysis shows a slight 9.5 % decrease in the overall usage of residential facilities between 2009 and 2012, a 6.34 % increase between 2013 and 2014, and a very slight 1.03 % decrease between 2014 and 2015.

Thus, the situation did not significantly change overall over those years. The decrease recorded between 2009 and 2012 did not give rise to the beginning of a cycle, and the slight fluctuations are not related to political choices.

⁷⁰⁸ 'Non-self-sufficient' is a classification of beneficiaries that, in Italy, is considered as a specific target. The target is a person who needs intensive support because she/he has a high level of assistance dependency. This term is a legislative category and it is used by the national and regional legislation and by the resulting regulation. Only people who fall within this category can obtain specific funds for deinstitutionalisation.

⁷⁰⁹ ISTAT (the Istituto Nazionale di Statistica / Italian National Institute of Statistics) defines institutional care facilities as 'community', and it defines facilities provided by an organisation that replicates the characteristics of life in a family as 'family based'.

⁷¹⁰ Those percentages can be affected by a minimal amount of questions not answered or data not categorised.

⁷¹¹ Children with a physical, psychiatric or sensory disability.

⁷¹² Adults between 18 and 64 years who have a physical, psychic or sensory disability, who have multiple disabilities or who have psychiatric problems.

⁷¹³ Non-self-sufficient elderly persons over 65, i.e. persons in a permanent state of invalidity or who suffer from chronic diseases and who consequently have a reduced level of independence, leading to a need for constant help from other people in order to perform essential daily activities.

⁷¹⁴ <https://www.istat.it/>

The data on the usage of residential facilities are extremely stable, in particular concerning residential facilities providing institutional care. Even if the regulatory fragmentation in Italy makes it difficult to reconstruct a clear and homogeneous picture of the usage of residential facilities across the country, it is evident that the community-based settings represent a marginal option in the Italian welfare system.⁷¹⁵

Some indirect indexes seem to confirm a stable picture up to the end of 2018. The main index concerns the reception capacity of the facilities, which can be obtained from the residential facilities Register Office managed by the National Guarantor for the Rights of Persons Detained or Deprived of Personal Liberty (GNPL) by cross-checking the data from various national and local databases. The data show a high level of stability in the amount of available sleeping accommodation in residential facilities in 2018 with respect to previous years. Furthermore, the geographical distribution of sleeping accommodation seems fairly stable from a macro standpoint. The type of usage of residential facilities is also stable. The Register Office of the GNPL is not publicly accessible, but it is tasked with monitoring the health and social care institutions. Some differences in the percentages can arise due to the fact that regions and municipalities, which are the main sources of data for the Register Office, do not update their databases on official residential facilities at the same time. Nonetheless, these tools are useful for obtaining a picture of the present situation, given the lack of data coming from ISTAT or from Government ministries.⁷¹⁶

During 2017, Italy permanently ended the process of abandoning judicial psychiatric institutions (OPGs), which had been replaced with residences for the execution of security measures (REMS). Admission to residential social and health care facilities replaced home care, day care or hospitalisation in judicial psychiatric hospitals. REMS are solutions of last resort, since the current legislation prefers solutions other than institutionalisation.⁷¹⁷

This change is just the latest event in a long process of deinstitutionalisation and criticism of the culture of segregation, which led, in 1977, to the abolition of specific classes devoted to students with disabilities⁷¹⁸ and, in 1978, to the abolition of the system of state mental institutions.⁷¹⁹

Nevertheless, in Italy the institutionalisation of persons with disabilities is still an essentially accepted practice, which particularly concerns persons with intellectual and/or psychosocial disabilities and non-self-sufficient elderly people.⁷²⁰

⁷¹⁵ <https://www.disability-europe.net/theme/independent-living?country=italy>

⁷¹⁶ Ibid.

⁷¹⁷ 'Minority Reports: Cultural Disability Studies' No 3, a special issue of the deposition of criminal lunatic asylum, 2016.

⁷¹⁸ See Act No 517 of 4 August 1977, <http://www.gazzettaufficiale.it/eli/id/1977/08/18/077U0517/sg>

⁷¹⁹ See Act No 180 of 13 May 1978, <http://www.gazzettaufficiale.it/eli/id/1978/05/16/078U0180/sg>

⁷²⁰ The present report does not deal with the situation and the problems related to psychiatric institutions. In Italy there is an historic and pronounced split between the field of mental health and the field of disability, so much so that the field of mental health uses different collection and monitoring systems. Recently, however, there have been signs of convergence between the two fields, as may be noticed, for example, from draft law No 180, Disposizioni in materia di tutela della salute mentale volte all'attuazione e allo sviluppo dei principi di cui alla legge 13 maggio 1978, which is explicitly placed within the framework of the CRPD. This draft law is not currently being examined by the Parliament (see <http://www.senato.it/leg/17/BGT/Schede/Ddliter/48103.htm>)

There are neither national data with respect to overall spending on institutional care nor data concerning the overall spending on support services for living independently and being included in the community. Thus, there are no available data on the proportion/amount of funding provided out of EU funds.

In 2013, the Programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità (Biannual National Action Programme on Disability) planned three actions related to Article 19 of the CRPD.⁷²¹ The Ministry of Labour and Social Policy planned for the funding of pilot programmes, as proposed by regions and autonomous provinces, to adopt a uniform model of intervention for support for living independently and for the inclusion of persons with disabilities throughout the country. This programme, with a budget of EUR 15 million, was mainly funded from the Fondo Nazionale per la non autosufficienza (the FNA, the National Fund for Non-self-sufficiency). This represented 3.75% of the annual fund.

The only other available data on this topic concern the expenditure of municipalities on institutional facilities and home care. The expenditure on home care is simply an index with respect to policies supporting services for living independently.

The most recent definitive data on the expenditure by municipalities on residential facilities and on home care concern 2014. In January 2019, ISTAT made available provisional data concerning 2016, but they are still not available with respect to a disaggregated representation of types of expenditure.

The contributions of municipalities to residential expenditure for persons with disabilities vary between 30 % and 60 % and come to 50 % for elderly people; the remaining share goes towards the National Health Service and, in proportion to salary, to users. Thus, the contribution of municipalities to the total expenditure on residential facilities is only partial and is usually minor.

In 2014, the expenditure of municipalities on residential facilities amounted to EUR 809.4 million with 313 million was devoted to disability and EUR 469.3 million for elderly people.

Municipal expenditure for home care in 2014 amounted to EUR 678.1 million, with EUR 223 million devoted to disability and EUR 455.1 million for elderly people.

Expenditure for home care for disabled persons includes EUR 147.9 million for social assistance home care, EUR 25.7 million for home care integrated with health services (ADI), and EUR 49.4 million for vouchers, care allowance and social health vouchers.

Expenditure for home care for elderly people includes EUR 312.3 million for social assistance home care, EUR 64.7 million for home care integrated with health services (ADI), and EUR 78.1 million for vouchers, care allowance and social health vouchers.

⁷²¹ See Decree of the President of the Republic of 4 October 2013, Adozione del programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità, <http://www.gazzettaufficiale.it/eli/id/2013/12/28/13A10469/sg>.

Moreover, in December 2018, the European Union Agency for Fundamental Rights (FRA) published two short reports which contain an overview of the European state of affairs on the transition from institutions to community living, together with some general opinions on the obstacles to deinstitutionalisation. These documents contain some information concerning Italy.⁷²² This study stresses that various forms of in-home support and hospitality are provided locally in several day-care centres to foster autonomy, as well as a number of labour inclusion services for persons with disabilities. These facilities and services tend to be run by social cooperatives that work closely with local authorities, often also in cooperation with regions committed to achieving deinstitutionalisation. It must be noted that the FRA report considers a very specific case study, therefore it is limited in scope. Below are some examples of such services available.

Associazione Scuola Viva onlus⁷²³ is a rehabilitation centre for persons with disabilities particularly involved in the rehabilitation of persons with disabilities through tailored projects. There are two main departments: a day centre for persons with intellectual disabilities and an outpatient department. In the first department rehabilitation projects are carried out, also for persons who have joined affective-interpersonal disturbances. The projects are mainly focused on self-statement through personal or cluster interventions of psychological, motor, cognitive, psychomotor, music therapy, gestural communication and animal attending therapy. There are also an art atelier, gardening and glasshouse, ceramics and autonomy programmes. The other department is devoted to the rehabilitation of persons at any age with orthopaedic problems, degenerative central and peripheral neurological diseases, children with speech problems and domiciliary care.

OPENGROUP offers job opportunities to disadvantaged persons, integrating production activities with rehabilitation and social reintegration. In addition, the sheltered workshops for people with mental and physical disabilities are the concretization of the OPENGROUP idea of integration, protection and socio-cultural richness.⁷²⁴

A.I.A.S. Città di Monza onlus is a non-profit organisation which is active in rehabilitation and social inclusion. They are a service provider of medical therapies to people with physical, psychological and intellectual disabilities. The organisation is part of the Health System of Regione Lombardia.⁷²⁵ The organisation, basically a public-private partnership, is a member of A.I.A.S., Italian Association for Spastic Assistance, which is a national organisation with about 120 departments in Italy.⁷²⁶

⁷²² 'From institutions to community living for persons with disabilities: perspectives from the ground', <https://fra.europa.eu/en/publication/2018/independent-living-reality>; and 'The right to independent living of persons with disabilities', <https://fra.europa.eu/en/project/2014/right-independent-living-persons-disabilities>.

⁷²³ <http://www.scuolaviva.org/>

⁷²⁴ <http://www.opengroup.eu/>

⁷²⁵ <http://www.aiasmonza.it/it/>

⁷²⁶ <http://www.interreg-care.org/network-aias.htm>

The Centre for Autonomy in Rome is a territorial service of ASL Roma 2, which, by means of a process of habilitation/rehabilitation, supports persons with serious and extremely serious disabilities in achieving the highest possible degree of self-sufficiency and self-determination.

⁷²⁷

The Centre for Autonomy of Umbria was created in 2003. Its mission is to guarantee persons with disabilities a lead role in choices relating to them by means of personal and community empowerment tools. ⁷²⁸

The Centre for Studies on Rights and Independent Living of the University of Turin supports the public service in the acquisition and development of support tools which give equal opportunities to adults with intellectual disabilities for their participation in social life, as well as promoting the protection of the right to choose where and with whom to live as established by the UN Convention. ⁷²⁹

L-inc (Laboratorio inclusione sociale disabilità — the Social Inclusion Disability Laboratory) is a project that has started to address the difficulties faced by the welfare system in promoting actions of real social inclusion for all persons with disabilities, due to the persistence of the idea of disability as a chronic disease. L-inc was conceived as a laboratory that seeks to change the present costs of care and assistance for persons with disabilities by investing in independent living plans and in the activation of the community. L-inc involves some municipalities located in the northern districts of Milan. This project is promoted and implemented by a collection of various public and private associations, supported by the Fondazione Cariplo. The leading institution is the Lombardy branch of ANFFAS (Associazione Nazionale Famiglie di Persone con Disabilità Intellettiva e/o Relazionale — the National Association of Families of Persons with Intellectual and/or Relational Disabilities). ⁷³⁰

For some years now, the Habitat-Microaree programme, promoted by the Trieste integrated university health authority, has been trialling innovative forms of territorial interventions, pursuing the ideas of rights promotion, combating institutionalisation and promoting community building, with a special focus on elderly persons, persons with disabilities and children living in areas dominated by public housing. ⁷³¹

To conclude, services for persons with intellectual and developmental disabilities (IDD) have evolved in Italy as legislation has increased understanding and appreciation of the rights of people with IDD in society. However, discrimination remains in areas such as employment and even education.

A case in point: Persons with disabilities in need of high support, if family help is lacking, have no access to non-institutional forms of housing. The lack of planning, development and funding of alternative forms of home support, of alternative services to segregating institutions, such as family type facilities, and of transition processes towards residential arrangements in the

⁷²⁷ <http://www.centroperlautonomia.it>.

⁷²⁸ <http://www.cpaonline.it>

⁷²⁹ <https://www.centrostudidivi.unito.it/progetti/officina-per-la-vita-indipendente>.

⁷³⁰ <http://www.laboratoriolinc.it/>.

⁷³¹ <http://www.secondowelfare.it/governi-locali/habitat-microaree-unesperienza-di-welfare-di-comunita-a-trieste.html>.

community constitutes a concern for the families of persons with intensive support needs. The number of families that complain that they cannot count on anybody's help and grows with the age of the person, together with the parents' concerns about the perspectives of the future life of their children with disabilities after their death. While the number of parents of children or teens with Down Syndrome up to 15 years who think about 'after us' in which their children will have an autonomous or semi-autonomous life varies from 30 % to 40 %, among parents of adults the percentage decreases to 12 %. The number of parents of children and adolescents with autism that imagine an autonomous or partially autonomous future situation for their children (23 %) decreases even more drastically (5 %) among families of adults with autism over 21. ⁷³²

Historically, persons with IDD were treated the same way as those with mental health problems and sheltered away in institutions or so-called 'lunatic asylums' and oftentimes abandoned and abused, but today there is now a clear distinction between persons with IDD and persons with mental illness. These same people were believed to be, in Italy's history, a castigation from Heaven as a result of the sins of their parents. Finally, in early 1978, reforms of the whole National Health Service system was launched, and the IDD field in Italy was totally changed.

One of the most important results of these reforms, which are outlined in Italian law ⁷³³ was the closing of the institutions that had, for a long time, been the inevitable home for Italians with IDD. Today, Italians with IDD and the groups that represent them, struggle for the realization of rights guaranteed them by law, with mixed accomplishment rates.

Prior to integration in Italy, there were special classes for 'handicapped' pupils and special schools for 'sub-normal' pupils (pupils with specific physical or intellectual disabilities). There were also separate classes, attended by 'nervous, retarded, unstable pupils who would not fit in regular classes, for whom common discipline and teaching methods would be unsuitable and who could only improve through special teaching methods' ⁷³⁴

Things have changed radically since those times, albeit not as quick and as assertive as the major Italian NGOs in this sector have been lobbying for. The government has also established monitoring mechanisms in this field for the professional analysis of the sector. As well as having an advisory role, the National Observatory on the Condition of Persons with Disabilities, established by the Ministry of Labour and Social Policy under Act No 18 of 3 March 2009, has an additional role of providing technical and scientific support for the development of national policies on disabilities. ⁷³⁵ On 18 October 2016, the Observatory approved the '*Secondo programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità*' (Second Biennial National Action Programme on Disability). ⁷³⁶ The title of action line 2 of the programme is '*Politiche, servizi e modelli organizzativi per la vita indipendente e*

⁷³² Censis, Diario della transizione, issue 3, 2014.

⁷³³ Act 180/1978

⁷³⁴ Italian government education policy in 1953

⁷³⁵ <http://www.osservatoriodisabilita.it>

⁷³⁶ Adopted by decree of the President of the Republic, 12 October 2017, <http://www.gazzettaufficiale.it/eli/id/2017/12/12/17A08310/SG>

l'inclusione nella società' (Policies, services and organisational models for living independently and inclusion in society).

Action line 2, 'Politiche, servizi e modelli organizzativi per la vita indipendente e l'inclusione nella società' (Policies, services and organisational models for independent living and inclusion in society) of the Second Biennial National Action Programme on Disability of the National Observatory on the Condition of Persons with Disabilities considers six programmatic actions:

- Tackling isolation and segregation in order to favour deinstitutionalisation;
- Providing services and facilities for the community which should be available to persons with disabilities by taking into account their needs and in accordance with the principle of parity;
- Promotion of living independently in houses;
- Providing stronger, more effective models of self-managed personal support;
- Sharing and disseminating the principles and tools of personal design and their application;
- Legal protection of persons with disabilities and their self-determination.

In Italy, the regions have primary legislative competence and regulatory power in planning and coordinating health and social services, in compliance with the minimum levels of service with respect to civil and social rights which have to be secured throughout the country, as established by the state.

In this regulatory system, some regions have approved or are in the process of discussing laws or measures inspired by the principles of living independently. These acts vary with respect to their conceptual structure, the solutions foreseen and the potential recipients. At the time of writing, those regions that have issued measures on the topic are Abruzzo, Emilia-Romagna, Friuli-Venezia Giulia, Lazio, Lombardy, Marche, Molise, Piedmont, Tuscany, Umbria and Veneto.⁷³⁷ This regional disparity inevitably creates national accountability analysis.

One must also mention, at this final stage of this country report, the National Guarantor for the Rights of Persons Detained or Deprived of Personal Liberty (GNPL), which became operational in 2016. The GNPL is an independent state body authorised to monitor places characterised by deprivation of freedom by visiting them without prior notification.

As a national preventive mechanism — as per the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and as per Article 33 of the CRPD — the GNPL monitors residential facilities to ensure that persons with

⁷³⁷ <https://www.disability-europe.net/theme/independent-living?country=italy>

disabilities, in particular intellectual or psychosocial disabilities, shall not be deprived of their freedom illegally or arbitrarily. The objective here is to ensure that disability is not used as a prerogative or excuse for restrictions of freedom or for segregation.^{738 739}

The National Guarantor started monitoring health and social care homes in June 2017.⁷⁴⁰ In light of the lack of official data, the GNPL created its own national register of residential and semi-residential facilities. This database allows facilities to be located according to a dedicated information and risk indexing system.

During its monitoring visits, the GNPL often found inadequacies in living and support conditions in the residential facilities, with improper forms of freedom reduction, abuses or treatments that did not respect the dignity of the person, as well as the use of restraint tools.

The main problem is de facto segregation: the process of involuntary institutionalisation that tends to arise after a person voluntarily joins the residential facility, when the social services do not put in place adequate forms of community-based support.

After a period of embargo, the GNPL makes its observations with respect to its monitoring visits publicly available.⁷⁴¹

⁷³⁸ The GNPL's work stems from recommendation No 42 of the Concluding observations on the initial report of Italy of 6 October 2016 of the Committee on the Rights of Persons with Disabilities.

⁷³⁹ <https://www.ohchr.org>.

⁷⁴⁰ The activities of the GNPL are scientifically supported by an operational research protocol on 'Places, forms and ways of segregated disability', which involves a collaboration between GNPL, L'Altro diritto, Centro di ricerca interuniversitario su carcere, devianza, marginalità e migrazioni of the University of Florence, Atypicalab for Cultural Disability Studies of the University of Calabria and the Robert Castel Centre for Governmentality and Disability Studies at the Suor Orsola Benincasa University of Naples.

⁷⁴¹ <http://www.garantenazionaleprivatiliberta.it/gnpl/it/rapporti.page>.

Latvia

Table 1 indicates the number of disabled people,⁷⁴² share in the population, number of disabled people in institutional care and receiving community-based services and share of persons with a mental disability from all disabled people from 2013 to 2017. The current figures and recent trends will be examined in the coming paragraphs, based on this table. The statistical source of the Table emanates from the Ministry of Welfare.⁷⁴³

Table 1	2013	2014	2015	2016	2017
Number of people with disabilities (PwD)*	163 945	169 860	176 189	182 792	187 830
inc. children with disabilities	8 038	8 310	8 365	8 362	8 292
Share of PwD in population (%)	6,90	8,00	8,31	8,14	9,25
Number of adult PwD in institutions**	6 721	7 045	5 735	7 098	7 460
Share from all PwD (%)	4,31	4,36	3,42	4,07	4,16
Number of children with disabilities in institutions	1 854	1 618	1 452	1 300	1 170
Share from all children with disabilities (%)	23,07	19,47	17,36	15,55	14,11
Number of PwD employed in subsidized workplaces	289	520	305	522	481
Share from all PwD (%)	0,18	0,31	0,17	0,29	0,26
Number of PwD receiving assistant services**	3 069	9 794	9 213	9 668	9 886
Share from all PwD (%)	1,87	5,77	5,23	5,29	5,26
Number of PwD receiving home care services***	1 797	1 970	2 097	2 025	2 051
Share from all PwD (%)	1,10	1,16	1,19	1,11	1,09
Number of PwD in daycare centres	1 387	1 856	2 047	1 702	1 631
Share from all PwD (%)	0,85	1,09	1,16	0,93	0,87
Number of disabled people with mental disability	19 078	22 534	24 405	24 237	25 158
Number of PwD in group homes (apartments)****	206	242	238	236	679
Share from PwD with mental disability (%)	1,08	1,07	0,98	0,97	2,70
Number of PwD in specialized workshops****	34	64	69	68	68
Share from PwD with mental disability (%)	0,18	0,28	0,28	0,28	0,27

** Additional Source: Local governments⁷⁴⁴

*** Additional Source: Central Statistical Bureau of Latvia⁷⁴⁵

**** Services for disabled people with mental disability

⁷⁴² According to the Disability Law (2010) person with a disability is 'a person for whom a disability has been determined in accordance with the procedure specified by this Law' (Section 1), disability is 'a long-term or non-transitional very severe, severe or moderate level limited functioning which affects a person's mental or physical abilities, ability to work, self-care and integration into society' (Section 5). Available at: <https://likumi.lv/ta/id/211494-invaliditates-likums>.

⁷⁴³ Sectoral statistical data. Social policy indicators. Available at: <http://www.lm.gov.lv/lv/publikacijas-petijumi-un-statistika/statistika>.

⁷⁴⁴ Official statistics in the field of social services and social assistance. Annual reports. Available at: <http://www.lm.gov.lv/lv/publikacijas-petijumi-un-statistika/statistika/valsts-statistika-socialo-pakalpojumu-un-socialas-palidzibas-joma/gada-dati>.

⁷⁴⁵ Central Statistical Bureau of Latvia database, SDG140. Home care at end of year. Available at: http://data1.csb.gov.lv/pxweb/en/sociala/sociala_socdr_aprupe/SDG140.px/?rxid=a39c3f49-e95e-43e7-b4f0-dce111b48ba1.

Thus, when analysing trends in this sector, one notes that the number of persons with disabilities has increased from 163 945 to 187 830 between 2013 and 2017. The ratio of people with disabilities among the population (%) has increased from 6.9 % to 9.25 %.

The number of people with disabilities in long-term social care and rehabilitation institutions (LTC institutions) remains at a steady level, with a slight increase from 7 165 people in 2013 to 7 772 people in 2017. Nevertheless, the share of people with disabilities in LTC institutions has decreased from 4.31 % in 2013 to 4.16 % in 2017; while the proportion of children with disabilities in these institutions has decreased from 23.7 % in 2013 to 14.11 % in 2017.

During the indicated period 2 000 people with disabilities on average, or 1.6 % of all people with disabilities, have received care at home per year. The largest increase is in the number of people with disabilities who receive assistant services. However, it should be noted that after 2013 the number of people with disabilities receiving assistant services has stabilised and, on average, 9 640 disabled people per year, or 5.4 % of all disabled people, received the assistant service.

The number of people with disabilities receiving social care and rehabilitation services in day care centres has fluctuated over the years indicated; 1,387 persons in 2013, 2 047 in 2015 and 1 631 in 2017. The proportion of people with disabilities receiving day-care services has increased only by 0.02 %, with a steady increase in the proportion of people with disabilities receiving services in the group house (apartment), from 1.08 % in 2013 to 2.70 % in 2017, and in specialised workshops from 0.18 % in 2013 to 0.27 % in 2017.

According to OECD Health Statistics, Latvia is one of the countries where public spending on long-term care (health and social components) in 2014 as a % of GDP was only 0.4 % of GDP, where the average for the OECD 30 was 1.4 %. Institutional care dominates: it was and remains the main form of social care.⁷⁴⁶

Latvian legislation, policy and practice on the subject matter still offer too few chances to people with intellectual disabilities (whose learning ability is significantly lower than average) to access education and employment. Although the numbers of children with intellectual disabilities attending mainstream schools are rising, the vast majority still attend special schools. Due to the complete lack of suitable, targeted employment programmes or initiatives, practically all people with intellectual disabilities have no work. They therefore have no chance of leading an independent life and are forced to rely on State benefits.⁷⁴⁷

To date, the Government has not addressed the specific needs of people with intellectual disabilities in the labour market and, as a result, almost none can find employment. In Latvia, there is no quota system for people with disabilities and no government incentives to encourage the employment of people with – specifically – intellectual disabilities.

⁷⁴⁶ [https://www.disability-europe.net/search?searchword&searchphrase=any&areas\[0\]=documents_search&areas\[1\]=42](https://www.disability-europe.net/search?searchword&searchphrase=any&areas[0]=documents_search&areas[1]=42)

⁷⁴⁷ <http://cilvektiesibas.org.lv/en/publications/rights-of-people-with-intellectual-disabilities-ac/>

According to official government statistics, expenditure for the provision of long-term social care services in institutions remains at one level. The 19 % increase in spending is only influenced by inflation ⁷⁴⁸ and wage increases. Between 2013 and 2017 (both years included), spending on alternative services to institutional care has increased. Expenses for home care services have increased by 113 %, expenses for assistant services by 47 % (from 2013 to 2017), costs of services in day care centres by 26 %. Costs of services for individuals with mental disability have increased by 52 % and special workshops by 109 %. Reduced funding was registered for technical aids with a reduction of around 2 % (2014-2017 data).

To implement the deinstitutionalisation (DI) project, government is allocating EUR 35 905 953 from ESF (European Social Fund funding) ⁷⁴⁹ and for the establishment of the necessary infrastructure EUR 37 775 681 (European Regional Development Fund (ERDF)). ⁷⁵⁰

If a child has a disability and requires care, one can apply for a special care benefit for a person with disability (i.e. the benefit for disabled persons requiring care and the disabled child care benefit). If a child has a disability and restricted mobility, one can apply for benefits to compensate transport expenses. If one has a group I visual disability and is not receiving assistance services or allowance to a disabled person who needs care, one can be entitled to benefit for assistance services for persons with group I visual disability.⁷⁵¹ If one is unable to work and earn income due to work incapacity or disability, or lost one's job or income is very low, and not entitled to the invalidity benefit, one can receive the State social security benefit under certain conditions. ⁷⁵²

To receive benefits for persons with disabilities, one must obtain a statement from the State Medical Commission for the Assessment of Health Condition and Working Ability (SMCAHCWA) declaring that you have a disability (for adults - a disability group) and a specific ruling indicating the basis for granting the benefits - restricted mobility or requiring special care. Disabled child care benefits are granted to a parent or another person (guardian, foster family or adopter) caring for a child up to 18 years of age, while benefits for disabled persons requiring care are granted to adults. To apply for one of the aforementioned benefits, one must obtain a statement from the SMCAHCWA certifying that the person in question requires special care. To receive benefits for compensating transport expenses, one must obtain a

⁷⁴⁸ Consumer Price Increase (Inflation) was 7.9% during the period from January 2013 to January 2019. Central Statistical Bureau of Latvia.

⁷⁴⁹ Cabinet Regulations No 313 on Implementation of European Social Fund operational programme 'Growth and employment' 9.2.2.specific objective 'Increase the availability of high quality services at home and close to family environment alternative to institutional care for persons with disabilities and children' measure 9.2.2.1.'Deinstitutionalization' (2015). Available at: <https://likumi.lv/ta/id/274957-darbibas-programmas-izaugsmenodarbinitiba-9-2-2-specifiska-atbalsta-merka-palielinat-kvalitativu-institucionalai-aprupei>.

⁷⁵⁰ Cabinet Regulations No 871 on Implementation of European Social Fund operational programme 'Growth and employment' 9.3.1.specific objective 'To develop the service infrastructure for childcare in a family environment and for independent life of persons with disabilities and their integration into society' measure 9.3.1.1.'Development of service infrastructure for the implementation of deinstitutionalisation plans' first and second selection rounds for project applications, 2016. Available at: <https://likumi.lv/ta/id/287725-darbibas-programmas-izaugsmenodarbinitiba-9-3-1-specifiska-atbalsta-merka-attistit-pakalpojumu-infrastrukturu-bernu>.

⁷⁵¹ Disability Groupings are explained further down this chapter.

⁷⁵² <https://ec.europa.eu/social/main.jsp?catId=1117&langId=en&intPagelId=4636>

statement from the SMCAHCWA certifying that one's child has restricted mobility. These benefits are granted to adult disabled persons or disabled persons up to 18 years of age. To receive benefit for assistance services for persons with Group I visual disability, one must obtain a statement from the SMCAHCWA certifying that one has a Group I visual disability and that one is not receiving assistance services or allowances to a disabled person who needs care.

In order to receive state social security benefit in case of disability, one needs to have resided permanently in Latvia for at least 5 years, of which the last 12 months have been uninterrupted residency. In addition, for the above assistance, one must have no right to receive a pension or compensation in connection with workplace accidents or work-related illnesses.⁷⁵³

Such a scenario underlines the fact that in Latvia, social and economic inclusion for persons with disabilities is still looked upon as a health/medical aspect instead of the common practice throughout Europe wherein it is regarded as a social aspect requiring social injections and solutions.

This is furthermore underlined when one takes into consideration that in the National Reform Programme (NRP) of Latvia for Implementation of the 'European Union 2020' Strategy,⁷⁵⁴ support measures for independent living in the community have not been included. Some progress reports include information on the development of policy planning documents for the development of social services. The Progress Report on the Implementation of the NRP (2013)⁷⁵⁵ states that 'In 2013, the work is continued on the action policy document for the development of social services',⁷⁵⁶ the Progress Report 2015 states that 'In 2015, the development of the DI plan, [...], is continued',⁷⁵⁷ while the Progress Report 2017 states that '[...] the subsidized employment measures were supplemented with a new type of employment for unemployed persons with mental disorders – a support person at work assisting with the integration in workplace' and the ESF co-financed project on Social Entrepreneurship Support⁷⁵⁸ has been launched. None of the progress reports specifies the concrete policy direction and measures.

To underline the above, one needs to note the Partnership Agreement for the European Union Investment Funds Programming Period 2014 – 2020.⁷⁵⁹ In paragraph (246) 'Social challenges' the below assertions are stated and published:

⁷⁵³ Ibid.

⁷⁵⁴ National Reform Programme of Latvia for Implementation of the 'European Union 2020' strategy, 2011. Available at: https://ec.europa.eu/info/sites/info/files/file_import/nrp_latvia_en_0.pdf.

⁷⁵⁵ Progress Report on the Implementation of the National Reform Programme of Latvia within the 'Europe 2020' Strategy, 2013. Available at: https://ec.europa.eu/info/sites/info/files/file_import/nrp2013_latvia_en_0.pdf.

⁷⁵⁶ Ibid, p.15.

⁷⁵⁷ Ibid, p.78.

⁷⁵⁸ Ibid, p. 69.

⁷⁵⁹ Partnership Agreement for the European Union Investment Funds Programming Period 2014 – 2020; 2014. Available at: https://www.esfondi.lv/upload/Planosana/FMPlans_230714_PA_updated_17.12.2014.pdf.

'[...] insufficient provision of social services to various target groups according to their needs, comparatively narrow available set of services [...] for example, individuals with mental disabilities, families which have children with functional disabilities etc., insufficient material supply of social services for provision of various services, including persons with functional disabilities [...], insufficient availability of premises for development of social services, [...], lack of qualified social work specialists [...] in municipalities'.⁷⁶⁰

The subsequent paragraph in the report contains the proposed solutions:

'[...] development of available set of social services to particular target groups according to their needs, bringing provision of services closer to their places of residence, including long-term and short-term care, social rehabilitation services, consultations provided by various medical specialists, technical aids rental etc., improvement of infrastructure and material supply of social service institutions, development of care forms alternative to institutions and improvement of existing forms of social services, expanding cooperation with adjoining municipalities in the field of social services provision, strengthening capacity of employees of social service institutions'.⁷⁶¹

The most important method by which unemployed people with disabilities gain access to employment in Latvia is through active employment measures provided by the State Employment Agency (SEA) – in particular subsidised employment programmes. However, few people with intellectual disabilities have the necessary training or professional education required for eligibility for such programmes.

Supported employment is internationally recognised as the most important way in which people with intellectual disabilities can access employment. It offers them the opportunity to work on the open market with the help of day-to-day support and coaching. However, in Latvia, there is no legal framework for supported employment.

The Association of Latvian People with Disabilities (reg. No. 50008000551) represents around fifty legal associations in Latvian cities and rural areas. By means of the internet there is a regular correspondence among organizations of people with disabilities, information received about various projects and initiatives from other structural units of the Latvian Association of people with disabilities, Civil Alliance, Sustento and other organisations. The Association of Latvian people with disabilities cooperates with the Ministry of Welfare, Parliament and Commission of Social Affairs, Ministry of Finance, Consultative Council established by the Council of Riga city that is dealing with disability related issues. To promote employment the organization cooperates with the State Employment Agency – which develops subsidized working places. By participating in drafting the laws and other legal acts thereby learning of people with disabilities is promoted, people with disabilities are trained to acquire computer skills.⁷⁶²

⁷⁶⁰ Partnership Agreement for the European Union Investment Funds Programming Period 2014 – 2020; 2014. Available at:

https://www.esfondi.lv/upload/Planosana/FMPlans_230714_PA_updated_17.12.2014.pdf.

⁷⁶¹ Ibid, para. (247), p. 68.

⁷⁶² <http://www.ngolatvia.lv/en/organizacijas-3/113?view=organizacija>

The need for the development of social services and DI, including objectives, indicators and activities, is identified in more detail in the Operational programme 'Growth and Employment'.⁷⁶³ The Operational Programme emphasizes 'to provide support and availability of qualitative community-based services to children and young people, disabled persons and their families, as well as to prevent disabled persons from being institutionalized and to facilitate transition from the institutional to community-based care, both the ESF and ERDF investments are necessary'.⁷⁶⁴ By means of ESF investments it will be possible:

'[...] to reduce the number of places in social care institutions for persons with mental disorders funded by the state, and 700 clients of these institutions will live in the community, which will result in closing of three branches of the State Social Care Centres'.⁷⁶⁵

Indicative target groups are 'children and young people in out-of-family care, people with mental disorders who have reached the full age and who receive services in long-term social care institutions or are at risk of getting into institutional care, people with disability, people with anticipated disability, families with a child having functional disorders'.⁷⁶⁶ But then the report continues:

'indicative actions to be supported: investments into social infrastructure in order to provide community based services for persons with mental disorders – development and improvement of day care centres, group housing, dwellings and specialised workshops; development of infrastructure of community based social rehabilitation services for children with functional disabilities, [...], creation of the functioning evaluation laboratory and the assisting technology (technical aid tools) exchange fund. [...]'.⁷⁶⁷

According to the European Agency for Special Needs and Inclusive Education, the integration of children with disabilities into mainstream education remains a challenge, in spite of the considerable efforts by central and local authorities and civil society actors.⁷⁶⁸

The assessment of disability for employment purposes, carried out by the State Medical Commission for Determining Health Condition and Working Ability and its regional structural units, establishes disability status according to one of three disability groups: I (the most severe), II or III.

Other policy planning documents related to the implementation of the DI include the Framework for Professional Social Work Development 2014-2020,⁷⁶⁹ providing support for social workers, for example, those working with families with children, young people with disabilities, as well as people with mental disabilities, and the Framework for Development of

⁷⁶³ Operational programme 'Growth and Employment', 2014. Available at: https://www.esfondi.lv/upload/Planosana/FMProg_270115_OP_ENG_2.pdf

⁷⁶⁴ Operational programme 'Growth and Employment', 2014. Available at: https://www.esfondi.lv/upload/Planosana/FMProg_270115_OP_ENG_2.pdf

⁷⁶⁵ Ibid, para (913), p.264.

⁷⁶⁶ Ibid, para (993), p.294 – 295.

⁷⁶⁷ Ibid, para (992).

⁷⁶⁸ <https://eeagrants.org/News/2014/We-re-Here-improving-the-lives-of-Latvian-children-with-disabilities>

⁷⁶⁹ Framework for Professional Social Work Development 2014-2020, Available at <https://likumi.lv/ta/en/en/id/263299-framework-for-professional-social-work-development-20142020>

Social Services 2014-2020,⁷⁷⁰ which 'objectives and measures are aimed at ensuring the provision of social services that are relevant to the needs of the individual, to maximise his or her self-care capacity and independent life opportunities [...]'.⁷⁷¹ It includes three directions of action: DI, community-based and successive social services appropriate to the needs of customers and effective social services management.

The Framework for Implementation of the United Nations Convention on the Rights of Persons with Disabilities 2014-2020,⁷⁷² the Implementation plan for 2015-2017⁷⁷³ and the Implementation plan for 2018-2020⁷⁷⁴ include measures to raise the public awareness and support for people with disabilities. The funding of support services is planned under the 9.2.2.1. measure 'Deinstitutionalisation' and includes the development of services alternative to institutions - the introduction of social care service for children with disabilities up to 5 years old; the services of day care centres for children with disabilities; temporary social care services for children with disabilities (respite service for parents); social rehabilitation services for children with disabilities; support person service for adults with severe or very severe mental disability (groups I or II disability).

All these programs point to a government strategy where it is planned to reduce the number of persons living in institutions⁷⁷⁵ by 1 000 by the end of 2023 (December). 700 persons with mental disabilities will start their own life outside long-term social care and social rehabilitation institutions (LTC institutions) and 2 100 persons with mental disabilities will be provided with social care services. As part of the project, it is planned that by the end of 2023, 3 400 children with functional impairments will receive social rehabilitation and care services, and their parents will receive respite services. At least 3 state LTC institutions are planned to be closed as a result of the DI project implementation.⁷⁷⁶ By means of ERDF funds, it is intended to establish infrastructure for the provision of community-based services. The measures started in 2018 and the final year of ESF funding is 2022/2023. The below Table indicates the statistical targeted situation as at November 2018.

⁷⁷⁰ Cabinet Decree No 589 'Framework for Development of Social Services 2014-2020', 2015. Available at: <https://likumi.lv/doc.php?id=262647>

⁷⁷¹ Cabinet Decree No 589 'Framework for Development of Social Services 2014-2020', 2015. Available at: <https://likumi.lv/doc.php?id=262647>.

⁷⁷² Cabinet Decree No 564 On Framework for Implementation of the United Nations Convention on the Rights of Persons with Disabilities 2014-2020, 2013. Available at: <https://likumi.lv/ta/id/262238-par-apvienoto-naciju-organizacijas-konvencijas-par-personu-ar-invaliditati-tiesibam-istenosanas-pamatnostadnem-2014-2020-gadam>.

⁷⁷³ Cabinet Decree No 802 on Implementation Plan for 2015 – 2017 of the Framework for Implementation of the United Nations Convention on the Rights of Persons with Disabilities 2014-2020, 2015. Available at: <https://likumi.lv/ta/id/278612-par-apvienoto-naciju-organizacijas-konvencijas-par-personu-ar-invaliditati-tiesibam-istenosanas-pamatnostadnu-2014-2020>.

⁷⁷⁴ Cabinet Decree No 672 on Implementation plan for 2018-2020 of the Framework for Implementation of the United Nations Convention on the Rights of Persons with Disabilities 2014-2020, 2018. Available at: <https://likumi.lv/ta/id/303670-par-apvienoto-naciju-organizacijas-konvencijas-par-personu-ar-invaliditati-tiesibam-istenosanas-pamatnostadnu-2014-2020>

⁷⁷⁵ From the beginning of the DI there were 4465 state financed places (492 places for children and 3973 for adults). Data on 01.05.2015. The Action Plan for Implementation of Deinstitutionalisation 2015-2020, 2015. Available at: http://www.lm.gov.lv/upload/aktualitates/4/ricplans_groz_22032016.pdf.

⁷⁷⁶ From the beginning of the DI there were five state social care and social rehabilitation institutions (28 branches). Data on 01.05.2015. The Action Plan for Implementation of Deinstitutionalisation 2015- 2020, 2015. Available at: http://www.lm.gov.lv/upload/aktualitates/4/ricplans_groz_22032016.pdf.

Midterm implementation of DI⁷⁷⁷

	2017	2020	NOV. 2018
Number of LTC institutions supported for closure	3		
Number of persons with mental disabilities receiving social care services at the place of residence supported by the ESF	850	2,100	153
Number of children with functional impairments receiving social services supported by the ESF, including the number of children receiving:	600	2,100	635
social rehabilitation services		2,926	429
'respite time' services		400	102
social care services (up to 5 years of age)		74	104
Number of persons with mental disabilities who start independent life outside the long-term social care and social rehabilitation institution		700	66 p/per year
Reduction of places in state-funded LTC institutions		1,000	283

Objectives and targets for generic business creation and self-employment by the unemployed and other key social target groups, including persons with disability are outlined in the employment framework "Inclusive employment strategy 2015-2020",⁷⁷⁸ which was approved by the Cabinet of Ministers in May 2015.⁷⁷⁹ This framework was developed to foster development of an inclusive labour market and includes two key policy objectives related to inclusive entrepreneurship:

- i) to increase self-employment and business start-up opportunities for registered unemployed; and
- ii) to promote social entrepreneurship, both as a labour market activity for various social target groups and also as a vehicle for supporting these groups in the labour market and society more generally.

While tailored support for key social target groups (e.g. women, youth and older people) are not clearly defined in this high-level policy paper, the regulation on its implementation defines target groups for each particular measure. In addition to self-employment measures, there are some measures to support social entrepreneurship that aim to support the vulnerable unemployed (i.e. those over 54 years old, those with caring responsibilities, those with a disability or mental health challenge).⁷⁸⁰

Employment related to persons with disabilities were specifically targeted in the 16th International Scientific Conference of Information Technologies and Management, which was held in April 26-27, 2018, at the ISMA University of Riga, Latvia. Zaiga Oborenko⁷⁸¹, Marga

⁷⁷⁷ Results of planned activities in the Action Plan for the implementation of deinstitutionalisation for 2015-2020, 2015. Available at

http://www.lm.gov.lv/upload/aktualitates/null/2015_15_07_ricplans_final.pdf.

⁷⁷⁸ In Latvian: Iekļaujošas nodarbinātības pamatnostādnes 2015.-2020.gadam

⁷⁷⁹ order Mmb. 244

⁷⁸⁰ <http://www.oecd.org/industry/smes/LATVIA-country-note-2017.pdf>

⁷⁸¹ Faculty of Economics and Social Development, Latvia University of Agriculture, 18 Svetes Street, Jelgava, Latvia.

Zhivitere ⁷⁸² and Maksym Bezpartochnyi ⁷⁸³ presented a paper entitled 'The change of disability policy to employment disabled persons: gaps in Latvia's practice'. ⁷⁸⁴ The abstract of this paper stated that:

'During the last ten years significant changes are observed in employment of Disabled persons: it is a changing paradigm for disability policy making from compensation towards human rights. The aims focus on research that supports implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the European Disability Strategy 2010- 2020. ⁷⁸⁵ The surveys are designed to assess the employment of persons with disabilities as well as to measure the level of implementation of disability inclusive practice and policies in the workplaces. The research carried out by analysing the situation in Latvia, as well as by compiling the statistical data, the opinions of experts and performed review of literature.

Despite state plans for measures to include people with disabilities in the labour market, the results show very slow improvement. It makes a vital gain for a better understanding of the employer policies and practices that can improve opportunities for them. Though it is well appreciated that policies and practices cannot be altered as fast as one would like them to, nonetheless it is well worth to examine the bottleneck and practice challenges that are encountered while operationalizing ambitious policies. The results of the study lead to the conclusion that in Latvia the gap between policy and practice for the employment of disabled people is constantly decreasing.' ⁷⁸⁶

The report submits that the Europe 2020 target for EU is 75% ⁷⁸⁷. The number of employed persons with disabilities in Latvia is 40 450, or 4.5% of all employed.

As the statistical data show, there is a problem of inadequate employment among people with disabilities and despite state plans and measures to include people with disabilities in the labour market, results show very slow improvement of employment of persons with disability. ⁷⁸⁸ Despite such an impressive array of policies, which undoubtedly demonstrates the novel intensions and realization on the part of State Social Insurance Agency and State Employment

⁷⁸² Centre for Entrepreneurship Innovation and Regional Development (CEIRD), Ventspils University College, 101a Inženieru Street, LV-3601 Ventspils, Latvia

⁷⁸³ Poltava University of Economics and Trade

⁷⁸⁴ https://www.isma.lv/FILES/SCIENCE/IT&M2018_THESES/03_MDM/53_IT&M2018_Oborenko_Zivitere_Bespartochniy.pdf

⁷⁸⁵ Cabinet of Ministers. United Nations Convention on Persons with Disabilities implementation guidelines 2014-2020 2013 <https://likumi.lv/ta/id/273969-par-ieklaujosas-nodarbinatibaspatnostadnem-2015-2020-gadam>

⁷⁸⁶ https://www.isma.lv/FILES/SCIENCE/IT&M2018_THESES/03_MDM/53_IT&M2018_Oborenko_Zivitere_Bespartochniy.pdf

⁷⁸⁷ ANED – Academic Network of European Disability Experts European comparative data on Europe 2020 & People with disabilities Final report January 2017, p.7

⁷⁸⁸ Ministry of Welfare of Latvia, Central Statistical Bureau of Latvia (CSP), The State Employment Agency (NVA)

Agency ⁷⁸⁹ regarding the approach to be embraced, studies and experiences on ground have brought out a degree of disconnect between policy and practice.

Moreover, the recent adoption of the UNCRPD, with the hope that it will come into force in the near future, such introspection gains enhanced importance. A closer scrutiny of the reasons for the disconnected trends between intentions, policies and progress made on the ground towards mainstreaming disability, reveals that problems exist at multiple levels – with International Development Agencies, National Governments and NGOs, including disability sector organizations. Similarly, there are challenges both at the structural as well as at the implementation level. Some of the practical issues that were discussed in the report included: National Government in Latvia has adopted mainstreaming issues of disability within their policies however, at the same time they have set up parallel structures to implement separate disability programs instead of institutionalizing the same across all sectors. This has often led to confusion regarding mainstreaming, with various ministries not taking the ones of including people with disability within their programs.

According to the respondents' answers on the questionnaire which forms part and parcel of the report in question, the main barriers to employment of persons with disabilities, as stated by the employers note that the latter required and demanded support to overcome their worries and possible problems. The main help for employers would have to come from vocational training and rehabilitation centres or from job coaches who follow up and support workers working in the disability sector. ⁷⁹⁰

The same change and upgrade in legislation and implementation is needed when it comes to educational inclusivity in Latvia. The Latvian Constitution guarantees the right to education. It is supplemented by the Child Rights Law, the Education Law and the Law on General Education. Latvian legislation provides for the right to education of children with intellectual disabilities, and addresses the provision of special education in both mainstream and special schools. Children with intellectual disabilities may attend a mainstream school if the school has the necessary provisions suitable for children with special needs, and if it offers a licensed special educational programme.

However, the law does not provide for their right to attend a mainstream school that does not have a licensed special educational programme. In Latvia, there is no national policy on the provision of early intervention services for children with intellectual disabilities under the age of six; the Government does not provide any early intervention services and has not allocated any funds towards making such services available.

One model that could be used for developing a clear Government policy in this area is the early intervention programme carried out by the Latvian Portage Association, an NGO. This programme offers a model of good practice that could be replicated at the national level given adequate State funding and support.

⁷⁸⁹ European Commission (Brussels, 15.11.2010 COM (2010) 636 final). European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe (Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions). Retrieved January 27, 2011 (p. 11), <http://eur-lex.europa.eu>

⁷⁹⁰ Information Systems Management institute. Study programme "Business administration" 2017 October

For educational purposes, the State and Municipal Medical Pedagogical Commissions assess children with intellectual disabilities with one of three levels of intellectual disabilities:

- A (mild intellectual disabilities),
- B (moderate intellectual disabilities) or
- C (severe intellectual disabilities).

On the basis of this assessment, the Commissions then suggest the special educational programme that the child with intellectual disabilities should follow. Parental choice should be respected as regards the selection of the school that a child should attend. Based on the suggestion of the Commission, and in collaboration with the parents, the District Education Board recommends a local school providing the type of educational programme suggested by the Commission. If the parents do not agree to their child's attending a special school, they should be able to enroll their child in a mainstream school. Nonetheless, if that school does not have the recommended licensed special educational programme, their child may not receive the support needed to achieve his or her full potential.⁷⁹¹

Article 15 of the Law "On municipalities" about the autonomous functions of the municipality mentions "to care for the inhabitants' education (ensuring the rights to basic education and general secondary education established for the inhabitants, ensuring a place in the educational institution for preschool and school age children, organizational and financial assistance to out-of-school educational institutions and education support institutions, etc.) as one of them, which agrees with the responsibility of the municipalities defined in the Law on education to ensure children with special needs (according to their health condition that influences the kind of acquiring education) in special education institutions, preschool education groups for children with special needs, special education classes as well as in boarding schools in order and scope defined by the Council of Ministers".

It means that municipalities have the main responsibility about ensuring education for children with special needs. Thus it is possible to conclude that the municipality organizes education envisaging that everyone can receive education corresponding to his individual needs.

And here complications emerge because the duty of the municipality is to take care of all children and if a child living in the administrative territory of the municipality is diagnosed with special needs but the educational institutions of the municipality does not have a licensed educational program corresponding to the specifics of these needs then the solutions often do not serve the child's interest to grow up in the family and receive all the necessary support that the state guarantees. The traditional practice is that children with special needs are sent to attend educational institutions which implement such programs thus formally these needs are met but at the same time if, for example, the child with behavioural disturbances lives in the territory of the municipality which does not have such an educational institution that has licensed the educational program for children with behavioural disturbances then the traditional solution is to send the child to another place of Latvia in order to ensure the child corresponding education.

⁷⁹¹ https://www.researchgate.net/publication/277887334_Children_with_Special_Needs_in_Latvia_Legislative_Frame

Children with behavioural disturbances according to the regulations of the Council of Ministers⁷⁹² have the respective program for “learners with health disturbances” and in Latvia there are 15 such programs available.⁷⁹³ In Latvia there are 109 municipalities so we can conclude that in case the child with such disturbances lives in the administrative territory of the municipality where there is no such program then the municipality performing its duty and trying to ensure the child’s rights to education according to his special needs violates the principle which is established in the Law on protecting children’s rights and the Law on social security that the child has the rights to grow in the family and these rights should be supported.

This separation from the family creates additional emotional strain to the child which influences his intellectual achievements. This means that the child who has serious health problems is torn away from his family, his environment and he spends most of the time in an unfamiliar place, with unknown people who are not his relatives. This allows concluding that this system contradicts the principles of the inclusive society.⁷⁹⁴

Children with special needs live in segregated environments, failing to learn from the childhood to live in the society and also to learn cooperating with people who have different special needs. Parents who are not ready for such a solution that the child has to spend time outside the family for a long time search for other different solutions – they organize home teaching that is envisaged by the regulations of the Council of Ministers.⁷⁹⁵ However, these regulations envisage that such education at home is possible for 6 months which can be prolonged checking the child’s health repeatedly, but it can be only short time solution. These regulations anticipate that the child who is learning at home needs the individual learning plan and it is provided that a teacher visits the child at home but it still means that the child does not socialize.

Or, for example, sometimes children with severe visual problems continue attending the mainstream educational institutions which do not have corresponding learning support materials (materials with larger letters, touchable materials, etc.), no licensed educational programs and teachers who have been specifically trained thus the child’s intellectual development is not facilitated. This allows concluding that none of the traditional solutions offered by the municipality is favourable for the child’s full-fledged development.⁷⁹⁶

The same problems are topical also for children with different other diagnoses, all in all 10 different groups of diagnoses that have been enlisted in the regulations of pedagogically medical commissions.⁷⁹⁷ The Law on general education states that the head of the educational institution is responsible for gathering information about the special needs of the

⁷⁹² Nr. 710(Regulations on provisions of general basic education and secondary education institutions according to learners’ special needs, 2012)

⁷⁹³ National data base of Learning opportunities

⁷⁹⁴ https://www.researchgate.net/publication/277887334_Children_with_Special_Needs_in_Latvia_Legislative_Frame

⁷⁹⁵ Nr. 253 ‘Order in which to organize education of continuously ill learners outside the educational institution’ (2006).

⁷⁹⁶ https://www.researchgate.net/publication/277887334_Children_with_Special_Needs_in_Latvia_Legislative_Frame

⁷⁹⁷ Regulations of the Council of Ministers Nr.709 ‘On pedagogically medical commissions’, 2012

learners and their education according to the special education programs.⁷⁹⁸ Some municipalities have already started solving this problem licensing the educational programs that are implemented by the educational institutions under their supervision corresponding to the special needs of children living in the municipality because when implementing the principle “money follows the child” municipalities have started to calculate also the financial expenses about sending the child to schools registered in other municipalities. Regulations of the Council of Ministers⁷⁹⁹ define the provisions needed to integrate children with special needs in mainstream educational institutions.⁸⁰⁰

Special basic education programs in Latvia

Special basic education programs	number
Visually impaired learners	7
Hearing impaired learners	9
Learners with disturbances of physical development	19
Learners with somatic diseases	14
Learners with language disturbances	20
Learners with learning difficulties	224
Learners with mental health disturbances	15
Learners with mental developmental disturbances	302
Learners with serious mental developmental disturbances or several serious developmental disturbances	69

According to regulations of the Council of Ministers⁸⁰¹ about the pedagogical commissions one of their responsibilities is to promote the integration of children with special needs living in the administrative territory of the municipality in the general comprehensive educational institutions situated in the administrative territory of the municipality. The legislative documents of the Republic of Latvia state that it is possible to license 10 different special education programs that correspond to children’s special needs.

Analysing the publicly accessible information about the licensed educational programs in Latvia⁸⁰² it is possible to make a summary which indicates that the most programs are available to children with mental developmental disturbances and children with learning disorders. The educational programs corresponding to other groups of special needs are licensed considerably less than there are municipalities in Latvia which allows the conclusion that the above given statements that all children in Latvia are not provided equal rights are true and there is still a long way to go in order to ensure fully the implementation of the principles of inclusive education in the education system of Latvia, evidence of which is indeed the above table.⁸⁰³

⁷⁹⁸ Para.3, Part 2, Article 11

⁷⁹⁹ Nr. 710

⁸⁰⁰ Regulations on provisions of general basic education and secondary education institutions according to learners’ special needs, 2012.

⁸⁰¹ Nr. 709

⁸⁰² National data base of Learning opportunities

⁸⁰³ https://www.researchgate.net/publication/277887334_Children_with_Special_Needs_in_Latvia_Legislative_Frame

Lithuania

One must perforce start the evaluation related to this particular country by taking a small glimpse of overall social policy practice within the country in question. The European Social Policy Network (ESPN) was established in July 2014 on the initiative of the European Commission to provide high-quality and timely independent information, advice, analysis and expertise on social policy issues in the European Union and neighbouring countries.⁸⁰⁴ In its evaluation of the Lithuanian situation of 2015, social investment in the country in question was analysed in detail. The summary of this report states unequivocally that social investment is not a central theme in Lithuanian social policy.

From 2009, the fiscal consolidation measures have dominated the social investment type of policies. Current social policy documents focus on the improvement of family and child situations. However, some features of family situations reflect traditional, conservative values, with a lower pre-school participation rate, a lower employment rate among young women, a high rate of child poverty, and largely unsupported informal care of the elderly.

Moreover, municipalities treat the social investment approach in different ways.⁸⁰⁵ Only a few of them prioritise social investment in child welfare when developing social services. The majority fail to develop a consistent network of social services: they limit themselves to using services provided by state agencies. In public and political discourse, a negative attitude prevails towards recipients of social assistance. The current social assistance reform increases monitoring of applicants and beneficiaries.

Lithuania Parliament member Justas Džiugelis in an interview mentioned that in his opinion not all Lithuania municipalities understand the importance of deinstitutionalization.⁸⁰⁶

Another Lithuania Parliament member Rimantė Šalaševičiūtė in an official statement declared that deinstitutionalization process in Lithuania is not running smoothly and noted that many municipalities do not even have information about it.⁸⁰⁷

For Lithuania, the European Council has recommended “(3) Better target active labour market policy measures to the low-skilled and long-term unemployed ... (4) Ensure adequate coverage of those most in need and continue to strengthen the links between cash social assistance and activation measures.”⁸⁰⁸

The report continues to state that social services for the education of children with special needs are increasing. However, the continuing shortage of special education teachers and

⁸⁰⁴ <https://ec.europa.eu/social/BlobServlet>

⁸⁰⁵ <http://ec.europa.eu/social/main.jsp?catId=1044>

⁸⁰⁶ Interview with Lithuania Parliament member Justas Džiugelis <https://lspzgb.lt/ar-padarysime-gala-neigaliuju-siuntimui-i-globos-istaigas/>.

⁸⁰⁷ Lithuania Parliament member Rimantė Šalaševičiūtė official statement about deinstitutionalization process in Lithuania <https://sc.bns.lt/view/item/259437>.

⁸⁰⁸ European Council (2014), Council Recommendation of 8 July 2014 on the National Reform Programme 2014 of Lithuania and delivering a Council opinion on the Convergence Programme of Lithuania, p. 70. http://ec.europa.eu/europe2020/pdf/csr2014/csr2014_council_lithuania_en.pdf

social pedagogues complicates the integration of disabled children into the educational system. Overall, neither school communities nor disabled children themselves and their parents are prepared for integration into general educational settings.⁸⁰⁹

In May 2019, experts Jonas Ruškus, Aidas Gudavičius were commissioned to write a report entitled Living independently and being included in the community for the period 2018 – 2019 for the Academic Network of European Disability Experts.⁸¹⁰ The report brings to light the present situation on this subject matter.

In 2017 in Lithuania there were 241 861 persons (all ages) with disabilities of whom 14 854 were children with disabilities and 122 010 working age people with disabilities. According to the official Lithuania statistics portal the latest information about institutional care in 2017 was that Lithuania had 39 social institutions housing 6 379 people with disabilities.

In 2017 community-based services in Lithuania comprised five group homes for people with disabilities (with 108 residents) and 23 homes in the community for people with disabilities (with 469 residents). Almost 3 100 people with disabilities received support services in their homes and almost 15 300 people with disabilities attended day care centres.

In 2017 Lithuania had 73 child care homes (for children with and without disabilities) and four social care homes for children with disabilities with 165 children. Almost 2 400 children with disabilities received support services in their homes and almost 2 700 children with disabilities attended at day care centres.⁸¹¹

The ANED report shows that from 2013 till 2015 number of children with disabilities who lived in institutional care remained almost the same but from 2016 that number starts to decrease and during 2017 only 165 children with disabilities remained in institutional care.

The situation is different for working age people with disabilities. From 2013 we can see an increase in the number of social institutions from 39 to 58 in 2016 and a decrease in 2017 back to 39.⁸¹²

In 2019 the average price for persons with disabilities in institutional care varied between 590 EUR per month and 977 EUR per month,⁸¹³ depending on the disability level and institution. This means that institutional care system every year could potentially cost between 45, 1 to 74, 7 million EUR.

⁸⁰⁹ VPVI, Lietuvos socialinių tyrimų centras (2011), Socialinės integracijos paslaugų socialiai pažeidžiamų ir socialinės rizikos asmenų grupėms situacijos, poreikių ir rezultatyvumo vertinimas, siekiant efektyviai panaudoti 2007-2013 m. ES struktūrinę paramą [Evaluation of social integration services for socially vulnerable and socially excluded individuals for the effective use of the EU structural assistance for the period of 2007-2013].

⁸¹⁰ <https://www.disability-europe.net/country/lithuania>

⁸¹¹ Department for the Affairs of the Disabled under the Ministry of Social Security and Labour information <http://www.ndt.lt/statistiniai-rodikliai/>.

⁸¹² <https://www.disability-europe.net/country/lithuania>

⁸¹³ Department for the Affairs of the Disabled under the Ministry of Social Security and Labour information <http://www.ndt.lt/laisvos-vietos-socialines-globos-istaigose/socialines-globos-kainos/>.

There is no official data about how much money is spent for community-based services. But the Lithuanian government allocated 37, 37 million EUR funding in 2018 to 60 Lithuanian municipalities for providing social services (including institutional care as well as community-based services). In 2019 funding should reach 44, 13 million EUR.

For comparison in 2017 Lithuania's biggest municipality Vilnius allocated 21, 8 million EUR for social services from which only 200 000 EUR were from EU funds. In 2018 Vilnius municipality planned 28 million EUR budget for social services. Only 251 300 EUR was used for development of social services. The largest part of the 2017 social services budget was spent on long-term and short-term social care – 4, 5 million EUR. ⁸¹⁴

In 2014 the Ministry of Social Security and Labour started reforms whose main aim was to change from institutional care to community-based care. From November 2015 the State Child Rights Protection and Adoption Service under the Ministry of Social Security and Labour together with the Department of Disabled Affairs under the Ministry of Social Security and Labour began implementation of the project "Creation of the conditions of the system in Lithuania of sustainable transition from institutional care to the services provided in the family and community". The purpose of the project is to create the conditions that are necessary for the development and implementation in Lithuania of an effective system of transition from institutional care to the services provided in the family and community. ⁸¹⁵

The main goal of the 2014-2020 action plan approved by the Minister of Social Security and Labour is to create a system of complex social services which will provide every child without parental care or persons with disabilities (and their family members) with individualized social services and assistance in the community not in institutional care. The programme is financed directly from European structural and investment funds.

The action plan consists of three main objectives:

1. Creating community based social services for children without parental care, people with disabilities and their family members;
2. Preventing access to institutional care for children without parental care and people with disabilities;
3. Promote change in public values by forming a positive attitude of society towards reform of social care system and ensure processes testability. ⁸¹⁶

The whole plan has two stages:

1. 2014-2017 creating conditions for transition from institutional care to community-based services and increase availability of the existing social services;
2. 2017-2020 development of community based social services in the regions. ⁸¹⁷

⁸¹⁴ 2018 Vilnius municipality social service plan <https://www.e-tar.lt/portal/lt/legalAct/5eeef810748211e8ae2bfd1913d66d57>.

⁸¹⁵ February 14 Number A1-83 Order "On the approval from the institutional care to family and community based services for disabled and children without parent care action plan 2014-2020" of the Minister of social security and labour

⁸¹⁶ <https://www.disability-europe.net/country/lithuania>

⁸¹⁷ Ibid.

Additionally, in 2016, packages of legal documents were prepared in relation to the assessment of individual needs of persons living in care institutions selected for reorganisation and to the drafting of plans. Sixty-one certified social workers were trained for the provision of services of training and consulting of guardians (foster parents) and adoptive parents under the programme of preparation of close relatives for the child's guardianship (foster care). In 2016–2017, a package of measures was introduced to test new forms of community-based services (a family type community-based child care home, supporting care, protected housing, a temporary respite service, etc.) and to increase accessibility of social services by the social groups which were mentioned above.

In 2016–2017, while carrying out the reform of institutional care, conferences focusing on interinstitutional, interdepartmental and cross-sectoral cooperation were held, round-table discussions, seminars on the theoretical and practical aspects of teamwork when modelling the system of integral community-based services and training for heads on the management of development of community-based services in municipalities were organised in all regions.

With regards to persons with disabilities living in institutional care, the number of people who are living in institutional care has remained almost the same from the beginning of deinstitutionalization until now. However, the number of institutions is changing.⁸¹⁸ It is possible that EU funds used for institutional care infrastructure development until 2015⁸¹⁹ have instead been used for renovating institutions so that the number of people who are living in institutional care remains almost the same.

Eglė Šumskienė (social worker, sociologist and expert on disability, mental health and human rights issues) and Rasa Genienė have written an article about reform of the residential care in Lithuania from the perspective of institutional theory that analyses the resistance of institutions to reform. The authors conclude that social care organisations aim to maintain their existing power using arguments about financial, human and technical resources. The authors also notice the vicious circle of the institutional functioning, in which the necessity to isolate persons with disabilities is justified by a lack of self-support as well as a lack of tolerance in the society. In the meantime, the institutions themselves exclude persons with disabilities and reduce their autonomy.⁸²⁰

Ugnė Grigaitė, Project Manager at Human Rights Monitoring Institute in her article about deinstitutionalization of Lithuania Mental Health Services in Light of the Evidence-based Practice and Principles of Global Mental Health concluded that the mental health care system and the mostly institutional-type services in Lithuania could be more effectively reformed and reorganised. The author suggests that it would be important that different Lithuanian Central

⁸¹⁸ Table “How social institution numbers changed from 2013 till 2017” at page number 2, ANED Report.

⁸¹⁹ Table “Funds allocated into development infrastructure of institutional care” at page number 4, ANED Report.

⁸²⁰ Rasa Genienė, Eglė Šumskienė REFORM OF THE RESIDENTIAL CARE IN LITHUANIA FROM THE PERSPECTIVE OF INSTITUTIONAL THEORY

https://www.researchgate.net/publication/291955261_Stacionarios_globos_pertvarka_Lietuvoje_institucionalizmo_teorijos_poziuriu.

and Local Authorities start working together with other key stakeholders in an inter-sectoral and multidisciplinary way in order to most effectively achieve the needed change.⁸²¹

With regards to access to education, over recent years, there have been several encouraging developments concerning access to education by children and young people with intellectual disabilities in Lithuania. This is evidenced by the significant increase in the number of children with intellectual disabilities who are fully integrated into mainstream schools.

Government policy on education is also progressive. The ongoing reform of the education system, in line with "National Educational Strategy for 2003-2012", will benefit children and young people with intellectual disabilities and improve the funding of special education. However, many important measures, in particular the introduction of the new system of education financing, have not yet been fully implemented. Lack of adequate funding at the municipal level has been one problem. Another is that necessary secondary legislation has either not yet been created or has not been implemented. To ensure that this reform process moves ahead as swiftly as possible, the Ministry of Education and Science should make it a priority to see that all necessary secondary legislation is drafted and implemented. In addition, the ministry should regularly review progress on its overall policy on the integration of children and young people with disabilities into mainstream schools, to ensure the successful translation of policy into improved educational opportunities for children with intellectual disabilities.

The comprehensive system of early intervention, or "early rehabilitation", services in Lithuania has already produced good results. Yet many children with intellectual disabilities, in particular those with more severe disabilities living in smaller towns and villages, are still not able to attend a kindergarten. For integration to be effective, it is important that it occurs at a young age.

However, the Lithuanian Disability Forum⁸²² projects a totally different picture than the above. Only around 1,000 persons with disabilities are able to get into higher education each year, which makes up less than one percent of all students. According to the Lithuanian Disability Forum, roughly half of disabled children in Lithuania are taught in isolation. This hinders efforts to fully include them and often stands in the way of their higher education: only around 1,000 persons with disabilities are able to get into higher education each year, which makes up less than one percent of all students.

According to the forum's representatives, while parents would like their children to attend primary and secondary school, most schools are still not ready to accept students with visual, hearing or mental impairments: there is a dearth of properly trained staff and a prevalence of negative attitudes towards such children.

⁸²¹ Ugnė Grigaitė The Deinstitutionalization of Lithuanian Mental Health Services in Light of the Evidence-based Practice and Principles of Global Mental Health - <http://www.zurnalai.vu.lt/STEPP/article/view/10806/8902>.

⁸²² <http://nlif.lt/en/organizations/lithuanian-forum-of-the-disabled-Inf/>

A large portion of schools have still not been adapted to accommodate children with reduced mobility, says Rasa Kavaliauskaite, the president of the Lithuanian Association of People with Disabilities.

She claims that of the 109 schools inspected in the 2011-2015 period, only 16.5 percent were accessible to people with disabilities, with 31.2 percent having limited accessibility and 52.3 percent being completely inaccessible. The inspection also covered 14 higher education establishments with a total of 48 buildings, finding that only 40 percent were adapted to the needs of disabled students. The remainder had no elevators, stair lifts or detectable warning surfaces to notify of changes in level, with obstacles en route to the assembly halls.⁸²³

The overall picture in Lithuania on the subject matter is furthermore underlined by the observations by the UN Committee on the Rights of Persons with Disabilities on Article 19. The Committee is deeply concerned at the lack of sufficient choice and range of adequate support mechanisms, including independent living schemes, to ensure that persons with disabilities can access accommodation within their local community, regardless of their sex, age or impairment. In particular:

- (a) Many children under three years of age with disabilities are still placed in residential institutions;
- (b) There are no guarantees that all younger persons with disabilities have realistic options of choosing not to live in residential facilities for the elderly;
- (c) There is no programme for individualized personal and financial assistance allowing persons with disabilities to live independently in the community, and a lack of range of community-based services.

The Committee recommends that the State party, in close collaboration with organisations of persons with disabilities:

- (a) Adopt an adequately funded strategy for deinstitutionalization ensuring a range of community-based services for the social inclusion of persons with disabilities, including for children with intellectual and/or psychosocial impairments, including their right to live independently in the community, with the possibility of individualised personal assistance support services in their home;
- (b) Effectively implement the action plan for the implementation of the national programme for the social integration of persons with disabilities for the period 2013-2019 at all levels of the State;
- (c) Adopt a moratorium on new admissions of children into institutionalized care;
- (d) Eliminate excessive waiting time for receiving support services by investing in developing new services and rendering existing services accessible and inclusive and ensure that persons with disabilities have access to sufficient financial resources for independent living and improved access to accessible services in the community.

The Committee is concerned that the national budget and European Union structural funds have been used in renovating existing institutional facilities and in constructing new ones.

⁸²³ <https://www.liberties.eu/en/news/lithuania-lack-of-inclusive-education/7431>

The Committee recommends that the State party further prioritize investing in a social service system for independent living in the community, and immediately refrain from using national and structural funds of the European Union to renovate, maintain or construct residential institutions for persons with disabilities.⁸²⁴

Additionally, the Commissioner for Human Rights of the Council of Europe Nils Muižnieks and his team visited Lithuania from 05 to 09 December 2016. During the visit, the Commissioner held discussions on issues pertaining to women's rights and gender equality; human rights of children; and human rights of persons with disabilities. In his report commissioner indicated that no particular progress has been achieved in relation to the deinstitutionalization process for adults with disabilities. While certain planned benchmarks are quite ambitious, they are not necessarily supported by concrete measures to develop community-based services and to ensure the right to independent living. There is also a need to promote a wider change of mentality among the authorities, institutions, and the public at large. Strong vested interests to maintain the current institutional care system may still exist at the municipal level, as well as within the medical and other relevant professions.

The Commissioner concluded that the deinstitutionalization process has thus far mainly been directed at a transition away from institutional care for children.

An issue which was raised during the Commissioner's discussions with various interlocutors was that EU structural funds are reportedly used for the renovation of institutional care facilities, instead of being entirely directed towards developing community-based services, providing families with support services and integrating people with disabilities into the community.

⁸²⁵

Not all the factors pertaining to this subject matter project a gloomy picture of the scenario in question. After the start of institutional reform Lithuania succeeded in making a big difference for children living in institutional care. From 2013 till 2015 the number of children with disabilities who lived in institutional care remained almost the same but from 2016 that number started to decrease and during 2017 only 165 children with disabilities remained in institutional care. Also 27 pilot institutions have been selected for deinstitutionalization i.e. reducing the number of people who are living in that institutional context.⁸²⁶

Also, during the period institutional reform new types of social services have been introduced in Lithuania – including temporary respite care for which there is a high demand. At the moment temporary respite care social services are provided in the regions of Vilnius, Kaunas, Klaipėda, Panevėžys, Šiauliai, Alytus, Utena, Tauragė and Marijampolė.⁸²⁷

⁸²⁴ Committee on the Rights of Persons with Disabilities concluding observations on the initial report of Lithuania - https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fLTU%2fCO%2f1&Lang=en, page 7.

⁸²⁵ 2016 Commissioner for Human Rights of the Council of Europe Nils Muižnieks report [https://rm.coe.int/ref/CommDH\(2017\)7](https://rm.coe.int/ref/CommDH(2017)7).

⁸²⁶ Order of the Minister of Social Security and Labour No. A1-271, of 05 May 2015.

⁸²⁷ Ministry of Social Care and Labour article about respite care – <http://www.pertvarka.lt/naujienos/laikino-atokvepio-paslaugos-tevams-ir-globejams>

Another community based social service which has started in Lithuania is protected housing. Protected housing is a social care service in the community for up to four partially independent adults with disabilities. This service is combined with individual case manager (social worker) support and other services in the community that help to develop and maintain the social and independent lives of individuals. The main goal is to promote the independence and integration in the community of people with intellectual disabilities. At the moment safe and secure housing is provided in the regions of Utena, Vilnius, Tauragė and Šiauliai.⁸²⁸

Also, from 2013 there has been systematic growth of government funds allocated to social services which could be invested in measures to promote independent living, such as protected housing.

But poor practice in the sector is still rife: The public and the specialists working in social services lack information on Lithuania's preparedness for the transformation and on the planning processes. Too little attention and financing is directed towards creation of actual community services and towards supporting families in the Deinstitutionalisation process in Lithuania.

There is lack of monitoring of the implementation of deinstitutionalisation process in Lithuania. The newest statistics show that the total number of people with disabilities who are living in institutional care remains the same and government didn't reach their goal to reduce that number by 40 %.

Despite having deinstitutionalization as a priority direction, in 2015 financial assistance was continued to be given to the social service institutions, subordinate to the Social Ministry and to the municipalities, in order to modernize them and to improve their material condition.

In NGO experts and academic level opinion there was no breakthrough in the most important areas of mental health policy, such as an effective suicide prevention programme, or development of mental health services for children, or the move from institutional care to effective provision of services in the community. Isolating people in institutional care is justified by the lack of self-support as well as lack of tolerance in the society. In the meantime, the institutions themselves exclude persons with disabilities and reduce their autonomy.

The Lithuanian government has not yet approved a plan for funding transition from institutional care to community-based system after 2020 when the measure "Reform of Institutional Care"⁸²⁹ will end.

All new forms of community based social services⁸³⁰ at the moment is financed from EU funds. The Lithuanian government and municipalities have not expressed any commitment to finance such services after 2020.

⁸²⁸ Ministry of Social Care and Labour article about respite care -

<http://www.pertvarka.lt/naujienos/startuoja-nauja-pertvarkos-projekto-bandomoji-paslauga/>

⁸²⁹ No. 08.4.1-ESFA-V-405

⁸³⁰ temporary respite care and protected housing

Lithuania still doesn't have effective personal assistant social services. The Minister of social security and labour order focuses only on social care institutions, completely leaving out of the planned reform the psychiatric hospitals and any other medical facilities or systems.⁸³¹ This is due to the medical facilities being the responsibility of the Ministry of Health, unlike the social care institutions that fall under the programs of the Ministry of Social Security and Labour. It appears to be inevitable that due to the lack of inter-sectoral collaboration, no synergies are currently being drawn between potentially reforming both systems in parallel with each other.

Even the Commissioner of the Human Rights of the Council of Europe waded into this situation. "While considerable progress has been achieved in protecting human rights in recent years, the Lithuanian authorities still have to address some remaining shortcomings, in particular as regards the protection of women, children and persons with disabilities" said Nils Muižnieks, Council of Europe Commissioner for Human Rights, in a report released in April 2017 based on a visit to the country.⁸³²

Commending the progress made to prevent and combat domestic and gender-based violence, the Commissioner recommended harmonising the provisions of the Criminal Code and Criminal Procedure Code with those of the 2011 Law on Protection against domestic violence, most notably with regard to the application of protection measures.

"Judges should be made fully aware of the important role they play in protecting victims, preventing repeated instances of abuse and bringing perpetrators to justice. Furthermore, a unified and systematic approach to preventing violence and responding to calls for help should be developed and consistently applied throughout the country", said the Commissioner.

He also called on the Lithuanian authorities to ratify the Council of Europe Convention on preventing and combating all forms of violence against women and domestic violence (Istanbul Convention), because it provides an effective framework and methodology to help address the root causes of gender-based violence.

The Commissioner recommended implementing the law banning all forms of violence against children through a coordinated strategy and effective and independent monitoring. "All national and local actors should be involved in preventing violence against children and in protecting and supporting the victims. It is paramount that the authorities let the public and professionals dealing with children understand that violence has no place in the education of a child, and that positive and non-violent forms of child-rearing should be adopted."

Furthermore, the Commissioner urged the Lithuanian authorities to avoid placing children deprived of parental care or with behavioural problems in institutions, and to develop instead community- and family-based care alternatives.

As regards the human rights of persons with disabilities, the Commissioner recommended accelerating the process of deinstitutionalisation and adopting measures to foster independent and autonomous living. Additionally, he encouraged the authorities to pursue their on-going

⁸³¹ 2014 Nr. A1-83 program approved by A1-83 order Action Plan

⁸³² <https://www.coe.int/en/web/commissioner/-/lithuania-should-strengthen-the-protection-of-women-and-children-against-violence-and-build-a-more-inclusive-society-for-persons-with-disabilities>

efforts to develop a system of supported decision-making based on individual consent, to treat persons with disability with equal standing in courts and tribunals, and to uphold their rights to vote and stand for elections. The authorities should also eliminate coercive practices in psychiatry and authorise involuntary placements in closed settings only on the basis of objective and non-discriminatory criteria and with adequate safeguards. “Placement of persons in closed wards and care homes against their will but with the consent of their guardians or legal representatives should be fully abolished.

Lastly, the Commissioner recommended establishing a truly inclusive education system for children with disabilities rather than placing them in special schools, doing away with segregated work environments, and implementing effective policies to facilitate employment opportunities and to ensure universal access to quality health care, housing, transport and public facilities for persons with disabilities. ⁸³³

⁸³³ <https://www.coe.int/en/web/commissioner/-/lithuania-should-strengthen-the-protection-of-women-and-children-against-violence-and-build-a-more-inclusive-society-for-persons-with-disabilities>

Luxembourg

Despite this country's small geographic area, a major challenge concerning Luxembourg in this specific field is the lack of data or the insufficient availability of data on some of the concerning issues. The international, European, and national compilations of data on independent living and related issues indicate sometimes "blanks" for Luxembourg or merely estimations in the corresponding tables. In addition, the figures do not allow direct evidence to be derived on the situation of people with disabilities, as no disability-related internal differentiation is made. For example, the OECD data collections⁸³⁴ on institutionalised and independent living are not broken down by disability: Thus, indicators like number of beds in nursing and residential care facilities; long time care recipients in institutions or at home can only be used as indirect estimates for independent living of people with disabilities.⁸³⁵

The beginning of de-institutionalization policy in Luxembourg is associated with the so-called Häfner report (1993)⁸³⁶ about psychiatry in Luxembourg. Following his report, the national central psychiatric hospital started a de-institutionalization process, which still continues to date particularly in the context of persons with intellectual disabilities. In 2005 the Rössler Report⁸³⁷ concludes that 0.25 places per 1,000 inhabitants offered in Luxembourg do not comply with WHO guidelines, which assume a minimum of 0,3 – 0,5 places per 1,000 inhabitants for long-term care of the chronically ill alone.⁸³⁸

Neither Häfner's nor Rössler's Report published precise data on independent living structures for persons with (mental) disabilities.⁸³⁹

Warnier and De Keyser⁸⁴⁰ had already stated in their report on de-institutionalisation and community living in Luxembourg that there is no national data on the number of people with

⁸³⁴ OECD 2019 (OECD.stat Homepage) The footnote to the WHO data contains the following entry: Luxembourg. Source: Fichiers de la sécurité sociale. Data prepared by General Inspectorate of Social Security (IGSS). Coverage: Data only cover long-term care insurance recipients. - Preliminary results for 2016. - Data refer to numbers as of 31st December every year. No brake down by disability. https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

⁸³⁵ <https://www.disability-europe.net/country/luxembourg>

⁸³⁶ Rössler, W., Salize, H.J., Häfner, H. (1993). Bestandsaufnahme der psychiatrischen Versorgung in Luxembourg -Zusammenfassung und Schlußfolgerungen, Empfehlungen zur Weiterentwicklung der psychiatrischen Versorgung. Mannheim: Zentralinstitut für Seelische Gesundheit.

⁸³⁷ Rössler W. (2005) Psychiatry Luxembourg. Luxembourg: Ministère de la Santé publique. <http://www.sante.public.lu/publications/systeme-sante/politique-nationale-sante/rapport-rossler-psychiatrie-luxembourg-planungsstudie-2005-bestandeserhebung/rapport-rossler-psychiatrie-luxembourg-planungsstudie-2005-bestandeserhebung.pdf>.

⁸³⁸ Rapport Rössler «Psychiatrie Luxembourg Planungsstudie 2005: Bestandsaufnahme und Empfehlungen» <http://sante.public.lu/fr/publications/r/rapport-rossler-psychiatrie-lux-planungsstudie-2005-bestandsaufnahme/index.html>.

⁸³⁹ Limbach-Reich, Arthur (2012). Luxembourg Desk Report Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities. <https://www.humanconsultancy.com/projects/fundamental-rights-of-persons-with-intellectual-disabilities-and-persons-with-mental-health-problems>.

⁸⁴⁰ Warnier, C. & De Keyser, H. (2007). Deinstitutionalisation and community living – outcomes and costs: report of a European Study Country Report Luxembourg In: Beadle-Brown, J. & Kozma, A. (2007). Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 3: Country Reports. Canterbury: Tizard Centre, University of Kent, 360-377. https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLLOC_Country_Reports.pdf

disabilities in Luxembourg. While there were 410 beds (lits/places conventionnés) in 1995,⁸⁴¹ Beadle-Brown and Kozma reported a total of 704 institutionalised places for people with disabilities in Luxembourg in 2006. Of those places 410 are in institutions with less than 30 inhabitants and 294 in institutions with more than 30 inhabitants. Furthermore, the authors break down the data according to the following aspects:

Institutionalised places for people with disabilities in Luxembourg (2006)⁸⁴²

	Places total	Male	Female	Children	Adults	Age unspecified
Number	704	395	309	48	655	1

In addition to this data, the Report on Fundamental Rights (FRA-Report) on independent living in 2017⁸⁴³ indicates that in Luxembourg, the number of persons living in residential institutions rose from 701 in 2010 to 785 in 2016. In this Report it was pointed out that in Luxembourg in contrast to the great majority of all other European countries the percentage of persons with disabilities who agree or strongly agree with the statement: ‘I feel I am free to decide how to live my life’ (84 %) is higher than that of persons without disabilities (82 %). The high approval rate may well be due to the fact that, (as a result of the data generation),⁸⁴⁴ only persons living in a household were included in the sample, which means that no statement can be made about persons living in institutions.

The national ANED report in 2009⁸⁴⁵ deplores the absence of clear statements in favour of independent living for disabled persons in legal documents in Luxembourg and states that there is not much pressure from self-advocate groups or users’ organisations to implement independent living, neither are there centres for independent living. However, the general tendency already noted in this report was that in Luxembourg there has been a constant movement away from big segregated institutions to smaller residential homes during the last 35 years. The above mentioned ANED report highlights three developmental steps in the implementation of Independent living:

- 1) In the beginning there have been efforts to close the huge psychiatric and religious institutions for persons with a disability.

⁸⁴¹ Ministre aux Handicapés et aux Accidentés de la Vie (1997). Evaluation de la situation des personnes handicapées au Luxembourg. Plan d'action en faveur des personnes handicapées. Luxembourg: MHAV.

⁸⁴² Warnier, C. & De Keyser, H. (2007). Deinstitutionalisation and community living – outcomes and costs: report of a European Study Country Report Luxembourg In: Beadle-Brown, J. & Kozma, A. (2007). Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 3: Country Reports. Canterbury: Tizard Centre, University of Kent, 360-377. https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLLOC_Country_Reports.pdf.

⁸⁴³ European Union Agency for Fundamental Rights. (2017) From institutions to community living - Part III: outcomes for persons with disabilities. <https://fra.europa.eu/en/publication/2017/independent-living-outcomes-based-on-data-compiled-by-the-ministry-of-family-and-the-integration>, Annual report 2016 (Rapport d'activité 2016); and Annual report 2010 (Rapport d'activité 2010), p. 76. <https://mfamigr.gouvernement.lu/fr/publications.html>.

⁸⁴⁴ EQLS 2012 Methodology <https://www.eurofound.europa.eu/de/surveys/european-quality-of-life-surveys/european-quality-of-life-survey-2012/eqls-2012-methodology>.

⁸⁴⁵ ANED country report on the implementation of policies supporting independent living for disabled people. 2009 <https://www.disability-europe.net/downloads/460-lu-7-aned-2009-request-07-task-5-report-on-independent-living-approved-final-in-layout-to-ec>.

2) Subsequently, small residential 'family like' groups were created, permitting a more participative way of living.

3) Finally, efforts were made to give people more opportunities to have private housing (to rent or buy their own housing / apartment), including specialised support services.

The national long-term care insurance ⁸⁴⁶ provides domestic assistance in day-to-day activities. The national act about employment for persons with disabilities ⁸⁴⁷ improved the financial basis for independent living of people with disabilities.

The ANED Synthesis Report in 2009, amended in 2010 ⁸⁴⁸ states that only a few summary statements could be made on Luxembourg because the national final report was not available in time.

The first National Action Plan (2012) ⁸⁴⁹ sets out the challenge of enabling people with disabilities in Luxembourg to decide: how, where and with whom they want to live, and this with the greatest possible autonomy, self-determination and responsibility in developing alternative housing options. Therefore, adequate offers of support and care in various forms in smaller housing units are called for.

As indicated in the FRA report (2012), ⁸⁵⁰ steady progress towards independent living can be observed, especially for people with cognitive impairments, but major challenges remain. In particular, no general personal care budget system has yet been established in Luxembourg ⁸⁵¹ and the high cost of rents and real estate makes it difficult to implement an independent living system.

⁸⁴⁶ Regulation of the long-time care assurance (Assurance dépendance) 1998.

<https://www.secu.lu/assurance-dependance/>

⁸⁴⁷ Loi relative aux personnes handicapées - service de travailleur handicapé/ salarié handicapé <http://legilux.public.lu/eli/etat/leg/loi/2003/09/12/n1/jo>.

⁸⁴⁸ Townsley, Ruth, Ward, Linda, Abbott, David and Williams, Val (2009). The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report of the Norah Fry Research Centre University of Bristol. (November 2009, amended January 2010). <https://www.disability-europe.net/downloads/284-aned-task-5-independent-living-synthesis-report-14-01-10>.

⁸⁴⁹ Ministry of Family Affairs Integration and the Greater Region (2012) First action plan to implement the CRPD in Luxembourg (Aktionsplan der Luxemburger Regierung zur Umsetzung der UNO-Behindertenrechtskonvention) <https://mfamigr.gouvernement.lu/dam-assets/le-ministère/attributions/personnes-handicapées/plan-d-action-du-gouvernement-luxembourgeois-en-faveur-des-personnes-handicapees.pdf>.

⁸⁵⁰ Luxembourg Desk Report Fundamental Rights situation of persons with mental health problems and persons with intellectual disabilities 2012 <https://www.humanconsultancy.com/downloads/342-luxembourg-desk-report-fundamental-rights-situation-of-persons-with-mental-health-problems-and-persons-with-intellectual-disabilities>

⁸⁵¹ There is a lumpsum system for some impairments, e.g. blindness. Loi du 1er avril 1971 portant création d'une allocation spéciale pour aveugles. <http://legilux.public.lu/eli/etat/leg/loi/1971/04/01/n1/jo>.

The initial report of Luxembourg on implementing the CRPD⁸⁵² in 2014 emphasizes the big shift towards decentralizing psychiatric care that has taken place in Luxembourg since 1994.

From 1994 onwards, persons with disabilities living in psychiatric hospitals have been transferred either to special institutions for persons with disabilities or, where possible, to sheltered accommodation. The mental health reform in Luxembourg, which gained renewed momentum in 2005, has been summarized as follows: “de-institutionalization, decentralization, de-stigmatisation and prevention.”

In 2011 a total of 3,995 disabled people (32,41%) benefited from long-term care insurance, among these disabled beneficiaries are 594 children under 19 years of age (226 girls and 368 boys) and 1,847 adult beneficiaries (811 women and 1,036 men) under 65 years of age.

The first shadow report (2016)⁸⁵³ deplores that to some extent, there is still a “parallel world” for persons with disabilities, mostly State funded or co-funded. The shadow report claims that, many persons with disabilities still live with their parents, because there are no better options for them. The shadow report recognises, however, that no reliable data are available on this topic and refers to interview data (“There was no data available, but about a third of adults with disabilities interviewed for this report lived with their parents or parent”, p. 29).

The Committee on the Rights of Persons with Disabilities (2017)⁸⁵⁴ expresses in their Concluding observations on the initial report of Luxembourg concerns about:

- (a) The reform of the long-time care assurance act, which continue to curtail the right to independent living by setting limits and controls on persons with disabilities;
- (b) The lack of an action plan for the deinstitutionalization of persons with disabilities with a specific timeline and appropriate funding;
- (c) The absence of a clear strategy to promote and ensure the transition to full independent living for all persons with disabilities within the community, including with support of a personal assistant, and that future plans and construction projects still contain elements that limit the rights of persons with disabilities under article 19.

⁸⁵² Initial country report on implementing the CRPD (Mise en œuvre de la Convention des Nations Unies relative aux droits des personnes handicapées - Premier rapport périodique du Grand-Duché de Luxembourg (2014). https://mfamigr.gouvernement.lu/content/dam/gouv_mfamigr/le-ministère/attributions/personnes-handicapées/premier-rapport-periodique-de-mise-en-œuvre-de-la-convention-onu.pdf.

UN-CRPD concluding observations on the initial report of Luxembourg (CRPD/C/LUX/1) https://webcache.googleusercontent.com/search?q=cache:Hnp_yXmX-0lJ:https://tbinternet.ohchr.org/Treaties/CRPD/Shared%2520Documents/LUX/CRPD_C_LUX_CO_1_28811_E.docx+&cd=1&hl=de&ct=clnk&gl=de&client=safari.

⁸⁵³ Alternative Report on Implementation of the United Nations Convention on the Rights of Persons with Disabilities Luxembourg 2016. https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fCSS%2fLUX%2f26160&Lang=en.

⁸⁵⁴ UN-CRPD Committee on the Rights of Persons with Disabilities (2017). Concluding observations on the initial report of Luxembourg (CRPD/C/LUX/1) https://webcache.googleusercontent.com/search?q=cache:Hnp_yXmX-0lJ:https://tbinternet.ohchr.org/Treaties/CRPD/Shared%2520Documents/LUX/CRPD_C_LUX_CO_1_28811_E.docx+&cd=1&hl=de&ct=clnk&gl=de&client=safari.

The national working group currently preparing the second national action plan (2018-2019) ⁸⁵⁵ identifies as current priorities: the implementation of personal assistance, the introduction of a general personal budget, and the creation of new housing structures that allow and encourage more autonomy and self-determination (independent living).

It is difficult to extract accurate figures on the situation of people with disabilities in independent housing. A first indicator to be mentioned here refers to the national number of beds in care facilities. The OECD ⁸⁵⁶ distinguishes between two indicators: The national number of beds in nursing and residential care facilities per 1,000 inhabitants and the national number of beds in nursing and residential care facilities per 1,000 inhabitants aged 65 or older.

Both time series indicate that from 2014 (no data are available for the year 2013) no proportional increase of beds in institutions can be observed, which suggests that living independently in the community generally has increased (given a rising population of persons with disabilities). The extent to which people with disabilities in particular are affected here cannot be determined.

A second indicator to be mentioned deals with the number of people in institutionalised long-term care facilities: 'Men and women receiving formal (paid) long-term care (LTC) in institutions (other than hospitals) or at home' ⁸⁵⁷

The number of people receiving care at home is higher than the number of people receiving care in an institution and this applies to both sexes. The OECD report contains data for 2013, but there are no more recent data than 2016 and there is no break down by disability.

In 2016, the number of people receiving care at home amounted at 9,182 persons (3,869 men and 5,313 women) and the number of people receiving care in institutions amounted to 4,560 (1,130 men and 4,330 women).

The reports "From institutions to community living - Part I: commitments and structures" and part II "From institutions to community living - Part II: funding and budgeting" prepared by the European Agency for Fundamental Rights (FRA) only addresses Luxembourg in a few places and does not provide systematically empirical data. ⁸⁵⁸

⁸⁵⁵ Ministry of Family, Integration and the Grand Region 2018 Working group on the development of the new National Action Plan for the implementation of the UN Convention on the Rights of Persons with Disabilities. (Ministère de la Famille, de l'Intégration et à la Grande-Région 2018 sur l'élaboration du nouveau Plan d'action national de mise en œuvre de la convention de l'ONU relative aux droits des personnes handicapées).

https://mfamigr.gouvernement.lu/fr/actualites.gouvernement%2Bfr%2Bactualites%2Btoutes_actualites%2Bcommuniqués%2B2018%2B07-juillet%2B03-reunion-personnes-handicapees.html

⁸⁵⁶ OECD 2019 (OECD.stat Homepage) Data based on and prepared by General Inspectorate of Social Security (IGSS). Preliminary results for 2016; Data refer to numbers as of 31st December every year and are not broken down by disability.

https://stats.oecd.org/Index.aspx?QueryId=30142&_ga=2.7185588.722996396.1547661294-1828482028.1541880394.

⁸⁵⁷ Ibid.

⁸⁵⁸ FRA (2017- 2018) From institutions to community living - Part I: commitments and structures <https://fra.europa.eu/en/publication/2017/independent-living-structures> And from institutions to community living - Part II: funding and budgeting <https://fra.europa.eu/en/publication/2017/independent-living-funding>

Luxembourg is also not 1 of the 10 member States of the “Funds Watch Group of the European Structural and Investment Funds (ESIF)” on community living in Europe to support independent and community living for persons with disabilities, children and older persons.⁸⁵⁹

Based on data from the Ministry of Family Affairs,⁸⁶⁰ it can be seen that the proportion of people with disabilities living in institutions has declined during the observation period. However, a simultaneous increase in independent living cannot be shown on the basis of the data.

These data (based on the statistics of the national long-term care assurance) show that almost three-quarters of all persons with disabilities continue to live in institutions in Luxembourg. But the actual number of people with disabilities who live autonomously is likely to be seriously underestimated by the available figures, because people who do not ask for counselling or support have not been included. No data are available for 2014. More recent data were not available when the report was compiled.

Measures that support independent living are mainly financed by the national long-term care insurance.

A comparison of the expenses from the current annual report (2017) of the national care insurance (data basis 2015) shows that the benefits for stationary measures exceed the benefits for domestic measures.⁸⁶¹ With regard to nursing services, the same report states the distribution of financing between home care and inpatient care in 2016 as follows: home care (prestations à domicile) EUR 211 million versus stationary care (prestation en milieu stationnaire) EUR 308.4 million. Thus, one notes that financial support for home care predominates in the early and middle stages of life, while financing institutional measures predominates in old age.

Budget developments 2013-2016 in millions of Euro⁸⁶²

Year		2013	2014	2015	2016	Trends since 2013
Home care	(million €)	208.5	218.6	215.1	211.0	+ 1.2 %
Stationary care	(million €)	299.6	321.5	326.9	308.4	+ 2.9 %

As the table illustrates, the budget for stationary services grew more strongly than the budget for domestic services during the observation period (2013-2016).

⁸⁵⁹ Community Living for Europe: Structural Funds Watch <https://communitylivingforeurope.org>

⁸⁶⁰ Ministry of Family affairs -MFI (2017) <https://gouvernement.lu/dam-assets/fr/publications/rapport-activite/minist-famille-integration-grande-region/2017-rapport-activite-famille/2017-rapport-activite-famille.pdf>.

⁸⁶¹ Ministry of social affairs (2017) http://www.mss.public.lu/publications/rapport_general/index.html

⁸⁶² Sécurité social 2017 http://www.mss.public.lu/publications/rapport_general/rg2017/rg_2017.pdf p.132.

The ministerial programme of action to improve the living conditions of people with disabilities (Plan d'action en faveur des personnes handicapées 1997)⁸⁶³ for the first time covered all existing regulations and pointed out the need for action.

The establishment of long-term care insurance with a performance-related billing orientation in 1999 required a detailed recording of the need for support and the expenses made available. The focus here was on ensuring financing in line with demand. In 2001, the law on the accessibility of public buildings and infrastructures laid the foundation for the expansion of accessibility in Luxembourg.

In 2003 followed the act on disabled worker (travailleur handicapé) and in 2011 Luxembourg ratifies the CRPD.

The legal measures in favour of disabled people in Luxembourg are assigned to different ministries depending on the subject area. The Ministry for Family, Integration and the Greater Region is responsible for coordinating the various measures and, if necessary, initiating new ones. In general, disability policy is based on the interaction of different actors in Luxembourg.

- The State organises certain areas itself, such as specialised education for pupils with disabilities.⁸⁶⁴
- The State concludes contracts / conventions with providers of services (workshops and housing facilities) and bears the costs relating thereto.
- Disability associations receive state or municipal subsidies
- Self-help groups do lobby work and take on tasks in the field of sensitization and public relations, thus influencing politics.

Luxembourg society has a long tradition of the institutional view of well-being and care,⁸⁶⁵ so that before the adoption of the UN Convention on Human Rights for Persons with Disabilities in 2011 there were hardly any clear statements in the legal documents in favour of independent living for people with disabilities, except for a brief declaration of intent in the Disability Action Plan⁸⁶⁶ published by the former Ministry concerned. (Plan d'action en

⁸⁶³ Ministère aux Handicapés et aux Accidentés de la Vie (1997). Evaluation de la situation des personnes handicapées au Luxembourg. Plan d'action en faveur des personnes handicapées. Luxembourg: MHAV. <http://www.info>

handicap.lu/index2.php?option=com_docman&task=doc_view&gid=36&Itemid=26

⁸⁶⁴ In 2018, the structures of the special education system (éducation différenciée) were replaced by a system of national competence centres designed towards better inclusion of pupils with special needs. <http://www.men.public.lu/fr/actualites/articles/communiqués-conference-presse/2018/06/26-centres-competences/index.html>.

⁸⁶⁵ Haas, C.; Gaitsch, R.; Limbach-Reich, A. & Peters, U. (2009). Professionalisierung sozialer Hilfeleistungen in Luxemburg: Entwicklungslinien und Zukunftsperspektiven der Ausbildung Sozialer Arbeit in Luxemburg. In H. Willems, G. Rotink, D. Ferring, J. Schoos, M. Majerus, N. Ewen, M.A. Rodesch-Henges, C. Schmit (Ed.), Handbuch der sozialen und erzieherischen Arbeit in Luxemburg. Manuel de l'intervention sociale et éducative au Grand-Duché de Luxembourg (unter Mitarbeit von C. Reuter, M. Schneider, K. Brandhorst). Luxembourg: Éditions Saint-Paul, 411-423.

⁸⁶⁶ Sagramola, Silvio (2009). Behindertenpolitik. In: H. Willems, G. Rotink, D. Ferring, J. Schoos, M. Majerus, N. Ewen, M.A. Rodesch-Henges, C. Schmit (Ed.), Handbuch der sozialen und erzieherischen Arbeit in Luxemburg. Manuel de l'intervention sociale et éducative au Grand-Duché de Luxembourg (unter Mitarbeit von C. Reuter, M. Schneider, K. Brandhorst). Luxembourg: Éditions Saint-Paul, 341-342.

faveur des personnes handicapées, 1997, p.15).⁸⁶⁷

Current statements of will are mostly manifested in the form of financing takeovers or subsidies as well as in the provision of corresponding structures, without an abstractly formulated conceptual directive being prescribed for them.

The national compulsory long term care insurance (assurance dépendance,1998)⁸⁶⁸ specifies as main purpose to provide benefits in kind, assistance and care as well as technical aids and housing adaptations and distinguishes between two scenarios : Payment of services in a stationary environment (Prise en charge des prestations en milieu stationnaire) and Coverage of services in the case of home support (Prise en charge des prestations en cas de maintien à domicile) without committing to a preference for the last mentioned, namely independent living.

One of the first governmental documents which tackles independent living is the above-mentioned ministerial programme of action to improve the living conditions of people with disabilities (Plan d'action en faveur des personnes handicapées 1997). Under the heading "Intégration sociale et vie autonome", (social inclusion and independent living) the report stated that in 1995/96, round about 70 % of people with disabilities lived in institutions, however these structures have changed enormously in terms of the quality of life offered. Luxembourg policy promotes a better quality of life for the disabled person through greater autonomy and independence and thus increased participation of the disabled person in the activities of his or her daily life. The report recommends the following measures to relieve the burden on families in the context of a disability and to help them to live a normal and independent life:

- to extend daytime placement measures for persons with severe disabilities;
- to extend the offer of occupational activities for any adult person unable to provide paid work;
- to extend the offer of leisure activities outside school hours for any child in home care;
- to provide a sufficient number of temporary or emergency beds in the various regions of the country;
- to create home support and assistance services that take into account the needs of people with disabilities.

The national Action plan on the UNCRPD (2012) mentions some aspects of independent living. For example, Inclusion requires infrastructures that respect the principle of "design for all". The aim is to make accessibility a standard in all areas of life in the long term. The area of application of the "Accessibility" Act should also be extended to the private sector. In addition, the legal scope of application will be extended to residential construction. Accessibility standards should apply primarily to new buildings and, as far as possible, to the existing building environment. In principle, no exceptions may be made for new buildings.

⁸⁶⁷ Ministère aux Handicapés et aux Accidentés de la Vie (1997). Evaluation de la situation des personnes handicapées au Luxembourg. Plan d'action en faveur des personnes handicapées. Luxembourg: MHAV. http://www.infohandicap.lu/index2.php?option=com_docman&task=doc_view&gid=36&Itemid=26

⁸⁶⁸ Assurance dépendance 1998. <https://www.secu.lu/assurance-dependance/>

With regard to independent living, the first national action plan emphasises the important role of long-term care insurance in day-to-day assistance for people with disabilities and support services, e.g. in the field of personal counselling and support, in semi-autonomous settings. This is followed by an equally indefinite declaration of intent aimed at ensuring that everyone receives the necessary assistance and support to realise his or her personal life plan. Barriers should be removed as early as possible.

In addition, the action plan highlights the imperative to enable people with disabilities to decide how, where and with whom they would like to live, with the greatest possible autonomy, self-determination and personal responsibility, alternative housing options must be developed. Adequate offers of support and care in various forms in smaller housing units are needed. However, the report does not comment on what will be the role of the state or what will be the public policy and what the government is willing to perform here. Also, the first national implementation report states that the Ministry of Family Affairs has chosen to persevere on the path of inclusion and to ensure that people with disabilities are not excluded from a process that affects them closely. A second National Action Plan is currently under development at time of writing.⁸⁶⁹

The coalition agreement of the new government (2018),⁸⁷⁰ does not speak directly about independent living, but some statements of intent are likely to have an impact on independent living. The coalition agreement indicates no data about completion dates for the development of alternative accommodations and services.

There is no government declaration dedicated solely to independent living. Only the first national UNCRPD implementation plan (2012)⁸⁷¹ can be used as an essential reference source, which identifies assessments, declarations of objectives, allocations of responsibilities and time horizons for implementation. However, the situation analyses, and target formulations are kept in a very non-binding and very general form, so that hardly any concrete information can be derived here, which also applies to the assigned measures. Particularly on de-institutionalisation and independent living, neither figures nor deadlines are given in recent declarations.

The following overview emphasises some of the points related to independent living, in the national action plan 2012:

⁸⁶⁹ Ministry of Family, Integration and the Grand Region 2018 Working group on the development of the new National Action Plan for the implementation of the UN Convention on the Rights of Persons with Disabilities. (Ministère de la Famille, de l'Intégration et à la Grande-Région 2018 sur l'élaboration du nouveau Plan d'action national de mise en œuvre de la convention de l'ONU relative aux droits des personnes handicapées).

https://mfamigr.gouvernement.lu/fr/actualites.gouvernement%2Bfr%2Bactualites%2Btoutes_actualites%2Bcommuniqués%2B2018%2B07-juillet%2B03-reunion-personnes-handicapees.

⁸⁷⁰ Coalition accord 2018 <https://gouvernement.lu/de/publications/accord-coalition/2018-2023.html>

⁸⁷¹ Ministry of Family Affairs Integration and the Greater Region (2012) First action plan to implement the CRPD in Luxembourg (Aktionsplan der Luxemburger Regierung zur Umsetzung der UNO-Behindertenrechtskonvention) https://mfamigr.gouvernement.lu/dam/assets/le_ministère/attributions/personnes-handicapées/plan-d-action-du-gouvernement-luxembourgeois-en-faveur-des-personnes-handicapees.pdf

- The aim is to raise awareness of the situation and needs of disabled people. Sufficient awareness of all those involved, in all sections of society, e.g. through national campaigns, should lead in the long term to an inclusive society in which people with disabilities can exercise their rights on an equal footing with all others. These include the introduction of a competence centre for easy language and the recognition of sign language. For these two topics, deadlines refer to the year 2012 and 2013 in achievement of the goals.
- With regard to accessibility, the aim is to ensure comprehensive accessibility as a basis for self-determination and participation of people with disabilities. This includes equal barrier-free access to all means of information and communication.
- Alarm signals of any kind should be made accessible to people with hearing impairments (e.g. by light signals, messages by SMS, FM transmitters or GPS indicating ambulances in the immediate vicinity). The target date for this is 2012.
- People with disabilities should be able to maintain their income independently of social support or employment measures. Training and transition to the world of work should be tailored to each person's personal strengths and goals. Competent bodies should advise and support the persons concerned so that they can lead a self-determined life. Measures to this regard are intended for 2012 and ongoing.
- The aim is to promote the mobility of people with disabilities through ensuring accessibility. It should be taken for granted that people in towns and villages can circulate barrier-free and, if possible, without an accompanying person. Accessibility should be actively promoted, and new barriers to mobility must be prevented.
- Inclusion must not be limited to a specific area. Inclusion must be understood as a project for society as a whole. Inclusion requires infrastructures that respect the principle of "design for all". The aim is to make accessibility a standard in all areas of life in the long run. An adaptation of the relevant Accessibility Act is planned for 2012-2014.
- The three different measures provided by Luxembourg law on the protection of adults with severe disabilities ("Incapables majeurs") merge into a single measure, the assistance. This assistance is designed in different ways according to the individual's needs and enables solutions to be tailored to the individual. There is a strict priority of assistance over care, and the proportionality of legal interventions is guaranteed by regular monitoring. Corresponding legislative changes are planned for 2012-2015.
- The concerns of people with disabilities are taken into account in all policy areas. Everyone receives the assistance he or she needs to realise his or her personal life plan. Barriers should be removed as early as possible. The measures provided for in this target are intended to apply between 2012 to 2015.
- Health services for people with disabilities should be regularly evaluated and adapted to their needs. (2012-2014)

There is no information available about milestones such as a defined number of people who are expected to leave existing institutional care facilities by a target date.

There were no legislative measures such as caps in the size of residential facilities, or introduction the right to personal assistance in Luxembourg. The development of personal assistance schemes is under discussion but still there is no individualised budget system in Luxembourg; Sector capacity building has mainly been based in inclusion of individuals with disabilities in mainstream structures; Training and development programmes focussed on labour market and employment (COSPH); ⁸⁷² Research or campaigns to improve public attitudes exist but particularly issuing to the inclusion of persons with disabilities in the context of independent living couldn't be found; also no improvements could be observed in data collection.

We must now, by necessity, look at the educational situation of the country in question. Special needs education (éducation différenciée) is designed for children who have specific education needs and cannot follow a traditional curriculum. The main official body dealing with special needs education is EDIFF (Education Différenciée). ⁸⁷³

The special needs schools in Luxembourg are managed by the Ministry of Education. The decision to send a child to one of these schools is taken by the parents and a committee (Commission médico-psycho-pédagogique nationale - CMPPN). Four options are generally available:

- full integration of the disabled child in a traditional school
- partial integration in a special needs school complemented by a traditional school full integration in a Luxembourg special needs school
- full integration in a foreign special needs school

School classes are limited in size to enable a personalised education depending on each child's specific needs. There are also schools situated throughout the country for mentally disabled children and children with specific learning difficulties. Additionally, there are six specialised schools for children with other specific needs. ⁸⁷⁴

⁸⁷² COSP-HR (Centre d'évaluation et d'orientation socio-professionnelle pour les demandeurs d'emploi ayant le statut du salarié handicapé et/ou du reclassement externe) Advisory office for persons with disabilities or reduced working capacity. <http://www.fonds-europeens.public.lu/fr/projets-cofinances/fse/2014-2020/1042/index.html> see also FSE: <http://www.fonds-europeens.public.lu/fr/projets-cofinances/fse/2014-2020/1042/index.html>.

⁸⁷³ Service de l'Education différenciée (in French) At: 29 rue Aldringen, L-2926 Luxembourg Tel: 24 78 51 78 Fax: 46 01 05

⁸⁷⁴ Centre d'observation et d'intégration scolaires: for children with severe behavioural, personality and relational problems

Institut pour Déficients Visuels: for blind and visually impaired children aged 4 to 15

Institut pour enfants autistiques et psychotiques: for autistic children

Institut pour Infirmes Moteurs Cérébraux (IMC): for children with cerebral motor impairment

Centre de Logopédie: for deaf and speech impaired children

The enrolment process set up by EDIFF is designed to be neutral and objective, aiming to ensure that children are also given the opportunity to follow a traditional curriculum. The committee (CMPPN) is composed of at least 11 members as well as some additional members chosen based on the nature of the disability. Around one percent of children in Luxembourg are sent to specialised schools.⁸⁷⁵

The CMPNN is the overseeing body for identifying children in need, assisting parents and guardians of children with special needs and recommending preventive measures and actions for children with special needs. If the CMPNN identifies a child as having special educational needs their role is to then analyse the child's specific needs. To do this, they take into account any information provided by specialists on the type and level of disability, a psychological assessment and any reports issued by schools, social workers and educational specialists. The CMPNN will propose the most appropriate options to the parents or guardians, who will make the final decision. Once a choice has been made, the CMPNN organises the transfer to the appropriate school. The CMPNN also reviews schooling arrangements on a regular basis.

Children in mainstream schools that present potential disabilities or learning difficulties may be assisted by the SDIP (Service de Détection et d'Intervention Précoce). The SDIP is the Education Department in charge of identifying children with psychological or psychiatric disabilities, with the approval of the parents or guardian.⁸⁷⁶ The SDIP works with another department called CPOS (Centre de psychologie et d'orientation scolaires) in charge of finding out the best educational options and providing help for children with learning disabilities.⁸⁷⁷ The CPOS provides services for children in secondary school with difficulties in following the mainstream curriculum. These include:

- a. After school homework assistance (enrolment form available at schools)
- b. Special classes specific to pupils facing learning difficulties either within or after normal school hours
- c. Lessons during school holidays for children having to retake one or more exams
- d. Lessons for under 18s with significant schooling problems

The law of 28 June 1994 stipulates that pupils with special needs education included in mainstream schools can benefit from support services. Early childhood education begins at the age of three and favours the development of language, as well as emotional, motor, intellectual and social development. There will be two qualified persons for each class: one teacher for pre-school education and one educational professional. This teamwork facilitates working in groups, learning differentiation and the inclusion of children with special needs.⁸⁷⁸

⁸⁷⁵ Commission Médico-Psycho-Pédagogique Nationale (CMPPN) At: 31, rue du Parc, L-5374 Munsbach Tel: 24 765 114 / 65 115 Fax: 24 795 114

⁸⁷⁶ Service de Détection et d'Intervention Précoce At: 14, avenue de la Gare, L-1610 Luxembourg Tel: 26 29 77-1 Fax: 26 29 77-20

⁸⁷⁷ Centre de psychologie et d'orientation scolaires At: 58 boulevard Grande-Duchesse Charlotte, L-1330 Luxembourg Tel: 24 77 59 10 Fax: 45 45 44

⁸⁷⁸ <https://www.european-agency.org/country-information/luxembourg/systems-of-support-and-specialist-provision>

The first ten years of education form a coherent and continuous whole which lay the foundations for any later training. According to the new law on education, pre-school and primary education are now grouped together under the name of 'basic school'.⁸⁷⁹ The mission of basic schools is not limited to teaching children. The law specifically underlines that the school has to contribute to the education of the children and to prepare them for societal life, as well as for work.⁸⁸⁰ In order to stress the importance of the first years of education, the law specifies the missions of pre-school education.⁸⁸¹

Basic education is organised in learning cycles. The first cycle consists of early training (optional) and pre-school education. The three subsequent cycles correspond to primary education and each last two years.⁸⁸² The normal duration of one cycle is two years. In exceptional cases, a cycle can be lengthened by one year.⁸⁸³ This decision, however, has to remain an exceptional one and must be taken by the teachers in close consultation with the parents.

If a child cannot reach the base of competence in two years, the educational team sets up an appropriate programme for three years. For children with serious learning difficulties, who are at risk of not reaching the bases of competences at the end of the cycle, the school inclusion commission sets up a personalised take-over plan. This programme fixes personal, realistic and demanding objectives.⁸⁸⁴ The law allows the possibility to take differentiation measures, ranging from temporary groupings of children of the same or different classes to the permission given to a pupil to follow teaching in a different stage.⁸⁸⁵

The support measures for children with learning difficulties range from adapting teaching and support by class teachers, to carrying out education in a special education class which is an integral part of basic education.⁸⁸⁶ In order to guarantee a coherent approach to the children with special education needs, one or more multi-professional team(s) is/are created in every inspection district. Consisting of specialists (logopaedic teachers, educationalists, motor function specialists, psychologists, special teachers, etc.), it ensures diagnosis and appropriate provision for these pupils.⁸⁸⁷

After the six primary school years or at the age of 12 (normally), the pupil enters post-primary education. Compulsory schooling ends at the age of 16. The pupil can choose between two types of education: Technical secondary education or a General secondary education.

The law of 14 March 1973, creating special education services and institutions, envisages that the government shall ensure that every child, due to their intellectual, sensory and emotional particular needs, shall receive within the special education structures the

⁸⁷⁹ Article 1

⁸⁸⁰ Article 6

⁸⁸¹ Article 7

⁸⁸² Article 1

⁸⁸³ Articles 22 and 23

⁸⁸⁴ Article 29

⁸⁸⁵ Article 22

⁸⁸⁶ Article 29

⁸⁸⁷ Articles 29 and 30

instruction required to meet their needs or situation. The Minister of National Education is responsible for the educational aspect, the Minister of Public Health for the medical aspect and the Minister of Family for the social aspect of special education.

According to educational needs, the following support structures have been created:

An ambulatory resource centre
Special regional schools and specific institution
Multi-disciplinary medico-psycho-pedagogical services.

For every child receiving support within the structures of special education, the ministerial order of 2 May 1991 envisages the establishment of an individual education plan including the following psycho-pedagogical aspects:

Personal independence;
Communication;
Basic school learning;
Cultural apprenticeship;
Psychomotor education;
Social health and hygiene;
Affective and social development;
Personal responsibility;
Initiation to professional life;
Spare time activities.

The individual education plan aims to advise the educational and pedagogical work in general; inform the parents about the principal educational options; and permit an approximate evaluation of the child's progress.⁸⁸⁸

Because policies targeting people with disabilities are often not coordinated, people have difficulty finding their way through the bureaucracy. A national disability information centre is a classic win-win solution: It assists people with their administrative procedures and helps policy makers to shape inclusive policies.

In 1989 the Government of Luxembourg decided that policies targeting people with disabilities should be coordinated. The Ministry of Family Affairs, Integration, and for the Greater Region was entrusted with the implementation of this idea, and it developed the project of a national disability information centre financially supported by the government, but managed under the control of national disability organizations. In April 1993, 16 disability organizations, which together formed the National Disability Council, founded Info-Handicap and signed a funding agreement with the government. Since then, Info-Handicap has constantly sought to carry out its mandate, including initiatives that have an impact beyond Luxembourg's borders. Recently, Info-Handicap assisted in elaborating a strategy for setting up

⁸⁸⁸ <https://www.european-agency.org/country-information/luxembourg/systems-of-support-and-specialist-provision>

a national disability action plan, and functions as a resource centre in this area⁸⁸⁹

Info-Handicap now has 55 member organizations in Luxembourg. In 2013, 2,271 persons asked for advice and 597 used the centre's legal information service.⁸⁹⁰

As one can note, civil society strives to be in the forefront for effective ameliorations in this regard in Luxembourg. This need is even more underlined in a specialised article in the International Journal of Inclusive Education (May 2018) entitled 'Inclusive education in Luxembourg: implicit and explicit attitudes toward inclusion and students with special educational needs.'⁸⁹¹

The aim of the published study in question was to investigate attitudes of Luxemburgish adults toward students with special educational needs (SEN) and their inclusion into mainstream schools. Positive attitudes can facilitate inclusion, furthering the acceptance of students with SEN. Implicit and explicit attitudes may have differential impact on behaviour toward students with SEN, however, to date, there is little research combining explicit and implicit attitudes measurement tools.

Participants (N = 161) completed an evaluative priming task, the Attitudes Toward Inclusive Education in the Population questionnaire as well as the German version of the Attitudes toward Inclusive Education Scale. Results show that participants expressed positive attitudes toward inclusive education in general. Participants' implicit attitudes toward students with differing types of SEN varied, with neutral attitudes toward students with learning difficulties and negative attitudes toward students with challenging behaviour.

In addition, participants' explicit attitudes toward the inclusion of students with learning difficulties or challenging behaviour in mainstream classrooms were negative. In sum, although people may support the general idea of inclusion, when asked about their attitudes toward students with specific types of SEN, and the inclusion of these students in mainstream schools, participants' attitudes were rather negative. The implications of these findings for the inclusion and acceptance of students with SEN in education and society are discussed at length.⁸⁹²

⁸⁸⁹ <https://zeroproject.org/policy/luxembourg/>

⁸⁹⁰ Ibid.

⁸⁹¹ https://www.researchgate.net/publication/325279925_Inclusive_education_in_Luxembourg_implicit_and_explicit_attitudes_toward_inclusion_and_students_with_special_educational_needs

⁸⁹² Ibid.

Malta

Malta, the smallest EU nation, as a signatory to the United Nations Universal Declaration of Human Rights (1948), the Convention on the Rights of Persons with Disabilities (UNCRPD) and the Optional Protocol ⁸⁹³ and other international documents ensures the protection of the fundamental rights and freedoms of Persons with Disabilities. These rights and freedoms are also given protection under the Maltese Constitution.

This analysis recognizes that whilst Persons with Disabilities are autonomous and independent, disability can place them at greater risk of discrimination. Thus, increasing recognition towards addressing the vulnerabilities arising from disability requires a human rights approach that empowers the individual towards greater autonomy and self-actualisation. This human rights approach is being reflected through a shift from institutionalised and residential services to independent living and a more community-based approach which prioritises prevention and early intervention.

Statistics on Persons with Disabilities are mainly collated by the Commission for the Rights of Persons with Disabilities⁸⁹⁴, but also by specific entities such as JobsPlus ⁸⁹⁵, the Department for Social Security (DSS), the Directorate for Health Information and Research (DHIR) and the National Statistics Office (NSO).

As at April 2018, the CRPD registered a total of 18,181 Persons with Disabilities (8,947 females and 9,234 males), out of which around 1,700 were young persons aged 17-30 years, having physical (594), intellectual (665), psychological (311), hearing (125) and visual (96) impairments. In the same period, out of the total amount of 3,598 persons receiving the disability allowance, the increased severe disability allowance and the severe disability allowance payable under the Social Security Act, there were a total of 1,077 young persons aged 15-29 years. Moreover, Persons with Disabilities registered at JobsPlus amounted to 3,726, out of which 453 were persons aged 16-24 years. A total of 283 persons were unemployed (71 females and 212 males), out which 42 (17 females and 25 males) were under 25 years of age.

Persons with Disabilities registered with CRPD (18,260), formed 3.97% out of Malta's total population ⁸⁹⁶ (460,297), while young Persons with Disabilities (1,445) aged 15- 29 years made up 0.3% of the total population. Young persons aged 15-24 years made up 11.7% (around 53,855 persons) of the total population, while young persons aged 25-29 years made up 8% (around 36,824 persons). Young Persons with Disabilities formed 1.8% (953 persons) and 1.3% (492 persons) of the young persons' groups aged 15-24 years and 25-29 years respectively.

⁸⁹³ Signed by Malta in March 2007, ratified in October 2012 and came into effect on the 9th November 2012 (<http://crpd.org.mt/un-convention/>).

⁸⁹⁴ The CRPD Register includes Persons with Disability to whom a Special ID card and/or an EU Disability Card was issued.

⁸⁹⁵ Malta's national Employment and Training Corporation.

⁸⁹⁶ Data collected by the National Statistics Office (NSO).

A number of institutions cater for persons with intellectual disabilities. Mount Carmel Hospital (MCH, Malta's central mental health hub offering hospital and community mental health services) was housing 530 in-patients in 2018 and providing services to around 11,750 out-patients in the community. Apart from services operated within hospital premises, MCH also provides community services through its 10 mental health clinics and 5 days centres.⁸⁹⁷ The Mental Health Strategy Consultation Document states that hospital discharge rates for people with mental health and behavioural difficulties in Malta are lower than the EU average, while their average length of stay is the highest in the EU.⁸⁹⁸

Id-Dar tal-Providenza (Providence House)⁸⁹⁹ is one of Malta's largest institutions for people with disabilities and is located away from the community. This is owned and run by the church in Malta. However, it has now opened a number of small community-based homes for disabled people.⁹⁰⁰ There are also other small community homes run by NGOs, as well as respite services for persons with disabilities and their relatives.⁹⁰¹

It is worth noting that data on independent living is not collected at a national level, but rather by the service providers themselves.

In Malta, support for independent living is mainly provided by the government agency, Aġenzija Sapport⁹⁰² (Agency Support), which offers day, community and residential services among others. At the end of 2017, 56 people with disabilities were benefiting from residential services and 327 people with disabilities were benefiting from community services (enabling people to live in the community).⁹⁰³

Richmond Foundation Malta,⁹⁰⁴ an NGO working with people with mental health problems, offers home support, in the home of the service user, in order to support them to manage their lives in their own environment. According to the organisation's annual report on 2017, there were 109 home support service users.⁹⁰⁵ The Foundation also runs three hostels (two for men and one for women), providing accommodation with 24 hour support to persons with mental health problems.⁹⁰⁶ There are currently 33 clients in these hostels. The Foundation also

⁸⁹⁷ National Audit Office. 2018. Performance Audit: A Strategic Overview of Mount Carmel Hospital. Available at: <http://nao.gov.mt/loadfile/b1adb86a-4ab4-49ac-95cf-534dc99c741c>.

⁸⁹⁸ Office of the Deputy Prime Minister and Ministry for Health. 2018. Building Resilience. Transforming Services. A Mental Health Strategy for Malta 2020-2030. Public Consultation Document. Available at: <https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx>

⁸⁹⁹ <https://www.dartalprovidenza.org>.

⁹⁰⁰ Academic Network of European Disability Experts (ANED). 2018. DOTCOM. Malta. Independent Living. De-institutionalisation. Available at: https://www.disabilityeurope.net/dotcom?l%5B%5D=24&t%5B%5D=24&view_type=list.

⁹⁰¹ Bezzina, L. 2018. Malta Fact Sheet on Social Care & Support Services Sector for Persons with Disabilities. Available at: <http://www.easpd.eu/en/content/publications>

⁹⁰² <https://sapport.gov.mt/en/>.

⁹⁰³ Aġenzija Sapport. 2018. Biennial Report 2016-2017. Available at: <https://sapport.gov.mt/en/Downloads/Documents/A%C4%A1enzija%20Sapport%20Biennial%20Repo%20rt%202016-2017.pdf>.

⁹⁰⁴ <http://www.richmond.org.mt>.

⁹⁰⁵ Richmond Foundation Malta. 2019. Home Support Service. Available at: <https://www.richmond.org.mt/>.

⁹⁰⁶ Richmond Foundation Malta. 2019. Attard Hostel. Qormi Hostel. Paola Hostel. Available at: <http://www.richmond.org.mt>; <https://www.tvm.com.mt/en/news/attard-hostel-female-persons-mental-problems/>.

provides a residential and day community-based and respite care for persons with mental health problems, to assist them to remain in the community. It has 12 beds and is always full.⁹⁰⁷ Finally, the Foundation has a residential programme for children with severe emotional and behavioural difficulties which has 9 beds and is also always full.

Persons with Disabilities are represented within civil society by the Malta Federation of Organisations Persons with Disabilities.⁹⁰⁸ The Federation is the umbrella organisation embracing and representing the vast majority of registered NGOs within Malta and its sister isle Gozo.⁹⁰⁹ MFOPD was instrumental in creating a national consensus for the introduction of the concept of supported employment in Malta, which, up to the year 2014, was frequently discussed but never implemented.

MFOPD, with the support and guidance of its advisor from Scotland,⁹¹⁰ founded and registered the Malta Association of Supported Employment⁹¹¹ and, by means of a public private agreement with the government,⁹¹² introduced this concept on an experimental basis with huge successes.⁹¹³ At the end of the experimental period, where targets were not only met but greatly surpassed, the Minister for the Family and Social Welfare announced that the concept of supported employment would now be incorporated within its own agency structures, albeit with limited results.⁹¹⁴ Additionally, in 2017, both these organisations started working closely by means of a published memorandum of understanding with the office of the President of the Republic in order to offer additional supported employment services to persons with intellectual disabilities, especially in the field of social and employment inclusion, job coaching and job mentoring.⁹¹⁵

In their report on deinstitutionalisation, Priestley *et al* (2018) report that 72.4 % of persons with limitations aged from 18 upwards in Malta feel that they are free to decide how to live their life; while 88.6 % of persons with limitations aged from 16 upwards feel they are “almost or almost always” (p. 30) free to spend money on themselves for their personal consumption, leisure activities and hobbies.

Meanwhile, 20.9 % of persons with some/severe limitations aged 18 and upwards feel left out of society; and more than 80 % have direct face-to-face contact with non-family members living outside their household. 26.8 % of people with limitations live in one-person households (with the

⁹⁰⁷ Richmond Foundation. 2019. Kids in Development. Available at: <http://www.richmond.org.mt/kids-in-development>.

⁹⁰⁸ <https://maltacvs.org/voluntary/malta-federation-of-organisations-of-persons-with-disability/>

⁹⁰⁹ [http://www.saintlazarus.org/pages/Malta%20-](http://www.saintlazarus.org/pages/Malta%20-%20Record%20Breaking%20Supported%20Employment%20Success%20Figures%20Reached.html)

[%20Record%20Breaking%20Supported%20Employment%20Success%20Figures%20Reached.html](http://www.saintlazarus.org/pages/Malta%20-%20Record%20Breaking%20Supported%20Employment%20Success%20Figures%20Reached.html)

⁹¹⁰ <https://timesofmalta.com/articles/view/Association-for-supported-employment.520143>

⁹¹¹ <https://maltacvs.org/voluntary/malta-association-of-supported-employment-mase/>

⁹¹² <https://family.gov.mt/en/Press%20Releases/Pages/The%20Minister%20Press%20Releases/Stqarrija-mill-Ministru-g%C4%A7all-Familja-u-Solidarjeta-Socjali-%E2%80%93-Iffirmat-ftehim-mal-Malta-Association-for-Supported-Employment.aspx>

⁹¹³ https://www.academia.edu/35347779/Positive_Supported_Employment_Program_-2016

⁹¹⁴ <https://www.independent.com.mt/articles/2019-02-12/local-news/Reflections-on-the-issue-of-employment-of-persons-with-disability-6736203559>

⁹¹⁵ <https://president.gov.mt/press-centre-statement/memorandum-understanding-presidentss-trust-malta-federation-organisations-persons-disability-jointly-malta-association-supported-employment/>

(percentage of women (29.3 %) being higher than that of men (23.8 %). Between 2006 and 2009, 93.6 % of persons with limitations in activities of daily living aged 15 upwards ⁹¹⁶ received personal assistance, 28.4 % received technical aids and 14.7 % benefited from housing adaptation. ⁹¹⁷

In 2014, 374 persons obtained funds from the special apparatus fund in Malta. ⁹¹⁸ The 'disability gap' – that is, the difference between disabled persons and non-disabled ones – with regards to using at least one of the five common types of services (including health care and public transport) in Malta is rather low. ⁹¹⁹

It is worth noting that there is a lack of statistics regarding children in institutional and community-based settings in Malta.

Aġenzija Sapport's latest biennial report indicates that during the period 2016-2017, two residences for disabled people became operational and another two were launched. Meanwhile, work on three other residences were initiated in 2017. ⁹²⁰ This indicates a growth in residential services.

The Mental Health Strategy Consultation Document states that Malta had the largest increase in the average length of stay in hospital for persons with severe mental health problems in the EU, which had risen from 34 to 47 days between 2010 and 2015. ⁹²¹

With regards to financing, Aġenzija Sapport's budget for 2017 was EUR 13,283,887, out of which EUR 11,749,965 were government subvention. In 2017, the agency's major expense was that related to payroll costs, which amounts to 69 % of day centres expenditure and 73% of the rest of the agency's expenditure (including residential services and other schemes). ⁹²²

⁹¹⁶ The different minimum ages cited are due to the different surveys covered in the report from which this data is taken: while the EU-SILC (European Statistics of Income and Living Condition) survey covers persons aged 16 and over, the EQLS (European Quality of Life Survey) covers persons aged 18 and over and the EHIS (European Health Interview Survey) persons aged 15 and over.

⁹¹⁷ Priestley, M., Grammenos, S., Zwamborn, M. and Groenendijk, I. 2018. From institutions to community living: Development of statistical outcome indicators. European Union Agency for Fundamental Rights. Available at: http://fra.europa.eu/sites/default/files/fra_uploads/independent-living-development-_statistical-outcomeindicators_en.pdf.

⁹¹⁸ European Union Agency for Fundamental Rights. 2017. From institutions to community living. Part III: Outcomes for persons with disabilities. Luxembourg: Publications Office of the European Union; available at: <https://fra.europa.eu/en/publication/2017/independent-living-structures>.

⁹¹⁹ Priestley, M., Grammenos, S., Zwamborn, M. and Groenendijk, I. 2018. From institutions to community living: Development of statistical outcome indicators. European Union Agency for Fundamental Rights. Available at: http://fra.europa.eu/sites/default/files/fra_uploads/independent-living-development-_statistical-outcomeindicators_en.pdf.

⁹²⁰ Aġenzija Sapport. 2018. Biennial Report 2016-2017. Available at: <https://sapport.gov.mt/en/Downloads/Documents/A%C4%A1enzija%20Sapport%20Biennial%20Report%202016-2017.pdf>.

⁹²¹ Office of the Deputy Prime Minister and Ministry for Health. 2018. Building Resilience. Transforming Services. A Mental Health Strategy for Malta 2020-2030. Public Consultation Document. Available at: <https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx>.

⁹²² Aġenzija Sapport. 2018. Biennial Report 2016-2017. Available at: <https://sapport.gov.mt/en/Downloads/Documents/A%C4%A1enzija%20Sapport%20Biennial%20Report%202016-2017.pdf>.

Id-Dar tal-Providenza relies to a large extent on benefactors, public donations⁹²³ and residents' pensions. However, most services provided in community homes are funded by the government. The same can be said for most NGOs in this sector, where limited government funds are injected to the former on a project by project basis related to social, economic or related inclusion for persons with disabilities.⁹²⁴

Mount Carmel Hospital absorbs approximately EUR33 million yearly from the government's annual budget. The Mental Health Strategy Consultation Document states that in 2016, 6% of the total expenditure on hospitals in Malta was spent on mental health care.⁹²⁵

The following documents all partially deal with support for independent living in the community for disabled persons:

- Malta National Reform Programme 2018;⁹²⁶
- Partnership Agreement of Malta 2014-2020;⁹²⁷
- National Policy on the Rights of Persons with Disability 2014;⁹²⁸
- Malta National Disability Strategy Consultation Document 2015,⁹²⁹
- National Standards for Residential Services for Persons with Disability 2015,⁹³⁰
- Social Regulatory Standards – Respite Services for Persons with Disability Consultation Document 2018;⁹³¹
- Mental Health Strategy for Malta 2020-2030 Consultation Document 2018;⁹³²
- National Health Systems Strategy for Malta 2014-2020.⁹³³

⁹²³ Id-Dar tal-Providenza – A Home for Persons with Disability. 2019. Available at: <https://www.dartalprovidenza.org/>

⁹²⁴ Bezzina, L. 2018. Malta Fact Sheet on Social Care & Support Services Sector for Persons with Disabilities. Available at: <http://www.easpd.eu/en/content/publications>.

⁹²⁵ Office of the Deputy Prime Minister and Ministry for Health. 2018. Building Resilience. Transforming Services. A Mental Health Strategy for Malta 2020-2030. Public Consultation Document. Available at: <https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx>.

⁹²⁶ Ministry for Finance. 2018. Malta National Reform Programme. Available at: <https://mfin.gov.mt/en/Library/Pages/National-Reform-Programme.aspx>.

⁹²⁷ Office of the Deputy Prime Minister, Ministry for European Affairs and Parliamentary Secretariat for the EU Presidency 2017 and EU Funds. 2014. Partnership Agreement of Malta 2014-2020. Available at: <https://eufunds.gov.mt/en/Information/Pages/Partnership-Agreement.aspx>.

⁹²⁸ Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, National Commission Persons with Disability and Kumitat Azzjoni Lejn Soċjetà Ġusta. 2014. National Policy on the Rights of Persons with Disability. Available at: <https://activeageing.gov.mt/en/Pages/Download-National-Policy-on-the-Rights-of-Persons-with-Disability.aspx>.

⁹²⁹ Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing. 2015. Consultation Document: The Malta National Disability Strategy. Available at: <https://activeageing.gov.mt/en/Pages/Malta-National-Disability-Strategy.aspx>.

⁹³⁰ Ibid.

⁹³¹ Social Care Standards Authority. 2018. Guidelines – Social Regulatory Standards. Respite Services for Persons with Disability – Public Consultation. Available at: https://meae.gov.mt/en/Public_Consultations/MFSS/Pages/Consultations/SocialRegulatoryStandardsRespiteServicesforPersonswithdisability.aspx.

⁹³² Office of the Deputy Prime Minister and Ministry for Health. 2018. Building Resilience. Transforming Services. A Mental Health Strategy for Malta 2020-2030. Public Consultation Document. Available at: <https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx>.

⁹³³ Parliamentary Secretariat for Health. A National Health Systems Strategy for Malta 2014-2020. Securing Our Health Systems for Future Generations. 2014. Available at: <https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx>.

Furthermore, in his Budget Speech of 2017, the Minister for Finance pledged to continue to promote the Just Society project to establish 10 small homes in the community for disabled persons, saying that up till that point (2016), they had established 3 such homes and will continue to complete several others in the coming year (2017).⁹³⁴ In 2017, in his Budget Speech 2018, the Minister for Finance pledged to continue with the programme of opening more residential homes for people with intellectual disabilities and challenging behaviour and persons on the autism spectrum.⁹³⁵

Regarding day centres, in his Budget Speech 2017, the Minister announced that they will continue refurbishing the 10 existing day centres for disabled persons and open another centre; while in his Budget Speech 2018, the Minister announced that they will demolish and rebuild one of the day centres.⁹³⁶

In his Budget Speech 2017, the Minister for Finance also stated that towards the last quarter of 2017, the Housing Authority⁹³⁷ will start – with the support of European funds – installing lifts and refurbishing government housing estates in 211 buildings which house more than 4 000 people (200 of whom are disabled persons).⁹³⁸ In the Budget speech 2018, however, the Minister stated that the Housing Authority was working to install lifts and embellish 109 government housing apartments, from which 101 disabled persons would benefit.⁹³⁹

The launching of a scheme providing personal assistants to disabled people (open to persons of any age, with the cost of service provision being shared between the government and service users) was also announced in the Budget Speech 2017, with the annual expenditure expected to reach around EUR 1 million.⁹⁴⁰

Finally, in the Budget Speech 2017, it was announced that work on the REACH project (a residential and transitional setting, targeting disabled people who have a high risk of social exclusion) has continued.⁹⁴¹ In November 2018, the Malta Monitoring Committee (Operational Programme I 2014-2020), in its updates on the implementation of Operational Programme 1, reported that excavation works began on the site of the REACH project in 2018 and that the Design and Build tender was contracted in November 2018.⁹⁴²

At this stage, one must keep in mind that the EU Fundamental Rights Agency (FRA)'s review of the 2014-2020 partnership agreements reports that Malta is one of the five EU Member States

⁹³⁴ Scicluna, E. 2016. Malta: Ġid li Jasal Għand Kulhadd. Budget Speech 2017. Available at: <https://mfin.gov.mt/en/The-Budget/Pages/The-Budget-2017.aspx>.

⁹³⁵ Scicluna, E. 2017. Malta: Inlestu Għall-Futur. Budget Speech 2018. Available at: <https://mfin.gov.mt/en/The-Budget/Pages/The-Budget-2018.aspx>

⁹³⁶ Ibid.

⁹³⁷ <https://housingauthority.gov.mt/en/Pages/default.aspx>.

⁹³⁸ Scicluna, E. 2016. Malta: Ġid li Jasal Għand Kulhadd. Budget Speech 2017. Available at: <https://mfin.gov.mt/en/The-Budget/Pages/The-Budget-2017.aspx>

⁹³⁹ Scicluna, E. 2017. Malta: Inlestu Għall-Futur. Budget Speech 2018. Available at: <https://mfin.gov.mt/en/The-Budget/Pages/The-Budget-2018.aspx>.

⁹⁴⁰ Scicluna, E. 2016. Malta: Ġid li Jasal Għand Kulhadd. Budget Speech 2017. Available at: <https://mfin.gov.mt/en/The-Budget/Pages/The-Budget-2017.aspx>.

⁹⁴¹ Ibid.

⁹⁴² Monitoring Committee. 2018. Update on Implementation of OPI. Operational Programme I – Fostering a competitive and sustainable economy to meet our challenges.

which has partnership agreements committing to deinstitutionalisation.⁹⁴³ In the Partnership Agreement of Malta 2014-2020, under Thematic Objective 09: Promoting social inclusion, combating poverty and any discrimination, the government of Malta states its commitment towards integrating disabled people into society and the infrastructural intervention (with the support of ERDF funds) that it intends to direct towards them. The document specifically states that “[t]his approach will ensure that this target group is actively integrated in society as opposed to institutionalisation” (p. 137). Stimulating independent living for disabled people is also mentioned as an aim to be achieved through ESF funds in supporting actions including empowering target groups in preventing dependency and building a network of community-based service providers which allow better outreach.⁹⁴⁴

The National Policy on the Rights of Persons with Disability issued in 2014 states that there should be a written policy on independent living. In the policy section dealing with independent living, the document states:

“7.1 It is a recognized fact that persons with a disability have the right to lead a productive and independent life in the community where they have the right to make their own choices, socialize and engage in any activities at par with non-disabled people. In order to achieve this goal, the government and civil society should ensure;

- a) Persons with a disability should, when they require such, be provided with a residential placement within the community where they can continue to live comfortably and with dignity.
- b) Persons with a disability should not be obliged to live in an imposed living arrangement, thus they should have the right to reside in a place of residence of their own choosing and with people they are comfortable with.
- c) Community services, goods and facilities should be available to persons with a disability, as required.
- d) Persons with a disability need to have access to a range of community support goods, services and facilities, including, but not limited to personal assistants, assistive technology and mobility equipment, to ensure effective social inclusion. Such services are to be made available at an affordable cost, and at the person's choosing. Choice of goods, services and facilities should reflect the person's own needs and preferences.
- e) Persons with a disability should have access to mobility training and use of assistive technology equipment by appropriately qualified persons to ensure community access. Government is to ensure a competitive provision of assistive technology equipment so that potential consumers can benefit from such healthy competition.
- f) All residential services should subscribe to the ‘Standards for Residential Services for Persons with Disability’.
- g) Social Trusteeships designed to safeguard the financial well-being of persons with a learning disability and the protection of their personal patrimonies are to be encouraged and made widely affordable. Such trusts should, wherever possible, take into account the preferences of the individual to whom the trust is to be made.

⁹⁴³ European Union Agency for Fundamental Rights. 2017. From institutions to community living. Part I: Commitments and structures. Luxembourg: Publications Office of the European Union. Available at: <https://fra.europa.eu/en/publication/2017/independent-living-structures>.

⁹⁴⁴ Office of the Deputy Prime Minister, Ministry for European Affairs and Parliamentary Secretariat for the EU Presidency 2017 and EU Funds. 2014. Partnership Agreement of Malta 2014-2020. Available at: <https://eufunds.gov.mt/en/Information/Pages/Partnership-Agreement.aspx>.

- h) Encourage the use of the Guardianship Act, when necessary and in collaboration with the social work services and/or other caring professionals.”⁹⁴⁵

In the policy’s section dealing with residential homes, community and rehabilitation centres, the relevant guiding principles are the following:

“8.1 Persons with a disability should have the freedom to decide where to live and with whom to live, namely either in a residential home or any other place of preferred choice.

8.2 Residential homes, community and rehabilitation centres should steer away from medical approaches in the way they are organized and managed and should focus more on person-centred approaches.

8.3 Residential homes, community centres and rehabilitation centres should have all the necessary amenities designed to maximise independent living and quality of life of persons with a disability, besides enabling them to actively participate in the community.”⁹⁴⁶

A year later, in 2015, the Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing issued a consultation document: the Malta National Disability Strategy, with the aim of having a national plan to address the aspiration of persons with disabilities and their families and formulates a strategic plan to improve their quality of life. This Strategy has 75 Strategy Initiatives grouped under thirteen different objectives. Objective 7 deals specifically with independent living, with its principles being:

“Persons with disability should, when they require such, be provided with a residential placement within the community where they can continue to live comfortably and with dignity.

Persons with disability should not be obliged to live in an imposed living arrangement, thus they should have the right to reside in a place of residence of their own choosing and with people they are comfortable living with.

Community services, goods and facilities should be available to persons with disability, as required.”⁹⁴⁷

Objective 8, dealing with residential homes, community and rehabilitation, is based on the following principles:

“Persons with disability should have the freedom to decide where to live and with whom to live, namely either in a residential home or any other place of preferred choice.

⁹⁴⁵ Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, National Commission Persons with Disability and Kumitat Azzjoni Lejn Soċjetà Gusta. 2014. National Policy on the Rights of Persons with Disability. Available at: <https://activeageing.gov.mt/en/Pages/Download-National-Policy-on-the-Rights-of-Persons-with-Disability.aspx>. Pages 42-43

⁹⁴⁶ Ibid. Page 46

⁹⁴⁷ Ibid. Page 45

Residential homes, community and rehabilitation centres should steer away from medical approaches in the way they are organised and managed and should focus more on person-centred approaches.

Persons with disability need to have access to a range of community support goods, services and facilities including, but not limited to personal assistants, assistive technology and mobility equipment to ensure effective social inclusion. Such services are to be made available at an affordable cost, and at the person's choosing. Choice of goods, services and facilities should reflect the person's own needs and preferences.

All residential services should subscribe to the Standards for Residential Services for Persons with Disability.”⁹⁴⁸

To date, no further action was taken with regards to this consultation document and no responses to the consultation document have been published.

The Social Regulatory Standards on Respite Services for Persons with Disability consultation document is based on principles which include the client's right to privacy and choice and individuality. It includes seven Standards, each of which has several quality indicators outlining what the service provider must ensure.⁹⁴⁹

The Mental Health Strategy Consultation Document⁹⁵⁰ presents proposals for measures to be taken in transforming the mental health system. It takes up some of the National Audit Office's recommendations⁹⁵¹ and the latest report of the Office of the Commissioner for Mental Health and “embraces a modal shift in the locus of care away from institutions towards community-based mental health care”.⁹⁵²

Relatedly, the National Health Systems Strategy had stated, in 2014, the commitment towards the reintegration of mental health patients living in institutional care back into society⁹⁵³

The only identified relevant research studies were the ones conducted in 2011 by the Malta Commission for the Rights of Persons with Disability (CRPD - then called the National Commission

⁹⁴⁸ Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, National Commission Persons with Disability and Kunitat Azzjoni Lejn Soċjetà Ġusta. 2014. National Policy on the Rights of Persons with Disability. Available at: <https://activeageing.gov.mt/en/Pages/Download-National-Policy-on-the-Rights-of-Persons-with-Disability.aspx>. Page 48

⁹⁴⁹ Social Care Standards Authority. 2018. Guidelines – Social Regulatory Standards. Respite Services for Persons with Disability – Public Consultation. Available at: https://meae.gov.mt/en/Public_Consultations/MFSS/Pages/Consultations/SocialRegulatoryStandardsRespiteServicesforPersonswithdisability.aspx.

⁹⁵⁰ Office of the Deputy Prime Minister and Ministry for Health. 2018. Building Resilience. Transforming Services. A Mental Health Strategy for Malta 2020-2030. Public Consultation Document. Available at: <https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx>.

⁹⁵¹ National Audit Office. 2018. Performance Audit: A Strategic Overview of Mount Carmel Hospital. Available at: <http://nao.gov.mt/loadfile/b1adb86a-4ab4-49ac-95cf-534dc99c741c>.

⁹⁵² Office of the Commissioner for Mental Health. 2018. “Breaking Silos, Building Bridges.” Annual Report 2017. Available at: <https://deputyprimeminister.gov.mt/en/CommMentalHealth/Pages/Annual-Reports.aspx>. Page 9.

⁹⁵³ Parliamentary Secretariat for Health. A National Health Systems Strategy for Malta 2014-2020. Securing Our Health Systems for Future Generations. 2014. Available at: <https://deputyprimeminister.gov.mt/en/Pages/National-Strategies/NHS.aspx>

Persons with Disability)⁹⁵⁴ on independent living in Malta up till that time. The study concluded that there was “an absence of a cohesive and Runiversal policy for independent supported living for disabled persons” as well as “an absence of data relating to all aspects of the disability sector – data without which good policy design is difficult to attain” (p. 7).

But what about the synergy needed in this sector between the educational system and inclusion? A number of legislative and policy structures and procedures are in place to promote and protect the rights of Persons with Disabilities to inclusive education - through the Education Act (Cap. 327) - and reasonable accommodation in employment – Persons with Disability (Employment) Act (Cap. 210).

Besides the Education Act (Cap. 327), inclusive education is also safeguarded by the Maltese Sign Language Recognition Act (Cap. 556) and the Persons within the Autism Spectrum (Empowerment) Act (Cap. 557). Correspondingly, a number of policy documents have been launched by the Ministry for Education and Employment (MEDE), including: ‘A National Curriculum Framework for All’ (2012); ‘Respect for All Framework’ (2014); ‘Framework for Education Strategy for Malta 2014–2024’, ‘Addressing Bullying Behaviour in Schools Policy 2014’; ‘An Early School Leaving Strategy for Malta 2012’; ‘A Whole School Approach to a Healthy Lifestyle: Healthy Eating and Physical Activity Policy 2015’; ‘A National Literacy Strategy for all in Malta and Gozo 2014-2019’, and the ‘National Youth Policy Towards 2020: A shared vision for the future of young people’.

Physical accessibility standards, both for newly built and older schools, fall under the responsibility of the Foundation for Tomorrow’s Schools (FTS). Besides this, the three directorates – the Inclusive Education Directorate, the Special Education Directorate, and the Education Psycho-social Services Directorate – falling under the National Schools Support (NSSS) at MEDE, all aim to provide learning and responsive environments “to the differing developmental capacities, needs, and potential of all students from kindergarten (including child care centres and private kindergartens) to tertiary and adult education”.⁹⁵⁷ Various services and resources are provided to reach this aim, including:

- i) spot-checks in schools by Inclusion and Education Officers (EOs);⁹⁵⁸
- ii) learning support zones/nurture groups;
- iii) services for unaccompanied minors;
- iv) the Autism Spectrum Support Team (ASST);
- v) home tuition;
- vi) the supply of teachers for the hearing and visually impaired;

⁹⁵⁴ Kummissjoni Nazzjonali Persuni b’Dizabilita’ (KNPD).

⁹⁵⁵ Spiteri Gingell, D. 2011. Policy on Independent Supported Living for Disabled Persons in Malta.

Available at: <http://crpd.org.mt/wp-content/uploads/2016/04/001-indsupliv2011rpt.pdf>.

⁹⁵⁶ https://www.academia.edu/35347779/Positive_Supported_Employment_Program_-2016

⁹⁵⁷ education.gov.mt, 2016

⁹⁵⁸ Inclusion is not only restricted to disability, but also encompasses other areas such as ethnicity, religion and gender.

- vii) the Statementing Moderating Panel which ensures that students are provided with a transdisciplinary assessment report establishing the nature and level of educational support needed, follow-up action and periodic reviews;⁹⁵⁹
- viii) the Access to Communication & Technology Unit (ACTU) – providing assistive technologies, augmentative and alternative communication (AAC) technologies;
- ix) the Early Intervention Service;
- x) the Social, Emotional and Behavioural Difficulties (SEBD) service;
- xi) Hospital Classes;
- xii) Resource Workers and Youth Workers, even at the YPU;
- xiii) Learning Support Centres; and
- xiv) Services within the four Resource Centres.

In its report entitled 'EDUCATION FOR ALL - Special Needs and Inclusive Education in Malta: External Audit Report' by the European Agency for Special Needs and Inclusive Education,⁹⁶⁰ the findings of the former need to be highlighted. For each of the five critical issues considered in the Audit, areas of strength in the Maltese system that potentially provide a basis for further work have been identified, as well as areas for development to address challenges for current policy and practice.

In relation to how effectively schools are enabled to implement inclusive education, the Audit data indicates that various system factors result in schools being only partially enabled to effectively implement inclusive education. Many system factors reinforce an integrative approach for some learners, rather than an inclusive approach for all learners.

In relation to how adequately school staff are enabled to meet learners' diverse learning needs, school-level stakeholders do not feel sufficiently enabled to meet individual learning needs and various critical system-level factors – training, provision of support and the degree of centralisation – appear to reinforce school-level practice that does not foster inclusion.

In relation to the ability of the official needs identification and statementing procedure to promote an approach to meeting individual learning needs that is based on children's rights, it can be argued that for the majority of learners, their right to access mainstream education is being met, but this is not sustainable in the long term as the current system does not provide equity and full participation for all, or promote mainstream capacity building.

In relation to how effectively systems of support enable all stakeholders in education, many stakeholders view support services as being relatively effective in providing for individual learners with SEN, but their role needs to be re-focused towards providing more enabling support for mainstream schools and staff.

⁹⁵⁹ From various professionals in public or private practice including educational, parental, medical, psychological, social, communicative, vocational, etc.

⁹⁶⁰ <https://education.gov.mt/en/Documents/Special%20Needs%20and%20Inclusive%20Education%20in%20Malta%20C2%AD-%20External%20Audit%20Report.pdf>

Finally, in relation to how effective the educational quality assurance processes are in enabling stakeholders to implement inclusive education, it can be seen that the current quality assurance system provides a good basis for further developments that will ensure transparency and accountability, as well as high quality education for all learners.⁹⁶¹

The Audit findings indicate that current challenges in a number of key areas can be addressed by:

- Ensuring that inclusive education becomes an integral part of all legislation and is consistent with the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Policy and practice should focus on maximising learning opportunities for all learners based on a clear vision for inclusive education shared with all stakeholders.
- Developing a longer-term approach to policy-making to reduce fragmentation, outline clear roles and responsibilities and provide support at all system levels.
- Developing a strong leaders to build the capacity of mainstream schools and to implement policy and practice that reduces barriers to learning and participation through greater collaboration among all stakeholders.
- Developing a continuum of support in schools/classrooms and providing support for teachers and other staff through specialist services that focus on upskilling school personnel.
- Providing training in inclusive education for all education stakeholders - policy makers, leaders, teachers and other professionals.
- Developing flexible curriculum and assessment frameworks and introducing teaching approaches approaches that engage all learners. All staff must take responsibility and work with all learners to ensure that the assessment process informs future learning with less emphasis on the summative examination system.
- Ensuring that needs identification and allocation of support emphasize early support and prevention rather than compensatory approaches. Parents and learners should be involved and links established between the classroom and the formal assessment process.
- Further developing monitoring and evaluation at all system levels to ensure that quality assurance procedures support capacity building for including all learners.

All the above-mentioned recommendations are inter-connected, but the quality of teaching and learning within a relevant curriculum and effective assessment procedures – is at the centre of all other recommendations.⁹⁶²

⁹⁶¹ <https://education.gov.mt/en/Documents/Special%20Needs%20and%20Inclusive%20Education%20in%20Malta%20C2%AD-%20External%20Audit%20Report.pdf> Page 13.

⁹⁶² Ibid. Page 16.

The Audit identified a number of inter-dependent priority steps that will be necessary to further develop effective policy and practice for inclusive education. These are:

- Creating clarity around the concept of inclusion through national dialogue, leading to a review of legislation and policy;
- Re-focusing support to increase the capacity of colleges and schools to meet the needs of all learners;
- Establishing a national training body to ensure the development of appropriate skills, knowledge and understanding for all education leaders, teachers and support personnel;
- Providing support to schools to help them to develop a curriculum to engage all learners and to use evidence-based assessment, teaching and learning approaches to meet diverse needs; and
- Promoting self-review at all system levels and using information to inform further improvement.

The Audit highlighted three critical levers considered as essential actions in the shorter term. These actions will underpin all future development.

1. Develop a stakeholder platform for discussion and agreement on key issues for inclusive education.
2. Audit current resourcing levels and identify possible models for more flexible resourcing.
3. Develop pilot projects to examine inclusive teaching and learning approaches.

Finally, the Audit suggested the development of a ten-year plan for education with wide stakeholder consultation and cross-party agreement to ensure that current plans for an inclusive system are implemented and sustained in the longer term.⁹⁶³

In order to fully grasp the importance of such findings, one must delve into the relative history of education targeted for persons with disabilities in Malta. Malta has one of the highest proportions of learners with disabilities and/or special educational needs attending mainstream education among the EU Member States.

Agency data from 2012 shows that from a population of 46,947 learners of compulsory school age (data from school year 2011–2012), 2,572 were formally recognised as having SEN, i.e. statemented.⁹⁶⁴ This is an identification rate of 5.5%, which is relatively high in comparison to other EU countries (the EU average is approximately 4.2%). Some 2,507 learners with SEN were placed in mainstream schools, giving a mainstream placement rate of 5.4%.

Fifty-four learners were placed in special schools and 11 in a special unit. This gives a segregated placement rate of just over 0.1%, which is one of the lowest across EU countries.

⁹⁶³ <https://education.gov.mt/en/Documents/Special%20Needs%20and%20Inclusive%20Education%20in%20Malta%20%20C2%AD-%20External%20Audit%20Report.pdf> Page 17.

⁹⁶⁴ European Agency for Development in Special Needs Education, 2012

Public special education services started in the 1950s and continued expanding until the 1980s. The early integration of children with disabilities into mainstream schools resulted from British influence through the Warnock Report.⁹⁶⁵ A British-style 'statementing' process was also introduced in 2000 to identify and assess children experiencing difficulties in the education system. The statementing procedure involves a formal multi-disciplinary assessment, while the Statementing Moderating Panel (SMP) advises on the special provision required.

In 1998, an independent evaluation of the Inclusive Education Programme in Maltese Schools was conducted.⁹⁶⁶ This was followed in 2005 by the Inclusive and Special Education Review.⁹⁶⁷ This report provided an evaluation of learning support and the statementing process and proposed a break with the expectation that learning support must be given by LSAs. It also made recommendations regarding training and support for class teachers and the role of specialist teachers.

Following this report, the Student Services Department (SSD) in the Directorate for Educational Services (DES) was set up in 2007, followed in 2008 by the appointment of Service Managers to manage the Inclusive Education Section, Special Education and Resource Centres and Psycho-Social Service.

Up to 2005, few learners with special needs were included in secondary or upper-secondary education. However, many learners now join lower-secondary schools while some also move into tertiary education. In 2009, the Student Services Department published proposals for special school reform.⁹⁶⁸ The four special schools were subsequently changed into resource centres: one primary, two secondary and one for young adults. Each centre is incorporated within a college and aims to offer services to mainstream schools, as well as providing full-time education for a small number of learners with complex needs.

Throughout these last years, disability issues in Malta have experienced positive developments. From a taboo subject, disability developed into a paternalistic care oriented approach, where persons with a disability were considered in need of care and protection.

Later, it shifted to a more human rights approach that recognises Persons with Disabilities as active and equal participants in society, including its governance. This "shift to a human rights model was contingent on both reinforcing a shift in approach to the way disability is viewed in Malta, as well as the creation and/or strengthening of necessary mechanisms to back up said approach" (first Parallel Report to the UNCRPD Committee submitted by CRPD in March 2018, p.4).⁹⁶⁹

Despite these important milestones, which have led to the development of various support and enabling services and the protection of fundamental rights and freedoms as well as the shift

⁹⁶⁵ Warnock Report (1978)

⁹⁶⁶ Borg, Borg, and Martinelli, 1998

⁹⁶⁷ Spiteri et al., 2005

⁹⁶⁸ Ministry of Education, Culture, Youth and Sport, 2009b

⁹⁶⁹ https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/countries.aspx?CountryCode=MLT&Lang=EN.

from a medical model to a social model of disability, ensuring the wellbeing of Persons with Disabilities, demands an ongoing commitment to safeguard and promote equality.

Although in 2015 and thereafter, the poverty or social exclusion rate and the unemployment rate in Malta declined, Persons with Disabilities were among the most vulnerable groups that still faced substantial risks in this regard, coupled with high levels of people with disabilities being early school leavers. Hence, adequate attention needs to be addressed to mainstream disability issues across the wider policy agenda and in turn ensure that disability policies take due account of factors and circumstances such as sexism, racism and xenophobia, violence and abuse, that may place Persons with Disabilities at higher risk of vulnerability, disadvantage and social exclusion.

Netherlands

The Netherlands has a relatively strong position on social inclusion. Indeed, some consider it a role model within the EU in this sector. Employment rates are high, unemployment and 'at risk of poverty' rates are relatively low.

The active inclusion strategy of the Netherlands can be characterised as comprehensive. In line with the 2008 Recommendation: it includes the three social pillars. Labour market participation is considered to be the key to preventing poverty and social exclusion. Dutch strategies, both before and after the 2008 Recommendations, thus focused on increasing employment and employability. The new and expanded active inclusion strategies (introduced after the 2008 Recommendation) aim to increase the labour market participation and working hours of women, the (partially) disabled and the long-term unemployed, for example. These measures have been successfully reached.⁹⁷⁰

In 2009 and 2010 the government introduced several measures to stimulate the economy and to combat unemployment. These measures included an increased availability of services as assistance to job-seekers, education and training programmes. Austerity measures also formed part of the crisis package. After a period of investments, in 2010 the former Dutch government decided to cut back the budgets for reintegration and sheltered employment and reducing health costs. In 2011 the previous government (the Dutch government fell on 21 April 2012)⁹⁷¹ announced reforms and major cutbacks to social security and welfare that had a negative effect on social inclusion. The fall of the Dutch Government¹ meant that this law had to be shelved. However the cutbacks in the reintegration budgets, for instance, have already taken place.⁹⁷²

Most of the social inclusion measures adopted in the Netherlands benefited persons with disability even though they were not exclusively targeted for this particular sector of Dutch society only. A paper written by Florence Kuyper from the Eindhoven municipality and Heidi de Bodt and Paulien van der Hoeven from the Ministry of Social Affairs and Employment underline this very factor.⁹⁷³

At a local level, social and well-being services are more and more organised around the principles of promoting personal autonomy, cooperation of organisations based on shared perspectives and goals, stimulation of participation and area based approach (territorial specificity). As for the general goal and the specific contents of the programme, the authors of the report found it difficult to measure.

⁹⁷⁰ https://en.unesco.org/inclusivepolicylab/sites/default/files/clearinghouse/document/2016/10/Netherlands%20-%202012%20report%20on%20active%20inclusion_en.pdf

⁹⁷¹ The Dutch Government fell after seven weeks of closed-door talks on austerity measures, which were aimed at reducing the budget deficit from an expected 4.7% to below 3% in 2013.

⁹⁷² https://www.opensocietyfoundations.org/sites/default/files/netherlands_2006_0.pdf

⁹⁷³ Local Social Inclusion from the Dutch point of view. Peer Review: Programme for Developing Local Plans for Social Inclusion in Cataluña, Spain.

The general goal of the programme was to stimulate measures for social inclusion through a model of intervention in collaboration with all the agents of the territory. At a city level, the municipality provides a policy framework. Together with the relevant organisations, a working plan is defined (including financial support). This process mostly occurs at the city level and only occasionally on a regional level (e.g. homeless).

The content of the programme seemed to be an elaboration of the guiding principles and therefore relevant for a city. The content seems not new in itself and the added value is probably found in the process more than in the content.

With regards to the potential transferability of the programme, the report found that at the national level the following elements might be of interest:

- Outcome Monitor developed by the Central Bureau of Statistics (CBS).
- 'Leefbaarometer' (quality of living barometer). This gives municipalities and counties online information about the situation of all neighbourhoods.
- The division of roles of local authorities and the national government
- The ways in which knowledge transfer is put in practice. This is amongst others, done by experiments on several key subject initiated by the national government and by independent experts visiting the cities involved.

At a local level there are possibly a couple of possibilities:

- working on social inclusion on a regional level would give the municipalities more insight in each other's problems and solutions: a learning experience
- treating social inclusion in the framework of a programme with a well-elaborated underlying structure, obliges to measure the coherence of approaches and the added value. It would definitely stimulate cooperation because it seems a process of co-creation.

The disadvantage was noted to be that this approach seems rather an analysis and policy driven method. A city needs operational force in order to tackle all the problems. If one adds to this the foreseen budget cuts, it is not very probable that much time could have been spent on policy and analysis. Taking into account the experience in the Netherlands there certainly are specific issues that the authors underline: the fact that the Netherlands insists that children with intellectual disabilities are required to attend school unless they have been granted an exception, which is often the case for people with a very low developmental age. A two-track educational system exists for children with intellectual disabilities, who may either be placed in a mixed school system, which is organised in local networks that include both mainstream and special schools, or in the special school system, in which students are grouped into one of four "clusters" according to their diagnosis. There are waiting lists for children seeking to be placed in the special education system, largely due to the extensive testing that is required for admission. Generally, concerns regarding the assessment process centre on the waiting periods and the bureaucratic requirements which must be met by schools and parents.⁹⁷⁴

⁹⁷⁴ Ibid.

Chuka Nwanazia, however, thinks differently. In an article in the Dutch Review⁹⁷⁵ he states that living with a disability, physical or mental, can be quite difficult in the Netherlands. There are over two million people in the Netherlands with a disability, including people with limited or no hearing or sight, and those with a physical or mental disability. The Netherlands has received EU funding, mainly from the EQUAL programme and the European Social Fund (ESF), to develop vocational training and secondary school programmes for children with intellectual disabilities. However, a substantial proportion of these funds have not been utilised, due to a lack of government co-funding and limited capacity of local schools to access the funds.

Although recent policy developments are phrased in the language of inclusion, the Dutch education system remains largely non-inclusive. Thus, the education system does not yet meet the aims of the UN Standard Rules and the Salamanca Statement. In fact, inclusion of children with intellectual disabilities in inclusive settings remains low, and even the goal for inclusion of children with disabilities through the “backpack” funding system over time is only 25 percent of the population of all children with disabilities. The maintenance of two separate systems, even with the introduction of pupil-specific financing, is not compatible with inclusion.

When the Netherlands ratified the UN Convention on the Rights of Persons with Disabilities in the summer of 2016, a wave of joy spread through the disabled community. The joy was also felt among parents and partners of people with disabilities. They felt that the long-awaited change had come, and the rights of people with disabilities would finally be respected and recognised. The Netherlands was going to enforce equal opportunities for work, education, housing, voting, etc. The introduction of the treaty brought hope.

The Netherlands only ratified the treaty nine years after the signing. The House of Representatives had repeatedly urged the government on an implementation plan.

Speaking at the European Disability Forum (EDF) conference in 2016, Martin van Rijn, the then Secretary of State for Health, Welfare and Sport, said, “Our guiding principle is that everyone in the Netherlands has the right to participate fully and equally in society. No one should be excluded.”

“But sadly’ it’s often more difficult for people who cannot participate in society than it is for people who don’t,” he added.⁹⁷⁶

Whilst, as mentioned, in 2016, the Netherlands ratified the UN Convention on the Rights of Persons with Disabilities (UN CRPD), it still was one of the last developed nations to do so. In a penetrating article entitled ‘Disability, Access to Food and the UN CRPD: Navigating Discourses of Human Rights in the Netherlands’ the authors explore how equal access to food provides a lens through which barriers to implementing a rights-based approach to disability equality can be examined in countries that are historically resistant to such discourses. Through a literature review, policy research, and interviews with disabled people, representatives of disabled people’s organisations, Dutch legal scholars, food researchers, and foodbanks, they have

⁹⁷⁵ <https://dutchreview.com/culture/living-in-the-netherlands/how-inclusive-is-the-netherlands-for-people-living-with-disabilities/>

⁹⁷⁶ Ibid.

barriers to equal food access in the Netherlands, and current approaches to overcoming social, economic and physical barriers. Their analysis indicates that implementation of the UN CRPD and other relevant international and EU policies continues to be limited in the Netherlands due to narrow interpretations, leading to policies and practices that do not foster equal access to resources and environments. Dutch understandings of disability equality are evolving, but encounter opposition from an entrenched system of separation and resistance to mandating change, including a reluctance to even collect data about inequality. From this basis, the authors duly identify knowledge gaps and make serious recommendations for steps the Netherlands could take to ensure equal access to food.⁹⁷⁷

About one million persons with disabilities, out of 16 million inhabitants, live in the Netherlands. The government has developed policies to ensure their participation in society as much as possible and to ensure education according to the specific needs of the child.

While there is no specific legal framework on the situation of children with disabilities, nor a national strategy for persons with disabilities, key legal instruments for children and persons with disabilities have been adopted which are equally applicable to children with disabilities, such as the law on persons with disabilities or chronic illness.

In some cases the right or principle is directly recognised in the Dutch legislation, such as for the right to non-discrimination on the grounds of disability. However in most cases, the right or principle is not formally provided in the legal framework but procedural safeguards, legal requirements, informal recognitions of the right in the case-law or direct applicability of the CRC provisions ensure its legal implementation.⁹⁷⁸ Furthermore, specific safeguards require the consideration of the best interests of the child in some matters, such as family and youth care matters.⁹⁷⁹

While in general children with disabilities benefit from protection and have their rights effectively guaranteed legally, in practice problems exist. The right to non-discrimination on the grounds of disability, as well as the right to reasonable accommodation, is guaranteed, however its scope is limited to employment, education and public transports. In addition areas such as access to public buildings need further attention from policymakers.

The legal framework ensures that children with disabilities have the possibility to opt for attending a special school, with smaller classes and adapted material or a mainstream school thanks to a personal budget system, known as the 'rugzakje'. However, children with severe and/or multiple disabilities are often institutionalised and receive no education at all. Announced budget cuts and the approval of the Senate of a new law regarding the appropriate education sparked fear for discrimination or problematic access to the educational system for children with disabilities.

⁹⁷⁷ <https://www.cogitatiopress.com/socialinclusion/article/view/1160>

⁹⁷⁸ This is the case for example for the right to family life, which is not present in the legislation but Article 8 of the ECHR is directly applicable. Another example is the right to education, where no right is recognised but a duty is imposed on the State to provide education and children are required to attend schools.

⁹⁷⁹ In addition, Article 3 of the CRC is considered directly applicable.

Access to healthcare and assistance to children with disabilities is ensured and relatively well organised. Parents can receive compensation (financial or material) for their child with disabilities living at home. Municipalities also offer different types of assistance; either financial (in the form of a personal budget) or material (adjustments at home). However, children with disabilities and children in need of mental healthcare in particular have been identified as extremely vulnerable groups. Children with psychological problems causing dysfunction in their everyday life do not receive adequate support as a result of lack of resources. It is also evident that little data is available on the situation of children with disabilities.

Some good initiatives and best practices have been established, such as enabling children's participation or ensuring awareness of children's rights, and many schools have an anti-bullying policy. An early intervention system has also been put in place to coordinate assistance for families with children with disabilities, including early diagnosis and an individual plan for the child and his/her family to ensure the child receives care and education.

Overall, children with disabilities in the Netherlands benefit from assistance and protection. However, children with disabilities still face barriers to the full enjoyment of their rights. Children with intellectual and psychosocial disabilities are identified as particularly vulnerable and unfortunately, budget cuts may affect the assistance and education provided to children with disabilities.⁹⁸⁰

From the number of around one million persons with disabilities, government officially notes that around 113,000 people living in the Netherlands have a serious intellectual, physical or sensory impairment. They need lifelong care and supervision, 24 hours a day. The Dutch government wants to invest extra effort in improving the care for these people, as well as their quality of life.

But let us take a closer look at the numbers, according to official data. The number of children and adults residing in institutional care or community-based setting can be deduced out of the number of people who are formerly declared to be entitled to residential care.⁹⁸¹ There is a very accurate account of the number of people declared (at their own request) eligible for residential care. Not all children and adults who have the eligibility status actually reside in institution. Care providers may provide care within someone's own home. People who are eligible may also opt for a direct payment and organise their care in their own home with that payment. At the same time, people who have direct payment, may use that payment to buy their place in a residential care institution.

The total number of children in residential care based on youth care act (paid for by municipalities) in 2017⁹⁸² was 46,185 children. This group includes children in foster homes

⁹⁸⁰ https://www.europarl.europa.eu/meetdocs/2014_2019/documents/libe/dv/25_nlcountryreport_/25_nlcountryreport_en.pdf

⁹⁸¹ Statistics Netherlands (CBS) <https://www.cbs.nl/en-gb/about-us/organisation> provides these figures and feeds into international data sources such as OECD 2018, Long-Term Care Resources and Utilisation: Beds in nursing and residential care facilities / Long-term care recipients - <https://stats.oecd.org/Index.aspx?QueryId=30142>.

⁹⁸² Jongeren met jeugdzorgcombinaties in natura; kenmerken, regio, 2015-2017 <https://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=82965ned&D1=a&D2=0,3-6&D3=0&D4=l&HDR=G3,G2,G1&STB=T&VW=T>

(when custody of their parents is taken away) children who committed crimes, children who show severe behavioural problems) and children with disabilities who need support. If children in foster homes, children with behavioural issues and children who committed crime are taken out, a group of 10,355 remain of children who receive long term residential care remain, likely due to disabilities.

Another group of around 3,200 children in 2018 (3,500 in 2016) are eligible for long term care and they actually live in residential settings. ⁹⁸³

The number of adults entitled to residential care was 295,115 (year 2017). ⁹⁸⁴ Of these 95,100 were between 18-65 years of age. The number of 95,100 can be broken down to 4,430 people with mental health disorders; 6,535 with physical disabilities and 84,135 people with intellectual disabilities or a combination of physical and intellectual disabilities. It should be noted that people with mental health disorders can be living long term in psychiatric hospitals or residential homes for people with psychiatric disorders. These psychiatric hospitals and homes are (for the first three years for every patient) financed based on Health Care Act ⁹⁸⁵ as opposed to Long term Care Act. ⁹⁸⁶ People living there in the first three years are not within the number of people eligible for long term care.

Adults who are eligible for long Term Care may opt for a “care package at home”. Of the total of 295,115 people receiving long term Care 14,190 people (4.8 %) opted for a care package at home. Another group of 22,985 people (7.7 %) opt for a direct payment with which they can organise either care in their own home or pay for a place in a residential home.

According to the Ministry of Health, Welfare and Sport about a quarter of people with an intellectual disability (to be distinguished from the elderly eligible for long term care) not the elderly) eligible for long term care opt to stay out of a residential home and one in five people with an intellectual disability opt for a direct payment. ⁹⁸⁷

The number of people with intellectual disabilities in the Netherlands has been estimated at 142,000 in the year 2013, measured as people with an IQ below 70. This represents 0,85 % of total population. Of that total of 142,000 an estimated number of 68,000 had an IQ below 50. ⁹⁸⁸

⁹⁸³ Estimation by a spokesperson of the association of care providers for people with disabilities VGN.

⁹⁸⁴ Statistics Netherlands CBS: Gebruik bijdrageplichtige Wlz-zorg; leveringsvorm, zzp, regio <https://mlzstatline.cbs.nl/Statweb/publication/?DM=SLNL&PA=40055NED&D1=0&D2=0&D3=0,10-12&D4=a&D5=0-2,13,44&D6=0&D7=l&HDR=G5,G1,G2,G3,T,G6&STB=G4&VW=T>.

⁹⁸⁵ Zorgverzekeringswet 2005 <https://wetten.overheid.nl/BWBR0018450/2019-01-01>.

⁹⁸⁶ Wet Langdurige Zorg 2014 <https://wetten.overheid.nl/BWBR0035917/2019-01-01>.

⁹⁸⁷ Noted in the report Volwaardig Leven by Ministry of Health, Welfare and Sport, page 56. <https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/09/30/programma-volwaardig-leven/Programma+Volwaardig+leven.pdf>.

⁹⁸⁸ Based on research by SCP the Netherlands Institute for Social Research and noted on the webpage: Prevalentie van verstandelijke beperking Gezondheidszorginfo. <https://www.volksgezondheidenzorg.info/onderwerp/verstandelijke-beperking/cijfers-context/huidige-situatie#!node-prevalentie-van-verstandelijke-beperking> and in the report Volwaardig Leven, page 56. <https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/09/30/programma-volwaardig-leven/Programma+Volwaardig+leven.pdf>.

The association of care providers VGN ⁹⁸⁹ stated that residential care is provided for a total of 87,650 people (adults and children) with disabilities, of which 75,750 have an intellectual disability, 2,400 have a sensory disability and 9,500 a physical disability.

Legislation for long term care makes it possible for people with disabilities to choose direct payment or to ask a care provider to provide care at home. Care providers are completely free to decide how they organise long term residential care: either in large residential settings (with usually groups of people clustered together with an individual bedroom, in group homes (of around 10 to 30 people living together) or in small group homes or individual homes. There is no inventory of living conditions known.

A major reform of long-term care was implemented from 2015. The aim was to provide more personalised care of higher quality, to have fewer people (elderly people and people with a disability) living in institutions, to enhance social cohesion (such that people within social networks would provide each other more informal care and support), and to reduce the growth of cost experienced in recent years. ⁹⁹⁰ The means to reach these aims were to shift responsibility of providing all long-term care for children and all non-residential care for adults to municipalities with a tighter budget and to introduce stricter eligibility criteria for long term residential care (only for people with intellectual disabilities and dementia in need of constant surveillance). Since this reform, the number of people receiving long term care decreased from 324,585 to 320,030 (2015-2017) and the number of people within this group requesting direct payment grew from 28,400 to 34,060. ⁹⁹¹

In The Netherlands, curative mental health care and supportive care for people with an intellectual disability (ID) are organised in separate domains. Prevalence of mental health problems is known to be high among people with borderline intellectual functioning (BIF) or mild intellectual disabilities (MID). By contrast, according to recent findings, prevalence of BIF and MID is high among patients in mental health care (17.5–58 per cent). In The Netherlands, a new quality standard of care (QSOC) on mental health care for people with BIF or MID is developed. It is designed to supplement existing guidelines on mental health care so that they can be used appropriately in people with BIF or MID and meant for use in both mental health care organisations (MHCO) as in organisations for ID care. To a large extent, the QSOC should describe the existing practice. ⁹⁹²

To assess the existing practice in current mental health care for people with BIF or MID in The Netherlands, celebrated researchers examined the views and accessibility of MHCO on the mental health care for patients with and IQ<85. ⁹⁹³ In addition, the authors of this research reviewed published criteria for in- and exclusion of all 39 top clinical mental health care departments for criteria on BIF or (mild) ID.

⁹⁸⁹ Webpage VGN, association of care providers: <https://www.vgn.nl/feitenencijfers>.

⁹⁹⁰ Country report Netherlands on the European semester, <https://www.disability-europe.net/downloads/889-task-eu2020-year-3>.

⁹⁹¹ Statistics Netherlands CBS: Gebruik bijdrageplichtige Wlz-zorg; leveringsvorm, zzp, regio <https://mlzstatline.cbs.nl/Statweb/publication/?DM=SLNL&PA=40055NED&D1=0&D2=0&D3=0,10-12&D4=a&D5=0-2,13,44&D6=0&D7=0,I&HDR=G5,G1,G2,G3,T,G6&STB=G4&VW=T>

⁹⁹² <https://www.emerald.com/insight/content/doi/10.1108/AMHID-03-2018-0014/full/html>

⁹⁹³ Awareness and accessibility of the Dutch mental health care system for people with borderline intellectual functioning or mild intellectual disabilities: Jannelien Wieland, Mascha ten Doesschate

The authors found there is a clear awareness of the high prevalence of BIF and MID among large Dutch MHCO. Dutch MHCO estimate the prevalence of BIF and MID among their patients to be around 30 per cent. Nonetheless, most MCHO surveyed (76 per cent) indicated they do not routinely estimate or measure IQ among their patients and 53 per cent of MHCO indicated not having knowledge and expertise on the dual diagnoses of mental health problems and BIF or MID. Fitting in with the new QSOC most of the MHCO (59 per cent) agreed on the statement in the survey that professionals should be able to treat patients with BIF or ID and all but one of the MHCO stated to have some form of collaboration with an institute for ID care.⁹⁹⁴

Little is known about the organisation of after-hours primary care for people with intellectual disabilities, and mainstream care is not self-evidently accessible or fit for this group. A first step towards improvement is a greater understanding of current after-hours primary ID care. A particular study explored the organisation of and experiences with after-hours primary care provided for people with ID in The Netherlands.⁹⁹⁵

A multitude of different after-hours primary care arrangements were found. Primary care physicians (PCPs) were involved in almost all care provider services, often in alliance with PCP cooperatives. Specialised ID physicians had differing roles as gatekeeper, primary caregiver, or consultant. Most problems during the after-hours arose regarding daily care professionals' competences. Facilitators and inhibitors of after-hours primary care were themed around complexity of, and need for, specialised care, multidisciplinary team of professionals, communication and information, and prerequisites at organisational level.⁹⁹⁶

Financing system and regulations leave much discretionary freedom to providers of residential care to organise housing options for people with disabilities dependent on their care. The financial budgets assume group living but there are possibilities to finance small living arrangements or even independent living. This freedom for care providers leads to a large variety of options offered by care providers in residential care.⁹⁹⁷ Two⁹⁹⁸ out of 31 larger care providers⁹⁹⁹ for people with disabilities have been known for their policy to close down all residential buildings and transferring all clients to small community-based group homes or to individual homes. One of these care providers, Arduin, decided December 2018 to relocate all clients back to clustered group living due to financial problems.

⁹⁹⁴ Advances in Mental Health and Intellectual Disabilities, Vol. 12 No. 3/4, pp. 114-120.

⁹⁹⁵ After-hours primary care for people with intellectual disabilities in The Netherlands—Current arrangements and challenges: Marloes Heutmekeers, Jenneken Naaldenberg, Tessa K. Frankena, Marleen Smits, Geraline L. Leusink, Willem J.J. Assendelft, Henny van Schroyensteyn, Lantman-de Valk.

⁹⁹⁶ Ibid.

⁹⁹⁷ Country study Netherlands on the right to independent living of persons with disabilities: Summary overview of types and characteristics of institutions and community-based services for persons with disabilities available across the EU. Fundamental Rights Agency, November 2017. https://fra.europa.eu/sites/default/files/fra_uploads/netherlands-services-mapping-independent-living-nl.docx.

⁹⁹⁸ Care provider Arduin <https://arduin.nl/> and Esdege Reigersdaal <https://www.esdege-reigersdaal.nl/>.

⁹⁹⁹ Members of the association VGN: <https://www.vgn.nl/feitenencijfers>.

The Ministry of Health, Welfare and Sport allocated in January 2019 EUR 20 million to this care provider to help finance what can be considered re-institutionalisation.¹⁰⁰⁰

On its part, the Ministry of Health, Welfare and Sport, responsible for this specific sector has published a thumbnail related how society and the authorities are working to improve disabled care together.¹⁰⁰¹ The government's aims are projected as follows:

Improving the position of people with a disability

People with a disability and their families should be able to make their own choices about the way they live their lives. This includes choices about their care and support.

Investing in people with special care needs

People with severe multiple disabilities, intellectual disabilities or serious mental health problems have complex care needs. People with acquired brain injury and ageing people may also need comprehensive nursing and personal care as well as companion care and support.

Ensuring care professionals are competent and involved

Care professionals must have or acquire the skills to engage fully with patients. They will be given more professional freedom.

Improving cooperation and governance

Managers must strive to achieve quality and improve cooperation between staff members within their institution and with institutions in other care domains.

Promoting transparency, technological innovation and cooperation

All this is set out in the online available letter to parliament entitled 'Working together to improve disabled care'.¹⁰⁰²

This ministry has embarked on a number of specific programs in order to reach the above targets:

*Implementation plan: 'Programma VN-verdrag Onbeperkt meedoen!' (2016).*¹⁰⁰³

The plan focuses on seven themes: building and living, work, education, transport, participation and accessibility, care and support and national Government as an employer. When it concerns the theme building and living, the aim is to improve accessibility of buildings and to provide 'enough' houses and group homes for people with disabilities. Within the theme care and support the aim is to guarantee 'good quality' of care and support as this is considered an

¹⁰⁰⁰ Letter to Parliament by the minister of Health, Welfare and Sport on the financial problems at care provider Arduin. <https://www.tweedekamer.nl/downloads/document?id=94e96d39-b643-4430-b565be0f640ba0dc&title=Continu%C3%AFteit%20van%20gehandicaptenzorg%20in%20Zeeland.pdf>.

¹⁰⁰¹ <https://www.government.nl/topics/nursing-homes-and-residential-care/care-for-people-with-disabilities>

¹⁰⁰² <https://www.rijksoverheid.nl/onderwerpen/verpleeghuizen-en-zorginstellingen/documenten/kamerstukken/2016/07/01/kamerbrief-samen-werken-aan-een-betere-gehandicaptenzorg>

¹⁰⁰³ Programma VN-verdrag Onbeperkt meedoen, Ministry Health, Welfare and Sport. June 2016. <https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2018/06/01/programma-vn-verdrag-onbeperkt-meedoen/programma-vn-verdrag-onbeperkt-meedoen.pdf>

important condition to participate in society. There is no explicit aim of deinstitutionalisation and no quantifiable targets in any of the themes.

*Plan for improving quality of care and standard of living for people with severe disabilities and complex needs 'Programma Volwaardig leven' (2018).*¹⁰⁰⁴

The aim is threefold; to improve quality of (residential) care for people with more severe disabilities, by making it more person centred and to enable people in residential care to gain more control over their lives; to provide 'enough' and at least 100 more residential places for people with complex needs and to provide at least 425 family members of people with severe disabilities support in organizing adequate care and support within the bureaucratic eligibility system. The aim is not to deinstitutionalize.

*Plan to improve opportunities to live independently: 'Programma Langer Thuis' (June 2018)*¹⁰⁰⁵

This programme is specifically aimed at elderly people who are in need of care and support. The aim is to enable elderly people to live independently during a longer period. National Government has the aim to reduce costs for long term care¹⁰⁰⁶ and implicitly aims to have a lower percentage of elderly people living in residential care. No quantifiable target is set.

*Action plan for youth care: Actie programma zorg voor de jeugd (2018)*¹⁰⁰⁷

This plan aims to improve quality of youth care, to improve access to youth care, to support children in need of youth care in an environment that resembles 'home' as much as possible and to end separation in closed residential settings for children.

But what about inclusivity in the educational sphere? The SLO is the National institute for curriculum development in the Netherlands.¹⁰⁰⁸ SLO was founded thirty years ago by the Dutch government to give independent, professional advice on, and support for curriculum innovation, development, and implementation. In performing our tasks, the SLO takes into account the developments in society in general, both nationally and internationally, and in education in particular. The SLO operates in virtually all sectors of education, including primary education, secondary education, special education, vocational education and teacher education, and covers all subject areas. SLO's central task is to advise the government on important education reforms and new curricula. It supports and coordinates curriculum development in collaboration with schools and universities, carries out curriculum evaluations, and provides information about teaching materials.

¹⁰⁰⁴ Programma Volwaardig leven (could be translated as Dignified Life), September 2018. <https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/kamerstukken/2018/09/30/kamerbrief-over-programma-volwaardig-leven/kamerbrief-over-programma-volwaardig-leven.pdf>

¹⁰⁰⁵ Programma Langer Thuis, by the Ministry of Health, Welfare and Sport, June 2018, letter to Parliament: <https://www.rijksoverheid.nl/documenten/kamerstukken/2018/06/18/kamerbrief-over-programma-langer-thuis>.

¹⁰⁰⁶ The programme Reforming Long Term Care as of 2015. See paragraph 2.1.

¹⁰⁰⁷ Actieprogramma Zorg voor de Jeugd, Ministry of Health, Welfare and Sport, April 2018.

<https://www.rijksoverheid.nl/documenten/rapporten/2018/04/01/actieprogramma-zorg-voor-de-jeugd>.

¹⁰⁰⁸ <https://slo.nl/international/>

Wherever possible, children with special needs in the Netherlands are encouraged to attend mainstream primary schools. The Passend Onderwijs (2014) stipulates that schools are obligated to investigate first whether they can provide additional support for children with special needs. If the child's needs fall beyond the resources available to the school, a child might be referred to a dedicated special needs school.

When searching for a school, it is important to realise that schools vary widely in their experience with special education support as well as their ability to provide it. It is always important to discuss your child's needs with any schools you are considering.

If one is arriving in the Netherlands with a child with special needs, one needs to note this with the municipality (gemeente) during the registration process so that appropriate steps can be taken to find support for the child. If your child was born in the Netherlands, their special needs care will be led by the GGD and/or their school.¹⁰⁰⁹

There are two types of dedicated special needs schools in the Netherlands: speciaal basisonderwijs (SBO) and speciaal onderwijs schools.

At SBO schools, the pupils follow the same program and have the same key objectives as regular primary schools but the class sizes are smaller and the children get more attention and support, if needed. They also get more time to complete primary school (until age 14, normally it is age 12). This type of education is especially meant for children who have learning difficulties, low IQ scores, and behavioural problems.

Speciaal onderwijs schools focus on a type or group of special need support and are known as cluster schools. The class sizes are smaller than at regular schools and the students get more tailor-made support. Cluster schools often work together in order to provide the most suitable support.

Cluster 1 schools are for children who are visually impaired or blind.

Cluster 2 schools are for children who have hearing or speech impairments.

Cluster 3 schools are for children who have cognitive or physical disabilities, or a chronic illness that makes going to school difficult.

Cluster 4 schools are for children with serious behavioural and/or social differences (Autism, ADHD, PDD-NOS, ODD, CD, etc.).

In order for a child to be accepted to one of such schools, s/he will need an indication first. They will have to get several evaluations and tests, and the parent will be interviewed. It can be a very lengthy process. An onderwijsconsulent can assist the family in this process. If the child makes enough progress at a special needs school, s/he can transfer to a mainstream school after a couple of years. After a special needs primary school, a child can go to either a regular secondary school (with extra support, if needed), or to a special needs school at secondary level. A special needs school at secondary level will make an educational plan with the child and guide them towards a suitable job.

The language of instruction at special education schools is Dutch.

¹⁰⁰⁹ <https://amsterdam-mamas.nl/articles/special-needs-education-support-netherlands>

Other Schools: Visio Education has seven schools that provide special education and secondary special education for pupils with visual impairments, as well as children with multiple (visual and mental) disabilities. They also guide pupils with visual disabilities in the regular education system. They moreover provide information and advice as well as different services related to research, counselling, rehabilitation, education, and living.

Lighthouse Special Education is an international primary school in The Hague, part of the HSV (Haagsche Schoolvereniging), which offers English instruction for children with special needs. Children between 3 and 5 years attend its International Pre-School Group, "Three Little Ships" (Early Intervention Program).

You will find Special Educational Needs (SEN) teachers at international schools (both private and partially-funded schools) where the language of instruction will be (mostly) English, but you might be required to fund the assistant. Many international schools in the Netherlands provide specific support programmes for their students, so it is worth contacting schools directly for more information.

Some regular schools have a dedicated department for gifted children, which provide extra cognitive challenges and subjects, such as Leonardo Schools for Gifted Children. Many schools also have a plusklas which offers gifted children some extra challenges for a few hours per week. The Day a Week School in Amsterdam offers a program for gifted children from various schools to work one day per week on special projects.¹⁰¹⁰

The Equal Treatment on the Grounds of Disability and Chronic Illness Act, adopted in 2003, brought the Netherlands fully into compliance with the EU's Employment Directive. The Act covers all aspects of the employment process, including hiring and placement. An extensive legislative framework establishes a range of benefits and services available to most people with intellectual disabilities. Many benefits include support for finding employment. Each employment-related benefit requires an assessment process, which also includes an assessment of capacity to work in a sheltered or supported setting.¹⁰¹¹

As in the education field, EU funding to support employment of people with intellectual disabilities has been underutilised. Both the EU's own application procedures, including age restrictions which many see as too high, as well as a lack of support for local governments wishing to apply for funding, contribute to the EU funds going unspent. Government policy has been shifting towards encouraging people with disabilities to support themselves, and to offer incentives for employment. There is no quota system in the Netherlands; the Government has urged employers to adopt voluntary two-percent hiring targets for people with disabilities, but it is unclear if this system is monitored in any way. A number of subsidies are available to employers who hire people with disabilities, including training and job coaching support. However, the number of people with intellectual disabilities who are in fact employed on the open market remains very small.

¹⁰¹⁰ <https://amsterdam-mamas.nl/articles/special-needs-education-support-netherlands>

¹⁰¹¹ <https://www.disability-europe.net/country/netherlands>

In the Netherlands, the number of people with intellectual disabilities able to access either supported employment or sheltered employment is relatively high; around 45 per cent of the estimated 73,000 adults with intellectual disabilities. The majority of people with intellectual disabilities who are employed work in sheltered employment, while many others have employment-like occupation in day centres. Only four per cent of people with intellectual disabilities participate in supported employment, although a much larger proportion has applied for such support under the relevant programmes.

The Government has allocated substantial funds towards helping young people with disabilities to find work on the open market, but in some cases local government has been reluctant to implement supported employment policies. In contrast, sheltered employment is well established in the Netherlands; where workers are under contract, they receive pay on a scale negotiated through collective bargaining, and have the opportunity to build skills. However, few people do make the transition from sheltered work to employment on the open market, and despite reductions in waiting lists, the demand for sheltered work still exceeds the available places.¹⁰¹²

¹⁰¹² <https://www.disability-europe.net/country/netherlands>

Poland

The institutionalised care provided in social care homes (dom pomocy społecznej - DPS) is the dominant model of state-funded care, and the de-facto main form of sustained, guaranteed daily support to persons with disabilities, when no support by the family is provided. There are several sources of data on institutions and it might be concluded that there are more than 800 institutions where more than 80,000 persons live, though the actual numbers reveal inconsistencies.

For instance, the Central Statistical Office (CSO) data shows that in 2016 there were 863 DPS (601 public and 262 non-public),¹⁰¹³ while the data provided by the Ombudsman reports 817 institutional settings where 83,967 persons were living in 2016. An average number of residents per nursing home amounts to approximately 103 persons per year.¹⁰¹⁴ The number of persons waiting for placement in DPS in 2017 per 1000 inhabitants reached 1.8.¹⁰¹⁵

The number of incapacitated persons in institutions is unknown, yet the estimations speak about at least 12 000 persons. Moreover, the data on DPS might not give a full picture as the role of nursing homes is often performed also by residential medical care facilities (zakłady opiekuńczo-lecznicze (ZOL) and zakłady pielęgnacyjno-opiekuńcze (ZPO)), yet it is not their statutory function. In 2016 there was 554 ZOL and ZPO (1.1% less than in 2015), providing 31,900 beds (this is 1.1% more than in 2015, 26,000 in general care and 5,900 in psychiatric care),¹⁰¹⁶ services were provided to 61000 persons.¹⁰¹⁷

The OECD data shows a higher number - in 2016 the number of long-term care recipients (all ages, without hospitals)¹⁰¹⁸ reached 102 721, and there were 72 460 beds in residential long-term care facilities.¹⁰¹⁹

The data on community-based setting provided by the Ministry of Family, Labour and Social Policy reports following numbers for 2017:¹⁰²⁰

¹⁰¹³ GUS (2018), Pomoc społeczna i opieka nad dzieckiem i rodziną w 2017 roku.

¹⁰¹⁴ RPO (2018), Informacja Rzecznika Praw Obywatelskich o działaniach podjętych przez Rzeczpospolitą Polską w celu implementacji postanowień Konwencji o prawach osób niepełnosprawnych w latach 2015-2017,

<https://www.rpo.gov.pl/sites/default/files/Informacja%20RPO%20dla%20komitetu%20ONZ%20z%20wdra%C5%BCania%20Konwencji%20o%20prawach%20os%C3%B3b%20z%20niepe%C5%82nosprawno%C5%9Bciam%20%28j%C4%99z.%20polski%29.pdf>.

¹⁰¹⁵ Analiza sytuacji województw w obszarach oddziaływania Europejskiego Funduszu Społecznego w latach 2015-2017, <https://www.power.gov.pl/strony/o-programie/raporty/opracowania/#/domyslna=1>.

¹⁰¹⁶ As of 2016 34700 beds are available in stationary psychiatric care (1,3% more than in 2015) (GUS 2017).

¹⁰¹⁷ GUS (2017), Health and health care in 2017,

<https://stat.gov.pl/obszarytematyczne/zdrowie/zdrowie/zdrowie-i-ochrona-zdrowia-w-2016-r-,1,7.html>.

¹⁰¹⁸ Number of long-term care patients in health resort hospitals and long-term care wards in hospitals amounted to 124 645 in 2016, 134 547 in 2015, 133 577 in 2014, 142 411 in 2013.

¹⁰¹⁹ OECD, <https://stats.oecd.org/Index.aspx?QueryId=30142>.

¹⁰²⁰ Ministry of Family, Labour and Social Policy (2018), Answer to the Ombudsman letter on deinstitutionalisation,

<https://www.rpo.gov.pl/sites/default/files/Odpowied%C5%BA%20MRPIPS%20ws%20deinstytucjonalizacji%20opieki%2C%204.10.2018.pdf>.

- Protected houses (pl. mieszkanie chronione) 677, offering 2,863 places (but they are not dedicated only to disabled persons, so the actual number is unknown).
- Mutual help centers (pl. środowiskowe domy samopomocy) - 779, 31,345 users
- Vocational development centers (pl. zakład aktywności zawodowej) : 715, 27,097 persons
- Senior + facilities 240, including 159 Day Homes (pl. dzienne domy), 81 clubs; offering 6,265 places for seniors.

Moreover, the ministry claims that approximately 900 persons per year in 2016 and 2017 are leaving institutions.¹⁰²¹ It is not clear however what are the reasons and destinations.

With regard to children, the report on the implementation of article 31 of the CRPD suggest there is no precise data on the institutionalization of children with disabilities in Poland.¹⁰²² The available data shows 3,610 living in institutions for children and young persons with intellectual disabilities, yet it is only one type of institution. The recent report on the deinstitutionalisation of foster care in Poland shows that there is an insufficient number of professional foster families, especially specialised in ill and disabled children which results in their placement in DPS and ZOL.¹⁰²³ The report states it is unclear how long children with disabilities stay in institutions, and suggest that a number of them might have never lived independently of institution or foster families. Lack of support in independent living in adulthood, results in families being reluctant to foster children with disabilities. Families also report that after years of fostering, they don't want to place them in DPS but often it seems it is the only option available.¹⁰²⁴

As one can see there is a huge disproportion of the institutional vs. community-based settings. In this context, it is crucial to highlight that the dominant model of support for persons with disabilities is provided by families of origin. Research show that there is a huge need to live independently from families yet for many it is unrealistic due to the lack of community-based solutions and economic reasons.

The guidelines for the implementation of projects in the area of social inclusion and poverty eradication funded by the ESF and ERDF 2014-2020 permit expenditure only on institutions of up to 14 places, in the case of children (in line with national law)¹⁰²⁵ and for adults up to 30. The Guidance states that institutionalised services must be personalised, enable choice and control, prevent isolation from the community and not force people to live together, and ensure that organisational requirements do not take precedence over individual needs.¹⁰²⁶

¹⁰²¹ Ministry of Family, Labour and Social Policy (2018), Answer to the Ombudsman letter on deinstitutionalisation, <https://www.rpo.gov.pl/sites/default/files/Odpowiedz%C5%BA%20MRPIPS%20ws%20deinstytucjonalizacji%20opieki%2C%204.10.2018.pdf>.

¹⁰²² Antczak R., Grabowska I., Polańska Z., (2016), Raport dotyczący wdrażania art. 31 konwencji o prawach osób niepełnosprawnych w polsce statystyka i zbieranie danych, Warszawa, p 43.

¹⁰²³ WiseEuropa – Fundacja Warszawski Instytut Studiów Ekonomicznych i Europejskich, Fundacja Przyjaciółka, Koalicja na rzecz Rodzinnej Opieki Zastępczej (2018), Postępy deinstytucjonalizacji pieczy zastępczej w Polsce, Warszawa.

¹⁰²⁴ Ibid.

¹⁰²⁵ Act of 9 June 2011 concerning Family Support and Foster Care (Text No. 887) ISN: POL-2011-L- 89639.

¹⁰²⁶ Community Living for Europe..., op. cit.

Moreover, the guidelines for the implementation of projects with the participation of the ESF in the area of health for 2014-2020, define the general conditions for support measures deinstitutionalisation of medical care for dependent persons, aiming at:

- a) The development of de-institutionalised forms of medical care to prevent the placement of non-self-reliant persons in stationary facilities, especially in hospital wards;
- b) The development of a variety of integrated services enabling the persons supported to leave the institutions and live in society with adequate support, to prevent further institutional care, and to improve the skills and qualifications of those involved in the care of the persons concerned;
- c) The development of models or standard solutions which can then be implemented.
- d) The relevant measures included in NSPF are not currently framed within any specific strategies or plans concerning the transition to community-based care. Nevertheless, the NSPF clearly states that institutionalisation is harmful and there is a need to intensify deinstitutionalisation, the strategy is to reduce number of persons residing in the institution and promoting new professions such as family assistant. The only precise commitment is related to childcare facilities (pl. placówki opiekuńczo-wychowawcze) and aims at settling age limit (10 years old or more) by 2020, and to reduce the number of residents up to 14 by 2021.¹⁰²⁷

The Responsible Development Plan 2020 addresses deinstitutionalisation in the context of the dominant model of care in Poland that is non-formal and family care (performed mostly by women). The Plan recognises domination of institutional care and commits to developing community-based services (including personal assistance and creating centres aiming at supporting family carers). The Plan obligates the prevention of placements in institutions unless health condition or safety does not allow that.

With regards to other national documents it should be mentioned that according to the Regulation on social welfare homes by the end of 2010 all social welfare homes in Poland were obliged to achieve new standards¹⁰²⁸. According to them newly established homes cannot have more than 100 residents, the number of residents living in one room cannot exceed four persons. Every home should ensure certain living, care and assistance services.

Through 24 national programmes, Poland benefits from €86 billion ESIF funding in the 2014-2020 period. The Thematic Objective 9 'Promoting social inclusion, combating poverty and any discrimination' (under which among others deinstitutionalisation is framed) is funded by €447,625,083.00 (EU: 86.6%, National: 13.4%).¹⁰²⁹ Yet it is not clear what part of the budget is spent on deinstitutionalisation. However, selected programmes¹⁰³⁰ commit to spending's related to community-based living, among them the Pro-life programme offers 2017-21 spending on the protected housing 108 million PLN (12 million in 2017 and 24 million annually 2018-21).

¹⁰²⁷ The National Programme for Prevention Poverty..., op. cit.

¹⁰²⁸ Regulation of the Ministry of Social Policy of 19 October 2005... op. cit.

¹⁰²⁹ Community Living for Europe..., op.cit. p. 6.

¹⁰³⁰ 2016 NRP also provides data on spending on the selected measures in the area of health care, facilitating improvement in health status and wellbeing of citizens (Ministry of Health) that include deinstitutionalization, see p. 59, https://ec.europa.eu/info/sites/info/files/european-semester-national-plan_poland_2016_en.pdf.

The same programme plans 347 000 000 PLN in 2017-21 for the development of mutual support centres.¹⁰³¹ Senior+ programme offers 80 million PLN for creating 330 facilities “Senior+”, among at 8279 new placements. Although the Accessibility Plus programme does not explicitly refer to deinstitutionalisation, indirectly it can have impact on the independent living (allocate PLN 23bn) for 2018–2025.

The official involvement of persons with disabilities and DPOs is limited. There has been a consultation with the civil society organized while PA was being developed; at the early stage the disability organisations pointed out the problem of accessibility of the European Funds for disabled persons. Since then NGOs emphatically report lack of continuity in the involvement of civil society.¹⁰³² Moreover, the way of organizing public consultations on diverse disability policies and general disabled people participation in decision-making raise substantial concerns.

One of the vociferous guardians of DPO involvement rights is the Polish Association for Persons with Intellectual Disability¹⁰³³. The Polish Association for Persons with Intellectual Disability (PSOUU) works for the benefit, and on the behalf of persons with intellectual disabilities living in Poland, their parents and legal guardians. Parents whose children have been diagnosed as persons with learning disabilities, wish to give them a new reality, providing new opportunities. This perspective applies to all; toddlers, teenagers and adults. It is not the parent/carers intention to give them an all-round permanent assistance but rather to provide opportunities that would enable them to develop physically, cognitively and socially, so as to allow them to have an active, autonomous and normal life within the society. This is their mission statement.¹⁰³⁴

The main aim of Association is to include people with specific needs - people with learning disabilities in real life. The Association is an established national organization, with significant achievements. The main areas of specific expertise are:

- Early intervention
- Youth education and rehabilitation
- Occupational therapy
- Supported employment
- Supported living
- ICT applied in education and therapy

As one can note, both NGOs and other interested parties are presently lobbying for the overdue total de-institutionalising of persons with intellectual disabilities. Slowly, institutional care facilities are being replaced by the protected houses.¹⁰³⁵ The protected housing services include support in mobility, hygiene, dressing, cleaning and shopping and meal preparation for not less than 3 hours per day. The legislation explicitly mentions support in maintaining family bonds and

¹⁰³¹ Ministry of Family, Labour and Social Policy (2018), Answer..., op. cit.

¹⁰³² Crowther N., Quinn G., Hillen-Moore (2017), Opening up... op. cit.

¹⁰³³ <https://ec.europa.eu/epale/en/organisations/polish-association-persons-intellectual-disability>

¹⁰³⁴ Ibid.

¹⁰³⁵ Ordinance of the Minister of Family, Labour and Social Policy of 26 April 2018 on protected housing <http://prawo.sejm.gov.pl/isap.nsf/download.xsp/WDU20180000822/O/D20180822.pdf>

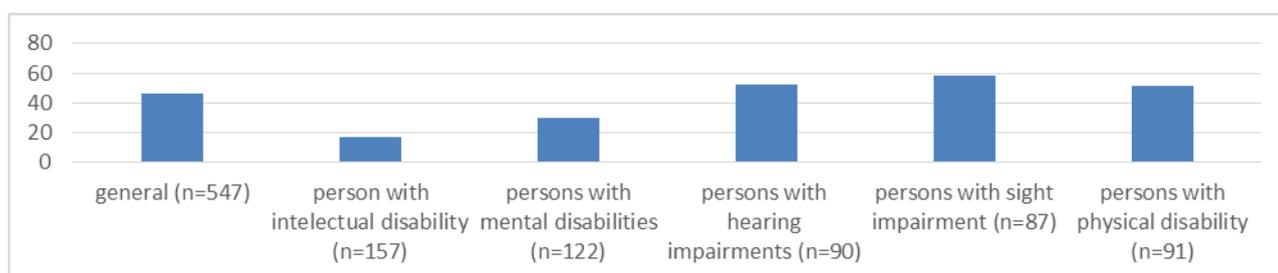
inclusion into local community. By law all the protected houses shall be accessible and the minimal space per person is 12 square meters. The number of persons living in protected housing cannot be higher than 12 by 31st December 2019, than 10 by 31st December 2021, and 7 post-2021. The legislation, though, in parts does not comply with the General Comment on art. 19 CRPD as it restricts the usage of protected housing for persons that need 24-hour support as well as poses no limit on the number of protected houses in a building. There is no detailed data with regards to the majority of persons residing in protected housing (there is only information for persons with mental health problems or exiting foster care). However, we can observe rising number of them as well as huge regional discrepancies e.g. in the Silesian region there were 558 residents that amounts to 26% of the total number, while the Podkarpackie there are only 16 users ¹⁰³⁶

While supported housing does not have a legal definition it is defined by guidelines for the implementation of projects in the area of social inclusion and poverty eradication. ¹⁰³⁷ Supported housing are closer to the CRPD definitions, yet the maximum number of residents is 12, and the units per building are not limited. What is important, temporary supported houses cannot be devoted to rehabilitation stays only.

Other forms of day-care include:

- Family care homes (26 houses, 241 residents)
- Commercial care homes (358 houses, 8514 residents)

Diagnosis ¹⁰³⁸ of the needs of persons with disabilities concludes that their general quality of life is low – the global indicator reached only 38,5 points on 100 scale, the lowest score was identified for persons with intellectual disabilities (24,5), and for persons living in institutions (20,8). Among quality of life indicators, the support of the family and friends was the highest (61,8), while housing reached 44,2. Moreover, housing and independent living (including PA and respite care) needs were the most common spontaneously reported needs (17% of respondents). Among disabled persons who live with their parents, 46% declare a will to live independently (see Table 6), yet among them only 63% believe it will be possible. The biggest obstacle to independent living identified by this group is financial issues (50%) and support/care needs (30%). Research reveals that for persons with congenital disabilities reaching independent living is especially difficult.



Percent of persons living with families or in institutions and willing to live independently by disability type

¹⁰³⁶ Analiza sytuacji województw... op. cit.

¹⁰³⁷ Wytyczne w zakresie realizacji przedsięwzięć w obszarze włączenia społecznego..., op.cit.

¹⁰³⁸ Sochańska-Kawiecka et al. (2017), Badanie potrzeb osób niepełnosprawnych, https://www.pfron.org.pl/fileadmin/Badania_i_analzy/Badanie_potrzeb_ON/Raport_koncowy_badanie_potrzeb_ON.pdf

In general, most of the measured housing needs are not fulfilled on satisfactory levels. Among the available support, the respondents have most often chosen the need for funding of the renovation of flat (52%), the subsidy for the purchase of flat (34%), subsidy for accessibility of flat (44%). The lack of protected housing, daily support and assistance were defined as major problems.

The 2018 protest of disabled persons and their parents in the parliament tackled issues connected to independent living, insufficient social transfers and lack of relevant community-based solutions. The protestors occupied the parliament for 40 days demanding (benefits including 500 PLN), and highlighting the lack of measures for adults with disabilities to independent living.¹⁰³⁹

Indeed, the dominant framework for providing care and support is family-centred, very often provided by single, ageing mothers. The extent to which disabled persons are lacking community-based solutions is commonly expressed thorough the fear of being placed in institution when the parents who provide care die. Recent reportage “So that they die before me”¹⁰⁴⁰ reflects fear of mothers who predominantly provide life-long care and support for disabled children and adults and fear that after they pass away the children will not get adequate support. The need of community-based solutions is expressed often also on regional level e.g. during a meeting of one of the commissions of the council of Warsaw disabled persons and their parents were holding slogans: “I want to live where my friends live”, “Do not separate me with my family”.¹⁰⁴¹

The annual Congress of Disabled Persons prioritizes independent living and deinstitutionalisation. Within created propositions for legal changes the Congress highlights the need to create National Independent Living and Deinstitutionalisation Strategy that would comply with art 19 CRPD and the European Guidelines on the Transition from Institutional to Community-based Care. It would require creating interdepartmental group on independent living that would include men and women with disabilities, seniors, NGOs and local governments.¹⁰⁴²

In recent years, the media also reported cases of residents of care facilities that were abused by staff (neglect, immobilizing by safety belts, verbally abuse). Moreover, media reports proliferation of on-public DPS (commercial and illegal institutions). There is no knowledge on how many of them exist as they bypass the law by creating civil contracts with clients over which nobody has supervision, or by running such houses as completely different economic activities (boarding houses, hotels).¹⁰⁴³

¹⁰³⁹ Prończuk M., Kocejko B., 3 things you need to know about the protest of people with disabilities and their carers in Poland, <https://oko.press/3-things-you-need-to-know-about-the-protest-people-with-disabilities-and-their-carers-in-poland/>.

¹⁰⁴⁰ Hołub J. (2018), „Żeby umarło przede mną”, Wołowiec: Wydawnictwo Czarne.

¹⁰⁴¹ Gajos-Koniweska D. (2016), W domach pomocy społecznej łamane są prawa pensjonariuszy - alarmuje Krajowy Mechanizm Prewencji, <https://www.rp.pl/Zadania/308259928-W-domach-pomocy-spoleszcznej-lamane-sa-prawa-pensjonariuszy---alarmuje-Krajowy-Mechanizm-Prewencji.html>.

¹⁰⁴² <http://konwencja.org/>.

¹⁰⁴³ <https://www.rp.pl/Zadania/308259928-W-domach-pomocy-spoleszcznej-lamane-sa-prawa-pensjonariuszy---alarmuje-Krajowy-Mechanizm-Prewencji.html>.

Another important issue is lack of support for parents with disabilities. A case of mother with disability was reported, who due to the lack of community-based support was supposed to give temporarily the child to the foster care. Due to the Ombudsman reaction the service was organized (personal assistance and accessible housing), yet the case demonstrates the lack of services for parents with disabilities. ¹⁰⁴⁴

We now need to turn to the subject of education opportunities for persons with intellectual and other disabilities. The Polish concept of special educational needs (SEN) is understood very broadly. Children or young people have SEN if their opportunities for education, development and learning are limited to such an extent that they cannot meet the educational requirements at mainstream schools without receiving additional assistance, both throughout the entire educational process (for example, because of disability or specific learning difficulties) or during a certain period of education (a learner showing signs of emotional problems resulting from trauma). Gifted learners are also included in the group of learners with SEN. The school should recognise their abilities and assist in their talents. ¹⁰⁴⁵

Special educational needs arise particularly due to disability; behavioural problems or a risk of behavioural problems; high abilities; long-term illness; adaptive problems; specific learning difficulties (dyslexia, dysgraphia, dyscalculia); speech impairment; trauma-induced emotional and behavioural difficulties; learning difficulties; environmental neglect related to living conditions of the learner and their family, a way of spending leisure time, social contacts; adaptation difficulties due to a change of cultural or educational environment, including those related to early education abroad and any other individual needs.

Learner's special educational needs should be determined in relation to the tasks, the requirements and the support the school should provide. Identification of the learner's needs must take into account the learner's environment, as well as their personal abilities, interests and expectations for the future. Thus, a teacher who knows the learner and their abilities and difficulties may recognise their educational needs during lessons or additional classes. Specialist assessment, including psychological diagnosis, is provided in the guidance and counselling centres which issue opinions and statements on special needs education or individual learning. ¹⁰⁴⁶

Those documents are issued at the request of parents or adult learners after a specialist diagnosis of SEN, which is carried out to obtain a qualitative and a quantitative profile of the learner. Consequently, information on the following areas is important:

- a. Intellectual capabilities
- b. Learning strategies
- c. Perception
- d. Social relationships
- e. Communication
- f. Individual and educational conditions.

¹⁰⁴⁴ <https://wiadomosci.onet.pl/tylko-w-onejcie/dramat-kobiety-slabosc-panstwa-opinia/kf6gj8>

¹⁰⁴⁵ <https://www.european-agency.org/country-information/poland/assessment-within-inclusive-education-systems>

¹⁰⁴⁶ Ibid.

Diagnosis is based on syllabus requirements and development standards for the age. Assessment is carried out by a psychologist, educator, speech specialist or other specialist, e.g. physical therapist (if necessary).

For education matters, a learner with disabilities or behavioural problems who requires special organisation of education, should have the relevant document – a statement of special educational needs (orzeczenie o potrzebie kształcenia specjalnego) – given by a public guidance and counselling centre at the request of the parents or legal guardians. This document entitles the learner to a tailored curriculum, specialist support during education and adjusted learning conditions. On this basis, funds for the organisation of special education are transferred from the state budget to the authority.

The statement is an administrative act based on legal and administrative regulations and parents can object to it. Parent or an adult learner are entitled to decide on the type of school (mainstream, integration or special) where education will be provided, taking into account the recommendation included in the statement. If, because of disability, a learner cannot attend the school nearest their home, parents may decide to place them in a residential special school.

The statement establishes the individual need for support as a right. There is no obligation for parents/learners to receive such a document. They could decide to apply for it and submit it to the school. When the statement is submitted to the school, the school head is obliged to implement it.

The tasks of the team of teachers and specialists include the periodic multi-specialist assessment of the effectiveness of education and therapy. Evaluation is conducted at least once during the school year. Based on this assessment, the individual and therapeutic programme is modified and adapted to the learner's needs and abilities, including different teaching forms and methods.¹⁰⁴⁷

The assessment comprises: educational attainments (curriculum-based assessment) – identifying level and progress in learning knowledge and skills described in curriculum as educational standards; learner's behaviour – identifying the level in respect of learner's ethical and social norms. The main goals for learners' assessment in schools are:

1. providing the learners with information on the level and progress of their educational attainments;
2. supporting learners in planning their development;
3. motivating learners to progress further in learning;
4. providing learners with information on attainments, progress and difficulties in learning and behaviour as well as on special abilities.

¹⁰⁴⁷ <https://www.european-agency.org/country-information/poland/assessment-within-inclusive-education-systems>

The assessment process at every school comprises:

- setting educational requirements for learners and informing all learners and parents about them – learners should know what is expected of them to obtain a good or just a satisfactory grade;
- on-going formative and summative assessment recorded according to the school rules, described in the document called ‘School Assessment System’ – this document states the assessment methods, how many terms are in the school year (which determines the frequency of the end-of-term assessment), the way of reporting, etc.;
- end-of-year assessment that has to be done using the same marks in the whole country.

So what do the experts say on this subject matter? For people with intellectual disabilities in Poland, access to inclusive education and to any kind of employment remains highly limited. Most children with intellectual disabilities receive education in a segregated environment and are not able to attend a mainstream school. A very positive development is the increasing number of children with intellectual disabilities attending an integrated school, where children with intellectual disabilities are educated alongside children without disabilities. However, at present there are not enough schools to meet the demand from parents. Children with intellectual disabilities do not leave school with the skills they need to access employment. Very few are employed on the open market and there is no framework for supported employment in Poland. As yet, the Government has not done enough to create programmes and initiatives specifically promoting the employment of adults with intellectual disabilities. ¹⁰⁴⁸

The Constitution and other legislation recognise the universal right to education but there is no anti-discrimination legislation which applies specifically to education. The education system is regulated by the Act on the Education System. This includes provisions on children and young people with disabilities, including the right to education at any type of school and to individual teaching, curricula and classes. Cases of discrimination in education can be brought to the Ombudsman or the Children’s Rights Ombudsman. Integration is both legislated and encouraged, and various schooling options are available for people with intellectual disabilities. ¹⁰⁴⁹

These include mainstream, integrated and special schools, individual teaching (home schooling), remedial classes and education in institutions as mentioned above. Schools are under the responsibility of local authorities and counties. Most funding is from the State budget in the form of educational subsidies, calculated according to a per-capita allowance on the principle of “funds follow the student”. However, there has been criticism that the weighting system for children with intellectual disabilities does not allocate enough funding to meet the real needs of some students.

Moreover, the local authorities do not always make budget allocations according to these per-capita regulations, further disadvantaging students needing extra support. While there are positive examples of early intervention services operated by NGOs, at present there is no formalised

¹⁰⁴⁸ https://www.opensocietyfoundations.org/uploads/3ac6b567-be56-4954-b75e-819274ec0ebb/poland_2005_0.pdf

¹⁰⁴⁹ POLAND EUMAP – EU MONITORING AND ADVOCACY PROGRAM OPEN SOCIETY MENTAL HEALTH INITIATIVE 15

(governmental) system of early intervention. Early intervention services are available in medical centres, non-governmental early intervention centres and psychological- educational counselling centres. However, parents are not always aware of these services, which are also under funded and not readily available to children in rural areas. Bureaucracy can present an additional barrier for many parents. ¹⁰⁵⁰

Assessments of disability for educational purposes are carried out in psychological educational counselling centres by a multidisciplinary team of specialists. These make evaluations of a child's need for remedial classes, individual teaching, or special education (including the form of special education to be provided). Although parents or guardians have the right to challenge an assessment or request a reassessment, in practice few actually exercise this right. Consequently, although the law provides for the transfer of students from special to mainstream education, in practice this rarely happens. The quality of assessment varies, as many centres are understaffed and overworked, and equipment for therapy and diagnosis is often inadequate. There is evidence that in some cases the local authorities have compelled the counselling centres to prescribe forms of education that were available within the county, rather than making a recommendation corresponding to the actual needs of the child. ¹⁰⁵¹

In 2014, almost 22,000 students with intellectual disabilities were receiving vocational training and education. Most were students with mild intellectual disabilities, who continue their education in special vocational schools. However, courses taught at these schools rarely correspond to the needs of the labour market and even those students who complete such vocational education are often not integrated into the workforce. ¹⁰⁵²

School-leavers with mild intellectual disabilities, who as adults do not meet with the criteria for legal disability status, face particular problems in competing for employment on the open market. The employment services (including employment counselling) provided through the labour offices are not well adapted to the special needs of people with disabilities, so few access these services.

The “Junior Programme” is an interesting new initiative intended to enable school-leavers with disabilities to take up apprenticeships. However, the number of apprentices taken on so far is quite low and it is likely that very few of these are people with intellectual disabilities. The fact that those receiving social benefits would have to suspend their entitlements to be eligible for this programme is likely to be the main reason for this. People with intellectual disabilities are effectively excluded from continuing education and their opportunities for rehabilitation are also limited. As a result, after completing school, a large number of young people with intellectual disabilities are not able to participate in any kind of activity or work and so just remain at home. ¹⁰⁵³

¹⁰⁵⁰ https://www.opensocietyfoundations.org/uploads/3ac6b567-be56-4954-b75e-819274ec0ebb/poland_2005_0.pdf

¹⁰⁵¹ POLAND EUMAP – EU MONITORING AND ADVOCACY PROGRAM OPEN SOCIETY MENTAL HEALTH INITIATIVE 15

¹⁰⁵² Ibid.

¹⁰⁵³ <https://ec.europa.eu/social/main.jsp?catId=1124&langId=en&intPagId=4724>

Very few are employed on the open market and there is no framework for supported employment in Poland.¹⁰⁵⁴ There are only a very limited number of Government programmes which train and maintain people with disabilities in employment, but these are not adapted to the needs of people with intellectual disabilities. The best example of supported employment is one operated by an NGO, the Job Coach Project, initiated by the Agency of Supported Employment, in Wrocław.¹⁰⁵⁵

Public employment services are the main bodies in Poland that provide a labour market programmes aimed at job-seekers and unemployed persons. According to the Act of 27 August 1997¹⁰⁵⁶, persons with disabilities, registered in labour offices as unemployed or job-seekers, have the right to use public employment services. However, some labour market programmes are only accessible by people registered as unemployed and people with disabilities who are entitled to incapacity pensions cannot register as unemployed. Persons with disabilities are also entitled to support specific to their situation. NGOs (e.g. Foundation Activation, Polish Association of Disabled People) assist the employment services in targeted job search and job matching.

Employment services for jobseekers (such as career counselling, support in preparing CVs, job search) can be provided by projects, but these projects operate in short term and lack continuity. Article 11 of the 1997 Act on Rehabilitation gives a right to persons with disabilities registered at labour offices as job-seekers to access some services and instruments (such as training, internship, a programme of intervention which provides subsidised, postgraduate courses) on same basis as other unemployed persons. These expenditures are, however, financed by the State Fund for Rehabilitation of Disabled Persons (PFRON) and not by the Labour Fund, which is the case in standard circumstances.

The country uses a rather medical approach towards disability that is based on the judgement of a medical expert. Applicability of employment policies for persons with disabilities are determined by assessments made by Disability Evaluation Boards. A legal document that confirms disability, a “certificate of disability,” is issued by the disability assessment team on the basis of a medical expert's opinion. The expert's opinion is crucial because the same type of disability may be qualified at different levels in different parts of the country.

According to the 1997 Act on Vocational and Social Rehabilitation and Employment of Persons with Disabilities, there are three levels of disability: severe, moderate and minor. Severe disability means a very restricted functional capacity, a full incapacity to work or a capability to work only in sheltered work. Moderate disability means that a person can work if given support and in a work environment adjusted to her/his needs. A minor disability means a person can work without support. In terms of access to support in employment (re-)integration, a disability certificate is a prerequisite.¹⁰⁵⁷

¹⁰⁵⁴ Supported employment is an employment option that facilitates competitive work in integrated work settings for people with disabilities. It provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision.

¹⁰⁵⁵ https://www.easpd.eu/sites/default/files/sites/default/files/Projects/PATHWAYS/pl_country_report.pdf

¹⁰⁵⁶ Vocational and Social Rehabilitation and Employment of Disabled Persons.

¹⁰⁵⁷ https://www.easpd.eu/sites/default/files/sites/default/files/Projects/PATHWAYS/pl_country_report.pdf

According to Polish laws, terms such as “inability to work” and “inability to live independently/need for long term care” are used. This creates a nomenclature issue as these terms may be misleading: employers often think that people classified in these categories cannot work at all. ¹⁰⁵⁸

Employers are supported in a variety of ways when they commit themselves to running one of two forms of sheltered employment: a sheltered workplace or an occupational workshop. The sheltered workplaces receive significant Government funding but employ relatively small numbers of people with intellectual disabilities, and then mostly those with a mild degree. These workplaces are segregated and do little to develop the skills needed for employment on the open market. The workplaces have also been criticised for inadequacies such as poor working conditions and mismanagement of funds, and it is also unclear whether they will meet recent EU requirements for sheltered employment. ¹⁰⁵⁹

Occupational workshops are a new form of sheltered employment in Poland and provide employment to people with more significant disabilities. However, to date, Government funding for these workshops has been quite limited. A final option for people with intellectual disabilities is the occupational therapy workshops, which are day centres providing individual therapy, often run by NGOs or local authorities. They are not considered as employment, but provide participation in social and vocational rehabilitation. However, although these workshops have trained participants capable of employment, in most cases there is no work available for them. ¹⁰⁶⁰

Inter-agency cooperation and integration of employment support services is not emphasised at policy level. The system of labour market activation for persons with disabilities is in general fragmented and cooperation between sectors is limited. In order to increase users’ and employers’ involvement, NGOs can obtain funding from PFRON for services such as information centres, preparation of workshops and conferences. However, financial resources given to NGOs are limited.

Social campaigns are carried out by NGOs and government bodies to promote the employment of people with disabilities (e.g. “Wroclaw without barriers” by the Wroclaw commune). NGOs and organisations of persons with disabilities also hold information meetings with employers to encourage them to hire persons with impairments. Legal advice is also often offered by service providers to help job seekers in administrative issues (e.g. information about disability certificates). NGOs are also active in compiling and initiating research on the subject matter. ¹⁰⁶¹

So far, and as can be seen from the above, the majority of both research and social policies regarding education of individuals with intellectual disabilities focused on children and adolescents, who were targets of numerous programs meant to adjust both learning materials

¹⁰⁵⁸ Laws such as the Act on Pensions from the Social Insurance Fund or the Act on Social Pension.

¹⁰⁵⁹ https://www.opensocietyfoundations.org/uploads/3ac6b567-be56-4954-b75e-819274ec0ebb/poland_2005_0.pdf

¹⁰⁶⁰ Ibid.

¹⁰⁶¹ https://www.easpd.eu/sites/default/files/sites/default/files/Projects/PATHWAYS/pl_country_report.pdf

and methods of teaching to their needs. At the same time, the issue of continuing education for adults with intellectual disabilities has been marginalised or even completely ignored. This was partially due to the fact that these people, no longer being subject to mandatory education, remained outside of the educational system and thus tended to be overlooked, which meant that there were few – if any – educational opportunities available to them.

Another issue to consider was the very low level of awareness in the society regarding the need to activate this group of people both socially and occupationally. This situation has changed considerably during the last 25 years and still continues to change. There are far more opportunities for adults with learning disability to actively participate in specially designed activities. There is also a fundamental shift in the perspective on the role of such activities, from programs meant to fill the disabled person's time to more structured educational programs aimed at promoting independent functioning and integration with the society, as well as acquisition of skills which would allow them to undertake meaningful work within supported work environment. These programs also aim to act against prejudice and discrimination and to shift the view of an intellectually disabled person from an "eternal child" to an adult with concrete skills and abilities. One therefore comes to the conclusion that although the educational opportunities of adults with intellectual disabilities have improved over the last two decades, mostly due to activities of many local non-governmental organizations and their innovative programs, there are still many physical, societal and psychological barriers in access to continuing education for adults with intellectual disabilities. It was found that currently in Lower Silesia the only form of meaningful and practically useful further education available are the occupational therapy workshops.¹⁰⁶²

So what would be our final thoughts on the situation in Poland vis-à-vis persons with intellectual disability and educational integration? ¹⁰⁶³ Integration is both legislated and encouraged, and various schooling options are available for people with intellectual disabilities, as we have seen. These include mainstream, integrated and special schools, individual teaching (home schooling), remedial classes and education in institutions. Schools are under the responsibility of local authorities and counties. Most funding is from the State budget in the form of educational subsidies, calculated according to a per-capita allowance on the principle of "funds follow the student". However, there has been criticism that the weighting system for children with intellectual disabilities does not allocate enough funding to meet the real needs of some students. Moreover, the local authorities do not always make budget allocations according to these per-capita regulations, further disadvantaging students needing extra support. ¹⁰⁶⁴

While there are positive examples of early intervention services operated by NGOs, at present there is no formalised (governmental) system of early intervention. Early intervention services are available in medical centres, non-governmental early intervention centres and psychological-educational counselling centres. However, parents are not always aware of these services, which are also under funded and not readily available to children in rural areas. Bureaucracy can present an additional barrier for many parents.

¹⁰⁶² <http://www.mcser.org/journal/index.php/mjss/article/view/4273>

¹⁰⁶³ https://www.opensocietyfoundations.org/sites/default/files/poland_2005_0.pdf

¹⁰⁶⁴ https://www.easped.eu/sites/default/files/sites/default/files/Projects/PATHWAYS/pl_country_report.pdf

Special schools for students with moderate/severe intellectual disabilities have separate programme principles of general education. The quality of special education depends very much on the school and there are sometimes waiting lists for schools with a good reputation. One of the most promising developments for the inclusive education of children with intellectual disabilities is the growth of integrated schools, in which children with disabilities are taught in the same class as children without disabilities, with the support of additional educators.¹⁰⁶⁵

The number of integrated schools is far too inadequate to meet needs, particularly at secondary level, and parents must compete to secure places for their children.

However, the conditions in mainstream schools often do not meet the particular special needs of children with intellectual disabilities, as they are not provided with the support they require. In particular there are not enough specialists to provide support, and teachers do not receive adequate training in disability issues. There is also a lack of flexibility and the curricula are not adequately adapted to the individual needs of the child. Integrated education is more difficult at the secondary school level, particularly for children with moderate intellectual disabilities. At present, the educational needs of children with autism are not adequately met in either mainstream or special schools.¹⁰⁶⁶

Finally, one must always keep in mind that the procedures used to assess disability for employment purposes and access to social security benefits can prove one barrier to the employment of people with intellectual disabilities. At present, such assessments are mainly based on a medical examination, are not well adapted to the special needs of people with intellectual disabilities and can be inconsistent. The Ministry of Social Policy and the Ministry of Economy and Labour should therefore jointly undertake a reform of all assessment procedures. These should in future be based on clear criteria designed specifically for people with intellectual disabilities and should, in particular, focus on the opportunities for their social inclusion, rather than on evaluating what they cannot do. The assessments should aim to determine the support needed by people with intellectual disabilities to be able to access employment on the open market. Legislators are currently working to update such scenarios.¹⁰⁶⁷

Most adults with intellectual disabilities are reliant on social security benefits, in most cases the social pension. However, present regulations constitute a “benefits trap” for people receiving social pensions who want to work, in that the social pension is suspended if income from employment exceeds 30 per cent of the average monthly wage. Another disincentive to employment is that people with disabilities with the right to a social pension do not have the right to receive an inability to work pension, a higher amount, even if they are employed (and paying compulsory social insurance).

¹⁰⁶⁵ https://www.opensocietyfoundations.org/uploads/3ac6b567-be56-4954-b75e-819274ec0ebb/poland_2005_0.pdf

¹⁰⁶⁶ Ibid

¹⁰⁶⁷ Ibid.

Such a situation also affects people with intellectual disabilities who do not have the right to a social pension and are partially incapable of working. Even if they are employed and paying compulsory insurance, they still do not have the right to receive an inability to work pension.

The main way in which the employment of people with disabilities is encouraged is through the quota system. However, most employers prefer to make payments rather than engage people with disabilities, so very few people with intellectual disabilities find work in this way. In addition, nearly none of the targeted programmes implemented by local governments are specifically addressed at people with intellectual disabilities, despite the fact that many could undoubtedly benefit from such programmes. This is particularly the case for adults with mild intellectual disabilities who do not receive disability status. They must compete for employment on the same basis as other adults, yet are disadvantaged by the fact that most attended special schools and so did not receive the education required to find employment under present labour market conditions.

In addition, they do not receive employment services tailored to their particular needs (in particular, vocational counselling, training, guidance and placement). To improve this situation, the Government should first seek to gather more detailed data on the employment situation and level of vocational training of people with mild intellectual disabilities. This should then be used as the basis for developing coherent policy and targeted programmes aimed at furthering their integration into the labour market.¹⁰⁶⁸

At present, the largest numbers of people with intellectual disabilities are found in sheltered workshops, rather than in employment in companies on the open market. There are two main forms of sheltered employment in Poland. Although most Government funding goes towards supporting sheltered workplaces these only employ a relatively small number of people with intellectual disabilities, and mostly of a mild degree. By contrast, occupational workshops, which play an important role in providing training and employment for people with more significant disabilities, have only received limited Government funding.

However, even those people with intellectual disabilities who are able to gain employment skills and training in sheltered work environments are not provided with the support they need to then take the vital next step and access employment in a company on the open market. For example, occupational therapy workshops have been able to train a number of participants with intellectual disabilities who are capable of employment, but in most cases there is simply no work available for them. The main reason for this is that at present there is no framework for supported employment in Poland. One of the most important steps which the Government could make towards promoting the employment of people with intellectual disabilities, is therefore to introduce legislation on supported employment. This would provide the basis for establishing a national system of supported employment which would at last provide real employment opportunities for people with intellectual disabilities and so promote their fuller inclusion into society.¹⁰⁶⁹

¹⁰⁶⁸ https://www.opensocietyfoundations.org/uploads/3ac6b567-be56-4954-b75e-819274ec0ebb/poland_2005_0.pdf

¹⁰⁶⁹ Ibid. pg. 125.

Portugal

In Portugal, mental health is integrated in the context of general health and there is a legislative framework which includes a Mental Health Law. The Mental Health Law, 36/98, dated 1998, includes the principles of mental health policy, organization of services, and protection of human rights of people suffering from mental disorders.

Under the framework of the Portuguese National Health Plan 2004-2010, mental health (including alcohol related problems) has been appointed as a top priority. Later, an updated national mental health plan for 2008-2016 was also approved by the Government.¹⁰⁷⁰

Several other initiatives after the above-mentioned mental health plan were introduced by the authorities. But it is not all that rosy. The reports of the EU Agency for Fundamental Rights (FRA)¹⁰⁷¹ provide very scarce information on the independent living measures in Portugal, mainly concerning general policy facts¹⁰⁷²; “private social solidarity institutions (IPSS) that run services for persons with disabilities”;¹⁰⁷³ and “the personal assistance scheme introduced as a pilot project”.¹⁰⁷⁴

This scarce information is mainly due to the fact that, in Portugal, ‘institutionalisation’ (as such) has never been a huge problem and did never reach the scale it achieved in countries such as the UK or France¹⁰⁷⁵ – however, most persons with disabilities are institutionalised within their families who, for lack of available supports are forced to care for them.¹⁰⁷⁶ The state provides some benefits to persons with disabilities (and their families) and a few support services are available in the community. Persons with disabilities end up in residential care institutions only when families are not able to care for them, either due to the severity of their needs or due to lack of family members.

As confirmed by data presented by Carta Social, in 2017 there were 6,659 places in 288 Residential Care facilities for persons with disabilities in Portugal (these are larger institutions, with up to 30 places) and 384 places in Autonomous Homes (smaller units such as apartments).¹⁰⁷⁷ The latter were introduced in 2015 by Ordinance 59/2015 of 02 March 2015.¹⁰⁷⁸ Some people with disabilities are also institutionalised in Elder Residential Care facilities, for lack of other options, but it is impossible to estimate their numbers, as such statistics are not available. Given that the population with disabilities in Portugal is estimated to be around 1,900,000 people, these numbers show the little impact of ‘typical’ institutionalization in this country

¹⁰⁷⁰ http://ec.europa.eu/health/ph_determinants/life_style/mental/docs/Portugal.pdf

¹⁰⁷¹ ‘From institutions to community living - Part I: commitments and structures’ (2018).

¹⁰⁷² Part I, p. 16

¹⁰⁷³ Part II, p. 18

¹⁰⁷⁴ Part III, p. 20

¹⁰⁷⁵ Fontes, F. (2016). *Pessoas com deficiência em Portugal*. Fundação Francisco Manuel dos Santos e Fernando Fontes, Lisboa, Portugal.

¹⁰⁷⁶ Pinto, P.C. (2011): “Family, disability and social policy in Portugal”: https://revista.aps.pt/wp-content/uploads/2018/02/N2_art-2_Paula-Campos-Pinto_visto.pdf.

¹⁰⁷⁷ Ordinance 59/2015, of 2 March on “Establishment and Functioning of Residential care facilities and Autonomous Homes for persons with disabilities”: <https://dre.pt/application/file/a/66639423>.

¹⁰⁷⁸ INR news: <http://www.inr.pt/content/1/3803/estabelecimentos-residenciais-nova-legislacao>.

For people with mental illness and psychiatric disorders, large psychiatric hospitals have been closing over the last decade, but again very few places are available in community-based care services. Therefore, the majority of people with psychosocial disabilities are cared for by their families. One can see the below table which summarises the numbers of users of different community-based care services for persons with disabilities and persons with psychosocial disabilities.¹⁰⁷⁹

<i>Users of community-based services, (retrieved on 31 January 2019)</i>						
Day-care Centres (CAOs)	Residential Care Facility	Autonomous Homes	Socio – Occupational Forums*	Autonomous Homes*	Supported Homes*	Protected Homes*
15,577	6,659	394	928	30	61	91

*Services targeted to persons with psychosocial disabilities

In addition to these, through Order 1269/2017,¹⁰⁸⁰ of 06 February, which provisioned the establishment of 366 places in the Network of Mental Health Integrated Continuing Care (CCISM) up until 2018, 189 places were made available in all types of these facilities (including 24 home-based support services) and that the total number of beneficiaries comprised 96 persons.¹⁰⁸¹

Data retrieved from the Social Security Institute Reports (reporting social security expenditures for 2013, 2015, 2016 and 2017), show a gradual increase of the number of users, mainly in Occupational Activity Centres¹⁰⁸² and Residential care facilities for people with disabilities.

An important step towards the implementation of Independent Living in Portugal took place in 2015, when the first Pilot Project on Independent Living was launched by the Lisbon City Council (CML).¹⁰⁸³ Under this Project, the first Centre for Independent Living (CVI)¹⁰⁸⁴ in the country was established in the city of Lisbon. It has been providing personal assistance and accommodation services for just five persons with disabilities to pilot-test the concept of independent living in the country.

¹⁰⁷⁹ Source: Carta Social, available at: <http://www.cartasocial.pt/index2.php> (retrieved on 31 January 2019)

¹⁰⁸⁰ Order 1269/2017 of 06 February: <https://dre.pt/application/file/a/106390741>; see also SNS news: <http://www.acss.min-saude.pt/2017/02/09/rncci-passa-a-integrar-saude-mental/>.

¹⁰⁸¹ RNCCI Monitoring Report 2017 (p. 17, Quadro 6, p. 31; Quadro 15, p. 38; Quadro 16, p. 39; Quadro 46, p. 84): <http://www.acss.min-saude.pt/wp-content/uploads/2018/11/Relatorio-de-Monitorizacao-da-RNCCI-2017.pdf>.

¹⁰⁸² CAOs are day-care centres where persons with disabilities aged 16 years old and over may undertake a number of social, recreational and rehabilitation activities, including some work-related tasks, for which they may receive a symbolic payment. The legislation that regulates CAO activities is Decree-law 18/89 of 11 January 1989, Order 52/SESS/90 of 16 July 1990, and the guidelines from the Social Security Administration (http://www.seg-social.pt/documents/10152/13475/gqrs_cao_processos-chave/4b052a99-b321-494f-9735-16332f7d1a41).

¹⁰⁸³ CML, Projeto-Piloto: <http://www.cm-lisboa.pt/viver/intervencao-social/pessoas-com-deficiencia/projecto-piloto-vida-independente>

¹⁰⁸⁴ CVI in Lisbon: <http://vidaindependente.org/projectos-piloto/conheca-o-projecto-piloto-de-vida-independente/>.

In 2017, the government launched a national programme of support to independent living - The Independent Living Support Scheme (MAVI) through Decree-Law 129/2017, of 09 October.¹⁰⁸⁵

MAVI is to be developed for a period of three years — 2017-2020, funded within the framework of Portugal 2020, through the ESF. It provisions to pilot a network of Independent Living Support Centres (CAVIs) throughout the country that will implement personal assistance projects.

Following the adoption of MAVI in October 2017, a call for proposals for the accreditation of independent living centres (CAVIs) was launched. Once accredited, these centres applied for funds to develop personal assistance schemes for up to 50 beneficiaries each. This whole process was quite bureaucratic and long and only in January 2019, some Independent Living Centres are starting their activities of recruitment and training of personal assistants. According to the newspaper 'Publico' (as of 29 November 2018),¹⁰⁸⁶ and as officially confirmed by the INR, I.P.,¹⁰⁸⁷ in total, 51 applications were received, of which 30 were approved in the North, Centre and Alentejo regions of Portugal. The government is planning to sign the first 21 contracts for CAVIs that will assist approximately 722 persons with disabilities for whom they will hire about 522 personal assistants.

In the Mental Health sector, Decree 8/2010¹⁰⁸⁸ (Article 8), of 28 January, amended by Decree-Law 22/2011 of 10 February (Articles 8 and 9),¹⁰⁸⁹ established a set of mental health care services that constitute the Mental Health Network of Continuing Care. Existing services (such as the different types of residential units, the socio-occupational units, and the home-based care services that were formerly funded through Social Security) should gradually be integrated into this network and become the shared responsibility of the Ministry of Health and the Ministry of Labour and Social Solidarity. However, for seven years, the plan was not implemented and only in 2017 it gained renewed attention with the publication of Order 1269/2017¹⁰⁹⁰ and Ordinance 68/2017 of 16 February,¹⁰⁹¹ this latter establishing the new norms and operational rules for service provision. Some of these new rules were quite demanding and different from previous one (for example in terms of the characteristics of the buildings, with no transition clauses that would enable service providers to adapt to the new rules over a number of years). All this created a lot of obstacles that delayed the implementation of the new network. This explains why, as of December 2017, only 96 users were benefitting from these new services, across the whole country, and the numbers today continue very low.

But what about public funding for independent living and inclusion? The OECD¹⁰⁹² reports that public spending on long-term care in Portugal comprises 0.5 % of GDP or USD 1,150 million, which is much lower than in other European countries.

¹⁰⁸⁵ <https://dre.pt/pesquisa/-/search/108265124/details/maximized>

¹⁰⁸⁶ [https://www.publico.pt/2018/11/29/sociedade/noticia/contratos-centros-apoio-vida-independente-assinados-proxima-semana-](https://www.publico.pt/2018/11/29/sociedade/noticia/contratos-centros-apoio-vida-independente-assinados-proxima-semana-1852961?fbclid=IwAR3AWGj7m_ChjR4YKaxZ2XnZtRCWQ_pSxeQEN4mKCK3oOsCu48YQmgtUjvQ)

[1852961?fbclid=IwAR3AWGj7m_ChjR4YKaxZ2XnZtRCWQ_pSxeQEN4mKCK3oOsCu48YQmgtUjvQ](https://www.publico.pt/2018/11/29/sociedade/noticia/contratos-centros-apoio-vida-independente-assinados-proxima-semana-1852961?fbclid=IwAR3AWGj7m_ChjR4YKaxZ2XnZtRCWQ_pSxeQEN4mKCK3oOsCu48YQmgtUjvQ)

¹⁰⁸⁷ INR, MAVI news: <http://www.inr.pt/content/1/5047/modelo-de-apoio-vida-independente>

¹⁰⁸⁸ Decreto-Lei 8/2010: <https://dre.pt/pesquisa/-/search/616776/details/maximized>

¹⁰⁸⁹ Decreto-Lei 22/2011: <https://dre.pt/pesquisa/-/search/280268/details/maximized>.

¹⁰⁹⁰ <http://www.saudementalpt.pt/backoffice/pdfs/dea97e8332.pdf>.

¹⁰⁹¹ <http://www.saudementalpt.pt/backoffice/pdfs/e6ee77c275.pdf>

¹⁰⁹²OECP:<http://www.oecd.org/els/health-systems/long-term-care.htm>

The funding for residential care facilities is provided by the Institute for Social Security. Overall, as reported by Carta Social,¹⁰⁹³ in 2017, the total public spending on all social care programmes amounted to EUR 1,340 million. However, the total public spending on social care services for persons with disabilities (which comprises more than just residential care facilities), amounted to just 13.4 % of total expenditure (compared to 39.3 % for children and youth and 43.1 % for the elderly). Yet, there was a slight increase compared to the 11.5 % spent in 2013.¹⁰⁹⁴

Funding for mental health units integrated in the Network of Mental Health Integrated Continuing Care (CCISM) is provided by both the Ministry of Health and the Ministry of Labour, Solidarity and Social Security - MTSSS (through the ISS, I.P.). The total spending in 2017 of the ISS, I.P with the CCISM amounted to EUR 10,995.52.¹⁰⁹⁵ Unfortunately it is unknown the corresponding contribution to the same services from the Ministry of Health.

The independent living projects that are about to start in the country will be funded with a total amount of EUR 23,506,254,¹⁰⁹⁶ of which 85 % comes through the ESF and 15 % from the State Budget.

The Social Security (ISS, I.P) spending on Mental Health units, under the Network of Mental Health Integrated Continuing Care (CCISM) has also increased, especially from 2017 onwards, as shown in the following Table below.

Annual expenditure of ISS, I.P. on Mental Health units (2013-2017), Mainland Portugal, thousand euros:

Annual expenditures of ISS, I.P.	2013	2015	2016	2017
CCISM	55,000	617,800	n/a ¹⁰⁹⁷	10,995.52

Source: Retrieved from the Reports of ISS, I.P. 'Conta da Segurança Social 2013, 2015, and 2016'.¹⁰⁹⁸

This increase in funding can be explained by the fact that Mental Health Units as part of the RNCCI only started being implemented on the ground from June 2017 on. Before that, even though, they were mentioned in the law, their numbers in practice were very low.

Since the independent living schemes at national level have just recently been launched, there is still no trend to observe in terms of spending.

Commitments to support independent living have been mentioned in the following government documents:

¹⁰⁹³ Carta Social, Relatório 2017: <http://www.cartasocial.pt/pdf/csosocial2017.pdf>

¹⁰⁹⁴ Report 2013 Carta Social: <http://www.cartasocial.pt/pdf/csosocial2013.pdf>

¹⁰⁹⁵ Monitoring Report RNCCI 2017 (Quadro 73, p. 124): <http://www.acss.min-saude.pt/wp-content/uploads/2018/11/Relatorio-de-Monitorizacao-da-RNCCI-2017.pdf>

¹⁰⁹⁶ http://poise.portugal2020.pt/documents/10180/73143/AAC_TO+3.18_POISE-38-2018-04_v1_20180313.pdf/Obd18758-5f42-4238-8daa-f9907a64351d

¹⁰⁹⁷ In 2016, quarto ano de execução do programa, não foi registada despesa com estes protocolos.

¹⁰⁹⁸ <http://www.seg-social.pt/publicacoes?bundleId=15671250> (milhares de euro). The data for 2017 is retrieved from RNCCI Monitoring Report 2017 (Quadro 73, p. 124), available at: <http://www.acss.min-saude.pt/wp-content/uploads/2018/11/Relatorio-de-Monitorizacao-da-RNCCI-2017.pdf>

- First National Disability Strategy (ENDEF I) 2011-2013;¹⁰⁹⁹
- The Programme of the XXI Constitutional Government for 2015-2019;¹¹⁰⁰
- Portugal 2020/ PO ISE (Operation Programme for Social Inclusion);¹¹⁰¹
- The National Reform Programme (NRP);¹¹⁰²
- The National Plan of Mental Health 2007-2016¹¹⁰³ and the new National Programme on Mental Health 2017-2020.¹¹⁰⁴

The aims and objectives of relevant strategies/government documents that specifically targeted promoting independent living of persons with disabilities in Portugal were the following:

- In the ENDEF I, the government set out the goal of implementing the first pilot project that would create a personal assistance service in Portugal. However, by 2013, when the Strategy ended, this measure was not yet put in place.
- The Programme of the XXI Constitutional Government announced the inclusion of persons with disabilities as one of its strategic objectives. While, it did not explicitly mention the independent living programme, it did provision the “transition of support provided on the basis of institutionalised models for the provision of services in the community”. Among other objectives, the Programme also gives importance to the establishment of the National Network of Continuing Mental Health units.
- The Portugal 2020 Programme (in Axis 3, Target 3.18) foresees the implementation of the Model to Support Independent Living (MAVI).
- The NRP 2016-2021 and 2017-2021 provisioned the establishment of the Independent living support model as a new measure, and the NRP 2018-2022 explicitly mentions the implementation of the Independent Living Model (MAVI) among its objectives.
- The National Plan of Mental Health 2007-2016 (1.2.) established the objectives of deinstitutionalisation and gradual closing of psychiatric hospitals (approved by the Resolution of the Council of Ministers 49 of 06 March 2008).¹¹⁰⁵ The new 'National Programme on Mental Health 2017' was extended up to 2020¹¹⁰⁶ and among its goals it promotes the establishment of the Network of Integrated Continuing Mental Health Care to reduce the institutionalisation of people with severe mental illnesses and psychosocial disorders.¹¹⁰⁷

¹⁰⁹⁹ ENDEF I 2011-2013: http://www.inr.pt/bibliopac/diplomas/rcm_0097_2010.htm.

¹¹⁰⁰ Programa do Governo Constitucional 2015-2019: <https://www.portugal.gov.pt/ficheiros-geral/programa-do-governo-pdf.aspx>.

¹¹⁰¹ Portugal 2020 (PO ISE, pp. 122-123): https://www.portugal2020.pt/Portal2020/Media/Default/Docs/Programas%20Operacionais/TEXTOS%20INTEGRAIS%20DOS%20PO/PO_ISE_17Nov14.pdf.

¹¹⁰² National Reform Programme: <https://www.portugal.gov.pt/pt/gc21/governo/programa/programa-nacional-de-reformas.aspx>.

¹¹⁰³ National Plan of Mental Health 2007-2016: <https://www.adeb.pt/files/upload/paginas/Plano%20Nacional%20de%20Saude%20Mental.pdf>.

¹¹⁰⁴ National Programme on Mental Health 2017-2020: <https://www.sns.gov.pt/institucional/programas-de-saude-prioritarios/programa-nacional-para-a-saude-mental/> and http://nocs.pt/wp-content/uploads/2017/11/DGS_PNSM_2017.10.09_v2.pdf.

¹¹⁰⁵ Resolution of the Council of Ministers 49/2008 of 06 March 2008: <https://dre.pt/application/file/a/247277>.

¹¹⁰⁶ Ordinance 1490/2017 of 2 February 2017: <https://dre.pt/application/file/a/106442742>.

¹¹⁰⁷ National Programme on Mental Health, see 'Metas de Saúde a 2020' (p. 15): http://nocs.pt/wp-content/uploads/2017/11/DGS_PNSM_2017.10.09_v2.pdf.

Among other measures recently adopted that also contribute to independent living of persons with disabilities in Portugal it is important to mention the following:

- **A new unified disability benefit – the Social Benefit for Inclusion** (Prestação Social para Inclusão – PSI) for people with impairments of 60 % or over (approved by Decree-law 126-A/2017, of 6 October).¹¹⁰⁸ The PSI benefit can be accumulated with other benefits and income from work, although with a cap for people with incapacity level 60- 80 %.
- **The new Law 49/2018 that entered into force on 14 August 2018**¹¹⁰⁹ which approves the new “regime of adult support” (o regime jurídico do maior acompanhado) that eliminates the previous regimes of inabilitation and interdiction and will also result in appropriate amendments in the Civil Code, and other related laws and regimes. ‘The regime of interdiction’ implied a severe containment to the exercise of rights, and could be assigned by the Court on the basis of a legal request (by a parent, the spouse, a child, the curator or the public attorney), a medical assessment of the individual, and statements of family members, friends, neighbours and others close to the person. Persons who were subjected to this regime remained in the status of minors, and could not exercise the right to vote, and were prevented from exercising paternity and testifying in court, and although they can marry, the marriage can be declared null. Once the status of interdiction was assigned, a Tutor/Guardian was designated. The ‘regime of inhabitation’ was also assigned by a Court, on the basis of a legal request and a medical assessment, but it implied only the suppression of the right to manage one's own property. A Curator was designated to assist the person in all acts related to property, or even to act on his/her behalf. In this latter case, a Family Council (composed of family members, neighbours, friends and others) was set in place, and a representative was nominated to supervise the acts of the Curator. In contrast to the previous regimes, the new “regime of adult support” aims to provide the support to the person to enable the full exercise of her/his rights. An ‘assistant assists the person in making decisions and the assistant should be chosen either by the persons who needs support herself, or his/her legal representative. This is considered an “historic moment in the promotion of the rights of persons with disabilities in Portugal alongside with the implementation of the UN CRPD”, as mentioned by the Secretary of State on Inclusion of Persons with Disabilities Mrs. Ana Sofia Antunes.
- **The new Decree-law 54/2018 on Inclusive Education**,¹¹¹⁰ which abolishes the term ‘special education needs’ and strengthens the path towards the inclusion of all children in mainstream schools, regardless the level of their disabilities.

As mentioned above, there is not a significant move in Portugal from institutions to community care as most people with disabilities have always lived in the community, although not independently, but ‘institutionalised’ within their families.

The main idea with the introduction of the MAVI is to pilot a network of Independent Living Centres (CAVIs) which will serve as the so-called ‘contact points’ to receive requests from persons with disabilities who need personal assistance and allocate the required personal assistants services. The provision of personal assistance will follow an individual plan. This plan will be defined by the person with disabilities in collaboration with the CAVI and it will identify:

¹¹⁰⁸ Decree-Law 126-A/2017 (summary in plain English): <https://dre.pt/web/guest/home/-/dre/108269605/details/maximized?res=en>.

¹¹⁰⁹ Law 49/2018: <https://dre.pt/home/-/dre/116043536/details/maximized>.

¹¹¹⁰ Decree-law 54/2018 of 06 July: <https://dre.pt/web/guest/home/-/dre/115652961/details/maximized?res=en>.

- the specific assistance needs of the person;
- how support activities are to be carried out;
- how the assistance will be monitored and evaluated.

The individual assistance plan will state the number of hours of weekly support the person is entitled to. Each person can receive up to 40 hours of support per week. Exceptionally, more hours of support can be provided — up to 24 hours a day. However, each CAVI can only provide more than 40 hours a week of support to a maximum of 30 % of its clients.

In addition to this new Independent Living Scheme, which is now being piloted in the country, people with disabilities used Home Care Support Services. However, these services are targeted to provide assistance with personal care and domestic work only, and not to provide inclusion in the community. The service is only provided in the home of the beneficiaries.

For persons with psychosocial disabilities, there is a huge lack of community-based services – the big psychiatric hospitals are all closed now, and people were sent back to families with very few care services provided in the community.

The implementation of various schemes have faced a number of delays, thus creating negative injections in the satisfaction levels among persons with disabilities. There are not yet persons with disabilities receiving personal assistance, which has caused a lot of criticism from the disability community.

Moreover, most schemes are being introduced through pilot projects, mainly funded through the ESF, and will cover around 700 persons with disabilities across the country, which is clearly insufficient. The future sustainability of the programme, after the three-year trial, is also a concern.

This conclusion is supported by a number of publications, e.g. the online Journal Público which presented an interview with the disabled activist Eduardo Jorge (of 22 November 2018),¹¹¹¹ who complained about the delay in the implementation of the programme and also about the exclusion of persons living in institutions (who are not so far entitled to apply for personal assistance). However, after his protest in front of the National Assembly in December 2018, the Secretary of State announced that an amendment would be introduced to the law to create a transitional period of six months enabling persons to apply for personal assistance even while living in an institution.

Another critique, according to researcher Fernando Fontes in his interview of 22 November 2018¹¹¹² is that “many of the established CAVIs will be run by existing service provider organisations. As such, the same provider that offers residential care may apply to become a CAVI”. Fernando Fontes suggests that, instead, CAVIs should be managed only by disabled people’s organisations.

Some other critiques have been raised by Jorge Falcato, a disabled deputy in the

¹¹¹¹ Público (22 November 2018): <https://www.publico.pt/2018/11/22/sociedade/noticia/atrasos-atribuicao-assistentes-pessoais-desmoralizam-espera-ha-anos-1851961>.

¹¹¹² Público (Interview with Fernando Fontes):

<https://www.publico.pt/2018/11/22/sociedade/entrevista/vida-independente-nao-vai-direito-pessoas-deficiencia-1851862>.

Parliament.¹¹¹³ He stated that “40 hours of assistance a week is not enough for those in need of constant care, and he doesn’t see why the minimum age for the program should be 16. Disabled people should be able to choose their own personal assistant, pay them directly, and define their own individual care plan.”¹¹¹⁴

As for the residential homes, cases of maltreatment of old persons and persons with disabilities are still being reported, especially regarding persons with psychosocial disabilities (see e.g. the case of Lar de Alijó¹¹¹⁵ and Casa dos Rapazes de Viana do Castelo).¹¹¹⁶ A complaint about the use of ESF funds to build an institution in Azores has also been filed with the European Commission.¹¹¹⁷

The pan-European civil society organisations (e.g. ENIL platform - the European Network on Independent Living) have contributed to raise awareness about independent living in Portugal. FENACERCI¹¹¹⁸ (The National Federation of Social Solidarity Cooperatives) disseminated information about the Independent Living Project and presents on its website the document ‘Demolidor de Mitos Vida Independente’ translated in Portuguese from the leaflet originally created by ENIL – “Myth Buster Independent Living”. In addition, representatives of the Portuguese DPOs publish their views on the ENIL platform.¹¹¹⁹

The most recent article published on 28 February 2019 is entitled “(In)dependent Living in Portugal” by Fátima Paulo¹¹²⁰ (a Portuguese activist). She criticises the new legislation on Independent Living and Personal assistance in Portugal saying that the “legislative scenario does not respect basic Personal Assistance requirements and represents an abusive appropriation of the Independent Living concept”, making the implementation of Article 19 of the CRPD “a distant dream”.

DECIDE (full title ‘Disability and self-determination: the challenge of Independent living in Portugal’) ¹¹²¹ is a research project launched in June 2016 and funded through the Foundation for Science and Technology that aims to analyse the living conditions and inclusion of persons with disabilities in Portugal. The Project team will also assess the impact of the independent living project of the municipality of Lisbon. The Project team has organised a number of events, including the International Colloquium “Disability and Self-Determination: The Challenge of

¹¹¹³ Financing of CAVIs (16 April 2018, by Jorge Falcato and José Soeiro):

<http://www.beparlamento.net/financiamento-dos-centros-de-apoio-%C3%A0-vida-independente-cavi>.

¹¹¹⁴ ‘Portugal’s disabled population continue to struggle for independent living’:

<https://www.equaltimes.org/portugal-s-disabled-population#.XD9vkIX7Tb0>.

¹¹¹⁵ Jornal de Noticias (30 janeiro 2017): <https://www.jn.pt/nacional/interior/maus-tratos-a-deficientes-em-lar-de-alijo-coordenadora-suspensa-5636707.html>.

¹¹¹⁶ Publico (08 October 2017): <https://www.publico.pt/2017/10/08/sociedade/noticia/suspeitas-de-violencia-na-casa-dos-rapazes-de-viana-do-castelo-1788056>.

¹¹¹⁷ http://www.azores.gov.pt/Portal/pt/entidades/srss-drss/textolmagem/ACORES-09-4842-FEDER-000010- Construc%27o_do_Lar_Residencial_dos_Valados.htm.

¹¹¹⁸ FENACERCI: <https://www.fenacerci.pt/2017/10/30/vida-independente-i-abertas-candidaturas-aos-projetos-piloto-nacionais-ppv/>.

¹¹¹⁹ ENIL: <https://enil.eu/news/independent-living-movement-in-portugal/>.

¹¹²⁰ ‘(In)dependent Living in Portugal’: https://enil.eu/news/independent-living-in-portugal/?fbclid=IwAR3lu4KX0mgiLdb30y_pvqcMsNYzS2oBmZ40NAEMG2kZRWBwLf1LDIq43pM.

¹¹²¹ DECIDE: <https://ces.uc.pt/en/investigacao/projetos-de-investigacao/projetos-financiados/decide>.

Independent Living” that took place in Lisbon on 18 June 2018.¹¹²² The project will publish its final results in 2019.

From 2009 to 2014¹¹²³ the project “Trajectories of Mental health Care” was implemented by the Association for the Promotion of Mental health ‘Encontrar-Se’ in Portugal on the issue of de-institutionalization of persons with psychosocial disabilities. The report, by Almeida et al. (2015)¹¹²⁴ presents a detailed analysis of the de-institutionalisation process in Portugal and provides a list of recommendations, including to integrate mental health care into the network of the “integrated continuing care” and to develop specialized community-based mental health services (e.g. centres and teams of mental health care).

When one analyses the interaction between integrated education policies and independent living within the disabled community, the overall picture gets more focused. As the education system in Portugal has evolved over the years, government initiatives have been taken to deal with individuals and/or groups identified as requiring special education. Some initiatives, no less important from the chronological point of view, will be omitted because they involved no specific, organised social or educational intervention. However, an important milestone was the creation, in 1946, of the first special classes in primary schools. Initially these were for learners with a physical or intellectual disability. However, later learners with learning difficulties and minor disabilities were included. The António Aurélio da Costa Ferreira Institute was the state institute responsible for giving guidance to these classes and for training the teachers involved.¹¹²⁵

In the 1960s, under the Ministry of Health and Assistance, the Institute for Providing Assistance for Minors was created. Centres for special education and centres for observation and assessment were set up. They adopted a medical pedagogic approach and were responsible for detecting, observing and referring learners to schools providing special education or similar provision. The first courses were also organised to give specialist training to teachers.

With the revolution in 1974, which replaced dictatorship with democracy, the parents’ associations’ movement, aided by specialists and teaching staff, was important in developing many socio-educational activities and in organising and creating schools for learners with disabilities, particularly those with intellectual disabilities. At the time, the state already provided some organised response to other types of disability (sensory), although this was insufficient and ineffective from an educational and social point of view. Therefore, it was through these associations and co-operatives that the first schools for learners with intellectual disabilities were introduced throughout the country. The most important centres were the Co-operatives for the Education and Rehabilitation of Children with Learning Difficulties. Today, these are still an important partner in finding solutions for people with disabilities and, in some cases, a specialised resource serving the educational community.¹¹²⁶

¹¹²² International Colloquium, DECIDE: <https://ces.uc.pt/pt/agenda-noticias/agenda-de-eventos/2018/deficiencia-e-autodeterminacao>.

¹¹²³ Trajectories Project: <https://www.encontrarse.pt/investigacao-avaliacao/projetos-concluidos/>.

¹¹²⁴ Almeida et al. (2015): http://spgg.com.pt/UserFiles/file/23_09_15report_JA_em_PORTUGUES.pdf.

¹¹²⁵ <https://www.european-agency.org/country-information/portugal/legislation-and-policy>

¹¹²⁶ <https://www.european-agency.org/country-information/portugal/legislation-and-policy>

In the early 1970s, the Ministry of Education began to pass legislation that specifically addressed educational structures for ‘those with disabilities and those with learning difficulties’. To this end it created, within the Ministry itself, the Department for Special Education to cover compulsory education (basic education) and the Department of Special and Vocational Education for upper-secondary education. Among other tasks and duties, the Ministry decided to give its support to the above-mentioned schools and to assume responsibility for providing specialised teacher training for those working with learners with disabilities. The courses administered by the António Aurélio da Costa Ferreira Institute were restructured accordingly. Similarly, in the mid-1970s, regional support structures were organised. Special education teams were only recognised in 1988 with the publication of a joint order.¹¹²⁷ This aimed to develop integrated teaching for children with disabilities and adolescents with sight, hearing or physical impairments. Eventually, this was also approved for those with intellectual disabilities.

Education for all, based on the protection of individual rights by applying the principle of equal opportunity to education and the criteria of pedagogic and social justice, is expressed clearly through full participation and co-operation among all those involved in education.

Special education is guided by the principles enshrined in legislation.¹¹²⁸ The underlying philosophy is based on several international resolutions, such as the Salamanca Statement and Framework for Action on Special Needs Education.

These principles can be summarised under three fundamental rights:

The right to education: all children with special educational needs (SEN), even as the result of a problem (or problems) in a particular area of development, have the right to education. At compulsory school age, education for children and adolescents with SEN, no matter how complex they are, should be provided within the mainstream education system.

The right to equality: the inalienable right of all children to equal opportunity in gaining access to and achieving success in education, without any type of discrimination, and with educational resources and support adequate to each one’s individual needs.

The right to be part of society: it is a principle that they have the right to attend mainstream schools of education which, from the perspective of a school for all, find the right solutions for the needs of each individual. The rule is that learners with disabilities should preferably be included in the mainstream teaching system, with special schools being the exception. Only when all means for keeping learners in a mainstream school alongside their peers have been exhausted may learners attend a special school.

For this attempt to enshrine the right, duty and responsibility of the state and civic society in dealing with persons with disabilities and/or SEN, the development of ideas and scientific and pedagogic research, at national and international level, related to special education was crucial. No less important was the contribution of reformist attitudes that brought change to the education

¹¹²⁷ Joint Order No. 36/SEAM/SERE/88, 17 August.

¹¹²⁸ The Education Act, Law No. 46/86, 14 October; Decree-Law No. 35/90, 25 January; Decree-Law No. 3/2008, 7 January

system since the late 1980s, expressed in the Education Act. Also important were recommendations made by international bodies on access for pupils with disabilities to the mainstream system of education and the experience gleaned over a number of years in which pupils with disabilities have attended mainstream schooling.

The Education Act ¹¹²⁹ understands special education as a specific type of education that facilitates the socio-educational recuperation and integration of individuals with SEN caused by physical or intellectual disability. Including such pupils in the mainstream schooling system, as the educational strategy adopted for pupils with SEN, was enshrined in Law No. 9/89, 2 May, on Prevention and the Rehabilitation and Integration of Persons with Disabilities.

Decree-Law No. 35/90, 25 January, stipulates that learners with SEN, resulting from physical or intellectual disabilities, are obliged to attend compulsory schooling. Decree-Law No. 319/91, 23 August, called for mainstream schools to take greater responsibility for the problems of learners with disabilities or with learning difficulties. It also opened schools to pupils with SEN ('schools for all') and more explicitly recognised the parents' role in their children's educational guidance. Moreover, it provided a set of measures, according to the principle that the education of pupils with SEN must be carried out in the least restrictive environment possible.

Decree-Law No. 3/2008, 7 January, defines the specialised support provided in state, private and co-operative pre-primary, compulsory and secondary education with the aim of creating the conditions to adjust the educational process to the special educational needs of pupils with major limitations in terms of activity and participation in one or more areas. These needs may be due to permanent functional and structural issues, which result in continued difficulty in terms of communication, learning, mobility, autonomy, interpersonal relationships and social involvement. Decree-Law No. 20/2006, 31 January, defines the procedures regarding the teacher placement application system, creating the special education recruitment group for the first time. It repeals Decree-Law No. 35/03, 27 February.

Law No. 85/2009, 27 August, establishes compulsory schooling for children and young people of school age and guarantees the universal right to pre-primary education for children aged five years and upwards. Law No. 46/2006, 28 August, outlaws and punishes discrimination concerning disability and severe health risk.

Mainstream schools are now supported by a national network of Information and Communication Technology Resource Centres for Special Education, which assess pupils' needs for assistive technology, and by a network of 93 Resource Centres for Inclusion (RCIs). The RCIs, which in the past were special schools, provide specialised support through partnerships with mainstream schools.

The transformation of the special schools into RCIs has become an essential tool for implementing Article 24 of the United Nations Convention on the Rights of Persons with Disabilities. The Ministry of Education introduced an accreditation process that enlarged the national coverage of the RCIs.

¹¹²⁹ Law No. 46/86, 14 October

The responsibility for the design, management and financing of public education has historically been linked primarily to the Ministry of Education, with an appropriate allocation in the state budget. In recent years, this responsibility has been progressively decentralised and the responsibility shared. Schools have more autonomy and municipalities are more involved. Municipalities are financed by the Ministry of Finance and by their own revenues, generated by local taxes. ¹¹³⁰

The global budget for education covers all learners, with some specific funding for learners with special educational needs (SEN). A bigger investment is required to provide public pre- primary education to all children, as well as early childhood intervention. Early intervention is of utmost importance to minimise the impact of disabilities, but stronger co-ordination efforts are required.

The National Early Childhood Intervention System (NECIS) is the responsibility of three ministries (Education, Health and Social Security). There are representatives from each ministry in each of the NECIS structures. ¹¹³¹ The local intervention teams include educators from the Ministry of Education, medical doctors, nurses and therapists from the Ministry of Health and therapists and psychologists from the Ministry of Labour, Solidarity and Social Security. The NECIS services are free of charge. ¹¹³²

The criteria for financial support for pupils with SEN, which indirectly benefits their families, ensure attendance at and completion of compulsory education. The allocation of funds for the acquisition and/or maintenance of technical assistance necessary to ensure the right conditions for access to the curriculum are also considered. Specific legislation establishes the maximum amounts and the regulations of the monthly payments by co-operatives and education and special teaching associations, as well as for-profit education and special teaching establishments, overseen by the Ministry of Education, whose fees are reviewed annually. ¹¹³³ The financial contribution that families make to special education for children and young people, to determine the special education subsidies from social security, is also established annually via specific legislation.

The system of funding is not tied to categories/types of disability. The Ministry of Education ensures the allocation of human resources (specialist teachers and other professionals) to mainstream schools. For special units in mainstream schools, the Ministry of Education also assigns a monthly allowance for operating funds. Spending on specialist teachers to support the implementation of inclusive education came to EUR 200 million in 2016. It was EUR 7 million for school-level specialised technicians, while over EUR 500,000 a year were used to operate 25 Information and Communication Technology Resource Centres for Special Education.

The Ministry of Education also allocates funds to support the partnerships between Resource Centres for Inclusion and mainstream schools. Resource Centres for Inclusion oversee activities for an annual amount of over EUR 10 million. ¹¹³⁴

¹¹³⁰ Source: FPIES – Portugal Country Report, p. 30

¹¹³¹ Both at regional and national level.

¹¹³² Sources: Financing of Inclusive Education – Portugal Country Report; IECE – Portugal Country Survey Questionnaire, p. 15.

¹¹³³ Ordinance No. 171/07 and Ordinance No. 172/07, 6 February

¹¹³⁴ Source: Financing of Inclusive Education, p. 36

In 1993, criteria were established for financial support for private special education establishments that were supplementary in nature and in line with the principles of school integration. In the following year, the family allowances of children and young people with disabilities attending special education establishments were stipulated.

The principle of free education was extended to private special education establishments in 1995, establishing the type of funding given by the Ministry of Education, as well as the techno-pedagogical measures used for pupils with SEN who attend such establishments. The consolidation of the principles and the updating of options and measures in this field were regulated in 1997, with the amount of financial support for pupils and their families reviewed annually.

Ordinance No. 1102/97, 3 November, establishes the access conditions for pupils in special education, the requirements in order for those institutions to function and the funding given by the Ministry of Education.

The target groups for special education are pupils with significant limitations in terms of activity and participation in one or more areas of life due to permanent functional and structural issues, which result in continued difficulty in terms of communication, learning, mobility, autonomy, interpersonal relationships and social involvement.

The transfer of children and young people who need special educational support is done by school and school cluster administration and management. After referral, the executive council requests that the special education department assesses the referred children and young people. The objective of the assessment is to collect information that permits:

- verification that it is a permanent special educational needs situation;
- guidance for drawing up an individual education plan.

Since the 1990s, Portugal has been improving the conditions for pupils with special educational needs (SEN) to access mainstream education and also to benefit from quality learning.¹¹³⁵

Nowadays, inclusive school basic principles – based upon humanistic beliefs concerned with human rights, equity and social justice – are unquestionable. Teachers, parents and politicians recognise that traditional, formal models can lead to segregation and discrimination, making social and educational inclusion difficult for people with disabilities. However, in order to maintain and develop quality education for these pupils it is important not only to preserve the availability of specialised human resources and specific tools, but also to implement major changes in school organisation and in pedagogical practice.

This is not a direct process and although inclusive education principles are considered unquestionable, there are some weaknesses in how they are put into practice. The concept of SEN applies to every child or young person showing any learning difficulty at any time during their academic life. Due to its very comprehensive nature, it has created some problems in schools

¹¹³⁵ <https://www.european-agency.org/country-information/portugal/systems-of-support-and-specialist-provision>

during the detection of needs and in the evaluation process. In effect, as it based on value principles, it can have different meanings in different contexts, allowing some pupils to be considered as pupils with SEN even if they do not show any considerable problem. Other pupils who really have special needs are sometimes not cared for appropriately.

These aspects have raised some debate about the lack of conditions in mainstream schools to meet the needs of these learners, highlighting the difficulty in getting specialised resources and the lack of specialised mainstream teacher training as effective obstacles to inclusive practice.

This division of opinions does not aim to bring back the traditional models, but rather to improve the quality of education offered to pupils with SEN in mainstream school settings. At least, that is the official position.¹¹³⁶

With the economic crisis, however, some caution was taken to avoid regression in the inclusion process.

Since 2008, many special schools have mainly served as resource centres for mainstreaming. They provide specialised support through partnership with mainstream schools, established as supporting structures for the inclusion of pupils with SEN. The new role of the special schools has been critical for developing sustainable and high-quality inclusive education.

However, support provided by resource centres and special education teachers remains primarily connected to the needs of individual learners, rather than aiming at capacity-building of class teachers and the whole school. Today, only a few special schools remain as such, covering 1.2% of learners with SEN.¹¹³⁷

The Education Act guarantees the principle of permeability between the mainstream and special channels. It proclaims that special education should be organised according to various models of inclusion in mainstream schools. It can be instituted in specific institutions when children and young people with SEN require specialised and differentiated support that entails significant adjustments to the educational or teaching and learning process that are demonstrably unachievable in mainstream education with the correct inclusion or when this inclusion proves demonstrably insufficient.

As stipulated in the Education Act,¹¹³⁸ special education aims to facilitate socio-educational recuperation and integration for individuals with SEN caused by physical or intellectual disability. The following objectives, which are part of the general education system, are particularly important in special education:

- Developing physical and intellectual potential
- Assistance in acquiring emotional stability
- Developing communication possibilities
- Reducing limitations caused by disability

¹¹³⁶ With the implementation of Decree-Law No. 3/2008, the pupils covered by SEN were restricted to those with permanent needs, redirecting the available specialised resources to them.

¹¹³⁷ Sources: Financing of Inclusive Education, p. 37; FPIES – Portugal Country Report

¹¹³⁸ Law No. 46/86, 14 October

- Support for family, school and social inclusion
- Developing independence at all levels
- Preparing for adequate vocational training and integration into working life.

Decree-Law No. 3/2008, 7 January, defines the specialised support given to pupils with permanent SEN and is implemented via the following measures:

- Personalised pedagogical support
- Individual curriculum adjustment
- Adjustment to the enrolment process
- Adjustment to the assessment process
- Individual specific curriculum
- Support technology.

In early intervention, ¹¹³⁹ Decree-Law No. 281/2009, 6 October, defines regulating guidelines for inclusive support for children with disabilities or children at high risk of impaired development and their families. Early intervention is an inclusive support measure that focuses on the child and the family. It involves a variety of services in the areas of education, health, social and other community services.

Specialised support provided in state, private and co-operative pre-primary, basic education and upper-secondary education aims to create the conditions for adjusting the educational process to pupils' special educational needs. The goals of special education are educational and social inclusion, educational access and success, autonomy, emotional stability, the promotion of equal opportunities, and preparation for further study or post-school or professional life.

Teachers from the special education recruitment group, with specialised training in specific areas, are placed in schools to promote support activities for learners with permanent SEN.

Information and Communication Technology Resource Centres for Special Education

The national network of Information and Communication Technology Resource Centres for Special Education (CRTICs) was created in the framework of the inclusion policy for pupils with permanent SEN in mainstream schools, dating back to 2007/2008.

CRTICs aim to assess pupils with permanent SEN with regard to assistive technology and the use of information and communication technology. The Ministry of Education finances part of the products and technologies they recommend.

CRTICs also have an important role in disseminating information and training teachers, staff and families in using the recommended devices, as well as in dealing with different kinds of disabilities.

There are 25 CRTICs distributed across the country, located in schools. Each CRTIC supports a large group of schools at district level. CRTICs carry out their activity according to central guidelines, presenting annual activity plans and activity reports to the central department that coordinates them. ¹¹⁴⁰

¹¹³⁹ Support for children from 0 to 6 years old, preferably from 0 to 3

¹¹⁴⁰ Directorate-General of Education

CRTICs have webpages, blogs and learning management system platforms to disseminate their services and activities to the school communities they support. The Directorate-General of Education manages a Moodle community area, integrating all CRTICs, as a sharing and discussion platform.

In 2006, a specific recruitment group was created for special education teachers.¹¹⁴¹ The organisation of educational provision in the area focus on a limited group of learners whose needs demand a specialisation of material and human resources. The school is responsible for managing those resources in such a way that it meets the needs of all learners. The school is involved in a set of activities based around the curriculum and curriculum enhancement, aiming to create conditions for the expression and development of exceptional capacities and the resolution of any problems.

For each learner, the school can implement measures to promote educational success, such as, among others:

- Study support
- Temporary constitution of groups of learners according to their needs and/or potentialities
- Classroom interaction
- Tutoring programmes
- Reception and follow-up of learners who do not have Portuguese as their mother tongue¹¹⁴²

Special education approaches are also organised with the aim of integrating adolescents with disabilities into the world of work. To this end, within the Ministry of Labour, Solidarity and Social Security – which is also an authority on social and socio-professional integration – there are official schools, residences and centres for occupational support. Similarly, this Ministry funds individuals through subsidies and finances private institutes for social solidarity with socio-educational schools. The major group in this sector is the Portuguese Associations of Parents of Pupils with Intellectual Disabilities, to which the Ministry of Education contributes significantly through the provision of teachers, support for school social action and co-funding with families.

Via support given to the vocational training units of the institutions, the Employment and Vocational Training Institute has incentives for practical vocational training courses in industry and for job adaptation. The Institute also gives support for self-employment and protected employment centres. According to Decree-Law No. 3/2008, 7 January, the specific types of education for learners who are blind, partially sighted, deaf and those with multiple disabilities and autism include:

- special schools for bilingual education of deaf learners and for the education of learners who are blind or partially sighted;
- structured teaching units for learners with autism and specialised support units for learners with multiple disabilities and congenital deafness and blindness.

¹¹⁴¹ It was made operational by Decree-Law No. 20/06, 31 January.

¹¹⁴² Order No. 1-F/206, 5 April

These responses are given in the mainstream school and integrate specialised human resources and specific material resources appropriate to learners' characteristics. ¹¹⁴³

As already mentioned, special schools have begun a re-orientation process for Resource Centres for Inclusion (RCIs). In partnership with the community, the RCIs support the inclusion of children and young people with disabilities by facilitating access to education, training, work, leisure, social participation and an autonomous life, while promoting the full potential of the individual. The RCIs work in partnership with school clusters.

The general objectives to be fulfilled are those legally enshrined for all pupils, with no discrimination against pupils with SEN. Special schools and specialised support units are created whenever the number of pupils in a school or adjacent school cluster and the nature of the response, the specific facilities and professional specialisation justify their presence. Many local authorities provide school transport for pupils, as do many special schools.

The Portuguese education system comprises three years of pre-primary education, which are not compulsory, and twelve years of mandatory schooling divided into cycles: first cycle – four years; second cycle – two years; third cycle – three years; secondary level – three years. Children start to attend compulsory school at six years old. The right and obligation to attend school lasts until the learner has completed 12 years of schooling or has reached 18 years old. ¹¹⁴⁴

Children and young people with permanent SEN benefit from special access and attendance conditions: They have priority in terms of enrolment and can attend nursery schools or mainstream schools regardless of their area of residence; In exceptional and duly justified circumstances, they can postpone enrolment for the first year of compulsory education for one year (this is non-renewable); They can sign up for individual subjects in the second and third cycles of basic education and secondary education, as long as the sequence of mainstream education is maintained.

If the measures provided for in Decree-Law No. 3/2008 prove to be insufficient, due to the type and degree of the pupil's disability, those involved in the assessment can suggest that the pupil attend a special school.

The number of pupils supported in each unit (structured teaching units for pupils with autism and specialised support units for pupils with multiple disabilities or congenital deafness and blindness) should not exceed six. There are 20 learners in pre-primary classes, first, second and third cycle classes and vocational classes that include learners with permanent SEN whose individual education plan provides for it and whose respective degree of functionality justifies it. These classes may not include more than two learners under these conditions. ¹¹⁴⁵

¹¹⁴³ Decree-Law No. 3/2008, 7 January, establishes, with regard to reference units and schools, the implementation conditions, the objectives, the human and material resources and the organisation and running of the above-mentioned units and schools.

¹¹⁴⁴ Sources: IECE – Portugal Example of Provision, pp. 1-2; IECE – Portugal Case Study Visit Report; CPRA – Portugal Country Report, p. 20

¹¹⁴⁵ Order No. 1-B/2017, 17 April

The school year is defined annually by ministerial order. It takes into account all the pupils who attend the mainstream school system, including the pupils with SEN. A school year is defined in the same way for pupils with SEN who attend private special education establishments. An individual education plan (IEP) is defined for pupils with permanent SEN. The IEP documents each pupil's specific needs and stipulates and justifies the educational response and the respective form of assessment. No form of adjustment to the teaching and learning process is permitted without an IEP.

The class teacher or class tutor is the co-ordinator of the IEP, depending on the teaching or education level that the pupil is attending. The IEP is drawn up by the pupil's teachers, a special education teacher and parents or guardians, i.e. whoever knows the pupil best and whoever works directly with them. For it to be implemented, it has to be approved by the pedagogical council and have express agreement from parents or guardians.

With regard to changes in the curriculum, pupils can benefit from individual curriculum adjustment or a specific individual curriculum. The individual curriculum adjustments mean not compromising the common curriculum or the pre-primary curriculum guidelines. To this end, subjects or specific curriculum areas can be introduced, allowing access to the common curriculum, as well as greater autonomy.¹¹⁴⁶ These adjustments can also mean the introduction of objectives and intermediate content or exemption from activities where the pupil's functional level means it is extremely difficult or impossible to achieve the respective task. Exemption should happen only when support technologies are insufficient to help achieve the task in question.

The specific individual curriculum presupposes significant changes in the common curriculum, which may mean:

1. the prioritisation of curriculum areas or certain content over others;
2. the elimination of objectives and content;
3. the introduction of complementary content and objectives regarding very specific aspects (i.e. non-verbal communication, the use of support technology in communication, mobility, accessibility);
4. the elimination of some curriculum areas.

For the teaching of specific areas of the curriculum, such as Portuguese Sign Language, Braille or the use of support technologies, special education teachers and other professionals with specific training, such as Portuguese Sign Language teachers and interpreters, are placed in schools by the Ministry of Education. The Ministry of Education resource centres produce school books in Braille, in large font and in DAISY format.¹¹⁴⁷ The network of Information and Communication Technology Resource Centres for Special Education also produces adapted material and trains teachers to use special software for different disabilities.

¹¹⁴⁶ Such as Portuguese Sign Language (L1) and Portuguese Language/Second Language Portuguese for deaf pupils (LP2), reading and writing in Braille, orientation and mobility, vision training and adapted motor activity, among others.

¹¹⁴⁷ Digital Accessible Information SYstem

In the field of internal summative assessment, Order No. 1-F/2016, 5 April, defines the evaluation and certification of learning, as well as measures to promote educational success that can be adopted in the monitoring and development of learning, among others that schools can adopt according to their own autonomy.

According to Decree-Law No. 3/2008, 7 January, pupils with permanent SEN can benefit from changes to the assessment process. These can consist of a change in the types of test, the assessment and certification mechanisms, and assessment conditions regarding, amongst other aspects, the ways and means of communication and how often they occur, their duration and location.¹¹⁴⁸

Whenever pupils have permanent SEN, which prevent them from acquiring the learning and competencies defined in the common curriculum, three years before they reach the age limit for compulsory education, the school should complement the IEP with an Individual Transition Plan (ITP). The first phase of the ITP is to discover the wishes, interests, aspirations and competencies of the respective young person. Based on this data and the learner's capacity to exercise a professional activity, this phase includes an assessment of the labour market needs in the learner's community and the seeking of training opportunities or real work experience.

Once the possibilities of training or internships are recorded, it is important to identify the competencies (academic, personal and social), adjustments and special equipment required. After this assessment, it is necessary to establish agreements with the services and institutions where the young person will train or be an intern, to define the tasks they will do, the competencies required and the

Once the possibilities of training or internships are recorded, it is important to identify the competencies (academic, personal and social), adjustments and special equipment required. After this assessment, it is necessary to establish agreements with the services and institutions where the young person will train or be an intern, to define the tasks they will do, the competencies required and the support needed to achieve these tasks, if and when necessary.

With regard to young people whose disabilities do not allow them to work, research should focus on finding occupational activity centres that can provide activities that interest them and are appropriate for their individual competencies. Decree No. 201-C/2015, 10 July, stresses that mainstream schools must seek support from existing organisations in the community (such as enterprises, municipalities, vocational training centres, etc.) in order to prepare the transition of pupils with disabilities from education to active life.¹¹⁴⁹

¹¹⁴⁸ With the exception of pupils with specific individual curriculums, all pupils with SEN are subject to the system of transition of year common in mainstream education, as defined in Implementing Order No. 1-F/2016, 5 April.

Pupils with specific individual curriculums are subject to specific assessment criteria defined in the respective IEP.

¹¹⁴⁹ Source: CPRA – Portugal Country Report, p. 3

Those legally stipulated formulations and norms commonly used for the educational system are the same for school certification in special education. Certification mechanisms should be adjusted to the special needs of pupils who have an IEP, identifying the adjustments to the teaching and learning process that have been applied.

After the political change in 1974 and the appearance of the new Constitution of the Portuguese Republic, which enshrined some general principles of education, covering state and private schooling, there was an upsurge in private and co-operative education. The number of co-operative schools increased, particularly in the area of special education, and the Ministry of Education began to give them funding.

In line with the Education Act, special education is preferably organised according to various models, taking into account specific service needs in mainstream schools, with special education initiatives belonging to central, regional and local authorities. Other collective bodies - namely parents' and residents' associations, civic and religious groups, trade union and company organisations, as well as social groups – can also be involved in creating special teaching and education initiatives.

General Supervision of Education, a central service of the Ministry of Education, is responsible for monitoring quality in education as far as every school is concerned, regardless of its nature and educational level. This is carried out by means of systematic monitoring methods and by examining educational practices, teachers' professional attitudes and integration of the school in the local community.

The Directorate-General of Education, another central service of the Ministry of Education, has a permanent observatory for educational support which annually collects data that helps to characterise and to monitor the education system in the field of special education. Decentralised education services of the Ministry of Education, at a regional level, also have responsibility for follow-up and monitoring led by educational support co-ordination teams.

The situation in Portugal is thus not yet there. According to an EESC study disability discrimination in Europe averages 15%, but in Portugal this figure stands much higher at 65%. As a result, the PSG DIS carried out a fact-finding visit to Lisbon, Portugal on 19-21 March 2018 to gather information about the situation for people with disabilities in the wake of the economic crisis and subsequent austerity measures.¹¹⁵⁰

Following the fact-finding visit the EESC concluded that combating discrimination begins with an inclusive education system. Portugal does well on this measure. Inclusion of students with disabilities within the wider education system stands at 99%. Of the 99% in attendance, 86% receive a mainstream education. However, the PSG DIS found that the school system sometimes struggles to provide students with disabilities with the additional support services they may need, such as therapy sessions. Therapeutic support for students with disabilities was reduced by half in 2015-2016 and is continuing to be cut. EESC also highlighted that attention must be devoted to addressing the gender gap among students. Girls with disabilities receive less support than boys and are also less present in schools.

¹¹⁵⁰ <https://www.esn-eu.org/news/1050/index.html>

The EESC also highlighted in their article that just 0.5% of the private-sector workforce in Portugal and 2.3% of the public-sector workforce is made up of people with disabilities, despite targeted objectives by the Portuguese government of 2% and 5% respectively. Lack of participation in the workplace can put people with disabilities at high risk of poverty and social exclusion. On top of this, unemployment figures for the Portuguese population have been declining steadily since 2013 and in December 2017 general unemployment was below 8%. Over the same period unemployment actually increased for people with disabilities and now stands at around 25%.

The European Social Network (ESN) recently published a report which addresses some of the themes raised by the PSG DIS fact-finding mission to Lisbon.¹¹⁵¹ An example of this is the first chapter of the report which is about active inclusion measures to improve the employment rate of people with disabilities. The chapter provides a review of strategies from several European countries that aim to increase the participation of people with disabilities in the labour market and a detailed local case study from the Netherlands. Through sharing examples of best practice, ESN hopes to help countries in Europe to increase independence and autonomy of people with disabilities.

Since 2016, the newly-elected Portuguese government has introduced two important advances to improve the situation of people with disabilities. As the European Commission highlighted in their European Semester¹¹⁵² report for Portugal for this year, these are a new social inclusion benefit and a scheme to support independence for people with disabilities by aiming to help them access employment. The government hoped these policies will help to move away from institutionalisation and towards empowering individuals, which is also something that ESN advocates strongly for in its work.

However, access to these benefits requires a minimum of 60% incapacity which the EESC argue is assessed based on a “contentious table of established physical disabilities” which discriminate against against intellectual disabilities. Ioannis Vardakastanis, President of the European Disability Forum¹¹⁵³, argues that the benefits assessment should be based on needs, not on the level of disabilities a person has. On top of this, funding remains a chronic issue for new initiatives in Portugal. The EESC argue that the Portuguese Government are dependent on NGOs carrying out crucial work on a voluntary basis or with very limited funds. The PSG DIS concluded in its article that there is a desperate need for additional funding for the organisations that implement community-led initiatives to improve the situation for people with disabilities.¹¹⁵⁴

New regulation was published in Portugal in January of 2019 establishing minimum quotas for disabled workers that must be adopted by medium and large sized employers when engaging and organizing their workforce.

¹¹⁵¹Towards more independent lives for people with disabilities

¹¹⁵² <https://www.esn-eu.org/glossary/term/1119>

¹¹⁵³ <http://www.edf-feph.org/>

¹¹⁵⁴ <https://www.esn-eu.org/news/1050/index.html>

The new rules became effective as from February the 1st and cover the following employers: medium-sized enterprises (companies having between 75 and less than 250 persons employed); and large-sized enterprises (companies having 250 or more persons employed).

Only individuals affected with a disability ratio of 60% or over – according to a national disability classification table – qualify as disabled employee/worker for the purposes of assessing quota compliance.

Quotas that must be respected are the following:

Medium-sized enterprises: 1% quota for disabled worker

Large-sized enterprises: 2% quota for disabled worker

The quota percentage is based on the average number of employees in the previous calendar year. A four or five year transition period is established, depending on whether the company does or not exceed 100 persons employed. ¹¹⁵⁵

The circumstances of people with disabilities in Portugal needs attention on a number of levels. Although the proportion of people with disabilities in education is good, representation is lacking in other fields such as employment where targets are not being met. ESN will continue to try and improve the situation for people with disabilities through actions like promoting the deinstitutionalisation of care in the EU to ensure greater independence for people with disabilities. The Portuguese government has brought in some measures to improve the situation, but as highlighted, some groups criticise the assessment procedure for the new initiatives. Finally, a lack of funding was also cited by PSG DIS as limiting the government's ability to act to tackle disability discrimination. ¹¹⁵⁶

¹¹⁵⁵ <https://knowledge.leglobal.org/portugal-new-rules-establishing-quotas-for-disabled-workers-in-portugal/>

¹¹⁵⁶ <https://www.esn-eu.org/news/1050/index.html>

Romania

For many years in Romania, people with intellectual disability received services through the psychiatric care system, where people with an intellectual disability were treated alongside patients with psychiatric conditions and were registered as 'oligofrenia' in psychiatric files. The use of psychiatric services prevailed because a proportion of people with intellectual disability had psychiatric disorders, most of which were caused by inappropriate living conditions. Even today, psychiatric disorders are considered the same as an intellectual disability.

Deinstitutionalization is an issue that the Institute for Public Policy (IPP) in Romania has been actively monitoring and advocating for more than a decade. As a matter of fact, during the 2008-2013 period, the IPP was the only non-governmental organisation (NGO) to research and publish yearly national monitoring reports on the situation of persons with disabilities. At the date of the last monitoring report in 2013, the IPP wrote that the main cause for entering the institutionalized system was the need for socio-medical care and that death was the main cause for exiting the system. Unfortunately, only 16 % of people who left the system did so due to family integration/reintegration.¹¹⁵⁷

The Romanian government first committed itself to the deinstitutionalization of a significant number of disabled adults in its first Regional Operational Programme (POR) 2007-2014 (when the country joined the European Union) and later again in the 2014–2020 Programme. This commitment was reaffirmed in the National Strategy "A society without borders for disabled people 2016–2020",¹¹⁵⁸ which together with the accompanying National Plan, has the objective to transition from the residential care system to the community-based one. These framework programmes also established multiple lines of financing available for public authorities (General Directorates for Social Assistance and Child Protection – DGASPC) and NGOs. One of the major problems with the first POR that the IPP identified in its monitoring report is that paradoxically, despite its objective to deinstitutionalise, due to some technical particularities regarding costs, it only allowed for the funding for the modernization and/or extension of large residential centres. In other words, it was not possible to apply for funding for the development of alternative residential centres in the community. Therefore, until 2014, some 43 projects were funded, some of which had as an objective the extension of large residential centres (such as DGASPC Mures – the extension and equipping of the Brancovenesti rehabilitation centre which already had a capacity of 300 places). Furthermore, the very large budgets and ambitious infrastructure objectives of these lines of funding set such conditions that only public authorities were capable of fulfilling them - with one exception – the Rainbow Foundation which won a project to renovate an elderly residential centre. These issues were fixed in the new ROP 2014-2020.

¹¹⁵⁷ Tudose, Elena and Oana Caloiu. (2015) Raport de monitorizare a implementarii Conventiei ONU privind Drepturile Persoanelor cu Dizabilitati. Bucharest, Institute for Public Policy.
<http://www.ipp.ro/wp-content/uploads/2016/02/Conventia-onu-5.pdf>.

¹¹⁵⁸ http://www.mmuncii.ro/j33/images/Documente/Proiecte_in_dezbatere/2015/2015-10-08-proiecthg-strateg-diz-anexa1.pdf.

In July of 2018,¹¹⁵⁹ the national Government adopted a series of modifications to Law 448/2006, through emergency ordinance, aimed at deinstitutionalization / transition from residential to community-based services as per its commitments within the 2020 European Semester framework. Calls for proposals were launched late in 2018 (Operational Programme Human Capital, with funding from the European Social Fund) and early 2019 (Operational Regional Fund, through funding from the European Regional Fund).

Presently, the disability community is dealing with a very problematic development regarding the national budget. After the adoption of the national budget in February 2019, the government announced that the financing of social services (including care centres, disability and other allowances, carers/assistants for persons with disabilities etc.) will be placed in the responsibility of the local authorities (until now it had been the government's). Numerous NGOs have heavily criticised this move saying that it not only ran the risk of leaving the hundreds of thousands of people who depend on governmental social assistance without any coverage (because the budgets of the local authorities is nowhere near as big as the government's and they would quickly run out of money), but that the concept of social care could become politicised. According to some NGOs, when the local authorities will ask for supplemental funds from the government, the latter will award it based on political interests.¹¹⁶⁰

The most recent data which are being quoted for this research is from the 30th of September 2018. As of that date, there were 812,594 registered people with disabilities (748,210 adults and 64,384 children) in Romania. 2.22 % (18,015 people) were residing in adult institutional care centres. There were 489 social care centres, of which 427 were residential (an increase from 407 from the previous year). The residential care institutions are divided into large care and assistance centres (6,543 beneficiaries) and protected shelter houses (135 houses hosting 929 beneficiaries). This marks an increase of 12 houses in comparison to 2017. There is also a significant number of beneficiaries in the 74 neuropsychiatric rehabilitation and recovery centres: 6,327. There were no disabled children registered as residing in institutional care.¹¹⁶¹

In 2013, there were 709,216 registered people with disabilities, out of which 60,993 were children. The institutional residential centres housed 17,123 people, of which 12 were children. In comparison to the figures from 2018, this means a 13 % increase in the overall number of registered people with disabilities, a 5 % increase in the number of disabled people housed in institutional centres and a decrease of 100 % for the number of children in residential institutional centres. In 2013 there were 335 residential centres of which 85 were protected shelters. The comparison to 2018 shows an increase of 22 % in the number of residential centres and an increase of 37 % in the number of protected shelter houses.

¹¹⁵⁹ Ministerul Muncii si Justitiei Sociale. (18.07.2018). Comunicat de presa. "Guvernul a modificat si completat Legea nr. 448/2006, prin care sunt acordate drepturi copiilor si adultilor cu dizabilitati. <https://www.juridice.ro/wp-content/uploads/2018/07/comunicat-mmjs-2.pdf>.

¹¹⁶⁰ "Buget 2019: Niciun leu pentru persoanele cu dizabilitati. 100,000 oameni lasati de izbeliste". Ziare.com. 1 February 2019. <http://www.ziare.com/economie/buget/bugetul-pe-2019-nu-prevede-niciun-leu-pentru-persoanele-cu-dizabilitati-100-000-de-oameni-lasati-pe-dinafara-1548054>.

¹¹⁶¹ National Authority for Disabled Persons. Statistical data for the 30th of September 2018. <http://anpd.gov.ro/web/wp-content/uploads/2019/01/BULETIN-STATISTIC-ANPD-TRIM-III-2018-1.pdf>.

Unfortunately, neither the central nor the local authorities keep public records detailing proportions of budgetary spending. This is another issue that the IPP encountered in its monitoring – the lack of centralized and coordinated data regarding budgets and the categories it was spent on. In order to receive this information, the IPP would annually request data on the amount of money spent on providing services at the centres versus how much was allocated to beneficiaries, through Freedom of Information Requests from each of the 41 DGASPCs as well as the Ministry of Labour and the National Authority for Persons with Disabilities. In its 2015 report, the IPP pointed out that in 13 out of the 41 Romanian counties, more money was allocated towards administrative costs (including staff) than towards medical staff or services.¹¹⁶²

The only public information available regarding specific categories of budgetary spending can be found in the press releases/communications of the Ministry of Labour.¹¹⁶³

In the educational system, the person is considered having a handicap if they have: an intellectual, visual, hearing, physical, and/or organic disability with permanent and/or severe disturbances of development (such as autism spectrum disorders or major psychiatric disturbances). Children with intellectual disability are identified where a standardised psychological assessment reveals a lower performance than that expected by children of the same age in the general population. Medical and psychological evaluations are conducted to establish the level of ability and special education needs of the child. These evaluations are then discussed by a special committee that makes recommendations regarding the education needs of the child.¹¹⁶⁴

Therefore, according to the website of the National Authority for Persons with Disabilities (ANPD), in 2018, the Government allocated 51,200,000 RON (approximately 11 million EUR) for the deinstitutionalization of adults with disabilities for the 2018-2020 period, as part of the National Interest Programme (NIP) for promoting and protecting the rights of disabled people. The DGAPSCs will be responsible for the implementation of the projects, together with local NGOs and other public local authorities. The objectives, as set by the NIP, are to decrease (by a minimum of 244 people) the number of people in the care centres, to build at least 61 new care shelters/protected dwellings, to build 38 new day centres, and to include as many DGASPCs as possible in the deinstitutionalization process.¹¹⁶⁵

Before 1989 people with intellectual disabilities living in Romania were cared for in families or in institutional care. Special schools were extremely limited throughout country, with most cities not providing special educational facilities. Most children with more severe levels of intellectual

¹¹⁶² Iorga, Elena and Loredana Ercus. (2012). Bilantul de 4 ani al furnizarii serviciilor sociale pentru persoanele cu dizabilitati intelectuale. Bucuresti, Institutul pentru Politica Publica.
<http://www.ipp.ro/wp-content/uploads/2015/08/bilan355ul-de-4-ani-al-furniz259ri.pdf>.

¹¹⁶³ The central authority in this case

¹¹⁶⁴ http://ec.europa.eu/health/ph_projects/2004/action1/docs/action1_2004_a08j_14_en.pdf

¹¹⁶⁵ "Guvernul aloca 51,200,000 lei pentru dezinstitutionalizare persoanelor adulte cu dizabilitati." Mediafax. 4 April 2018. <https://www.mediafax.ro/social/guvernul-aloca-51-200-000-lei-pentru-dezinstitutionalizarea-persoanelor-adulte-cu-dizabilitati-17119903>.

disability were educated within an institutional setting, while children with mild or moderate intellectual disability could be educated into the local schools, depending on the wishes of their parents.

Upon reaching adulthood, people with intellectual disability had the possibility to learn handicrafts and to engage in 'special jobs' that is, jobs which were completed only by people with a disability. For example only people with visual impairment could manufacture brushes. Small manufacturing units were established in institutionalised settings where the residents were engaged in an activity appropriate to their level of ability. Any income resulting from these activities was used for care provision.

There were two main forms of residential care, institutions and family homes. Institutionalised care was provided free to a wide variety of people with physical, mental or neurological disorders. This care was largely medical in nature. Those providing care within the family home received no financial support and no advice from social support services regarding the care they provided.

Thus the evolution in this field in Romania, whilst slowly continuing throughout the decades, still falls short of what is expected of a modern EU country. Romania's commitments to date concerning support for independent living in the community are set out in two main framework documents: the National Strategy "A society without borders for people with disabilities 2016-2020"¹¹⁶⁶ (adopted in September 2016) and in the country's National Interest Program on protection and promotion of rights of persons with disabilities adopted in October 2016.

Law 448/2006 regarding the rights of children and adults with disabilities was amended in July 2018, through an emergency ordinance aimed at improving the quality of life of persons with disabilities in line with international commitments and obligations. The most significant of these measures addressed deinstitutionalization and local authorities had until the end of 2018 to implement them or run the risk of losing 25 % of their government funding. Projects targeting deinstitutionalization would be eligible for funding through NIP and EU funds.¹¹⁶⁷ The calls for proposals which would enable public authorities and NGOs to respect the amended law and new deadline for deinstitutionalization were launched late in 2018 and at the beginning of 2019. There is no current information published online regarding actions taken by public authorities to implement the requirements of the emergency ordinance or penalties paid by those who did not respect the new amended law.

Romania's commitment to deinstitutionalization was stated in the National Strategy "A society without borders for disabled people 2016–2020", which was launched as part of Romania's obligations as a signatory of the UN Convention on the Rights of Persons with Disabilities. The Strategy also aims to fulfil Romania's commitments under the European Disability Strategy 2010-2020 and the Europe 2020 Strategy.

¹¹⁶⁶ National Authority for Disabled Persons. "Strategia Nationala—O societate pentru fara bariere pentru persoanele cu dizabilitati 2016-2020." 27 September 2016 <http://anpd.gov.ro/web/strategia-nationala-o-societate-fara-bariere-pentru-persoanele-cu-dizabilitati-2016-2020-si-planul-operational-privind-implementarea-strategiei-nationale/>.

¹¹⁶⁷ Ministry of Labour and Social Justice. Press Release. "Guvernul a modificat si completat Legea nr. 448/2006 prin care sunt acordate drepturi copiilor si adultilor cu dizabilitati." 17 July 2018. <http://www.mmuncii.ro/j33/index.php/ro/comunicare/comunicate-de-presa/5189-cp-modif-lege-448-2006-drepturi-copii-adulti-dizab-17072018>.

One of the main objectives outlined in the National Strategy was the achievement of the transition from an institutional-type care system to a community/family-based one.¹¹⁶⁸ This is to be achieved through a restructuring and dismantling of the present-day large centres and transitioning the residents into newly-built family-style dwellings (apartments, located within the communities, not at the periphery, where 2-3 disabled persons live, with adapted support). Financing will be available through calls for proposals under the Regional Operational Programme, EU funds, NIP funds etc. The list of institutional centres eligible for financing was published in 2017 after an analysis started in 2015.

Because progress is so slow and halting, it is difficult to talk about a direct and continuous involvement of NGOs and the target group in the development of the governmental strategies. Relevant NGOs: Alaturi de Voi Foundation, NGOs Federation for Social Services, ProAct Support Association, Dizabnet – Foundation of service operators for people with disabilities. Their major outputs are providing social services for some of them and advocacy, information, assistance for people with disabilities for others. Officially, of course, the objectives of the strategies are all ones that NGOs and other international bodies (EU, Council of Europe, UN etc.) have repeatedly advocated for. However, because progress is, at best, incremental, the relationship between NGOs and the Government does not follow the usual consultation – feedback loop. The role of NGOs is split into advocacy and watchdog.¹¹⁶⁹

In the period of 2017–2018, the National Authority for Disabled Persons (ANDP) organized two calls for proposals with the objective of increasing the quality of life for disabled persons and the specific objectives of

- (1) Ensuring the access of adult disabled persons to family-type centres or sheltered homes and
- (2) Education and recreational activities.

The calls were open to all NGOs. The maximum amount awarded for the establishment of a protected shelter was 135,000 RON (around 28,700 EUR) per building.¹¹⁷⁰

In 2017, the ANDP had to repeat the call for proposals because only one NGO responded the first time. In the final call for proposals report,¹¹⁷¹ the ANDP points out the fact that only one proposal was submitted (from a different NGO than in the first call for proposals) and subsequent

¹¹⁶⁸ National Authority for Disabled Persons “Documentul de analiza a serviciilor sociale pentru asigurarea transferului in alternative de tip familial a persoanelor adulte cu dizabilitati din institutii rezidentiale de tip vechi.” <http://anpd.gov.ro/web/despre-noi/programe-si-strategii/programul-operational-regional-2014-2020/>.

¹¹⁶⁹ <https://www.disability-europe.net/search?searchword=ROMANIA&searchphrase=all>

¹¹⁷⁰ National Authority for Disabled Persons Programe finantate de ANPD. <http://anpd.gov.ro/web/despre-noi/programe-si-strategii/programe-finantate-de-anpd/>.

¹¹⁷¹ ANDP. Raport in vedere atribuirii conventiilor de finantare nerambursabila. http://anpd.gov.ro/web/wp-content/uploads/2017/03/Rapo{"IsDistinguishedFolder":true,"FolderId":{"__type":"FolderId:#Exchange","Id":"AQMkADJhNTlwMTEAMi1jMmY1LTRiZjgtOTRiMS1mZWExYjQ5Y2U0NmEALgAAA2s+gy1Z9aNlgDNvLYSh53MBAH2o5dD60GJFudD6mYXjjBUAAAIBDAAAAA==","ChangeKey":"AQAAAABYAAAB9qOXQ+tBiRbnQ+pmF44wVAACtNXub"},"DragItem":4}rt-final-ONG-2017-Sesiunea-2.pdf.

to the committee evaluation, the project was rejected. The reasons given for the rejection were that the judicial status of the proposed building was unclear, and the NGO did not have the one year mandatory experience in having established and run a previous centre for disabled people.

In the 2018 call for proposals, no proposal regarded the establishment of a residential centre. Calls for infrastructure projects with the objective of deinstitutionalization through the building of protected homes have been launched at the end of 2018 (Operational Programme Human Capital, with funding from the European Social Fund) and at the beginning of 2019 (Operational Regional Fund, through funding from the European Regional Fund).

According to December 2018 data available on the website of the Ministry of European Funds, 6 deinstitutionalization projects focusing on infrastructure had received an approximate total of 23 million euros in funding under priority axis 8.1 from the Regional Operational Programme.¹¹⁷² Despite research, there was no evidence on the website of the Ministry of European Funds of programmes funded under priority axis 4 within the Operational Programme Human Capital. There was only one call launched regarding the deinstitutionalization of adults and the transition to community-based social services, on the 10th of September with two corrigenda regarding the revision of the minimum targets, the types of eligible activities, the maximum value of the project and the timeframe allocated for application.¹¹⁷³

Progress in achieving targets and milestones has been slow and nonlinear, at times even regressive. The adoption of the Strategy along with its corresponding Action Plan was frequently postponed until it was finalised eight years after the initial pledge. It is also difficult to measure progress because targets are vague and non-specific. The Strategy provides a list of specific objectives to be accomplished by 2020 but in the absence of clear indicators and monitoring, it is difficult to measure the progress of its implementation.

The European Commission justly highlighted deinstitutionalization as a challenge for Romania in the country's 2016 Country Specific Recommendations (CSR), written by the European Commission. However, there was no mention of this issue in the 2018 CSR.

During a recent visit, the Council of Europe Commissioner for Human Rights, Dunja Mijatovic, stated that Romania's most pressing problem regarding people with disabilities is the overpopulation of institutional centres. Therefore, deinstitutionalization is an urgent matter that Romania must address as soon as possible.¹¹⁷⁴

A 2013 UNICEF country report regarding Romania on "Children with Disabilities", the authors criticized the lack of availability of unified, coordinated, clear and uninterrupted statistical data on the topic and the limited mandate of the independent monitoring mechanisms. To this end, the

¹¹⁷² Ministry of European Funds. "POR – Lista proiectelor contractate 31.12.2018". Excel document available on: <http://www.fonduri-ue.ro/>.

¹¹⁷³ FSE-Sud Muntenia. 2019. "Anunțuri." <http://www.fsesudmuntenia.ro/anunturi.html>

¹¹⁷⁴ Ofiteru, Andreea. "Interviu: doua subiecte sensibile pe care Romania nu le-a rezolvat inca." Hotnews.ro. 16 November 2018. <https://www.hotnews.ro/stiri-educatie-22817417-interviu-doua-subiecte-sensibile-care-romania-nu-rezolvat-inca-dunja-mijatovic-despre-atitudinea-absolut-rusinoasa-fata-persoanele-dizabilitati-prejudecata-violenta-domestica-tine-traditie.htm#self>.

authors recommended the finalizing of the Electronic Registry of Persons with Disabilities which would allow the centralizing of statistical data, the creation of integrated services to allow for societal reintegration, and the implementation of a dedicated monitoring instrument. Presently, the Electronic Registry is still in a developmental phase without any clear date to be launched and there is no public information regarding the availability of monitoring reports from the Monitoring Instrument.

In its fifth periodic country report launched in 2017, the UN Committee on the Rights of the Child noted that the number of institutionalized children is still quite high and concluded that Romania needs to strengthen its measures addressing this issue.¹¹⁷⁵

As we have written above, the IPP was the only organisation who committed to the yearly monitoring of Romania's obligations under the Convention and implicitly Article 19. However, according to a 2013 monitoring report¹¹⁷⁶ written by the IPP, one concludes that there was very little progress on achieving the targets set by the UN Convention, noting that there was even a regression regarding the reintegration of people with disabilities into the community.

With regards to the achievement of Article 19, the only point achieved was the announcement for plans for the creation of a national strategy for deinstitutionalization. This point was revisited in the 2015 monitoring report because the Strategy still had not been adopted. Furthermore, the IPP criticized the government for its *“lack of preoccupation regarding the evaluation of necessary needs for persons with disabilities, the need for the development of new services and the need to perform a supply-and-demand analysis of the social care market.”*¹¹⁷⁷

Civil society organisations, including the IPP, have long called for the Government to take direct action to implement the EU and the UN's recommendations regarding deinstitutionalization. In absence of the implementation of a coordinated strategy at national level, most deinstitutionalization efforts have come from NGOs. Hopes and Homes for Children, SERA Romania, World Vision, SOS Children's Villages and others are some of the NGO's whose activity is centred on offering not only family-type dwellings, but also services for reintegration into society.

Furthermore, although NGO's have welcomed the national strategies and objectives towards deinstitutionalization, they have been quite critical of the methods and of the slow pace with which they are implemented. The IPP repeatedly criticized the Romanian government for its continued funding (using both national and EU funds) of large residential centres and for its lack of committing to a coordinated policy regarding the development of community-based services.

Recently, the Centre of Judicial Resources (Centrul de Resurse Juridice) wrote an open letter regarding the POR and POCU calls to action, criticising the lack of transparency of the

¹¹⁷⁵ United Nations Human Rights Office of the High Commissioner. Committee on the Rights of the Child considers the report of Romania. 24 May 2017.

<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=21658&LangID=E>.

¹¹⁷⁶ Institute for Public Policy. Raport de monitorizare a implementarii Conventiei ONU privind Drepturile Persoanelor cu Dizabilitati. December 2013. <http://www.ipp.ro/wp-content/uploads/2014/07/ipp-raport-implementare-conven355ia-o.pdf>.

¹¹⁷⁷ <http://www.ipp.ro/wp-content/uploads/2016/02/Conventia-onu-5.pdf>.

consultation process. IPP was one of the few NGOs fully involved in the advocacy and monitoring process for de-institutionalization, acting as a voice for people with disabilities, having insights/information/support from the NGOs providing services for people with disabilities.

Furthermore, the Centre of Judicial Resources, pointed out that, taking into consideration the fact that the main aim of the deinstitutionalization programs, according to the UN Committee on the Rights of Persons with Disabilities, is to ultimately change an entire society's mentality regarding disability and its treatment, the fact that the POCU call does not address some key target groups (such as social workers, child psychologists, or academic staff from universities who teach these programs) is very problematic.¹¹⁷⁸

Another Romanian NGO, Hopes and Homes for Children, stated that, taking into consideration the complexity of the deinstitutionalization necessities, the deadlines given for the submission of projects within the calls to action are much too short, not leaving the interested NGOs with enough time to fulfil all the conditions imposed by the Applicant's Guide.

Unfortunately, the main conclusion is that state public service providers often forget the needs of the beneficiaries and the fact that the main objective should be the social inclusion of persons with disabilities. The large number of institutionalized adults and children, the slow progress of deinstitutionalization, the lack of preoccupation in hiring staff specialized on rehabilitation of persons with disabilities demonstrate that the funds spent in Romania on social care often forget that their aim should be to increase the persons' quality of life.

In the absence of national regular objective monitoring, the European Commission should assess the efficacy of projects and measures adopted by the Romanian government addressing deinstitutionalization. Monitoring should focus on the mid and long-term impact of the projects financed through EU funds and measured against priorities set out in the National Strategy for Persons with Disabilities.

Furthermore, such a scenario strongly urges the development of a system of centralized statistical information which would be publicly available online and continuously updated. The Electronic Registry for Persons with Disabilities was initially proposed in 2012 by the Ministry of Labour (through the ANPD) in response to its obligation to establish a data-collection mechanism. However, since the Registry has not been updated since 2016 (and the link appears to not be functional), we strongly urge a revision of its functionality and an update of its data. It is impossible to measure the success-rate of public policy without establishing clear and measurable indicators which can be followed over a period of time.

One also strongly urges more transparency regarding the projects which receive funding under the Strategy's calls for proposals and the centralisation of the data on the website of the ANPD. Presently, information is scattered throughout the websites of the public authorities who have

¹¹⁷⁸ Centrul de Resurse Juridice. CRJ si Pro ACT Suport: Fonduri aruncate pentru dezinstitutionalizare epe hartie. 30 March 2018. <http://www.crj.ro/crj-si-pro-act-suport-fonduri-aruncate-pentru-dezinstitutionalizare-pe-hartie/>.

applied for projects, the Ministry of European Funds or the Ministry Labour. Finally, the situation urges international organisations to provide financing lines for monitoring projects so that NGOs can maintain their watchdog activities. ¹¹⁷⁹

So, with such findings related to inclusive policies and integration, what about educational opportunities for persons with disabilities in Romania? The Constitution guarantees the right to education to all Romanian citizens, and specific education legislation establishes that all children, regardless of the type or level of disability, have the right to education either in school or at home.

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Concerns have been raised that the assessment procedure, although conducted by an interdisciplinary team, may be superficial and result in children's inappropriate placement in special schools, or even in alternative, informal educational services, rather than in mainstream schools. In particular, the disproportionately high number of Roma children in special schools indicates that assessment process should be carefully monitored to ensure that individual capacity and potential are evaluated fully and without discrimination. Early intervention services are available only to the few families in Romania who are fortunate enough to live near the single NGO providing such support.

Although, in theory, Romanian law and policy support mainstream education for children with disabilities, and all children have the legal right to some form of schooling, in practice, mainstreaming of children with even mild intellectual disabilities is very limited, though there are no official figures. The majority of children with intellectual disabilities who attend school attend special schools, but even special schools exclude children with anything more than mild intellectual disabilities. Teachers receive little support, training and resources to promote an inclusive environment. The highly inflexible, curriculum-focused approach to education in Romania has been cited as a problem for children with intellectual disabilities. These children also require training in basic independent living skills, in addition to academic skills, to pave the way for social integration and self-sufficiency. An attempt to mainstream thousands of children from special schools in 1999 was not a success, as there was little preparation or support for inclusion in the long-term; many of the children have since returned to special schools. Special schools in Romania offer substandard education in the form of basic reading and counting skills, and thus fail to equip their students with genuine, marketable skills that would allow them to access employment after graduation. ¹¹⁸¹

Euroactiv's partner Ouest-France reports, as recently as February 2020 that Romania's adult centres offering deplorable reception conditions for people with disabilities, and the country's school system struggling to ensure the inclusion of children with disabilities, are a source of concern. ¹¹⁸²

¹¹⁷⁹ <https://www.disability-europe.net/search?searchword=ROMANIA&searchphrase=all>

¹¹⁸⁰ <https://www.sciencedirect.com/science/article/pii/S1877042811001637>

¹¹⁸¹ Education of Children with Special Needs in Romania; Attitudes and Experiences by AloisGhergut

¹¹⁸² <https://www.euractiv.com/section/economy-jobs/news/romania-is-slow-at-integrating-people-with-disabilities/>

Georgian, a ten-year-old paraplegic, is one of the thirty-nine so-called 'special' students at the Sfântu-Iacob School in Câmpulung Muscel (centre). The school, which welcomes 2,000 students, does not discriminate.

"We are an inclusive school," explained support teacher Ana Aron, who is delighted to see Georgian's progress. "We help all children. Each class has at least one child with special needs. Some have autism, hyperactivity, while others are paraplegic or quadriplegic," she added.

This kind of integration works and Georgian's mother can testify to this.

"In his previous school, the other children shunned him, and the teachers neglected him. Here he is not marginalised. I can see that he is happy and progressing," said Georgian's mother.

Out of the 100,000 handicapped children and children with special needs (the two categories are different), only 8,000 are currently integrated across Romanian schools.

Before 2016, it was impossible to send such a child to school, at least in the public sector, which meant those children remained in so-called 'special schools'. And although this looks like progress, segregation is still rampant.

Created by a catholic congregation in 1997, the Sfântu-Iacob school is still the exception. While it is private, the school does not refuse anyone, and with admission costing less than €200 per year per child, it also remains accessible. Besides, the school employs three support teachers for 39 of these students and has also created a day centre.

"Public schools are not ready to integrate disabled children," explained Mădălina Turza, who was recently appointed to preside over the National Authority for the Rights of Disabled People. "There are only 1,400 support teachers in the whole country. Nothing is adapted, and the teachers are not prepared either," she added.

The issue of disability is a recurring theme in Romania. Last year, four people died in degrading conditions in an adult centre. Mădălina Turza, as the mother of a 15-year-old girl with Down's syndrome, has years of activism behind her and wants reform. ¹¹⁸³

"Nothing has been done. Whether at school or in these centres, the happy cases can only be explained by the presence of exceptional people. It's not a solution," she said.

As can be seen with the above illustration, one of the strategic goals of Romanian secondary education is the involvement of disabled children in ordinary or special schools. Even a severe disability certificate is compatible with mass education. ¹¹⁸⁴ The certificate in question is guaranteeing involvement in the support program. For a child with disabilities the normal educational options are : special school according to the disability type or support socio-

¹¹⁸³ Ibid.

¹¹⁸⁴ T. Vraşmaş, T, School Inclusion of Children with Special Educational Needs. Aspirations and Realities, Bucharest, Ed. Vanemonde, 2010

educational services in the mass schools but also different cabinets such as speech therapy, psycho-pedagogy or support services with special or itinerant teachers or school mediators. The example quoted above is not the rule but rather the exception.

Special schools are usually for mental, physical, audio or visual impairments, with classes of 8-12 students and 4-6 students in the case of severe or associate disabilities. During the morning time classes are organized while during the afternoons different therapies for rehabilitation are taking place. All the schools have dormitories and canteens so that all the children are institutionalized during the school period. The staff is constituted by teachers, rehabilitation specialists and auxiliary personnel.

Inclusive education is based mainly on the teachers' capacity to organize the process so that every child receives some knowledge. An important role has the support teachers that help special needs children in different public schools. In some mainstream schools there are psycho-pedagogues who help the students to solve their problems (disabilities but also social or behavioural problems) and assist the teachers and the families to better understand and help the students with such problems. ¹¹⁸⁵

Thus it would be an understatement to comment that Inclusive education is confronted with a number of challenges, primarily:

- a. The inter-institutional evaluation of children with disabilities (the family doctor should refer earlier the case to a specialist and inform the parents, parents are often discouraged because they have to address to different institutions, population's poverty leads to confusion between disabilities and difficulties or disadvantages because of the social facilities from the special schools);
- b. Challenges because of team-work (difficult cooperation of the professionals with the parents, communicational barriers and rivalry between specialists but also lack of organization of services);
- c. Difficulties in the collaboration with the parents (parents are resisting to sending children in special schools or getting a handicap certificate because of stigma, especially the high social status parents, some parents are not fulfilling the required actions saying that it is too complicated);
- d. Different students' communities (inclusive schools have students with different educational levels and needs, Romanian schools are performance oriented and special needs students are diminishing the school prestige, students with disabilities are evaluated formally without having real knowledge acquisitions). ¹¹⁸⁶

¹¹⁸⁵ <https://icehm.org/upload/7074ED1214168.pdf>

¹¹⁸⁶ <https://icehm.org/upload/7074ED1214168.pdf>

The professional's dilemma is about choosing the right alternative for each child: to be kept in family or to send him to a special institution, to put him in a special school or to send him in a general school. Sending a child from the very beginning to a special school is not a popular choice between professionals because at early age deficiencies are unequally manifested and children could often recuperate. In addition coming back from special schools to general education is very difficult and almost impossible. Also the large majority of parents reject the special schools because of stigma. There are also parents whose main revenues are due to their children's disabilities and they refuse the special school under the pressure of losing these revenues. The actual situation about education of disabled students is more formally described in a recent study on behalf of Academic Network of European Disability Experts (ANED).¹¹⁸⁷

The report mentions that, despite the fact that the rights of persons with disabilities are protected by specific policies, in practice there is a lack of adaptation in terms of materials and logistics for students with disabilities. Also there is a lack of qualified professionals and not enough resources to provide specific services for their particular needs (i.e. occupational therapists).

The Ministry of Education's decision to abolish the Arts and Trades schools has had a negative impact, reducing the opportunities for training among students with disabilities. "In 2009-2010, the Ministry of Education decided to abolish the Arts and Trades Schools, together with the completion year. These schools have been transformed into so called "technological high schools", of two years duration. "This measure affected significantly the students with disabilities, who very often could not meet the high school requirements or/and the professional training in only 2 years".¹¹⁸⁸

Although students with disabilities and their families have the right to choose the form of education they want to attend, in practice they are they mainly oriented toward special schools. The disability awareness of teachers, parents and students in mainstream schools remains low, despite efforts that have been constantly made by the Government and NGOs over the years. According to the law, students with disabilities and their families have the possibility to choose the form of education they want to attend.¹¹⁸⁹ In practice, a vast majority of students with disabilities are still oriented by the assessment commission towards the special system, despite improvements that have been made in the last decade.

Mainstream schools were completely unprepared to receive children with disabilities on a large scale, parents were very concerned about whether their children could adapt and the consequences of the transfer, and the special schools felt threatened in terms of whether their work would continue.

¹¹⁸⁷ D. Chiriacescu, A. Pinte, A. Moraru, A., Gyorki, V. Cretu, V., M. Vlad, ANED Country Report on Equality of Educational and Training Opportunities for Young Disabled People: Romania, Academic Network of European Disability experts (ANED), Human European Consultancy, University of Leeds, 2011.

¹¹⁸⁸ Ibid, Pg. 5.

¹¹⁸⁹ inclusive or specialized education

A national evaluation of this decision ¹¹⁹⁰ showed that the decision was inappropriate and produced a lot of negative effects: “among which was a critical rate of student drop out after several months, as well as the return of numerous children to special schools. ¹¹⁹¹ Although in Romania NGOs have had an important role in promoting the image of disabled students, they are still discriminated and stigmatization is rampant in mainstream schools.

In Romania there was no culture of continuous education for disabled people but in recent years there has been some progress, on the one hand due to several NGO activities and initiatives and on the other hand, thanks to the funds received from the European Union.

There is a poor accessibility to public space and there are also important limitations regarding devices for communication for disabled students. On the other hand, the poor integration of young disabled on the labour market is due to the fact that only recently did the vocational curricula of special schools relate to labour market demands: “young adults with disabilities are confronted with significant problems, since vocational programs in special schools have not been adapted, until more recently, to the reality of the labour market. Subsequently, young people who cannot pass the baccalaureate examination are at more risk of exclusion in employment. ¹¹⁹²

In September 2018, research by Ana-Maria Bolborici and Diana-Cristina Bodi, both renowned lecturers in the Transylvania University of Brasov, Romania (Faculty of Sociology and Communication), was published in an eminent and specialised journal. ¹¹⁹³ The research was entitled Issues of Special Education in Romania. Related to this project the authors had a workshop attended by a large number of itinerant teachers (about 30). The participants worked in teams and conducted some SWOT analyses on the socio-educational system of children with SEN in Romanian schools.

The discussions proved to be amazing and lead to some very interesting conclusions. The SWOT analysis revealed that the teachers unanimously appreciate the existence of a well-established legal framework regarding the access of children with SENs to mainstream schools in mass school. By integrating children with SENs, they have models, they copy the behaviours from other children and thus gradually learn to behave and adapt to everyday life.

Itinerant teachers consider that the existing Romanian legislation is in accordance with the needs of children with SENs, thus benefiting from financial support. They also consider that there is a specialized human resource, even if there are not enough itinerant teachers, but the professors unanimously stated that working with these special pupils is a very rewarding experience.

The professors appreciate the existence of a curriculum and an evaluation method adapted for pupils with SENs. The discussions revealed that itinerant teachers working with children with SEN built a long-lasting relationship both with them, and with their parents. The participants

¹¹⁹⁰ Jointly organized by UNICEF and the Government of Romania.

¹¹⁹¹ D. Chiriacescu, A. Pinteaa, A. Moraru, A., Gyorki, V. Cretu, V., M. Vlad, ANED Country Report on Equality of Educational and Training Opportunities for Young Disabled People: Romania, Academic Network of European Disability experts (ANED), Human European Consultancy, University of Leeds, 2011. Page 11.

¹¹⁹² Ibid, Page 12.

¹¹⁹³ European Journal of Education September-December 2018 Volume 1, Issue 3 Page 140

at the focus-groups acknowledged that there are many Romanian NGOs which support children with SENs.

The itinerant teachers consider that the existing Romanian legislation is in accordance with the needs of children with SENs. The itinerant teachers have underlined that a strong point is also the fact that there are training programs to specialize them in the specific problems of children with SENs.

The WEAKNESSES mentioned by the itinerant professors were as follows:

The reality shows a high number of children with SENs and on the other hand an insufficient number of teachers who have limited time (just one hour) to deal/counsel one child per week.

Even though there are a lot of itinerant professors enrolled in working with children with SEN, there is however a general lack of human resources, for instance, a lack of specialists in speech therapy, physiotherapy and so on. The professors believed that the reduced number is due to the low number of candidates on the one hand, but also due to the low interest in working as a teacher (the salary being quite small in the budgetary Romanian system).

Another important aspect stressed by the itinerant teachers is the necessity of a better involvement of the team of specialists in the evaluation process of the children with SEN for a correct framing (and not by IQ tests).

Unfortunately in the Romanian mainstream school there are still teachers in mass schools that do not understand the importance of working differently with children with SENs and they ask for the same demands and common evaluations with the other pupils from the mass class; still, those professors see the SEN pupils as "a burden" for the entire educational system.

Another weak point would be the need for curricular adaptation depending on the level of children's ESCs, keeping in mind that at present teachers have to explain what they teach in mass schools and do not have a separate curriculum; in other words, the purpose of the education should be focusing on the perception of children with SEN.

It is obvious that at the Romanian national level, there are no subjects adapted to pupils with ESCs, for example, at the Bacalaureate exams, pupils with SEN extra time to solve the problems and they have the possibility to be supported in writing if they have vision problems. The focus-groups revealed that there is a lack of equipment and material resources especially in schools in small towns and also a lack of training for school principals as well as for teachers in mass schools for them to better understand the particularities of pupils with SEN and to better integrate them.

The SWOT analysis pointed out some opportunities such as services free of charge for children with SEN and the emphasis on the individualistic strategies which is in the benefit of children with SEN. During that past few years, many projects have been registered and NGOs came to meet and integrate children with SEN while also offering complementary services. The itinerant teachers appreciate the importance of workshops, training courses and conferences dedicated to these children with issues, although they seldom take place in Romania.

Over the last decade, Romania harmonized internal regulations and now there is a comprehensive legal framework in matters related to the European legislation, but also international legislation which protects the rights of these special children.

Finally, the main important threats resulted from those focus-groups are as follows:

Many pupils with SEN drop out of the school and hence, there are little chances of adaptation and integration into society of those in the next future. On the other hand, because of these children's drop-out, future adults can become a real danger to society.

The reality shows that the special education system in Romania isn't focused on the products of the activity. Frequently, children with SENs have to repeat the classes because they cannot even read or write and eventually they abandon school.

The itinerant professors admitted that some repeated transfers between schools have been registered because these pupils with SEN are not accepted by the pupils in the mainstream schools or by the teachers. They cannot integrate themselves and they do not feel comfortable thus, dropping out of mainstream schools.

The same itinerant professors recognized that there is some confusion among teachers about the role of the itinerant teachers (for example, curricular adaptation), their job description.

Another vulnerability is related to the reduced professional integration of these children with SEN at the end of the school, usually, employers avoid to hire them because of the less level of performance in the companies, although they may have some substantial tax breaks.

So what were the conclusions derived from this research?

As previously mentioned in the theoretical framework, the approach to inclusive education must be an integrated and holistic: one that embraces the individual, one's family, one's community, and society.

We notice that the educational system for children with disabilities is still in development. If at the legislative and institutional level, things seem to evolve and work, we cannot say the same about applying inclusive education. There are still barriers, regarding the individual, families, communities, as well as organizational barriers.

Unfortunately, nowadays in Romania, pupils with SENs have a "tolerated status" they do not fully benefit from the idea of inclusion in its true meaning.

Teachers involved in the project stressed that the change should occur primarily among teachers in their thinking and approach, so the prospects can be positive in terms of inclusion of these extraordinary children.

Family, parents have an extremely important role and they should be given the emotional support, besides the material one, that is not always so important.

Aside from the fact that these systems that need to work together in order to truly achieve inclusive

education, there is a need for more training programs for itinerant teachers. The program described in the article is the first one in Brasov County. The need for training for itinerant teachers is high and it is necessary to develop continuous training programs for them so that they can truly provide an inclusive education to children with SENs. ¹¹⁹⁴

Lastly, one needs to look at the employment initiatives for persons with intellectual disabilities. Romanian law guarantees the right to work and to choose a profession. While anti-discrimination legislation requires employers to adapt facilities to the needs of people with disabilities, in practice such accommodation is not universally enforced.

The main mechanism the Government has put in place for improving the employment situation of people with disabilities is a quota system that requires companies and state agencies of a certain size to hire people with disabilities. Larger companies are required to make sure that four per cent of their employees are people with disabilities, but, in practice, employers evade compliance with quota requirements and avoid penalties by advertising positions with qualifications that no person with disabilities could meet. Companies that have a 30 per cent or higher level of employees with disabilities are eligible for various benefits, including tax exemptions. Legislation provides for the Government to pay the salary of employees with disabilities, but only for 18 months, after which the employer is under no obligation to retain the employee.

Romania has a relatively high overall unemployment rate, making it even more difficult for people with intellectual disabilities to compete for jobs on the open market. Supported employment, in which people with intellectual disabilities work closely with a coach or colleague on the job, has been an effective model for improving employment opportunities for people with intellectual disabilities. A local NGO in Romania has helped a limited number of people to find work by offering this type of support, and the Government should look to the experience and practical knowledge developed by civil society in the development of national employment policy.

There are no Government-operated sheltered workshops specifically for people with intellectual disabilities. A very limited number of NGO-operated workplaces do cater specifically to people with intellectual disabilities, but these function primarily as training and occupational facilities, and offer only a segregated working environment for people with disabilities.

Employing persons with disabilities can be realised in the following ways: on the free labour market; at home or in protected forms (protected workplace or protected authorized unit). Persons with disabilities seeking a job or already employed benefit from:

- professional training courses;
- reasonable adaptation to the workplace;
- counselling before and during employment, as well as in the trial period, from a counsellor specialized in labour mediation;
- a period of trial before employment, paid, of at least 45 working days;
- a paid notice, of minimum 30 working days, at the termination of the individual work contact at the initiative of the employer, out of reasons non imputable to him;

¹¹⁹⁴ http://journals.euser.org/files/articles/ejed_v1_i3_18/Bolborici.pdf

- possibility to work less than 8 hours per day, according to the law, if he benefits from a recommendation of the evaluation Commission in this respect;
- excuse from payment of taxes on salary.

It should be mentioned that, aiming to encourage employment, the Romanian legislation stipulates that, once employed, a person with disabilities does not lose the right to the social benefits granted on the bases of disability certificate.

Public institutions and authorities, juridical persons (public or private) that have at least 50 employees, are obliged to employ persons with disabilities in a percentage of at least 4% of the total number of employees, otherwise they may also choose to pay a certain amount to the state or purchase products or services provided by persons with handicap, employed in authorized protected units, based on a partnership agreement, in the same amount owed to the state budget. In order to encourage employment on the open labour market, economical agents that employ persons with disability benefit from a series of fiscal facilities.¹¹⁹⁵

In order to tackle the challenges of the Romanian legislation related to persons with disabilities there was developed the project “Equal opportunities on the labour market” which was wholly funded by the European Social Fund in Romania.¹¹⁹⁶ The goal of this project was to promote social inclusion of people with disabilities by facilitating their access to vocational and rehabilitation services and by increasing the opportunities towards employment in the open labour market.

This pilot project introduced the concept of developing vocational rehabilitation services for persons with disabilities in order to facilitate their integration in the labour market by means of :

- Vocational assessment and extended assessment service;
- Vocational training programme;
- Employment enterprise service;
- Supported employment service.

But official numbers show that the initiatives in this specific sphere still have a long way to go. The total number of disabled people amounts to around 765,000 persons (3.4% of Romanian population).

About 416,000 (54.8%) were aged between 18 and 64. The rate of employment of disabled persons is still very small (14%).

¹¹⁹⁵ ‘Active measures for integration on the Romanian labour market of persons with disabilities’ by Irina Badea from the Ministry of Labour, Family and Social Protection and Adolf Papp, an Independent expert.

¹¹⁹⁶ Between November 2008 and April 2011 by the Romanian Ministry of Labour, Family and Social Protection in partnership with European Platform for Rehabilitation Belgium, Bernard Brunhes International France and 4 other Romanian partners.

People with somatic disability represent the most employed category (38.4%); least employed were the mental (3.1%) and psychiatric (5.2%) categories. About 750 authorized protected units (sheltered employment) were recorded from 2015 onwards. ¹¹⁹⁷

And lastly, one needs to underline the fact that a terminology clarification and unification approach, at national level (between concepts of disability vs. handicap), has become a necessity. Romanian legal frame regarding labour policy and working with disabilities imposes material obligations for employers (the 4% quota system) but also offers fiscal facilities for them. Disabled persons (with accentuated and severe disability) are exempt from income tax and also accumulate the non-taxable income and disability benefits. ¹¹⁹⁸

This is an integrative approach to the Romanian strategy and policy of (re-) employment of people with disabilities. It underlines the main achievements, improvements and limitations in the continuous endeavour of implementation of the legislative framework on the protection, integration and inclusion of disabled persons in Romania. Much still needs to be done.

¹¹⁹⁷ https://www.researchgate.net/publication/311947351_Employment_Of_People_With_Disabilities_In_Romania

¹¹⁹⁸ Employment Of People With Disabilities In Romania - Article in International Archives of Medicine Vol. 9(365) · December 2016

Slovakia

When one analyses the numbers and proportions of disabled children and adults residing in institutional care or community-based settings, there are no consolidated data on deinstitutionalisation (DI), as the DI pilot project which was running in 2013-2015 included only 10 residential care facilities.

The following tables show the current situation in social services for care dependent persons. Between 2013 and 2016, the vast majority of places in social care facilities (domovy socialnych sluzieb) were year-round residential. These places are considered as institutional care according to the National Priorities. As the following table shows, in 2016, they consisted of almost 85 % of total social care facilities capacity.

Places in the social care facilities on institutional year-round basis ¹¹⁹⁹

	2016	2016	2013	2013
Places	No.	% of total capacity	No.	% of total capacity
Year-round stay_places	11,822 ¹²⁰⁰	84.8	18,399	90.1
Total social care facilities places	13,934 ¹²⁰¹	100.0	20,426	100.0
Total social care facilities	280		425	

Community based social services facilities include supported housing facilities (zariadenia podporovaneho byvania), day care centres (denne stacionare), rehabilitation centres (rehabilitacne strediska), care service facilities (zariadenia opatrovatelskej sluzby), home-based care service (domaca opatrovatelska sluzba), transportation services (prepravna sluzba) and interpreting services for hard-of-hearing persons (tlmocnicka sluzba). According to the National Priorities daily, weekly and temporary places in social care facilities also include community-based social services.

As the following table shows, in 2016 there were 34 supported housing facilities with 574 places, 195 day care centres with a total capacity of 5,148 places, 24 rehabilitation centres with 727 places and 100 care service facilities with 2 309 places.

Home-based care service was provided by 173 providers for 16,749 dependant recipients living in home environment (usually elderly people). 46 transportation service providers worked for 9,785 clients. Interpreting service was provided to 4,472 clients by 14 providers.

¹¹⁹⁹ Source: Report on the Social Situation (2018)

¹²⁰⁰ Out of this number 163 were places for children. These data do not include children in foster care.

¹²⁰¹ The rest 2,112 places refer to community based social services, see table 2.

Community based social services¹²⁰²

	2016	2016	2013	2013
Places	Facilities ¹²⁰³ / Providers ¹²⁰⁴	Places ¹²⁰⁵ / Clients ¹²⁰⁶	Facilities/ Providers	Places/Clients
Day care centres	195	5 148	36	578
Home-based care service	173	16 749	92	13 530
Transportation service	46	9, 85	23	6 826
Rehabilitation centre	24	727	17	426
Interpreting service	14	4 472	9	3 134
Social care facilities (daily, weekly and temporary places)	n/a	2 112	n/a	2,027
Care services facilities	100	2 309	99	1 888
Supported housing facilities	34	574	48	466
Support of independent living	4	*	**	**

Report on the Social Situation (2018), Report on the Social Situation (2014), Central Registry of Social Services Providers¹²⁰⁷

Note to the above table:

n/a: The value is not available for social care facilities providing social services on community basis. Only the total number of social care facilities (institutional and community based) is available.

* Value is not available

** This service was not in place in 2013

One of the key measures to support independent living of persons with disabilities is the cash benefit for personal assistance,¹²⁰⁸ that is, the collection of direct payments for compensation of severe disability.

¹²⁰² According to the conceptualization of community care in the document National Priorities.

¹²⁰³ Number of facilities refer to supported housing, day care centres, rehabilitation centres and care service facilities.

¹²⁰⁴ Number of providers refer to home-based care service (only non-public providers), transportation services, interpreting services and its mediation and support of independent living.

¹²⁰⁵ Number of places refers to social care facilities, supported housing, day care centres, rehabilitation centres and care service facilities and support of independent living.

¹²⁰⁶ Number of clients refers to recipients of home-based care service, transportation services, interpreting services and its mediation.

¹²⁰⁷ Available at:

https://www.employment.gov.sk/sk/centralny-register-poskytovatelov-socialnych-sluzieb/?searchBean.kraj=&searchBean.druhSluzby=podpora+samostatn%C3%A9ho+b%C3%BDvania&searchBean.forma=&searchBean.typPoskytovateľa=&searchBean.lenNevymazani=true&btnSubmit=Vybra%C5%A5&_sourcePage=yEUhjnYVOXE5J_S9kf5vdy1d_XJ6mxGCooMFFX46NVI%3D&__fp=PS0_TLy3vpmCLBf2iqmepqJD5_zbwmzvqa`Vhs8GkMIYAxmyO0WapWQP8-AfBaZVUK8WsJat50XnSxxYrp2L0w5NWvHKAuI03LJtO-xytBQYVRnBYiLHni0zLjUclYnAgqaVhs8GkMIYxTOluhePUqY2Fe WjnsWgT

¹²⁰⁸ Regulated by the Act No. 447/2008

There were 10,173 people with disabilities (5,119 of which were women) receiving the cash benefit for personal assistance in December 2018.

Personal assistance recipients

2018	10173
2013	8 583

Monthly statistics on social benefit recipients and spending. CoLSAF. December 2018 ¹²⁰⁹

According to the latest 2017 data, there is a large gap between the share of children with disabilities in institutional care – 16 % out of all 3,210 children in institutional settings), and children with disabilities in foster families (the alternative to institutions) – less than 6 % of all 1,373 children in foster families have disabilities.

The following table shows numbers of children with disabilities placed in institutional care of children’s homes, vs. those placed in foster families. The table is based on children’s homes statistics data which were clustered into three categories:

- 1) The number of children with various types of disadvantages - children with disabilities, children with mental disorders (as a separate group irrespective of children with disabilities), children with behaviour disorders, abused children and drug addicted children
- 2) The number of children in a specific living situation - refugee minors without being accompanied by an adult, young adults, minor mothers and their children
- 3) Other children – who are in foster care without an additional disadvantage as described in categories 1 and 2. ¹²¹⁰

Children with disabilities placed in foster care

2017	Institutional Care		Foster Families	
	No. of Children	% of all Children	No. of Children	% of all children
Children with disabilities	515	16.0	78	5.7
Children with mental disorders	145	4.5	17	1.2
Children with behavior disorders	488	15.2	60	4.4
Abused children	50	1.6	33	2.4
Subtotal children with various disadvantages	198	37.3	188	13.7
Subtotal children in a specific living situation	226	7.0	34	2.5
Other children	1 786	55.6	1 151	83.8
Total	3 210	100	1 373	100

¹²⁰⁹ Available at: https://www.upsvr.gov.sk/statistiky/socialne-veci-statistiky/2018/2018-socialne-davky.html?page_id=771091.

¹²¹⁰ The proxy for this category was calculated by authors of this report as a difference between total number of children minus disadvantaged children and children in specific living situation.

2013				
<i>Children with disabilities</i>	464	13.6	69	5.0
<i>Children with mental disorders</i>	161	4.7	36	2.6
<i>Children with behavior disorders</i>	523	15.4	74	5.3
<i>Abused children</i>	38	1.1	34	2.4
<i>Drug addicted children</i>	3	0.1	0	0
Subtotal children with various disadvantages	1 189	34.9	213	15.3
Subtotal children in a specific living situation	413	12.1	38	2.7
Other children	1 802	53.0	1 143	82.0
Total	3 404	100	1 394	100

Report on the Social Situation (2018), Report on the Social Situation (2014)

To support placement of children with disabilities into foster families / compensate for care of disabled child, foster parents who accept a child with disabilities are entitled for additional monthly cash benefit “specific regular allowance to foster parent” (in addition to the cash benefits that all foster families get).¹²¹¹ In December 2017 there were 55 recipients of this benefit.¹²¹²

With regards to institutional care in social services: despite a permanent high prevalence of year-round stay places in total social care facilities capacity, some improvements in this regard are seen. In 2013, the year-round stay places created 90 % of total social care facilities capacity; in 2016 their prevalence decreased by approx. 5 %. Places decreased by 36 % (from 18,399 in 2013 to 11,822 in 2016) which was faster than total social care places reduction by 31 %.

As for community-based services, the data also show some positive trends. Among the most relevant from a disability perspective are supported housing facilities. Between 2013 – 2016, the number of recipients increased by almost 19 % - from 466 to 574 persons with disabilities. Similarly, capacities of rehabilitation centres also increased by more than 40 %, from 426 places in 2013 to 727 in 2016. These places were established in 24 rehabilitation centres, which is 7 centres more than in 2013.

The biggest step forward has been among day care centres, which are however more often for older persons. Their number increased almost 5.5-times (from 36 in 2013 to 195 in 2016). Places' increase was steeper – almost 9-times (from 578 in 2013 to 5,148 in 2016).

Cash benefit for personal assistance has also become more available. Between December 2013 and 2018 the number of personal assistance recipients increased by approx. 15.6% (from 8,583 in 2013 to 10,173 in 2018).

¹²¹¹ Osobitný opakovaný príspevok náhradnému rodičovi [Specific regular allowance to foster parent], for more details see: Act No. 627/2005 Coll. on allowances for support of foster care. Available at: <http://www.zakonypreludi.sk/zz/2005-627>.

¹²¹² Monthly statistics on number of social benefits recipients and spending. December 2017. CoLSAF. Available at: https://www.upsvr.gov.sk/statistiky/socialne-veci-statistiky/2017/2016-socialne-davky.html?page_id=672863.

In foster care, the improvements seem not as fast. Whilst the number of all children in institutional care decreased (by almost 6% from 3,404 in 2013 to 3,210 in 2017), the number of children with disabilities in institutional care increased by almost 10 % (from 464 in 2013 to 515 in 2017).

Moreover, the number of all children placed in foster families remained almost unchanged (decrease from 1,394 in 2013 to 1,373 in 2017). Despite the decrease of children with disadvantages in foster families (from 213 in 2013 to 188 in 2017) the number of disabled children in foster families increased but very slightly (increase from 69 in 2013 to 78 in 2017).

Similarly, the number of recipients of special regular allowance to foster parents remained roughly the same (57 recipients in Dec. 2013 and 55 in Dec. 2017).¹²¹³

To sum up, the following findings regarding the institutional and community based social services since 2013 can be observed:

- the number of institutional care places in social care facilities together for adults and children has been reduced by 36 %
- the number of places in adult supported housing increased by almost 19% to 574 places
- the number of personal assistance recipients (persons with disabilities) has increased by approx. 15.6 %
- the number of children with disabilities placed in institutional arrangements of children's homes has increased by almost 10 % since 2013
- the number of children with disabilities placed in foster families instead of institutional arrangements of children's homes has lower prevalence compared to children with disabilities placed in institutional settings.

Regarding social care facilities, one notes that spending is not disaggregated by the type of places (year-round, weekly, daily, temporary). This is the main reason why it is not possible to separate spending for institutional and community-based service in social care facilities. Total spending is presented in the following chart.¹²¹⁴

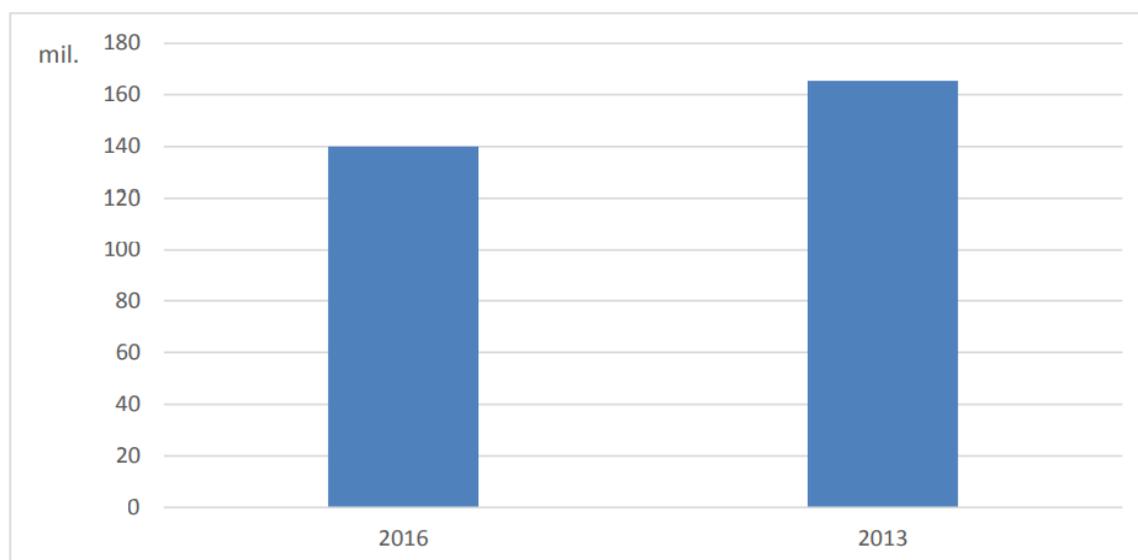
As the social care facilities have the highest number of places and clients from all social services facilities for persons with disabilities, they had also the highest spending - in 2016, the amount was of approximately EUR 140 million.

¹²¹³ Monthly statistics on number of social benefits recipient and spending. December 2017. CoLSAF.

Available at: https://www.upsvr.gov.sk/statistiky/socialne-veci-statistiky/2017/2016-socialne-davky.html?page_id=672863. Monthly statistics on number of social benefits recipient and spending. December 2013. CoLSAF.

¹²¹⁴ <https://www.disability-europe.net/search?searchword=slovakia&searchphrase=all>

Spending in the social care facilities (EUR)



Report on the Social Situation (2018), Report on the Social Situation (2014)

As the following table shows, in 2016 the highest spending among community based social services was for home-based care service (approx. EUR 49 million). The second largest spending was for care service facilities (almost EUR 20 million). The lowest spending was for interpreting services and their mediation (approx. EUR 123,000). Spending on supported housing and rehabilitation centres reached roughly the same level (almost EUR 3.7 million and EUR 3.4 million).

Selected community based social services facilities (EUR)

	2016	2013
Home-based care service	49 007 260	30 259 417
Care service facilities	19 821 129	13 424 494
day care centres	11 988 772	n/a
supported housing facility	3 697 332	2 380 654
rehabilitation centre	3 350 745	3 310 561
Transportation service	702 640	1 584 019
Interpreting services and their mediation	122 713	106 977
Support of independent living	*	*

Report on the social situation (2018), Report on the social situation (2014)

Notes to the above :

n/a: 2013 data not available but 2014 spending was EUR 2,723,595

* values not available in the statistics

Finally, total spending on the cash benefit for personal assistance was almost EUR 5.5 million in December 2018. With regards to disability-specific foster care, only data regarding spending on specific regular allowance to foster parent is available in CoLSAF statistics.¹²¹⁶

¹²¹⁵ <https://www.disability-europe.net/search?searchword=slovakia&searchphrase=all>

¹²¹⁶ Number of facilities refer to supported housing, day care centres, rehabilitation centres and care service facilities.

In December 2017, spending was EUR 4,225.88 which makes annually approximately EUR 50,710.56.¹²¹⁷

Between 2013 and 2016 total spending of social care facilities reduced by 15.3 % (from EUR 165,101,739 in 2013 to EUR 139,901,059 in 2016).

Among community based social services, spending on the provision of most of them was raised. Between 2013 and 2016 the steepest increase occurred among home-based care service, supported housing facility, care service facilities. Home-based care service spending increased by approx. 38 %, which represents approx. EUR 18,747,843. Supported housing spending raised by almost 36% and care service facilities spending increased by approx. 32%.

A huge expansion of day care centres between 2013 and 2016 caused their steep spending increase. 2013 data is not available, but between 2014 and 2016 total spending increased almost 4.5 times (from EUR 2,723,595 in 2014 to EUR 11,988,772 in 2016). Personal assistance spending increased, as well. Between December 2013 and 2018, spending on personal assistance increased by approx. 40% (from EUR 3,251,514 in 2013 to EUR 5,441,377 in 2018).

In the current decade, several interrelated national documents have been adopted to set out government commitments for the support of independent living of persons with disabilities and/or care-dependent older persons in their communities.

In 2011 the *Strategy for Deinstitutionalisation of the System of Social Services and Substitute Care in the Slovak Republic*¹²¹⁸ was adopted as a basic conceptual document for the process of deinstitutionalisation, followed by the *National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for 2012 – 2015*.¹²¹⁹ The latter document provided more details like managing, financing and monitoring of the deinstitutionalisation process and stated concrete activities for the respective time period implemented within the National project DI –I., funded by the ESF.

Consequently Slovakia was one of 12 EU member states who were supposed to meet the ex-ante conditionality 9.1 to “have in place and implement a national strategic policy framework for poverty reduction, aiming at active inclusion that depending on identified needs, includes measures for the shift from institutional to community-based care”.¹²²⁰ This conditionality was

¹²¹⁷ The trend remains rather unchanged between 2013 and 2017 (4,263.29 euro in 2013).

¹²¹⁸ Strategy on deinstitutionalisation of the social services system and foster care in Slovakia (Stratégia deinštitucionalizácie systému sociálnych služieb a náhradnej starostlivosti v Slovenskej republike). Available at: <https://www.employment.gov.sk/files/legislativa/dokumenty-zoznamy-pod/strategia-deinstitucionalizacie-systemu-socialnych-sluzieb-nahradnej-starostlivosti-1.pdf>.

¹²¹⁹ National action plan on transition from institutional to community-based care in the system of social services for years 2012-2015 (Národný akčný plán prechodu z inštitucionálnej na komunitnú starostlivosť v systéme sociálnych služieb na roky 2012-2015). Available at: https://www.employment.gov.sk/files/slovensky/rodina-socialna-pomoc/socialne-sluzby/nap_di.pdf.

¹²²⁰ Neil Crowther, Gerard Quinn & Alexandra Hillen-Moore: Opening up communities, closing down institutions: Harnessing the European Structural and Investment Funds. Community Living for Europe: Structural Funds Watch, November 2017. Available at: https://eustructuralfundswatchdotcom.files.wordpress.com/2017/11/cle-sfw_opening-up-communities-november-2017_final.pdf.

fully met by the approval of the National Framework Strategy on the Support of Social Inclusion and Fight against Poverty¹²²¹ by Government Resolution no. 301 of 3 June 2015.

As regards the ESIF, the Partnership Agreement states that “In Slovakia, the traditional institutional model still prevails. For this reason, it is necessary to gradually redesign this system towards the development of community-based social services and foster care systems.”¹²²² The transition from institutional to community based care is included as a priority in two Operational Programmes, namely Specific Objective 4.2.1¹²²³ under Priority Axis 4 of the Operational Programme Human Resources (OPHR),¹²²⁴ co-financed by the European Social Fund and, Specific Objective 2.1.1¹²²⁵ under Priority Axis 2 of the Integrated Regional Operational Programme (IROP)¹²²⁶ co-financed by the European Regional Development Fund (ERDF).¹²²⁷

Deinstitutionalisation became the top priority in the national document entitled National Priorities for the Development of Social Services for 2015 – 2020¹²²⁸ which was adopted in 2014. This policy document sets out as public interest to ensure availability of social services in accordance with the needs of the target groups and communities, as well as the transition of clients from institutional to community-based care. Deinstitutionalisation ambitions became interrelated to the goal of increasing the quality of social services according to the standards set out by the Act No. 448/2008 Coll. on Social Services,¹²²⁹ as amended.

In line with the national priorities in the area of social services and taking into account the outcomes of the pilot deinstitutionalisation project, the National Action Plan for Transition from

¹²²¹ <https://www.employment.gov.sk/files/slovensky/rodina-socialna-pomoc/narodna-ramcova-strategia-socialneho-zaclenenia-boja-proti-chudobe.pdf>.

¹²²² The Partnership Agreement, p. 37. Available at: https://ec.europa.eu/info/sites/info/files/partnership-agreement-slovakia-summary-june2014_en.pdf.

¹²²³ Transition from institutional to community-based care.

¹²²⁴ <https://www.minv.sk/?operational-programme-human-resources>.

¹²²⁵ To facilitate the transition of social services and socio-legal protection of children and social guardianship in institutions from institutional to community-based form and to support the development of child care services for children below three years of age at the community level.

¹²²⁶ https://www.google.com/search?ei=Aq43XOLvJcrNwAL6r6XQDw&q=Slovakia+Integrated+Regional+Operational+Programme+&oq=Slovakia+Integrated+Regional+Operational+Programme+&gs_l=psy-ab.3..0i8i30.187852.195990..196588...0.0..0.124.1746.19j2.....0....1..gws-wiz.....35i39j0i22i30j35i304i39j0i8i7i30j0i8i13i30.KqvxAANigvE.

¹²²⁷ For more details, see also: European Structural and Investment Funds (ESIF) supporting the transition from ‘institutional to community based care’ – Country Profile of Slovak Republic (SK). Available at: <https://communitylivingforeurope.org/country-specifics/>.

¹²²⁸ National priorities for development of social services for years 2015-2020 (Národné priority rozvoja sociálnych služieb na roky 2015-2020). Available at: <https://www.employment.gov.sk/files/slovensky/rodina-socialna-pomoc/socialne-sluzby/nprss-2015-2020.pdf>.

¹²²⁹ Act No. 448/2008 Coll. on Social services (Zákon č. 448/2008 Z.z. o sociálnych službách). Available at: <https://www.slov-lex.sk/pravne-predpisy/SK/ZZ/2008/448/20180101>.

Institutional to Community-based Care in the Social Services' System for years 2016 – 2020¹²³⁰ (hereinafter referred to as “DI NAP”) was adopted in 2016. The DI NAP and its concrete tasks were formulated with respect to the UN Concluding observations on the initial report of Slovakia,¹²³¹ particularly its Article 19 (points 55-58 of the observations). The document became a basis for adoption and implementation of the DI –II. National project funded by ESIF.

Furthermore, the commitment for deinstitutionalisation is specified also in the following national documents focused more generally on the support of social inclusion of persons in social risks (arranged in time sequence):

- the National Disability Programme for 2014-2020¹²³² (2014) - strategic goal 4.5.1 – to support process of deinstitutionalisation and transformation of the social services' system,
- the 2nd Report on fulfilment of provisions related to the National disability program 2014-2020 for the period 2016-2017 and a draft of its actualisation¹²³³ - strategic goal 4.14.1 - to analyse assessment of health status of children in substitute care in children's homes for the purpose of their placement into special group,
- the National Program of Active Ageing for 2014-2020¹²³⁴ (2014) - strategic goals 7.4.2 and 7.4.3 – to improve domiciliary and out-patient services and humanisation of social services through deinstitutionalisation,
- *the National Framework Strategy on the Support of Social Inclusion and Fight against Poverty*¹²³⁵ (2015) - deinstitutionalisation and transformation of social services is mentioned as one of key measures for social inclusion of people in social risks),

¹²³⁰ National Action Plan on Transition from Institutional to Community-based Care in the System of Social Services for years 2016-2020 (Národný akčný plán prechodu z inštitucionálnej na komunitnú starostlivosť v systéme sociálnych služieb na roky 2016-2020). Available at:

<https://www.employment.gov.sk/files/rodina-soc-pomoc/soc-sluzby/narodny-akcny-plan-prechodu>

¹²³¹ https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD/C/SVK/CO/1&Lang=En.

¹²³² National Disability Program for years 2014-2020 (Národný program rozvoja životných podmienok osôb so zdravotným postihnutím na roky 2014-2020). Available at:

<https://www.employment.gov.sk/files/slovensky/rodina-socialna-pomoc/tazke-zdravotne-postihnutie/narodny-program-rozvoja-zivotnych-podmienok-osob-so-zdravotnym-postihnutim-roky-2014-2020.pdf>.

¹²³³ 2. Report on Fulfilment of the Provisions related to the National Disability Program for years 2016-2017 (Správa o plnení opatrení vyplývajúcich z Národného programu rozvoja životných podmienok osôb so zdravotným postihnutím na roky 2014-2020 za roky 2016-2017). Available at:

<http://www.rokovania.sk/Rokovanie.aspx/BodRokovaniaDetail?idMaterial=27658>.

¹²³⁴ National Program on Active Ageing for years 2014-2020 (Národný program aktívneho starnutia na roky 2014-2020). Available at: <https://www.employment.gov.sk/files/slovensky/ministerstvo/rada-vlady-sr-prava-seniorov/npas-2014-2020.pdf>.

¹²³⁵ National Framework Strategy on the Support of Social Inclusion and Fight against Poverty (Národná rámcová stratégia podpory sociálneho začlenenia a boja proti chudobe). Available at:

<https://www.employment.gov.sk/files/slovensky/rodina-socialna-pomoc/narodna-ramcova-strategia-socialneho-zaclenenia-boja-proti-chudobe.pdf>.

- the Manifesto of the Government of the Slovak Republic for 2016-2020¹²³⁶ (2016) – decentralisation of provision of social services and increase of their quality, it is recognised as a commitment of a high priority in the social policy field;
- the Concept of execution of court decisions in the institutions of social and legal protection of children and social curatorship for years 2016-2020 - Plan of transformation and deinstitutionalisation of substitute care¹²³⁷ as an action plan of the *Strategy for Deinstitutionalisation of the System of Social Services and Substitute Care in the area of substitute care, adopted by the Office of Labour, Social Affairs and Family of the Slovak Republic*; strategic goal 3.2.18 – to update assessment procedure of health status of children younger than six years as regards their placement into professional family or special group in children’s home.

The intention to step up deinstitutionalisation is most of all formulated in the document *National Priorities for the Development of Social Services for 2015 – 2020*, which describes deinstitutionalisation as “*creation and ensuring of conditions for independent and free life of all persons dependent on social assistance, life in their natural settings and community, through the social services of a high quality which are provided in public interest. The relevant national priority is to create conditions for independent living of young and adult persons with disabilities, or with mental disorders, through the transition from institutional to community - based care*”.¹²³⁸

According to the DI NAP for 2016-2020 “*Deinstitutionalisation of the social services’ system has become a new social policy for the next 20-30 years*” (DI NAP, 2016, p. 14). This policy builds upon three pillars of the independent living:

- a) employment as a main source to achieve one’s economic independence;
- b) community-based social services; and
- c) supportive technology and compensatory devices and aids.

Consequently, the document sets out goals, measures and procedures to replace the institutional care by the community-based services in line with individual support and care needs of a person. According to the DI NAP the main deinstitutionalisation objective is not only limited to transformation of the existing institutional care facilities, as rather to extending the supply and delivery of community-based social services for all community members in social need. Therefore, transformational plans have to reflect on both current and potential future local needs.

¹²³⁶ Manifesto of the Government of the Slovak Republic for 2016-2020 (Programové vyhlásenie vlády SR na roky 2016-2020). Available at: <https://www.vlada.gov.sk/programove-vyhlasenie-vlady-sr-na-roky-2016-2020/?pg=2>.

¹²³⁷ Koncepcia zabezpečovania výkonu súdnych rozhodnutí v zariadeniach sociálnoprávnej ochrany detí a sociálnej kurately detí na roky 2016 – 2020. Plán transformácie a deinštitucionalizáci náhradnej starostlivosti. Available at: https://www.upsvr.gov.sk/zariadenia-socialnopravnej-ochrany-deti-a-socialnej-kurately/detske-domovy/dokumenty.html?page_id=143942.

¹²³⁸ National priorities for development of social services for years 2015-2020 (Národné priority rozvoja sociálnych služieb na roky 2015-2020). <https://www.employment.gov.sk/files/slovensky/rodina-socialna-pomoc/socialne-sluzby/nprss-2015-2020.pdf>.

In the mentioned documents, the deinstitutionalisation targets and milestones are dated mainly up to 2020 (funding up to 2023) as they are linked to ESIF, namely to the ERDF and ESF, in combination with national, regional and/or local resources. However, most of the expected outputs of the deinstitutionalisation are formulated rather generally – for instance: “*to increase percentage of community-based social services*”¹²³⁹ - without any further specification of the target value. There is an ambition to support within the DI - II. National project in total 90 institutional care facilities sized more than 40 clients. Concerning the quality issue, it is expected that 60 % of all assessed service providers will meet quality standards at good level as defined by the law, up to 2020 (priority 2.4 of the National priorities, 2014).

With the aim to implement the DI Strategy (2011) and related action plans (first for 2012-2015; another for 2016-2020) and to ensure synergy between the ERDF and the ESF, the Committee of experts for deinstitutionalisation was established in 2012. The committee ensures monitoring and evaluation of the deinstitutionalisation processes, coordinates relevant subjects of deinstitutionalisation, formulates recommendations how to support the deinstitutionalisation processes and their effectiveness and finally, negotiates and approves reports on implementation of the DI Strategy. Two of the thirteen committee experts for deinstitutionalisation of social services are representatives of persons with disabilities and/or older people. In the years 2016-2018, mainly provision of mutual information about the calls for the deinstitutionalisation project proposals within the ERDF and the ESF was the agenda of the committee’s meetings.¹²⁴⁰

This does not mean that there are no active NGOs in Slovakia working in this sector. A number of examples can be given, such as:

The Alliance of Organisations of Disabled People in Slovakia ¹²⁴¹ was created as a coordinator for the promotion of the rights and interest of disabled people in Slovakia towards the parliamentary bodies and other state organizations. It was registered at the Slovakian Ministry of Inner Affairs on March 8, 1994. The aim of the Alliance is the active pursuit and creation of equal conditions and opportunities, according to the international documents of civil rights, accepted by the Member State of the UN.

Any civil association of disabled people with the status of a legal entity can become a member of the Alliance. Membership is based on an agreement of cooperation between the member organizations. The legal independence of the member organizations of the Alliance remains untouched

The Alliance co-operates with international and national partner organizations throughout Slovakia and Europe to create equal conditions and opportunities for disabled children, youth and

¹²³⁹ National priorities for development of social services for years 2015-2020 (Národné priority rozvoja sociálnych služieb na roky 2015-2020).

<https://www.employment.gov.sk/files/slovensky/rodina-socialna-pomoc/socialne-sluzby/nprss-2015-2020.pdf>.

¹²⁴⁰ Information was provided at the meeting of the Committee for Persons with Disabilities of the Governmental Council of the Slovak Republic for Human Rights, National Minorities and Gender Equality being held in June 29, 2018 (unpublished material).

¹²⁴¹ http://www.aozpooz.sk/archiv/index_eng.html

adults and the promotion of their civil rights. The Alliance is member organization of the Disabled People International (DPI) and Rehabilitation International (RI).

People with intellectual disabilities and people with psychosocial disabilities in Slovakia suffer significant violations of their human rights. The problems include people with disabilities being stripped of their legal capacity and placed under guardianship. This results in autonomy being taken away, including consenting to medical treatment, accessing justice and political participation. Children with disabilities are denied their right to inclusive education. Instead they are sent to segregated special schools.

The Mental Disability Advocacy Centre ¹²⁴² in the Slovak Republic was established in 1980. At the present time, the Association is active in the whole territory of Slovakia and covers 44 local associations with about 10.000 members¹²⁴³.

The major aim of the Association is the inclusion of people with intellectual disabilities into the society. They want to achieve that fundamental human rights become a natural attribute of life also for people with intellectual disabilities.

These, and other NGOs and representatives of civil society, have ensured that a number of initiatives and close cooperation with other NGOs from across Europe are made available to persons with disability.

There were other measures which were introduced in Slovakia which positively affected persons with intellectual disabilities. A significant amendment of legislation abolishing full deprivation from legal capacity was adopted in 2016. Amendments to the Rules of Civil Non-Contentious

-Litigation No. 161/2015 Coll. ¹²⁴⁴ introduced stronger safeguards, abolished full deprivation of legal capacity (plenary guardianship), but still allow for partial guardianship. This was also seen as a progress in deinstitutionalization ¹²⁴⁵, as many people with disabilities living in institutions are those with intellectual disabilities.

Previously, most of them were completely deprived from legal capacity, and had no right to make their choice on where they prefer to live, and whether they want to live in institutions or not.

In July 2018, a significant amendment of Act No. 447/2008 Coll. on direct payments for compensation of consequences of severe disability came into force,¹²⁴⁶ which introduced following the changes to the scheme of personal assistance, as well as the care allowance scheme:

¹²⁴² <http://mdac.info/en/http%3Amdac.info/http%253Amdac.info/where-we-work/europe/slovakia>

¹²⁴³ <http://www.zpmpvsr.sk/index.php/o-nas/kto-sme>

¹²⁴⁴ <https://www.slov-lex.sk/pravne-predpisy/SK/ZZ/2015/161/>.

¹²⁴⁵ See e. g. Gallová Kriglerová, E., Holka Chudžíková, A., Kadlečíková, J., Medľová, K. (2018) From institutions to community living: drivers and barriers of deinstitutionalisation. Case study report: Slovakia. European Union Agency for Fundamental Rights (FRA). <https://fra.europa.eu/en/country-data/2018/country-studies-project-right-independent-living-persons-disabilities-case-study>.

¹²⁴⁶ Amendment of the Act No. 447/2008 Coll. on direct payments for compensation of severe disability consequences. <https://www.slov-lex.sk/pravne-predpisy/SK/ZZ/2008/447/20180701>.

- Removal of the income means-test with regards to the eligibility of persons with disabilities for personal assistance - under previous conditions, persons with disabilities had to co-pay this service if their income exceeded four-times the subsistence minimum. This led to the benefit trap and had mostly negative impact on those having a job. People living in institutions, who are usually outside the labour market, were affected by this change to a lesser extent. Moreover, once being placed in institution, a person is allowed for personal assistance only for specific purposes
- which include guidance of a person to school or to working activities, i.e. only few people living in institutions have access to personal assistance.
- Increase of the hourly rate for personal assistance from EUR 2.82 to EUR 3.82 which might help encourage recruitment of personal assistants in a strengthening labour market. Such change can also be seen as positive in the context of deinstitutionalisation and community-based services, where it is expected that personal assistance is an important measure to support independent living of people with disabilities especially after the transition to community-living arrangements.
- Increase of the monthly rate for care allowance from EUR 254 to EUR 370 per care for one care dependent person, and from EUR 330 to EUR 492 per care for two or more persons. Moreover, when a carer is not working and cares for (an) age-dependent child/children with disability his/her care allowance is raised by EUR 100 monthly (from previous EUR 50). The purpose of this change was to improve social situation of those care-givers who cannot reconcile work and care-giving and prefer care-giving, i. e. prefer home-care instead of institutional care for a care-dependent person. The ambition of the Slovak government is to increase the care allowance gradually each year until 2020 up to the net minimum wage in Slovakia.¹²⁴⁷

Thus one notes that in the context of independent living, availability of personal assistance seems very positive especially after the transition of a person from residential care, or as a tool to prevent institutionalisation. According to the current legislation¹²⁴⁸ a person can choose his/her assistant/s, the personal assistance direct payment is no longer means-tested.

Similarly, it is indeed positive that Slovakia has already gained extensive experience in deinstitutionalisation field thanks to the pilot project NP DI-I. Based on that experience from the pilot project, the on-going project NP DI-II. seems also promising, especially due to the partnership of expert organisations in all relevant areas, including access to the labour market and physical accessibility.

However, in the area of social services, it seems quite challenging that the responsibility over the provision of social services is decentralised to almost 3,000 local and 8 regional municipalities. It is then, for example, more difficult to engage so many local policy-makers for deinstitutionalisation, to increase their awareness in why it is worth investing into community-

¹²⁴⁷ National Reform Program 2018, point. 4.3.3.

https://www.ceit.sk/IVPR/images/IVPR/vyskum/2016/Repkova/vyvoj_socialnej_situacie_osob_so_zp_vu_repkova_2016.pdf <http://www.finance.gov.sk/en/Default.aspx?CatID=450>.

¹²⁴⁸ Act No. 447/2008 Coll. on direct payments for compensation of consequences of severe disability.

<https://www.slov-lex.sk/pravne-predpisy/SK/ZZ/2008/447/20150201.html>.

based services. There is no general commitment that all residential services have to undergo deinstitutionalisation and in which time, their participation in deinstitutionalisation is rather voluntary.

In the area of foster care, the progress in deinstitutionalisation has been more obvious as support of placement of children to foster families instead of children's homes has become common practice, although this is not so much the case for children with disabilities. Especially the assessment of health status as a single criterion for placement of a child to the specialised group in children's home instead of foster family seems challenging, as was also indicated by the UNCRPD Committee.

Specific regular allowance to foster parents is too low to compensate for a care of disabled child.¹²⁴⁹ Finally, as mentioned in the early part of this report, the transition of children with disabilities from children's homes to independent living is proving to be difficult as well. But what about the Slovakian educational system? The Constitution of the Slovak Republic secures the general right to education for each Slovak citizen¹²⁵⁰ and guarantees persons with disabilities special assistance in preparation for their profession.¹²⁵¹

The public administration in education is guaranteed by both the state administration and territorial self-governance, which is executed by municipalities and higher territorial units. The central body of state administration in education is the Ministry of Education, Science, Research and Sport of the Slovak Republic. It develops educational aims, curriculum and methods for education. Local administration is the responsibility of municipalities, which provide most pre-primary, primary and lower-secondary education in Slovakia. Public schools provide education free of charge.¹²⁵²

The first stage of the education system is pre-primary education, attended by children from three to six years and provided by kindergartens. There is a high pre-school attendance rate in Slovakia (around 90%). Despite the wide network of kindergartens, higher demand for places is being recorded due to population growth.¹²⁵³

Primary and lower-secondary education are organised as a single structure system, beginning at the age of six and lasting for nine years. Education is provided by basic (primary and lower-secondary) schools, where a child starts to fulfil compulsory school attendance. Compulsory schooling lasts ten years and pupils complete it by finishing the first year of upper-secondary education.

Higher education is provided at three levels: bachelors, masters and PhD study programmes in autonomous universities and higher education institutions.

¹²⁴⁹ According to the Act No. 627/2005 as referred in footnote 10, its sum equals to 0.8-fold of the subsistence minimum for a child.

¹²⁵⁰ Article 42

¹²⁵¹ Article 38, Section 2

¹²⁵² CPRA – Slovak Republic Country Report

¹²⁵³ IECE - Slovak Republic Country Survey Questionnaire, p. 2. [https://www.european-agency.org/sites/default/files/agency-](https://www.european-agency.org/sites/default/files/agency-projects/IECE/Qs/Slovakia%20IECE%20Country%20Survey%20Questionnaire%202016.pdf)

[projects/IECE/Qs/Slovakia%20IECE%20Country%20Survey%20Questionnaire%202016.pdf](https://www.european-agency.org/sites/default/files/agency-projects/IECE/Qs/Slovakia%20IECE%20Country%20Survey%20Questionnaire%202016.pdf)

Adult education includes further professional education, special interest education and civic education.

The Ministry of Education co-operates with central bodies of state administration and other bodies and organisations. The State School Inspection is the body of the state administration in education that exercises state control over the level of pedagogical management and the level of education. Evaluation of the quality of education, research, development, artistic and other creative activity of higher education institutions is under the remit of the Accreditation Commission.

Until 1990, the administration of education was centrally executed. Act No. 542/1990 of the Law Code on State Administration in Education and School Self-Government replaced the previous Act and created a branch system of administration as amended by the subsequent provisions, conditions for pluralistic development of the education system, and conditions for strengthening schools' autonomy.

The Amendment to Act No. 542/1990 of the Law Code on State Administration in Education and School Self-Government set the new competencies of decision-making which operate within the system – municipalities, self-governance regions, school self-government bodies, state bodies which ensure the professional and methodological management, head teachers and heads of school establishments.

The Act sets out two forms of competencies of territorial self-government (municipalities and self-governance regions):

- Transferred execution of the state administration.
- Execution of territorial self-governance (the so-called self-governing competencies).

The reform of public administration (state government and territorial self-government) and the organisation of the education system in the field of management, establishment and dissolution of schools and school facilities, and self-governance of schools has continued. The changes are anchored in the legislation through the Act on State Administration in Education and School Self-Government Act No. 596-2003 of the Law Code. In 2008, the new Education Act, which created legislative space for the implementation of content reform of regional education, was approved (Act No. 245/2008 of the Law Code). The Ministry of Education, Science, Research and Sport is the central body of the state administration of the Slovak Republic for primary, secondary and higher education, educational facilities, lifelong learning, science and for the state's support for sports and young people. The Ministry manages schools and school facilities within the Slovak Republic through generally binding rules. By providing vocational guidance to all founders, it administers the network of schools and school facilities in the Slovak Republic.

At local level, school state administration is realised through municipalities and higher territorial units, which secure activities laid down in their founder competencies. Higher education institutions are legal entities and their organisation and activities are decided by the bodies of academic self-government in compliance with the Act on Higher Education Institutions.

Slovakia committed to several international conventions with the challenge of directing the education system towards inclusive education, such as the Salamanca Statement, the Lisbon Strategy, the United Nations Convention on the Rights of Persons with Disabilities and the UNESCO Policy Guidelines on Inclusion in Education. Slovakia is obliged to address the issue of inclusive education and of inclusive society.

The Education Act does not use the term 'inclusive education' as such. However, it sets out 'equality of access to education, taking into account the educational needs of an individual' and emphasises the 'prohibition of all forms of discrimination, particularly segregation'.¹²⁵⁴

In 2016, the Government of the Slovak Republic approved the Government Programme for 2016–2020, in which a significant part is dedicated to education – particularly:

- (1) to support pre-primary education, with a special focus on learners from a socially disadvantaged background;
- (2) to create conditions for inclusive education;
- (3) to improve service of professional psychological and special educational counselling and diagnosis;
- (4) to promote vocational training in the system of so-called dual education (Source: Raising the Achievement of All Learners in Inclusive Education – Slovak Republic Country Report).

In 2013, Slovakia spent 3.8% of its gross domestic product (GDP) on primary, secondary and tertiary education, compared to an average of 5.2% in the other OECD countries.¹²⁵⁵ Public funds for education come from the public budget, which comprises the state budget, the municipal budgets and the budgets of higher territorial units.

The position, function and drawing up of budgets are regulated by the Act of the National Council of the Slovak Republic No. 253/2004 of the Law Code on Budgetary Rules of Public Administration. Funding sources include rental revenues from renting space, profits from business activity, contributions and gifts, and other sources, subject to a special regulation. Act No. 597/2003 of the Law Code on Financing Primary Schools, Secondary Schools and School Facilities established normative financing per pupil from 1 January 2004.

In 2004, financial resources for education came from the state budget allocated under the Chapter of the Ministry of Education, Science, Research and Sport (higher education institutions, primary schools, secondary schools, school facilities). Since 2013, they have been allocated under both the Chapter of the Ministry of Education, Science, Research and Sport and the Chapter of the Ministry of Interior. Following the 2004 tax reform, resources from other public budgets were added to the public resources from the state budget, namely from the municipal and higher territorial unit (self-governing regions) budgets. This ensures in particular the performance of the original competencies of the municipalities and higher territorial units. School financing is based on the normative principle; schools are financed according to the number of pupils and staff and the financial demands of the educational process.

¹²⁵⁴ IECE – Slovak Republic Country Survey Questionnaire, pp. 6–7 <https://www.european-agency.org/sites/default/files/agency-projects/IECE/Qs/Slovakia%20IECE%20Country%20Survey%20Questionnaire%202016.pdf>

¹²⁵⁵Source: CPRA – Slovak Republic Country Report

The coefficients for calculating the school budget vary for different categories of learners with special educational needs (SEN), depending on the level of their needs. The individual coefficients are higher for the education of learners with SEN in mainstream education or in special classes than in special schools. ¹²⁵⁶

Act No. 245/2008 of the Law Code on Education and Training (the Education Act) and certain amending acts define children/pupils with special educational needs (SEN), including those with:

- disabilities;
- cognitive impairment;
- hearing impairment;
- visual impairment;
- physical impairment;
- impaired ability in communication;
- autism;
- multiple impairment;
- specific learning difficulties, specific behavioural difficulties, illness and physical weakness;
- behavioural disorders;
- social disadvantages;
- particular gifts and talents, prodigies.

The Act guarantees that children/pupils with SEN are provided with education reflecting their individual abilities, with special forms and methods. For people with hearing and visual impairment, it secures the right to education in their language with the use of sign language/Braille. ¹²⁵⁷

The Concept of Education of Children with Disabilities, approved by the Ministry of Education, Science, Research and Sport, intensified many activities, which are aimed at new trends in the educational process of children and pupils with SEN. The specific modification of educational conditions enables a large part of the population of these pupils to complete primary and secondary education within the mainstream education system. It not only contributes to better quality educational results, but also positively supports the process of continual social participation and overall personal development so that more persons with disabilities are ready to move into higher education and then apply their skills in social and working life.

The proposal to admit children/pupils with SEN into the system of special education in special schools and special classes or education within mainstream schools (inclusive education) is commented on by experts from the sectors of health and education. In some cases, the social affairs and family sector is also involved.

In the case of a child with a disability, the starting point should be the medical diagnosis. Within the framework of a screening examination – to be undertaken before the child reaches the age of 36 months – the physician identifies a potential disability in various areas of the child's health,

¹²⁵⁶ Source: CPRA – Slovak Republic Country Report

¹²⁵⁷ Act No. 245/2008 of the Law Code on Education and Training (the Education Act) enables the admission of pupils with SEN to mainstream primary and secondary schools (inclusive education).

and sets an indicative diagnosis with a recommendation for further professional medical examinations.

After stating the medical diagnosis, the physician can recommend to the parents further examination of their child in counselling establishments within the educational sector. The medical diagnosis is supplemented by psychological and special education examination and diagnosis. Subsequently, in these establishments the psychological and special educational interventions are also defined.

From the point of view of time, the counselling centres provide professional support to children with disabilities and to their parents, from 0 to 3 years of age – so-called early intervention. The early intervention programme has been developed in agreement with the intentions of special education. It is structured into several areas, such as:

- solving problems through early intervention at the level of individual sectors and inter-sector co-operation;
- uniform registration of children with disabilities at an early age;
- provision of information and interventions into the problems through early intervention for children with SEN with the intention of providing the family with as much information as possible and securing their active participation in the process of complex care for their child;
- networking of establishments of special educational counselling, supply of staff in relation to priority activities and professional interventions of special educational counselling services and child integration centres;
- the further education of professional employees in issues of early intervention;
- adjustment of regulations.

Upon reaching the age of three years, the child is recommended for one of the forms of pre-school institutional education either in a special or mainstream kindergarten. Special kindergartens admit children according to their type of disability. In mainstream kindergartens, children with disabilities may be educated in special classes or in mainstream classes.

There is a network of educational counselling and prevention centres (special educational centres and centres of educational-psychological counselling and prevention), where the team of experts comprises physicians, psychologists, special pedagogues, rehabilitation workers, social workers and technicians, and other specialists. These professionals carry out a complex evaluation of the child/pupil with disabilities, learning difficulties (specific learning difficulties, specific behavioural difficulties) or disadvantages. Finally, a special pedagogue determines the final special educational diagnosis, after an assessment of all examinations and special educational interventions. At the same time, special educational needs are defined by stating the educational prognosis. The complex evaluation given like this is part of the proposal for admission of the child/pupil with special educational needs to the special school, special kindergarten, primary school and to secondary school.

It is recommended that children with disabilities/difficulties/disadvantages with a special educational diagnosis be integrated into special educational care in the system of counselling and into the educational process as soon as possible – before starting to attend school.

Parents have the right to enrol their child in mainstream education. If they wish for their child to attend a special school or a special class, they must receive all information on this type of education and give their 'informed consent' in writing.

According to the Education Act (2008), a learner with special educational needs (SEN) is a learner that has been diagnosed with SEN by the educational counselling and prevention centre. The Education Act secures such a form of education for learners with SEN, which enables them to achieve the same level of education as their peers. The main aim of education for learners with SEN is to reach the same level of education as their peers and to support social inclusion.

Learners with SEN are enrolled in mainstream schools, special schools or special classes. The levels of education of learners with SEN at special schools are equivalent to the levels of education of the mainstream population. Differences arise from the kind of disability.

After persons with disability pass through the Slovakian educational system, they have to gear themselves for the employment world. In Slovakia, various data sources point to the fact that the employment of people with disabilities (PWD) remains far below the employment rate of total population, although in the last few years, the situation has been slightly improving – mainly as a consequence of positive economic growth.¹²⁵⁸

According to the EU-SILC, in 2015 the employment rate of total population in Slovakia was 74.4 %, whilst the employment rate of people with severe disability¹ was 28.9 %.¹²⁵⁹ These shares are even slightly above the EU average, set at 73.1 % employment rate for total population and 27.6 % for people with severe disability.¹²⁶⁰

Slight improvements in the labour market participation of PWD can be seen on grounds of three national administrative data sources. First, the enterprise statistics, a register of all enterprises employing more than 20 employees operated by the Statistical Office, indicates that the total number of employees with disabilities in these enterprises has increased by more than 47 %, from 34,125 in 2012 to 50,257 in 2016.¹²⁶¹

Second, the data of the Social Insurance Agency (SIA), a public body administering the social insurance and holding the data on all employers and employees in the country, also show an increasing share of people recognised as disabled who are employed. Whereas in 2014 the share of employed people among those recognised as disabled was 31.42 % (75,545 out of 240,445 people recognised as disabled).

In 2016 this share increased to 37.14 % (92,157 out of 248,160).¹²⁶² Third, in 2016, after a three-year increase, the number of disabled registered as job-seekers at the Office of Labour, Social

¹²⁵⁸ Peer Review on 'Work-capacity assessment and employment of persons with disabilities' – Peer Country Comments Paper April, 2018

¹²⁵⁹ Grammenos, 2017.

¹²⁶⁰ Ibid

¹²⁶¹ Report on the Social Situation of Population of the Slovak Republic for 2016", 2017.

¹²⁶² Repková, Kešelová & Ondrušová, 2016.

Affairs and Family fell by 16.39% from 12,917 PWD in 2015 to 10,800 PWD in 2016.¹²⁶³ The highest proportion of working as well as unemployed PWD among all age categories is aged 50+.

In fact, according to Labour Force Survey – LFS, in 2016, 48.1 % of unemployed PWD in Slovakia were over 50 years of age, while amongst non-disabled population, only 8.4 % were aged 50-54 years. The largest share of the unemployed non-disabled people was aged between 20-24 years (almost 21.4 %).¹²⁶⁴

The share of employed people recognised as disabled by SIA is related to the assessment for invalidity pension. This assessment includes a medical assessment of reduced work capacity conducted by a specialist based at the SIA. In particular, the purpose of the medical assessment is to assess the presence of long-lasting unfavourable health conditions, supposed to last for more than one year, on grounds of medical reports written by the claimant's general practitioner or other specialist doctors. These reports contain the medical diagnoses, the

treatment, and the prognosis for further development in the given health issue. The face-to-face meeting of the claimant and the assessment doctor is a mandatory part of the assessment process as well.¹²⁶⁵ On the basis of the assessment, a person is recognised as disabled provided that he/she has a reduced work capacity of more than 40 %. If a person has a reduced work capacity by more than 70 %, he / she is recognised as person with severe disability.¹²⁶⁶

Once a person is recognised as disabled in this assessment, he/she also becomes eligible for participation in disability targeted ALMPs. Still, unemployed PWDs are not obliged to register with the PES.

In Slovakia, a PWD who is registered with the PES is eligible to any support defined in legal acts, and, at the same time, to targeted measures available only for PWD. However, in Slovakia most targeted ALMPs are addressed to sheltered workshops / sheltered workplaces. In April 2016, the UN Committee on the Rights of Persons with Disabilities made a recommendation in its Concluding Observations on the implementation of the UNCPRD, regarding the large number of PWD employed in sheltered workshops. The Slovak government was recommended to adopt the action plan on the transition from sheltered workshops to an open labour market for all¹²⁶⁷ (Article 74 of the Concluding Observations, 2016).

This challenge has to do with legal definitions rather than to a large number of PWD working in segregated work environments. In particular, Act No. 5/2004 Col. on Employment Services defines a sheltered workshop as a working arrangement in which at least 50% of all employees are persons with disabilities. Sheltered workplace is typically such arrangement with only one employee with disability. As a result of defining sheltered workshops through share of employees with disabilities in %, without setting out minimum number of these employees, almost half of all sheltered workshops have no more than five employees, with only three of these employees (i. e. more than 50 % of all five employees) being persons with disabilities.

¹²⁶³ "Správa", 2013-2016

¹²⁶⁴ "Informácia", 2017.

¹²⁶⁵ <http://www.socpoist.sk/lekarska-posudkova-cinnost/48017s>

¹²⁶⁶ "Zákon", 2003.

¹²⁶⁷ The proposal of the action plan was prepared in 2017, see Ondrušová, Kešelová, Repková (Eds.), 2017. It has now been subject to approval in the Ministry of Labour.

In fact, in 2016, there were 1570 sheltered workshops, of which only 14 were employing more than 20 employees with disabilities.¹²⁶⁸ A more clear definition of the difference between sheltered and open work environment, might have significantly positive consequences. For example, a greater access to work adaptation subsidies for employers in the open labour market, or providing different support intensity for sheltered workshops, and the employers in the open labour market.

The Act on Employment Services No. 5/2004 Col. As amended¹²⁶⁹ sets out the following disability specific ALMPs:

- The allowance to set up a sheltered workshop or a sheltered workplace. This allowance is provided to an employer who creates jobs for people with disabilities and intends to adapt workplace to the needs of disabled employees. The level of funding varies, according to the unemployment rate in the district where the workplace or workshop would be set up compared to the national average unemployment rate. It may range between 4 and 5.2 times the total labour costs, calculated on the basis of the national average wage + mandatory rental, social and health levies. In 2018, the maximum level of the allowance is between 5,002 EUR for employers in districts where the unemployment rate is below the national average, and 6,503 EUR for employers in districts with the unemployment rate higher than national average. The employer receiving a contribution is obliged to maintain the established workshop or workplace for at least two years.
- The allowance to maintain employees with disabilities at work. Since May 2013 this allowance supports employers in the open labour market provided that the total number of their employees with disabilities is at least 25% of their workforce. Sheltered workshops are not eligible for this allowance. The allowance is a kind of wage subsidy and may cover mandatory social contributions paid by the employer. The maximum level of funding for an employee with disabilities in 2018 is 555 EUR every three months.
- The self-employment allowance. This allowance is designed to enable people with disabilities to start up a business. The idea behind this allowance is very similar to the allowance to set up a sheltered workshop or sheltered workplace, i. e. not only to ensure additional adaptations of the workplace, but also to support the creation of a workplace as such. A person with disability who receives the allowance is obliged to keep this workplace for at least two years. The maximum level of the allowance varies between 3.2 and 4.8-times the monthly total labour costs, i. e. in 2018 between 4,002 EUR and 6,003 EUR.
- The allowance to cover the expenses related to support persons. This allowance is aimed at ensuring the provision of assistance to the employee with disabilities by some of his / her colleagues both in work-related activities and in daily living activities during work performance. The allowance is provided monthly and its level is between 41 % and 70 % of total labour costs (in 2018 between 513 and 875 EUR monthly). This measure resembles the Latvian measure for ensuring a support person at work for people with mental health issues, but it is of broader scope, as it has no limit in duration or in the type of disability.

¹²⁶⁸ Zoznam, 2016

¹²⁶⁹ "Zákon", 2004

- The allowance to partially cover the operating expenses of sheltered workshops and sheltered workplaces. This allowance may cover gas and electricity charges, rental expenses, transport of materials and products, mandatory social contributions paid by employer for persons with disabilities and other administrative expenses. All these are eligible rather than refunded expenses, since the maximum support for one workplace is between 2.5- and 5- times total labour costs ¹²⁷⁰ (in 2018, between 3,126 and 6,253 EUR). ¹²⁷¹ The aim of this allowance is to support the sustainability of sheltered workshops and sheltered workplaces. To some extent it also substitutes non-existing wage subsidies. ¹²⁷²
- Besides that, among the latest developments, in March 2018, the Parliament has approved the Act No. 112/2018 Col. on Social Economy and Social Enterprises. ¹²⁷³ The act recognises several types of social enterprises, including integrative social enterprise, i. e. such enterprise which employs at least 30 % disadvantaged employees, and meets other legal requirements. People with disabilities are explicitly considered disadvantaged. Integrative social enterprise is eligible to apply for the investment aid (including workplace adaptations), as well as compensation aid (wage subsidies). The act has come into force in May 2018.

Furthermore, Slovakia already has quite a long experience (since 1995) with the employment quota. Employers with more than 20 employees have an obligation to meet a 3.2% employment quota for disabled employees. If an employer employs a person with severe disabilities (who has reduced work capacity by more than 70 %), such employee counts for three PWD. Employers not meeting the employment quota, may perform this obligation either by contracting out to sheltered workshops or self-employed PWD the provision of certain products or services, or by paying a levy of 0.9 times the total labour costs (calculated from the monthly national average wage) or each employee with disabilities who is missing in order to meet the quota.

A combination of these options (e. g. outsourcing certain goods/services to sheltered workshop + paying the levy) is also possible. Over the last few years, the share of employers who meet the quota by directly employing PWD has been increasing, from 57.3% in 2012 to 66.76 % in 2016. At the same time, the share of employers who pay the levy has been decreasing over time, from 11.1 % in 2012 to 7.02 % in 2016. ¹²⁷⁴

Finally, Slovakia supports the employment of PWD by the requirements for equal opportunities and reasonable adjustments set out in the anti-discrimination act; the protection of PWD in cases of dismissals; and the reduced social and health insurance levies for both the employees with disabilities and their employers. These particular measures are rarely subject to evaluations, and even mentioned in the debates among key stakeholders. It is also worth mentioning that between 1992 and 2003, employers could reduce their income tax per each employee with disabilities by a fix sum. Since then, this measure has been cancelled.

¹²⁷⁰ See European Semester 2014-2015 ANED Slovakia report

¹²⁷¹ The ceiling per each employer employing more than one PWD is limited by the de minimis Regulation of the European Commission on small aid amounts. For more details see: http://europa.eu/rapid/press-release_IP-13-1293_en.htm

¹²⁷² Ondrušová, Kešelová, Repková, 2017

¹²⁷³ "Zákon", 2018

¹²⁷⁴ Repková, Kešelová, Ondrušová, 2016.

However, in the proposal of the action plan ¹²⁷⁵ a new measure is proposed, which would allow the employer to count twice the wage expenses for each PWD in the allowable tax deductions (Zubařová, 2017). ¹²⁷⁶

With regards to the next steps, two policy documents indicate further policy developments in the support of employment of PWD in Slovakia in the near future. First, the National Employment Strategy of the Slovak Republic until 2020, adopted by the government in 2015 in order to “to set out a path for creation of sustainable jobs for all, and especially for the disadvantaged groups of job-seekers in the labour market”. To achieve this overall objective, the strategy explicitly emphasises the need for coordinated and cross-sectoral policy approach. Some of its targets directly focus on PWD: e. g. to examine the possibilities of linking social and employment services (target 4.5.5); or, in order to increase the employability of PWD, to promote the cooperation between the public offices of labour, social affairs and family, and non-public employment services providers (i.e. agencies of supported employment) (target 4.6.7 of the Employment Strategy, 2015).

Second, the National Disability Program for years 2014-2020 ¹²⁷⁷ is a cross-sectoral policy document setting out strategic objectives and measures for the improvement of living conditions of PWD in several areas, including health, justice, education and employment. The strategic objective in the area of employment is to ensure for PWD conditions for their labour market participation, especially by increasing the accessibility and availability of public employment services and counselling services, as well as paying a greater attention to their employment in the open labour market.

This target shall be achieved by, e. g., providing that pupils with disabilities in secondary education are involved in mandatory traineeships in the open labour market; or by creating and implementing specific programs to support their transition from school to work. Apparently, in both documents a focus is on better access to the open labour market. One of the issues to be solved in this context is setting out a funding mechanism to support supported employment services, as currently, most ALMPs are aimed at subsidising employers, rather than assisting PWDs in finding and maintaining a job. Non-public providers of supported employment (i.e. agencies of supported employment), are underdeveloped in Slovakia, ¹²⁷⁸ for there is very limited co-operation with the PES, which do not contract out the provision of individualised services for PWD to these agencies. Nor there is a regular and predictable funding of supported employment services.

Finally, with regards to the work capacity assessment, the UN Committee has stated that the medical approach to disability is still used in assessments and provisions addressing persons with disabilities. A recommendation was made to adopt a human rights-based definition of disability in the regulations on the assessment of disability (Articles 11 and 12 of the Concluding Observations, 2016). This has been a case in the assessment for purposes of compensation for the consequences of severe disabilities.

¹²⁷⁵ Ondruřová, Keřelová, Repková, Eds., 2017

¹²⁷⁶ As employers could decrease due this measure the tax base per each PWD as per two persons, they would in the end pay lower tax.

¹²⁷⁷ “Národny”, 2014

¹²⁷⁸ Filipová, 2015

An Interdepartmental working group of the Ministry of Health, and the Ministry of Labour, was created to prepare a new legislation on long-term social and health care, which should also contain changes in the current assessment approach. As stated in the Legislative plan of the government for year 2018, the proposal of the act should be completed in July. However, the proposal is not likely to also affect the assessment for invalidity pensions, i. e. the work capacity assessment. On this aspect, Slovakia currently looks for transferable examples of good practice from other countries.¹²⁷⁹

¹²⁷⁹ “návrh plánu”, 2018

Slovenia

In Slovenia over 22.000 children and adults with disabilities are placed in institutional care. The figure does not include children and young persons in correctional institutions (about 450 persons), although almost half of them are diagnosed with mental health problems.¹²⁸⁰ Until 2015 there was no exact data of how many people live in different long stay institutions; only after two studies partially funded by European Social Funds, did the data become available. The study by Flaker et al. (2015) show that there are 22.106 disabled children and adults in institutional care. Some of them live in large buildings and some in smaller houses which were built in recent years as part of the existing institutions. In addition, there are 58.717 persons who use some forms of community care services.¹²⁸¹

The second study by Zaviršek et al. (2015) provides similar figures and shows that 22.792 persons with disabilities age 18- 64 live in long-stay institutions or associated accommodation. 21.814 disabled live in large buildings (from 100-700 persons in one building), while 978 persons live in smaller units close to the main buildings or in towns or cities. These units are institutional parts of long-stay institutions, as the staffs, administration, food, comes from the main buildings and people are not given any choice of daily routine, they all work in sheltered workshops.¹²⁸² Slovenia has 146 long-term institutions for children, adults and elderly with different disabilities. They are divided into: social protection institutions for persons with psychiatric diagnoses and multiple disabilities; boarding schools for children and adults predominantly with intellectual and multiple disabilities called "centres for orientation, work and protection"; old people's homes; institutional-based sheltered workshops for people over 18 years of age diagnosed as intellectually or severely physically disabled.

The system of community-based settings consist of the following care services: family helpers (around 1.000 helpers); group homes (around 48); personal assistance and the service of accompanying the persons (163 persons were given assistance and support); day centres, home care (in 2017 476 disabled persons were given social care allowance and lived at home); centres

¹²⁸⁰ Ministry of Education, Science and Sport, Public call, The integrated treatment of children with emotional and behavioural disturbances in long-stay institutions [Celostna obravnava otrok s čustvenimi in vedenjskimi motnjami v vzgojnih zavodih]. 12 May 2017. zavodih"

http://www.mizs.gov.si/si/javne_objave_in_razpisi/okroznice/arhiv_okroznic/okroznice_razpisi_in_javna_narocila/javni_razpisi/?tx_t3javnirazpis_pi1%5Bshow_single%5D=1537 (03 February 2019).

¹²⁸¹ Flaker, V., Rafaelič, A., Bezjak, S., Dimovski, V., Ficko, K., Fojan, D., Žitek, N. (2015), The Preparation of the Point-of-departure for Deinstitutionalisation in Slovenia [Orig.: Priprava izhodišč deinstitutionalizacije v Republiki Sloveniji], Ljubljana, Faculty of Social Work.

http://www.mju.gov.si/fileadmin/mju.gov.si/pageuploads/JAVNA_UPRAVA/NVO/FP_2007-2013_-_dosezki/MDI_Analiza_final.pdf (01 February 2019).

¹²⁸² Zaviršek, D. & Krstulović, G. & Leskošek, V. & Videmšek, P. & Bohinec, M. & Pečarič, E. & Jeseničnik, N. & Poropat, K. (2015). The Analysis of the institutional social welfare system and the impact of the non-governmental organisations to provide community services in order to support the process of deinstitutionalisation. Ljubljana: YHD.

http://www.mju.gov.si/fileadmin/mju.gov.si/pageuploads/JAVNA_UPRAVA/NVO/FP_2007-2013_-_dosezki/MDI_Analiza_final.pdf (01 February 2019).

for young persons, intergenerational centres, counselling centres, different programmes for the elderly, home nursing (patronažna služba) and programmes for social inclusion of disabled (1.138 persons were included).¹²⁸³ The Resolution on the National Programme of Social Welfare¹²⁸⁴ 2013-2020¹²⁸⁵ describes sheltered workshops as part of the community based services, which is rather surprising.¹²⁸⁶ In regard of persons with intellectual disabilities, the above mentioned community care services are rarely used by persons with intellectual disabilities, with the exception of the sheltered workshops.

Numbers of disabled persons living in institutions, type of institutions and numbers of personnel

Type of long-stay institution	Number of all residents in long-stay institutions	Number of all living in the main building	Number of persons living in smaller units	Number of persons age 18-65 living in long-stay institutions	Number of employed personnel
Special long stay social protection institutions for adults	1.522	1.063	459	1.094	964
Centres for orientation, work and protection for children, young people and adults	1.203	963	240	961	1.353
Combined long stay social care institutions	2.824	2.791	33	497	1.450
Old people's homes	16.554	16.554	0	945	No data
Sheltered workshops as long-term institutional care	689	443	246	689	No data
TOTAL	22.792	21.814	978	4.186	/
Sheltered workshops as day care institutional service	3200 Persons				

¹²⁸³ Institute of Social Protection of the Republic of Slovenia. The evaluation of the social welfare programmes: the report of the implementation of the programmes in 2017.

https://www.irssv.si/upload2/SVprogrami_koncno%20porocilo_2018.pdf (02 February 2019).

¹²⁸⁴ Zaviršek et al., 2015

¹²⁸⁵ Orig.: Resolucija o nacionalnem programu socialnega varstva za obdobje 2013–2020 (ReNPSV13–20); adopted in April 2013.

¹²⁸⁶ See Shadow report of the group of non-governmental organisations from Slovenia on implementation of CRPD in Slovenia (2008–2017; Art 27.)

Institutional and community-based settings ^{1287 1288}

Type of care	Number of persons (children and adults together)
Institutional care (children and adults); living in larger long-stay institutions (from 100-700 persons)	22.106
Number of persons who live in smaller community living units, which belong to long stay institutions (20-25 persons; or 6-8 persons)	1.259
Day care facilities (part of institutions or independent)	5.020
In-between services (group homes 4-8 persons)	6.279
Number of persons who use community-based services	58.717

Long-term community placements run by NGOs in 2015 ¹²⁸⁹

Type of long-term community placement	Number of placements	Number of persons living in the community
Group homes	48	250
Living units	11	85
TOTAL	59	335

Different funding's of the family helpers in the five years period 2012-2016. ¹²⁹⁰

Year	Total funding of family helpers (EUR)	Funds from the Ministry of Labour, Family, Social Affairs, Equal Opportunities (EUR)	Funds from the local municipalities (EUR)	Private funds and Pension and Disability Insurance Fund (EUR)	Total number of family helpers	Number of family helpers funded only by local municipalities
2012	6,786,949	2,311,714			745	
2013	7,391,310	2,922,016			801	
2014	8,034,131	3,404,521	3,149,562	1,480,048	878	42
2015	8,203,771	3,679,023	2,939,072	1,585,676	912	29
2016	9,011,443	3,972,571	3,275,713	1,763,159	1,006	65

¹²⁸⁷ Extracted and accommodated from Rafaelič et al., 2017.

¹²⁸⁸ Andreja Rafaelič, Katarina Ficko in Vito Flaker (2017), The Transition to Community-Based Care in Slovenia [Prehod k skupnostnim oblikam oskrbe v Sloveniji]. Social pedagogy, 21 (3–4):183-210.

¹²⁸⁹ Zaviršek et al. 2015

¹²⁹⁰ Ministry of Labour, Family, Social Affairs and Equal Opportunities of the Republic of Slovenia.

Family Helper. http://www.mddsz.gov.si/si/delovna_podrocja/sociala/druzinski_pomocnik/ (02 February 2019)

The community-based settings mostly for people with long-term mental health problems is predominantly run by 6 state funded larger NGO's. The existent non-governmental services cannot fulfil the great need of disabled people who already live in the community, not to mention another number of people who would potentially come out of large institutions and would need services.¹²⁹¹

In 2015 there were (in addition to the previously mentioned dislocated units which are run by larger institutions) 48 group homes and 11 living units with altogether 335 persons who live in the community-based settings, most of them for persons with long-term mental health problems and run by these NGO's. These are all long-term community-based facilities, rather than transitional arrangements which would facilitate further move towards independent living.

While the long stay institutions are widening their activities and buildings (either larger institutions or smaller units in the community), NGOs obtain short-term project funds from the state (ministries, local communities, or state lottery funds) and cannot build up sufficient funds to expand their activities or ensure their longevity. Different NGOs provide some programmes for the disabled and in 2017 there were 1,299 disabled persons included in different programmes; among them 37 persons were minors.¹²⁹²

Since 2013 the trend is almost unchanged with yearly increase of persons in institutional care as well as those who live in smaller buildings/ units. The exact number for 2018 is not part of the official governmental data to the public. One needs to read each yearly report of each institution separately, in order to get the numbers of persons in large institutions and those living in smaller units (as it was done in the research from 2015).

In the official national documents and by the managers of the long stay institutions these smaller units are described as the examples of deinstitutionalisation. There is a large increase of sheltered workshops; currently day care sheltered workshops have over 3.500 persons who work in them from 8.00 am till 3.00 or 4.00 pm.

Instead of closing down the long-stay institutions some people were moved into smaller institutions; some are based on a social model, but the smaller building does not necessarily mean a move towards community-settings. The staff who work there were not re-trained and no evaluations were done on the quality or services from the disabled persons' perspective and from the perspective of independent living philosophy. The new smaller institutions are mostly living units, which consist from 20-25 persons (officially called "dislocated units"); group homes (4-8 persons) and sheltered workshops (for the long-term stay or for daily work only; the places are from 20-40 persons working at the same place).

In recent years, an increasing number of NGOs (28 in total) developed programmes of personal assistance. However, only a few conducts personal assistance that enables people to live outside the institutions (12 hour/day or 24-hour support are provided for about 300 persons in the whole

¹²⁹¹ Zaviršek et al. 2015.

¹²⁹² Institute of Social Protection of the Republic of Slovenia. The evaluation of the social welfare programmes: the report of the implementation of the programmes in 2017.

https://www.irssv.si/upload2/SVprogrami_koncno%20porocilo_2018.pdf (02 February 2019).

country). In most NGOs, personal assistance primarily means companionship, daily support of several hours, or even just one-hour visits and escorting to the shops and is more akin to home-help than a personal assistant. One such organisation employs two assistants for twelve disabled people. The Society of disabled students provides assistance mainly inside the students' dormitories focuses on study obligations and is limited to working days.¹²⁹³ Personal assistance was initiated and developed during the 1990s by the disability-activist-led organisation, the Youth Handicapped Deprivileged (YHD), founded upon the principles of the European Network of Independent Living (ENIL).¹²⁹⁴

The YHD operates 115 assistants for over a decade and, takes care of an equal number of disabled persons who can, because of the personal assistance, live independently. The assistance is not fragmented to caregiving, medical and other tasks after the example of the bureaucratic social policy system where the tasks of the ministries for health, social affairs or education do not seek to synergise, but rather to fragment human lives, but is based on the principle "all from one hand".

As one can note, the role of the NGOs in Slovenia is very important and essential, especially when tasked to initiate services to persons with intellectual disabilities. One of the key civil society components is Sožitje, the Slovenian Association for Persons with Intellectual Disabilities, is an independent, non-profit, non-party, voluntary organisation with social and humanitarian objectives that strives for the improvement of both collective and individual care of people with intellectual disabilities and their families. Its members, the Societies for Persons with Intellectual Disabilities, operate in the area of the Republic of Slovenia.¹²⁹⁵

Founded in 1963 as a national society for mentally disabled persons' aid, the organization began establishing other community and intercommunity societies. Today there are 52 local societies included in the Sožitje Association, their activity is spread out through the entire area of Slovenia. 51 of them are the so-called Sožitje Societies – Societies for Persons with Intellectual Disabilities. The 52nd member of their organization is the Special Olympics of Slovenia that promotes and provides the intellectual disabled with various sports and recreational activities.¹²⁹⁶

In 2014 some NGOs established the Deinstitutionalisation Network (15 disability organisations), which is currently not active.¹²⁹⁷ The Network held a conference on deinstitutionalisation in 2015 in harmony of the "Point of departure of the deinstitutionalization in

¹²⁹³ Zaviršek, D. & Krstulović, G. & Leskošek, V. & Videmšek, P. & Bohinec, M. & Pečarič, E. & Jeseničnik, N. & Poropat, K. (2015). The Analysis of the institutional social welfare system and the impact of the non-governmental organisations to provide community services in order to support the process of deinstitutionalisation. Ljubljana: YHD.

http://www.mju.gov.si/fileadmin/mju.gov.si/pageuploads/JAVNA_UPRAVA/NVO/FP_2007-2013_-_dosezki/MDI_Analiza_final.pdf (1 February 2019).

¹²⁹⁴ Pečarič, 2002

¹²⁹⁵ <http://www.zveza-sozitie.si/>

¹²⁹⁶ Ibid.

¹²⁹⁷ Deinstitutionalisation Network, <http://www.za-mdi.si/domov.html>; and <http://www.za-mdi.si/home-203.html> (10 February 2019).

the Republic of Slovenia". The coordinating organization is the disability NGO organisation YHD which was the initiator of personal assistance since the 1990s and actually wrote the legislation for the government in 2017. The traditional disability organisations were mostly not involved in the Network. Like the authors of the "Point of departure of the deinstitutionalization in the Republic of Slovenia", the NGOs involved in the Network support the philosophy of deinstitutionalization, community services and personal assistance. The Network was meant to closely collaborate with the governmental bodies, but no development is noted.

In 2018 the Ministry of Labour, Family, Social Affairs and Equal Opportunities invited selected disability organizations to a series of meetings (for each meeting different organizations were chosen) to present the governmental plans for the spending of the ESIF funds and the ideas of the pilot projects in the area of persons with disabilities.¹²⁹⁸ The governmental officials also wished to hear the ideas of the disability organisations. Many present felt that there were no signs that the ministry is going to take service users' perspectives into account. A president of a large NGO's for persons with intellectual disabilities commented: "The whole system is focused on the providers of services not the receivers of the services."

One of the biggest worry of disability organizations is the implementation of the Law on Personal Assistance. Firstly, the Law does not define that relatives cannot be personal assistants and therefore, since the Law is in place (January 2019), the majority of individuals who applied to become personal assistants are parents. Disability organizations which raised this issue are not listened to.

Secondly, several disability organisations which actually practiced personal assistants in the last decade and which literally wrote the legislation for the Ministry of Labour, Family, Social Affairs and Equal Opportunities and also advocated for its acceptance by the parliament of the Republic of Slovenia, are excluded from the trainings provided by the Ministry for those who want to become personal assistants and for the organisations which will offer this service. The paradox is that the organization YHD which is the very founder of personal assistance in Slovenia since early 1990's and achieved that in 2017 after years of lobbying different political parties a right-wing party eventually put the proposal into the parliament, has to go through the training to become a provider of personal assistance and is not among those who are the trainers. The training is currently given mostly by those organisations and individuals who opposed personal assistance in the past and which are ironically the gatekeepers of deinstitutionalisation.

But let us turn back to state initiatives. The largest portion of state funds remain dedicated to maintaining and developing existing institutional care.¹²⁹⁹ The costs of institutional care (for the long stay institutions for disabled children, adults, elderly) provided by the government is EUR 295,766,478 on a yearly basis, while for the community care services (in-between structures; community services) the government spends EUR 51,880,986 on a yearly basis. This is much less than the money for institutions, which shows that the government encourages institutional care and that the money has not shifted from institutional care to community care in

¹²⁹⁸ Invitation letters for the meetings 30 August 2018 and 07 September 2018.

¹²⁹⁹ Flaker 2017, Zaviršek 2017

recent years.¹³⁰⁰ The funding for the governmental long stay institutions for adults and elderly comes from three major sources: from the person and his/her relatives (pension, relatives' contribution); the local municipality and the governmental funds if the person's income does not cover the monthly expenditure of the placement.

The monthly price for the institutional placement for adult person is between EUR 1,000 up to EUR 1,500, depending from the type of the institution and the medical care needs of the person. Since January 2019 the monthly price for institutional placements for adults, especially in the elderly people's home has increased.

In previous years some EU funds were used for the restructuring and enlargements of long- stay institutions, sheltered workshops, old-people's homes.

The funds for community-based services and support for disabled persons to live in community partially comes from Lottery funds which are managed by the Foundation of the Disability and Humanitarian Organisations –FIHO. In 2019 this organisation distributed about EUR 16 million for disability and humanitarian organisations which provided some community projects and services. This is less than in previous years, when their budget was around EUR 22 million per year. The FIHO organisation has been often accused for corruption and abuse of funds by disability activists and also the Commission for the Prevention of Corruption of the Republic of Slovenia, but no legal action was taken.¹³⁰¹

In Slovenia, as already described, a double track exists. One track consists of smaller institutions which are part of long-stay institutions, as disabled children and adults can be either moved out of the large building into a smaller units or group homes managed by the same institution, but on the condition that they work in sheltered workshops.

Institutions are, while growing, branching out and developing smaller units¹³⁰² and group homes in communities, both in the immediate vicinity of the institution, and throughout the region where the institution is placed and beyond. One of the boarding schools spread out to 15 different locations; another accommodates children, youth and adults from 38 different local municipalities; a third one has adults from 55 local municipalities.

¹³⁰⁰ Andreja Rafaelič, Katarina Ficko in Vito Flaker (2017), The Transition to Community-Based Care in Slovenia [Prehod k skupnostnim oblikam oskrbe v Sloveniji]. *Social pedagogy*, 21 (3–4): 183-210. p, 198.

¹³⁰¹ See: Commission for the Prevention of Corruption of the Republic of Slovenia <https://www.kpk-rs.si/en/> and a short report in Slovenian language which says that the investigation of the Organisation FIHO remains a priority for the CPC also in the year 2019; <https://www.kpk-rs.si/2019/01/23/komisija-aktivno-glede-problematike-fiha/> (26 January 2019); Mager, Ingrid (2018b), Long and Complicated Way: a Quarter of Century of Implementing the Law on Personal Assistance [Dolga in zapletena pot: Četrto stoletje sprejemanja zakona o osebni asistenci]. *Dnevnik*, Saturday edition Objektiv, 1 December 2018, p.14.; see also Shadow report of the group of non-governmental organisations from Slovenia on implementation of CRPD in Slovenia (2008–2017). Pečarič, Elena (2018), Disability catch the cash – state supported lottery games. [Invalidski catch the cash –državne loterijske igre], YHD, Ljubljana.

¹³⁰² Also referred to as called “dislocated units”; dislocirane enote.

Instead of locally-based small scale services these traditional institutions are transforming into national centres that maintain their institutional culture. Still, most people are happier to live in smaller units and group homes than in the large buildings. The so-called dislocated units accommodate from 11 to 24 persons; group homes comprise of 4 to 6 persons.¹³⁰³

One of the major problems of these semi-community-based services is that the people who are moved into them are expected to work in sheltered workshops and the places they live are closed from 8.00 am-4.00 pm. It is important to emphasise that sheltered workshops are not real jobs, but are defined as a form of protection, care and education for persons with mostly intellectual and multiple disabilities; they have no work contracts and receive a monthly award of about EUR 20 on average. In the sheltered workshops lunch is still brought from the main kitchen of the large institution.

In the smaller units, most people share a room with at least one other person and in the units, which don't offer 24-hour staff, a person employed by the institution would regularly come during the night for surveillance. Residents are often grouped by their diagnoses rather than their wishes, interests and friendships. Some residential units get closed during the weekend, and some remain shut for five entire weeks during the summer.¹³⁰⁴

Although spending time with their families may seem useful at first glance as the person is thus able to maintain contact with their home environment, many people are returned into abusive environments simply because they have no other choice. It is paradoxical that work remains one of the most important activities of the people who are simultaneously defined as incapable of independent life and work in accordance with the socialist 1983 Act on Social Care of Mentally and Physically Disabled Persons, still in force today.

Instead of a monthly payment, the patients receive a monthly remuneration that amounts to between EUR 5 to a EUR 100, the average being EUR 20 per month. Nevertheless, the study by Zaviršek et al. (2017) showed that in the places without choices the long stay residents gladly do the work assigned to them by the personnel, as well as the daily errands such as tidying up, washing, ironing, or tending the plants. Participation in the life in the local community is primarily collective: going shopping or visiting local cultural and sports events, going to the seaside or for an outing.

The routine activities are called "work therapy" and one institutional document even quoted integration into the community as a form of work therapy. Inclusion is understood to be an organised activity where the personnel is indispensable. Because privacy is rare, the residents greatly appreciate every small sign or gesture that makes them feel autonomous and people with dignity and choice. One person was satisfied merely by being allowed to have a TV set in his room; another with living in a room where all visitors have to use the doorbell before entering. It is important to emphasise that for the government, this is already seen as deinstitutionalisation and the move to the community-based setting.

¹³⁰³ Zaviršek, Darja (2017), Delayed deinstitutionalisation in post-socialism. *European Journal of Social Work*, Vol 20: 6; 834-845. <https://doi.org/10.1080/13691457.2017.1344623>.

¹³⁰⁴ The jargon of the personnel and users refers to this practice as the "vacation for the residents", as the residents are free from working in the sheltered workshops during this time. Zaviršek 2017, *ibid.*

A small number of persons live in group homes (4-8 persons), social flats provided by local municipalities or living units (one room in a larger communal building). Some of them left long-stay institutions in the period 2000-2006 when the government was keener to support community-based settings than it is today (some persons with long term mental health problems then left the largest institution Hrastovec with 700 inmates).¹³⁰⁵

The second track is community based services described in the Resolution which offer some support and help mostly when the person has high level of needs and when parents or relatives does not want or cannot care for a disabled (with the support of the monthly care allowance) or to become family helpers, the person has to move to an institution.

In relation to the Art. 19, Living independently and being included in the community, the observations of the UN CRPD says: "The Committee is concerned at the large number of persons with disabilities still residing in institutions because of the lack of an explicit policy, national and municipal capacity and measures for deinstitutionalization of persons with disabilities, and the insufficient provision of independent living services in the community. It is also concerned about the practice of transferring persons with disabilities from larger to smaller institutions and about plans to build new institutions." The Committee recommended that the State party:

- (a) Adopt and implement a strategy and action plan, within a time frame, aimed at deinstitutionalisation;
- (b) Prevent any form of re-institutionalisation and provide sufficient funding for developing community-based independent living schemes;
- (c) Allocate sufficient resources to ensure that services in the community are available, accessible, affordable, acceptable and accommodating of persons with disabilities, so that such persons may exercise their right to live independently in their communities, in both urban and rural areas;
- (d) Strengthen the national and municipal capacity to implement deinstitutionalisation, in close cooperation with organizations of persons with disabilities.

But what about access to education? ¹³⁰⁶ The education of children with intellectual disabilities is regulated by general legislation applicable to all children and by the Placement Act, which specifically addresses the education of children with special needs. The Placement Act entered into force in 2003 and opened the door for the integration of children with intellectual disabilities into mainstream schools. However, current legislation still excludes the majority of children with intellectual disabilities from mainstream education; by law, only children with borderline intellectual disabilities can be placed in mainstream schools, while children with moderate to profound intellectual disabilities being ineligible even for special schools.

In 2001 there were 3,213 children with intellectual disabilities registered in Slovenia, of which over 70 per cent had borderline or mild intellectual disabilities. The Placement Act regulates the diagnosis of intellectual disability in children by the Placement Commissions. Since the Act entered into force there have been a number of changes in placement procedures. Nonetheless,

¹³⁰⁵ Andreja Rafaelič, Katarina Ficko in Vito Flaker (2017), The Transition to Community-Based Care in Slovenia [Prehod k skupnostnim oblikam oskrbe v Sloveniji]. *Social pedagogy*, 21 (3–4): 183-210.

¹³⁰⁶ https://www.opensocietyfoundations.org/sites/default/files/slovenia_20051102_0.pdf

there are still complaints that they are over-medicalised; that parents and experts who know the child personally are not sufficiently involved; and that there are often significant delays.

In Slovenia, the integration of children with intellectual disabilities is at an early stage. The ongoing reform of the education system for children with special needs has led to recent changes in the educational and vocational educational programmes available for children and young people with intellectual disabilities. However, the reform focuses more on the integration of children with physical and sensory disabilities, than on children with intellectual disabilities. This means that while increasing numbers of children with physical and sensory disabilities are enrolled in mainstream schools, children with intellectual disabilities are still to a large extent segregated in special schools. Nonetheless, the numbers of children with intellectual disabilities integrated into mainstream primary schools and kindergartens has steadily increased.

Pre-school age children with mild and moderate intellectual disabilities can be enrolled in mainstream kindergartens and follow a special educational programme, while those with moderate and severe intellectual disabilities can attend special units ¹³⁰⁷ in mainstream kindergartens.

There is now a special educational programme for children with special needs in mainstream primary schools, although this does not specifically refer to children with intellectual disabilities and does not specifically address their needs. In addition, children with intellectual disabilities integrated in mainstream schools receive additional expert support and an individualised educational programme. However, some parents have sought a diagnosis of borderline intellectual disability in order to place their children with mild intellectual disabilities in a mainstream school, and these children may, as a result, not receive the support they need.

Despite some positive examples, many parents and social workers are not satisfied with the first results of integration. In particular, teachers in mainstream schools have not been adequately prepared for working with children with intellectual disabilities and have not received any additional training. Many teachers remain resistant to the integration of children with intellectual disabilities, and most special educators still promote special schools as the best solution for children with intellectual disabilities.

Only children with mild – and in exceptional cases only moderate – intellectual disabilities can be placed in primary special schools ¹³⁰⁸ for children with intellectual disabilities, which can be boarding schools or day schools.

It is very uncommon for children with intellectual disabilities to receive home schooling. No budget resources are allocated for this purpose, so the costs of home-schooling fall to the parents. Children and young people with moderate, severe or profound intellectual disabilities are usually placed in special programmes of care and education in residential institutions and receive education according to a special programme of education and care.

¹³⁰⁷ Also referred to as “development units”.

¹³⁰⁸ Also referred to as “schools with an adapted programme”.

All this needs to be perceived against a full background of the Slovenian educational system. The majority (99%) of basic and upper-secondary school pupils attend public schools, which are set up and funded entirely by the state and municipalities.

In the school year 2011/2012, there were 450 mainstream compulsory schools, 27 special schools with adopted and special programmes and 16 special institutions for all eight recognised groups of learners with special educational needs (SEN).

There has been an increasing trend of including learners with SEN in mainstream basic schools – from 3.33% in 2005/2006 to 6.51% in 2012/2013. The total population of learners with SEN has increased over the years, mostly due to an increasing number of official decisions. The percentage of learners with SEN included in specialised forms of education has remained stable, at 1% of the total population of learners in basic school. ¹³⁰⁹

Private schools, which are set up by private entities and provide education according to state-approved programmes, are subsidised by the state. ¹³¹⁰ Less than 1% of learners were enrolled in six private schools in 2015/2016.

Upper-secondary education is not compulsory and is provided by public upper-secondary schools. Learners can choose between two education programmes: general education and vocational-technical education. ¹³¹¹

Administration responsibilities are distributed among the national authorities, local authorities and schools (mainstream schools and special schools with adopted and special programmes). The special institutions for learners with SEN are under the responsibility of the Government (Ministry of Education, Science, Culture and Sport).

At the beginning of 2012, the former Ministry of Education and Sport was merged with the Ministry of Higher Education, Science and Technology and with the Ministry of Culture. The new ministry was named the Ministry of Education, Science, Culture and Sport. It is responsible for the development of pre-higher education policies, inspection procedures, the allocation of funds, the implementation of laws and administrative decisions relating to pre-primary, compulsory and upper-secondary education institutions.

Local authorities are responsible for setting up pre-primary institutions and basic schools; they take part in their administration and co-finance their operation and the salaries of employees. School councils (sveti šol), composed of representatives of the founder, employees and parents, are the central governing bodies, with considerable responsibilities regarding management, finances and the teaching process.

Pre-primary education is part of the education system. Pre-primary provision includes unitary centre-based childcare and education which is mainly public. Pre-primary institutions (kindergartens) are set up by municipalities. Attendance is optional. Children can attend pre-primary institutions from the age of 11 months until they enter compulsory education at the age

¹³⁰⁹ Source: FPIES – Slovenia Country Report, p. 26.

¹³¹⁰ The grant rate is approximately 85%.

¹³¹¹ Source: FPIES – Slovenia Country Report, pp. 5–6

of 6 (that is, from 5 years and 8 months to 6 years and 8 months). The percentage of children with SEN in the population of all children enrolled in public pre-primary schools has increased in recent years, from 1.2–1.3% between 2006 and 2011, up to 1.7% in 2015/2016. The inclusive trend is evident. ¹³¹²

The fundamental objectives and principles in the education of children with SEN in the acts listed are underpinned by the following principles and objectives contained in the Guidance of Children with Special Needs Act:

- The principle of equal opportunities while taking into account the diversity of children
- Maintaining a balance between different aspects of the child's physical and mental Development
- Integration of parents in the education process
- Providing for appropriate conditions for the optimum development of each individual child
- Guidance to the most suitable education programme at the right time
- Organisation of education at a location close to the child's home
- Consistency and complexity of education
- Individualised approach
- Continuation of education programmes
- Inter-disciplinary approach.

The education of learners with special needs is regulated by the Placement of Children with Special Needs Act (2000, 2006, 2007). The Act defines procedures for the placement of learners with special needs in all types of education, from pre-primary to upper-secondary education.

In addition to this Act, the education of learners with special needs is also regulated by the:

- (1) Organisation and Financing of Education Act;
- (2) Pre-Primary Institutions Act;
- (3) Primary School Act;
- (4) Vocational and Technical Education Act;
- (5) Gimnazije Act;
- (6) Order on Norms and Standards for Education of Children with Special Needs.

The 1996 Pre-Primary Institutions Act, Primary School Act, Vocational and Technical Education Act and Gimnazije Act partially regulate the education of those learners with special needs who are integrated into mainstream forms of education. The basic act, which determines the placement of learners with special needs in appropriate forms of education, was adopted in the year 2000, with amendments in 2007.

New legislation was implemented in September 2013.

The Placement of Children with Special Needs Act regulates procedures for the placement of learners with special needs into the appropriate educational programmes. Depending on the learners' psychological and physical status, the Act enables their inclusion in education at all

¹³¹² Source: FPIES – Slovenia Country Report, p. 23.

levels, from pre-primary to secondary education, based on the assumption that additional help from experts and adaptation of the implementation of programmes will help learners to achieve a comparable standard of knowledge. Learners with severe disorders can still attend special forms of education in schools for learners with special needs and institutions for the education and training of learners with severe developmental difficulties.¹³¹³

Along with the primary legislative acts, the secondary regulations that govern the field of education at the operative level and are issued by the Minister of Education are also significant. The most important are as follows:

- Regulations for the organisation and work of the commissions – these regulations lay down the criteria for the assessment of professional disabilities, barriers and/or disorders, as well as the Children with SEN Guidance Commissions' operation.
- Regulations on additional professional and physical assistance for children and young people with SEN – these regulations lay down the scope, form and requirements for the provision of additional professional assistance.

Both documents apply to the population of learners and pre-primary children with special needs. The following are also important:

- Regulations on basic school education for pupils with SEN provided at home, laying down the requirements for education at home and the criteria for funding
- Regulations on the norms and standards for the provision of education programmes for learners with special needs.
- Regulations on the implementation of the Matura examinations for candidates with SEN.

¹³¹⁴

The approach introduced in Slovenia recognises the needs of learners with special educational needs (SEN) as disabilities, barriers and/or disorders that require changes or adjustments in the learner's environment or adaptation of the latter to the needs of the learner. The medical approach to the learner's disability, in use during the 1970s, has been abolished, at least according to government sources.¹³¹⁵

The guidance of learners with special needs (2000, including amendments in 2006 and 2007) defines the groups of learners with SEN as follows:

- Learners with intellectual disabilities
- Learners who are blind and learners with visual impairments Learners who are deaf and learners with hearing impairments Learners with speech problems

¹³¹³ <https://www.european-agency.org/sites/default/files/agency-projects/FPIES/CountryReports/FPIES%20Slovenia%20Country%20Report.pdf>

¹³¹⁴ <https://www.european-agency.org/country-information/slovenia/legislation-and-policy>

¹³¹⁵ <https://www.european-agency.org/sites/default/files/agency-projects/FPIES/CountryReports/FPIES%20Slovenia%20Country%20Report.pdf>

- Learners with physical disabilities
- Learners with long-term illnesses
- Learners with learning problems in specific fields of education Learners with emotional and behavioural disorders.

The Act is based on the principle that a learner's needs must be recognised as soon as possible and that early childhood intervention is a dynamic process. The recognition of the learner's needs and early intervention occur simultaneously.

Learners are recognised as having SEN when they get an official decision by the National Education Institute of Slovenia (NEIS). Parents usually request the introduction of official guidance procedures for learners with SEN, but schools or learners themselves (from 15 years old) can also request it.

The Children with SEN Guidance Commissions, founded by NEIS, are responsible for the placement. They work according to the Regulations for the organisation and work of the Children with SEN Guidance Commissions¹³¹⁶ and the Criteria for the assessment of the type and degree of disadvantage, impairments and disabilities of learners with SEN.¹³¹⁷

Co-operation between mainstream schools and specialised institutions, where examples of good practice are present, has been established at the national level. Most commonly, this applies to examples where there are units from schools offering the adapted programme. This form of provision allows transfer between programmes, meaning that pupils with special educational needs (SEN) integrated in a special unit attend special subjects in mainstream schools.

Within special institutions and schools with the adapted programme, there is a mobile service provided by disability experts. They are responsible for the provision of aid required to overcome disabilities, barriers and disorders. Their job is to visit children and learners at pre-primary institutions and schools and provide them with additional professional support. They also offer advice to teachers and educators on the adjustments of school activities required for each learner.

The inclusion of children and young people with emotional and behavioural problems requires co-operation between the Ministry of Education, the Ministry of Social Affairs and the Ministry of Health to provide the most suitable solution.

The Institute of Education of the Republic of Slovenia has an important role in introducing novelties and innovations in the field of pupils with SEN. Its mission is to manage projects and introduce innovations which are transferred into practice following trials. One of its projects was the experimental introduction of units for learners with SEN suffering from autistic spectrum disorder. Following the amendments of the Act on the Guidance of Children with Special Needs in 2007, the Centre for Guidance also operates within the framework of the Institute. The Centre administers the operation of Children with SEN Guidance Commissions which, on the basis of a completed medical examination, direct learners to the most suitable education programme, specify the scope and form of the additional professional support and potential limitations for the number of learners in groups/classes, and also inspect whether all staffing, spatial and material

¹³¹⁶ Official Gazette No. 88/13

¹³¹⁷ Source: FPIES – Slovenia Country Report, pp. 15–16

requirements for the education of children in schools and pre- primary institutions have been provided for. The formal document, laying down the adjustments and additional support requirements, is called a guidance order.

Learners with SEN who suffer from severe development disabilities and attend mainstream schools are provided with support offered by four consultation centres for children, young people and their parents. These centres offer an integral treatment of the child together with the family and, on the basis of a multi-disciplinary approach, advise schools and parents and/or provide the child with the corresponding treatment.¹³¹⁸

A significant role in the state has been entrusted to the special institutions for people who are deaf, people who are blind and people with physical disabilities. Within the scope of their competences, these institutions provide mobile treatment of disabilities for children and young people. Their work includes training for teachers of groups that include a child or young person with a specific disability, barrier or disorder. Institutions for people who are deaf include well-developed healthcare units which also provide treatment to children with complex or severe speech problems that are the result of an impaired development and require instant treatment.

Children with SEN who are in pre-primary institutions, schools and special units within pre- primary institutions, with more severe disabilities, are provided with the assistance of different professionals (i.e. special teacher, physiotherapist, work therapist) and occasional assistance from the speech and language expert and psychologist.

Children with SEN with more severe physical disabilities are provided with a permanent or occasional assistant to support their inclusion in education. The assistant is paid for by the Ministry of Education, Science, Culture and Sport. An assistant to children with physical disabilities in pre-primary education is provided by the local community.

A regular/full-time physical assistant is granted to children who require assistance during pre-primary education, during the provision of compulsory or extended curriculum of single structure schools or during educational activities in secondary schools.

Children and learners with SEN included in mainstream schools or pre-primary institutions are entitled to additional hours of professional help as prescribed in their guidance order. Additional hours are intended for overcoming barriers, disabilities and disorders (rehabilitation support) or can take the form of learning support with the aim of facilitating learning in a specific subject.¹³¹⁹

In the school year 2006/2007, the Ministry of Education, Science, Culture and Sport published the network of basic schools, meeting all the requirements concerning infrastructure adjustments for pupils with severe physical disabilities using wheelchairs according to international standards.

¹³¹⁸ <https://www.european-agency.org/country-information/slovenia/systems-of-support-and-specialist-provision>

¹³¹⁹ <https://www.european-agency.org/country-information/slovenia/systems-of-support-and-specialist-provision>

Since 2008, the rental of more complex technical aids for learners who are blind attending mainstream schools was organised. These aids enable learners who are blind and learners with visual impairments to participate in the education process.

In practice, learners who are blind and learners with visual impairments receive an increased number of hours of professional assistance, aiming to assist them with overcoming their disabilities, barriers and/or disorders. The extended assistance is condensed and takes the form of a course provided by the main centre for education of the blind in Ljubljana. Exercises consist of different communication techniques, i.e. the use of Braille system for writing on a computer and the use of technical aids. In the field of orientation, activities include exercises for improving movement in the nearer and the wider environment, training of other senses, activities for the acquisition of social skills and skills for day-to-day life.

The latest amendments to the regulations on standards and norms in basic schools allow schools to reduce the number of pupils in a class if the latter includes pupils with SEN, according to the Children with SEN Guidance Commission. The group of professionals in each school decides the number of pupils in a class. If the group's decision requires the formation of an additional class/group, the school must obtain permission from the Ministry of Education. Additional classes may only be formed at the beginning of the school year.¹³²⁰

Learners with SEN have the option to attend:

- Mainstream schools and nursery schools
- Schools offering individual adapted programmes
- Units in mainstream schools that follow the adapted programme
- Units in special institutions.

Most learners attending special institutions have one or more other disabilities aside from their main one. Thus, they require specially adapted forms of work, healthcare and rehabilitation, none of which can be provided during inclusion in mainstream schools.

A large majority of learners with SEN are educated in mainstream schools where they are provided with additional professional assistance as decided by the Guidance Commission. The latter can take the form of additional hours of assistance to overcome the disabilities, barriers and/or disorders (e.g. pupils who are deaf receive the help of a teacher for the deaf) or learning assistance with the objective of facilitating learning for a specific subject. A permanent or temporary assistant can be assigned to pupils with more severe physical impairments, depending on the severity of their impairments, so as to assist them during lessons or with other activities during school time.

The groups of learners with SEN integrated in mainstream schools are as follows:

- Learners with disabilities in specific fields of education who could be very successful with adjustments and additional assistance.

¹³²⁰ <https://www.european-agency.org/country-information/slovenia/systems-of-support-and-specialist-provision>

- Learners with emotional and behavioural problems, excluding learners who, in addition to their emotional and behavioural disabilities, have additional problems (mental problems, reduced cognitive skills) and attend schools within a specialised institution; such problems are mainly the result of a dysfunctional domestic environment.
- Learners with a long-term illness who, during their hospital treatment, attend the hospital school – a unit of a mainstream school, located in the same city as the hospital.
- Learners with speech and language problems, provided that such disabilities are not too severe (autism); in such cases learners attend special institutions for people who are deaf or schools offering an adapted programme.
- Learners with physical disabilities attending education at an institution that corresponds to their intellectual abilities, if their movement is heavily restricted or they suffer from any other disability that requires medical rehabilitation, or they are integrated into special institutions.

Most learners who are deaf or learners with hearing impairments and learners who are blind or learners with visual impairments. Only learners who suffer from an additional disability, in addition to their main disability, are integrated into specialised institutions.

Learners with complex or severe cognitive disability attend schools with adapted programmes that provide education at a lower level and special education programmes. Formal recognition of practice based on the formation of groups, following the adapted education programme(s) within mainstream schools is increasing.

Pre-primary children have the option to attend nursery schools providing adapted programmes adjusted to specific disabilities within special institutions. However, they may also decide to attend mainstream nursery schools where they are provided with assistance from a relevant professional. Pre-primary children with complex disabilities can access development units within nursery schools that have been recognised in practice as an effective treatment for this group of pre-primary children. The education process within these units also involves a physiotherapist, a work therapist and the occasional involvement of a psychologist. The prescribed maximum number of children in such groups is limited to six, while the group must be constantly supervised by at least two professional members of staff.

Learners with SEN are also provided with the option of opting for basic school education provision at their place of residence. Through the education, a learner must acquire the same education standard as required by the programme of the public school. The decision on education at the place of residence is made by the commission that examines the learner and assesses that, due to disabilities, barriers or disorders, a pupil cannot attend education at school. Parents are required to ensure suitable learning and teaching conditions at their home. Assessment and evaluation of the pupil is organised at the school and/or institution where the pupil has been enrolled. Resources for education are provided from the state budget, whereas the Minister of Education adopts the decision on the allocation of funding for each individual school year.

The number of learners assigned to mainstream schools and nursery schools, in co-operation with special institutions upon their first examination by the commission, is constantly increasing. Special institutions organise in-service teacher training programmes and provide practical advice for work with learners with SEN. Mobile teachers from specialised institutions and schools with an adapted programme provide for learners with special needs in mainstream

schools, providing individual and professional group aid for overcoming disabilities, barriers and disorders.¹³²¹

The Basic School Act (1996, 2008, last revised 2012) allows pupils to transfer between programmes. Basic school pupils can transfer from adapted education programmes to education programmes with professional support offered in mainstream schools. Permanent or temporary transfers of pupils in specific subjects or subject groups are also possible. Learners attending special programmes may, occasionally, also participate in the adapted programmes.

The objectives and outlines of programmes for the education and training of learners with SEN are incorporated into the individual education programme. Parents are required to take part in the process of writing the individualised programme. Evaluation of the programme is provided at least once a year or in circumstances of major changes within the learner's development, especially changes that affect the implementation of the education and training programme. In terms of their other individual skills and abilities, learners may be guided and placed into various education and training programmes. Educators in both pre-primary and primary schools provide the necessary adjustments in their endeavours to attain the required standards of knowledge. Instructions for working in a specific programme of education and training provide the necessary support to the educators in implementing the curriculum.

Once a year, learners who are part of the individualised education programme with extra professional support take the national examination on general knowledge. The examination material is adapted to the individual learner's type and level of disability or disorder. Primarily, the purpose of the general knowledge examination is to obtain information. The other purpose of the examination is to supply learners and their parents with information about the outcomes, strengths or weaknesses of these learners. The information is also important for teachers and school directors as they can then analyse the outcomes and the reasons behind them and apply the results to improve didactic equipment and ways of teaching and evaluation. In this way, they are able to adapt the instruction and the school. There are also examinations at national level.

The results of the 'national knowledge examinations' provide information about the level of attainment of curriculum standards and thereby enable the evaluation of outcomes at the national level.

Educators apply different methods in their work and often appreciate and use tailored information technologies.

The National Examination Centre and the Evaluation Board at the national level are the chief evaluation institutions within the state that are responsible for evaluating knowledge outcomes. The Board evaluates all innovative education and pilot projects that receive consensus from the most important scientific authorities in the state.

In special institutions for learners with special needs, periodic supervision is carried out, primarily concerning the more challenging population of learners with special needs.

¹³²¹ <https://www.european-agency.org/country-information/slovenia/systems-of-support-and-specialist-provision>

School inspection is the responsibility of the National Inspectorate for Education and Sport, which falls under the authority of the Ministry of Education, Science, Culture and Sport.¹³²² The National Inspectorate is also responsible for inspecting the education of learners with SEN. When one analyses employment laws and their co-relation with persons with disabilities, there are some factors one has to keep in mind. Slovenian law guarantees the right to work and to choose a profession. Recent legislation has strengthened protection against discrimination in employment for people with disabilities.

A long-term national employment strategy is defined in the “National Programme for the Development of the Labour Market and Employment by 2006”. This includes a number of progressive measures to encourage the employment of people with disabilities in general, but does not specifically refer to people with intellectual disabilities. The programme is mainly implemented through active labour market programmes, which include people with disabilities as a target group. At present, such programmes are the main way through which adults with mild intellectual disabilities may seek employment (and receive training) in companies on the open market, although no official data on this is available.¹³²³

Those who cannot find work in this way can instead be employed in sheltered companies, which must fulfil a quota of at least 40 percent of people with disabilities and in return receives tax relief and Government subsidies. Although a quota system was introduced as of May 2004, it is still too early to assess the implications of this new system for the employment of people with mild intellectual disabilities.

The unemployment rate for people with disabilities of all types has been rapidly increasing since 1992. Data on the level of employment and unemployment of people with intellectual disabilities is not currently available, although a new register is presently being introduced which should improve data collection. At present, there are two main possibilities for people with mild intellectual disabilities to find employment: full-time employment on the open labour market or work in sheltered companies. There are no current examples of supported employment. However, most people with intellectual disabilities are placed in sheltered workplaces. These cannot be considered as constituting employment as the workers do not have an employment contract and do not receive a wage, only a token “award”. In 2001, over 2,000 people with intellectual disabilities (mostly of a moderate degree) were working in sheltered workplaces. There are some examples of good practices, including a sheltered workplace which has placed people with intellectual disabilities in a company on the open market. However, in most cases the work in sheltered workplaces is repetitive and, as a segregated environment, does not seek to provide people with intellectual disabilities with the employment and social skills they need to access employment on the open market.

That was the scenario a decade ago. Was there any progress registered? The main specialist programmes for people with disabilities today are:

- Vocational rehabilitation under the Vocational Rehabilitation and Employment of Disabled Persons Act;
- Vocational Rehabilitation under the Pension and Disability Insurance Act.

¹³²² Inšpektorat Republike Slovenije za šolstvo in šport.

¹³²³ <https://za-vse.eu/en/accessibility-4-all/>

Inclusion in vocational rehabilitation is possible:

- Under the Vocational Rehabilitation and Employment of Disabled Persons Act: after a person is assessed by a vocational rehabilitation provider, the person can obtain the status of person with disabilities, what is based on decision taken by rehabilitation commission (on the basis of the assessment) or
- Under the Pension and Disability Insurance Act after person is assessed by a disability commission.

The assessment of rights under the Pension and Disability Insurance Act, performed by a special commission from the Pension and Disability Insurance Institute of Slovenia,¹³²⁴ is based on a medical model focusing on disability. According to their remaining work capacity insured persons are classified in one of the three disability categories by the Board of Examiners as follows:

Category I: when an insured person is not able to perform organized gainful activity or when an insured person is not able to carry out their job, and has no remaining work capacity;

Category II: when an insured person's work capacity to perform their job has been reduced by 50% or more;

Category III: when insured persons are not able to perform their job on a full-time basis, yet can work part-time for at least four hours a day, or when their capacity to work in their occupation has been reduced by less than 50%, or when they can still work in their occupation full-time yet are not able to perform their current job.

Persons categorized with the following disabilities are entitled to a disability pension:

- category I;
- category II, if without vocational rehabilitation another suitable job with full working hours would not be possible, however, this is not guaranteed where the person is above 55 years of age;
- category III, if without vocational rehabilitation another suitable job with part-time working hours would not be possible (minimum 4 hours a day), however, this is not guaranteed when the person is above 50 years of age;
- category II or category III if suitable work has not been assured when the person has reached 65 years of age.

The Pension and Disability Insurance Act also provides vocational rehabilitation services, such as integration in the process of formal or non-formal education, on-the-job-training, adaptations to the workplace, the work environment and the equipment.

The assessment of rights under the Vocational Rehabilitation and Employment of Disabled Persons Act is based on the bio-psycho-social model focusing on ability.¹³²⁵ This results in the following classification:

¹³²⁴ Zavod za pokojninsko in invalidsko zavarovanje Slovenije, ZPIZ

¹³²⁵ see: Rules on Criteria and Method for Acquiring the Status of Person with Disability; Right of Employment Rehabilitation, Assessment of Employment Possibilities of Persons with Disabilities and Rehabilitation Committees, 2005)

Level 0: No disability (0-4%), nor the right of employment rehabilitation services;
Level 1: Mild disability (5-25%), no right of employment rehabilitation services;
Level 2: Moderate disability (25-49%) → status of person with disability → right to employment rehabilitation services;
Level 3: Severe disability (50-95%) → status of person with disability → right to employment rehabilitation services;
Level 4: Complete disability (96-100%) → status of person with disability, but no right of employment rehabilitation services.

During the (interdisciplinary) assessment for the employment rehabilitation services the most appropriate services are offered given the disability, the personal characteristics and the environment.

The Action Programme for Persons with Disabilities (2014-2021) states in the introduction that to achieve greater social integration of persons with disabilities and better regulation of the issues relating to disability, closer cooperation between individual ministries, governmental institutions, disabled people's organizations and other organizations addressing issues relating to disability must be enhanced.

Under point 3 Action Programme Objectives / Chapter 5. Objectives Work and Employment – Measures 5.5 .it calls for: “Ensuring a network of professional support for the provision of vocational rehabilitation services: (...), ensuring a network of vocational rehabilitation service providers; (...) encouraging the development of employers' network for providing training (...); the inclusion of non- governmental and/or disabled people's organizations in the system of support services within the framework of supported employment.”

Policy provisions promoting persons-centred approach and individualised service provision Vocational rehabilitation is a public service and it covers all of the Slovenian territory at the level of the regional units of the Employment Service. The services are delivered by teams of several members, one of them is a medical doctor, others are occupational therapists, psychologists, social workers etc.

Vocational rehabilitation is provided through different services, which include: motivating activities, employment assessment, psychosocial rehabilitation, vocational guidance, social skills development, job finding, work place analysis and accommodation, training, counselling in training and education, follow up professional support and supported employment.

Vocational rehabilitation is based on a rights oriented and active approach, with person centred planning (individual rehabilitation plan) and working towards constant improvement. Policy provisions on localised and accessible employment service provision.¹³²⁶

The vocational rehabilitation services are organized at the same regional level as the units of the Employment Service of Slovenia. Vocational rehabilitation in Slovenia is carried out as a public service within the network of public and private providers of vocational rehabilitation. All providers must conduct services according to a national recognized and verified program.

¹³²⁶ https://www.path-ways.eu/wp-content/uploads/country_report_si.pdf

From 2004, it is possible to get services for persons with disabilities in the form of supported employment. Approval by the Employment Service of Slovenia is required. On the basis of the Employment and Rehabilitation of persons with disabilities Act, the Public Guarantee, Maintenance and Disability Fund of the Republic of Slovenia has an obligation to pay supported employment services to persons with disabilities who have obtained decision on employability in supported employment and are employed in the open labour market.

Supported employment services can be offered for a maximum of 30 hours per month. Another possibility is to get supported employment services from the network of the vocational rehabilitation providers. Support could include expert and technical support, awareness raising activities/information activities, counselling, training, personal assistance, follow-up support at the workplace and assessment. A wage subsidy is also possible. The person has to be trained, motivated and must have an individual support plan. ¹³²⁷

Candidates are referred by the Employment Service of Slovenia, the key Slovenian labour market institution, to vocational rehabilitation programmes and can stay in the programmes up to 2 years. They can also be referred by employers, by the Pension and Disability Insurance Institute of Slovenia or in some case by third party. The legal ground for vocational rehabilitation in Slovenia is the Vocational Rehabilitation and Employment of Persons with Disabilities Act (2004) with its implementing regulations. Vocational rehabilitation is defined as the right of the persons with disabilities to certain vocational rehabilitation services specified in a rehabilitation plan.

All persons with disabilities assessed as level 2 or 3 can receive vocational rehabilitation and training. In order to empower and prepare candidates for work they receive various types of training and work experience and in different organizations, depending on what is most suitable for them.

In Slovenia there are some people with disabilities in self-employment but the estimated percentage in the population is rather low. Like any other job seekers, job seekers with disabilities can benefit from a national grand scheme for encouraging self-employment. If the criteria are met they are entitled to different types of support for people with disabilities (for themselves or for the people with disabilities they employ): wage subsidies up to 70%, compensation for adapting jobs including adaptation of premises, purchasing equipment and providing a specific training; exemption from payment of contributions for pension and disability insurance of employees with disabilities; bonuses for exceeding the quota and annual awards to employers for good practices.

Protections and privileges: ¹³²⁸

- Employees with disabilities are protected against dismissal (on the basis of the disability) as part of the anti-discrimination legislation.

¹³²⁷ Ibid. Pg. 5

¹³²⁸ https://www.path-ways.eu/wp-content/uploads/country_report_si.pdf

- Adaptation of the working hours can be part of the individual rehabilitation plan. There is a possibility of financial compensation for adapting jobs including adaptation of the premises and purchasing equipment, wage subsidy, supported employment services, award for exceeding the quota, and exemptions from tax and social security contributions (for employers).

There are social cooperatives in Slovenia but it is not clear how many people with disabilities are among the workforce.

The Vocational Rehabilitation and Employment of Persons with Disabilities Act defines sheltered work as the employment of persons with disabilities in a flexible working environment adapted to the needs and working capacities of employees who are not able to be employed in a regular job. The sheltered work sector is a network of specific centres across the country (just over 463 employees with disabilities in 43 Employment Centres in 2015). Workers have a labour contract which includes among general provisions also support, training and counselling according to the needs of the disabled employee. Employment centres are very much dependent on the quota system, because businesses, which do not employ enough persons with a disability, can buy out of that obligation by providing work to employment centres.¹³²⁹

Financial incentives for employers to recruit/retain persons with NCDs:

- wage subsidies for employers who hire people with disabilities (5% to 30% of the minimum wage in the open labour market, 30% to 70% in the sheltered employment; depending on the level of disability);
- payment of the workplace adaptation;
- payment of supported employment services;
- exceptions of tax and social contributions;
- award for exceeding the quota;
- annual award employers for good practices.

All non-financial incentives are aimed at all people with disabilities, for example supported employment services provided by the vocational rehabilitation providers, different training programmes, education etc. The duties of persons with NCDs are the same as the duties of all persons with disabilities. There are no obligations to undergo vocational rehabilitation or any others employment activation programmes before being eligible for disability benefits.

For obtaining the status of person with disabilities under the Vocational Rehabilitation and Employment of Persons with Disability Act, persons with disability can be required to actively participate in vocational rehabilitation programme/s.

According to the Vocational Rehabilitation and Employment of Persons with Disabilities Act, private and public companies and organizations with a work force of more than 20 employees must hire between 2% and 6 % of employees with disabilities, depending on the business branch. Employers who fail to meet the quota criteria are obliged to a monthly payment of 70% of the minimum wage for each person with disabilities that should be employed by the company. That money goes into a special Fund which in turn provides financial support and awards to employers, who exceed the quota.

¹³²⁹ Ibid. Pg. 6-7

The government has not adopted any specific policy and strategy or programme, regulation or act to promote employment only/specifically for persons with chronic diseases/disorders.

Employment rights of people with disabilities in Slovenia are not granted in one act that would serve as umbrella legislation for employment of persons with disabilities. The government has adopted several documents to promote employment persons with disability, regardless of the type of disability, thus also covering employment of people with chronic diseases/disorders.

Besides programmes for promoting employment of people with disabilities, there are other psychosocial programmes aimed at promoting inclusion and development on other life areas, but these programmes are not directly aimed at promoting employment of people with disabilities. The significance of those programmes lies in raising self-esteem and quality of life in general, which can in turn influence employment possibilities.

The target group is all people with disability (people with mental health, physical, intellectual and/or sensory impairments), regardless of the disability type. The strategies, legislation and programmes listed below are long-term oriented.

There are some (voluntary) programmes in companies, such as a special programme for return to work of blue-collar workers people with chronic illness in a company for freeway maintenance and toll collection (DARS).¹³³⁰

¹³³⁰ https://www.path-ways.eu/wp-content/uploads/country_report_si.pdf

Spain

We will start this chapter with an in-depth analysis of the current figures related to disabled children and adults residing in institutional care or community-based settings.

Long-term care in Spain is characterized by low intensity of residential care, high levels of informal care, and low level of community care.¹³³¹ Data from the largest and most recent survey on the situation of people with disabilities in Spain (EDA 2008)¹³³² estimated that 3.85 million people with disabilities reside in homes and around 269,000 people with disabilities live in institutions.

That is, although less than 7 % of Spanish people with disabilities live in institutions, in absolute numbers, almost 300,000 people live in institutions. Out of this total, 60.5 % are older than 80 years of age.¹³³³ Of the group living in institutions, 222,260 are over 65 years old and of these 162,894 are over 80 years old.

If we analyse separately those who live in residences for the elderly, in centres for people with disabilities, and in psychiatric or geriatric centres, the number of people with disabilities who live in an institution is almost 36,000 (0.9 % of that 3.85 million people with disabilities), and 91 % of them have intellectual disabilities, in contrast to approximately 216,000 people who live in institutions for the elderly, and approximately 17,000 people who live in psychiatric facilities.¹³³⁴ In absolute numbers, 20 % of people with intellectual disabilities live in an institution.¹³³⁵

The document “The right to independent life and its realization in Spain: a distant horizon for people with disabilities?”¹³³⁶ states that there is no updated data about the entire population with disabilities. There has not been a survey like AGE since 2008 but we can analyse the statistics of the System for Autonomy and Care for Dependency. In the report published on 31st

¹³³¹ Huete, A. (dir). (2015). Observatorio Estatal de la Discapacidad. Institucionalización de las personas con discapacidad en España. Madrid: Observatorio Estatal de la Discapacidad. 2015.

Available at:

<https://observatoriodeladiscapacidad.info/attachments/article/65/ESTUDIO%20INSTITUCIONALIZACION%20PCD.pdf>.

¹³³² Instituto Nacional de Estadística (2008). Encuesta de Discapacidad, Autonomía personal y situaciones de Dependencia (EDAD). Available at: http://sid.usal.es/estadisticas_edad2008.asp.

¹³³³ Huete, A. (dir). (2015). Observatorio Estatal de la Discapacidad. Institucionalización de las personas con discapacidad en España. Madrid: Observatorio Estatal de la Discapacidad. 2015.

Available at:

<https://observatoriodeladiscapacidad.info/attachments/article/65/ESTUDIO%20INSTITUCIONALIZACION%20PCD.pdf>.

¹³³⁴ Huete, A. (dir). (2015). Observatorio Estatal de la Discapacidad. Institucionalización de las personas con discapacidad en España. Madrid: Observatorio Estatal de la Discapacidad. 2015.

Available at:

<https://observatoriodeladiscapacidad.info/attachments/article/65/ESTUDIO%20INSTITUCIONALIZACION%20PCD.pdf>.

¹³³⁵ Verdugo, M.A., Navas, P., Martínez, S., & Sainz, F. (2016). Todos somos todos. Derechos y calidad de vida de las personas con discapacidad intelectual y mayores necesidades de apoyo. Informe Ejecutivo. Available at: <http://www.plenainclusion.org/sites/default/files/30-11-16-todossomostodos-informeejecutivo.pdf>.

¹³³⁶ Alonso Parreño, M. A. (2015). El derecho a la vida independiente y su realización en España: ¿Un horizonte lejano para las personas con discapacidad?. Available at:

<http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

January 2019¹³³⁷ one notes that of the 1,057,190 beneficiaries of the benefit system, 166,658 (12.58 %) lived in an institution. In previous years the figures were as follows:

Percentage of people living in institutions:

Date	People living in institutions	Total beneficiaries	Percentage
December 31, 2010 ¹³³⁸	119,253	654,499	15.27 %
December 31, 2011 ¹³³⁹	122,040	741,713	13.30 %
December 31, 2012 ¹³⁴⁰	125,792	764,969	13.10 %
December 31, 2013 ¹³⁴¹	130,424	753,842	13.80 %
December 31, 2014 ¹³⁴²	135,346	745,720	14.55 %
December 31, 2015 ¹³⁴³	148,382	796,109	14.87 %
December 31, 2016 ¹³⁴⁴	151,719	865,564	14.19 %
December 31, 2017 ¹³⁴⁵	157,174	954,831	13.34 %
December 31, 2018 ¹³⁴⁶	166,579	1,054,275	12.61 %

¹³³⁷ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 31 de enero de 2019, <http://www.imerso.es/InterPresent1/groups/imerso/documents/binario/estsisaad20190131.pdf>.

¹³³⁸ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2010, <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20101201.pdf>.

¹³³⁹ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2011 : <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20111201.pdf>.

¹³⁴⁰ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2012 : http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/im_070847.pdf.

¹³⁴¹ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2013 : http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/im_082047.pdf.

¹³⁴² Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2014: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20141231.pdf>.

¹³⁴³ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2015: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20151231.pdf>.

¹³⁴⁴ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2016: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20161231.pdf>.

¹³⁴⁵ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2017: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20171231.pdf>.

¹³⁴⁶ Instituto de Mayores y Servicios Sociales (Imerso), Información Estadística del Sistema para la Autonomía y Atención a la Dependencia, Situación a 1 de diciembre de 2018: <http://www.imerso.es/InterPresent2/groups/imerso/documents/binario/estsisaad20181231.pdf>.

That is to say, the trend is to slightly reduce the number of places in institutions. And (the report states) that the authorities know that the waiting lists to obtain places in institutions are still very long. We do not know the ages of the people who occupy those places in residences.

The System for Personal Autonomy and Care for Dependency offers the same range of services to octogenarian people, and to minors and young people who are just beginning their lives. The type of benefit is not broken down by age or type of disability. We also do not know if it is a person with disabilities who applies for a place in a residence or their legal representatives, when they are minors or are legally incapacitated, nor how many cases involve involuntary placement (Article 763 of the Civil Procedure Act).¹³⁴⁷ Yet, according to data included in the following table, whereas at-home services (e.g. telecare, home help) and some financial aid linked to services (Economic benefit linked to service) have increased, the economic benefits aimed at families have experienced a significant reduction. In some instances, the reduction of economic aids associated to the Spanish financial crisis could help explain those changes.

Beneficiaries and types of services (years 2013-2019) ¹³⁴⁸

	2013	2014	2015	2016	2017	2018	2019
Beneficiaries	753,842	745,720	760,109	856.56	954,831	1,054,27	1,057,19
Prevention Dependence and Promotion of Personal Autonomy	2.2	2.5	3.0	3.6	3.9	4.0	4.0
Telecare	12.7	12.4	14.1	15.4	15.8	17.0	17.0
Home help	12.8	14.3	14.8	16.0	16.5	17.9	17.9
Day / Night Centres	13.8	14.6	14.9	14.2	13.3	12.6	12.6
Residential Care (Institutions)	7.04	7.9	8.5	8.0	7.7	7.2	7.2
Economic benefit linked to service	7.6	7.9	8.4	8.5	9.4	10.0	10.0
Economic benefit for Family Care	43.2	40.3	36.1	33.8	32.7	30.8	30.8
Economic benefit for personal assistant	0.2	0.2	0.3	0.5	0.6	0.5	0.5

It also seems that these residences are institutions with a medical model of service delivery approach. The 2008 INE survey revealed that people had very little capacity to decide on their daily lives (for example, the percentage of those who could decide when to get up and when

¹³⁴⁷ Alonso Parreño, M. A. (2015). El derecho a la vida independiente y su realización en España: ¿Un horizonte lejano para las personas con discapacidad? Available at: <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

¹³⁴⁸ Developed with Data obtained from IMSERSO available at: http://www.imserso.es/imserso_01/documentacion/estadisticas/info_d/estadisticas/est_inf/inf_gp/inde x.htm

to go to bed, what to eat and when and with whom to share his or her room was very low).¹³⁴⁹ Each autonomous community has its own accessibility laws that contain general principles, objectives and definitions on what accessible housing is. The technical norms are regulated by national laws.

On 29 November 2018, the Plenary of the General Council of the Judiciary approved a report that endorses the draft law prepared by the Ministry of Justice to reform civil and procedural legislation on disability issues. The purpose is to adapt this legislation to the rights set forth in the Convention and, more specifically, in Article 12, which states that persons with disabilities have full legal capacity, and obliges States to implement appropriate measures that allow people with disability, having access to the support necessary in each case to fully exercise their legal capacity. It is expected that this draft will have positive consequences for the right to choose who and where to live.¹³⁵⁰

According to the Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU¹³⁵¹ Spain has a broad variety of institutional services for people with disabilities: Sheltered housing, care homes, group homes, and day centres. It also has a broad variety of community-based services for people with disabilities: In-home, Day care centres, Residential, Foster care, Family support/respite care, Personal assistance, Direct payments/personal budget/individual budget, Peer support/counselling, Befriending.

As the document states, concerning the level of user control of services, low levels of autonomy are found in relation to foster care in Spain where children seem to have little control over decisions relating to the family in which they will be placed.¹³⁵² Also, persons with disabilities who receive personal budgets and cash payments are earmarked for particular types of services or for services authorized by the governments from the autonomous communities.

Community-based services are typically funded by municipalities, drawing on funds they receive from the State, although in some cases, users are asked to contribute directly to funding services, including day care centres and in-home support.¹³⁵³

¹³⁴⁹ Alonso Parreño, M. A. (2015). El derecho a la vida independiente y su realización en España: ¿Un horizonte lejano para las personas con discapacidad?. Available at: <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

¹³⁵⁰ DOTCOM: the Disability Online Tool of the Commission (Spain). Available at: https://www.disability-europe.net/dotcom?!%5B%5D=31&t%5B%5D=23&t%5B%5D=24&t%5B%5D=25&t%5B%5D=26&t%5B%5D=27&t%5B%5D=28&t%5B%5D=29&t%5B%5D=30&view_type=list.

¹³⁵¹ FRA (2017). Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU November 2017. Available at: https://fra.europa.eu/sites/default/files/fra_uploads/2017-10-independent-living-mapping-paper_en.pdf.

¹³⁵² FRA (2017). Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU November 2017. Available at: https://fra.europa.eu/sites/default/files/fra_uploads/2017-10-independent-living-mapping-paper_en.pdf.

¹³⁵³ FRA (2017). Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU November 2017. Available at: https://fra.europa.eu/sites/default/files/fra_uploads/2017-10-independent-living-mapping-paper_en.pdf.

There is a trend, although not at a very rapid pace, to increase the number of places of residence in institutions.¹³⁵⁴ In 2011, the UN Committee on the Rights of Persons with Disabilities expressed their concern at the lack of resources and services to guarantee the right to live independently and be included in the community.¹³⁵⁵

This is still true in Spain. The CERMI (Spanish Committee of Representatives of People with Disabilities) published its annual report in April 2017 on the compliance of our country with the UN Convention on the rights of persons with disabilities during 2016.¹³⁵⁶ Here, CERMI argues that in relation to Article 19: Right to live independently and to be included in the community, the lack of resources and services is worrisome, particularly in rural areas where placement in residential facilities is the only possibility. On the other hand, there is concern about the restriction of the scope of aid for personal autonomy both in relation to people with disabilities who are eligible, as well as in the field of activity for which personal assistance can be utilized (only education and work).¹³⁵⁷

The right to choose where and with whom to live requires physical conditions of the homes that make it possible. Most people in Spain live in multi-unit housing or apartment buildings, and there are several laws applicable to these living arrangements, both public and private properties. The owner or the landlord is responsible for meeting the requirements for an accessible building. There is funding support available for different adaptations and removal of barriers that can be requested by disabled people to adapt their houses, or by a community of owners if additional adaptations (e.g. elevators, ramps, etc.) are required.¹³⁵⁸

Concerning money invested, we do not have specific information, because, as mentioned earlier, Spain has a very complex and disperse system of services and support, and data are not disaggregated.¹³⁵⁹ There is money available at national and regional level to make housing accessible.

Spain is a decentralized country. There are 17 Autonomous Communities (CCAA). The Autonomous Communities have exercised their competences in social assistance in very unequal and uncoordinated ways. That means that, in Spain, there are 18 systems for social services (17

¹³⁵⁴ <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

¹³⁵⁵ Consideration of reports submitted by States parties under Article 35 of the Convention. Concluding observations of the Committee on the Rights of Persons with Disabilities (September 2011): <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPrICAqhKb7yhslxq2MulDp%2FqMKQ6SGOn0%2FNZ5trZrfgNmKdTjE%2FScMKF96xMrtyzhDx7aguCpqdK4xQVGCY502yRGHBFyeVZXNw00SiVNraxD5auFDv%2FVv2m>.

¹³⁵⁶ CERMI (2017). Derechos Humanos y Discapacidad. Informe España 2017. Available at: https://www.cermi.es/sites/default/files/docs/colecciones/Informe%202017%201_0.pdf.

¹³⁵⁷ CERMI (2017). Derechos Humanos y Discapacidad. Informe España 2017. Available at: https://www.cermi.es/sites/default/files/docs/colecciones/Informe%202017%201_0.pdf.

¹³⁵⁸ DOTCOM: the Disability Online Tool of the Commission (Spain). Available at: https://www.disability-europe.net/dotcom?!%5B%5D=31&t%5B%5D=23&t%5B%5D=24&t%5B%5D=25&t%5B%5D=26&t%5B%5D=27&t%5B%5D=28&t%5B%5D=29&t%5B%5D=30&view_type=list.

¹³⁵⁹ Alonso Parreño, M. A. (2015). El derecho a la vida independiente y su realización en España: ¿Un horizonte lejano para las personas con discapacidad?. Available at: <http://semanal.cermi.es/noticia/opinion-derecho-vida-independiente-horizonte-lejano-maria-jose-alonso-parreno.aspx>.

run by the CCAA and an additional one run by the Ministry of Health, Social Services and Equality (MHSSE) (Ministerio de Sanidad, Servicios Sociales e Igualdad, MSSSI) for the

Autonomous Cities of Ceuta and Melilla. The CCAA Social Services are financed by the CCAA (although there might be contributions of the users). In addition, there is the Social Security which covers health services and cash payments for retirement, unemployment, disability, under certain conditions, and certain family situations.

Social Security has the same rules in all the Spanish territory. The Social Security is financed by the national administration (although there are contributions of working citizens and their employers). Finally, there is the System for the Autonomy and the Attention to Dependency (SAAD) created in 2007. The SAAD was originally intended to cover dependency situations of people 80 years old or more. Later, people with disabilities of all ages were covered, but the SAAD framework has not the spirit of the UN Convention on the Rights of Persons with Disabilities, although it was designed in parallel to the Convention.

The SAAD could have been included in the Social Security, but it was decided by the Government first, and the Parliament later, not to do so. Therefore, it is a universal system but managed by a Territorial Board in which there are representatives of both the national administration and the CCAA. The town halls also have certain competences when they are big enough. There are national, regional and local level laws. The result is extremely complex. The SAAD is financed by both the national administration and the CCAA. The SAAD services and cash payments are integrated in the CCAA social services and users pay part of the cost whether for all or for some of the services, in an amount that is different in each Autonomous Community, sometimes reaching more than 90 % of the cost. Therefore, it is impossible to give a complete and accurate picture of the Spanish situation.

As mentioned earlier, The CERMI (Spanish Committee of Representatives of People with Disabilities) has published its annual report in April 2017 on the compliance of our country with the UN Convention on the rights of persons with disabilities during 2016. In this regard, CERMI argues that in relation to Article 19: Right to live independently and to be included in the community, the lack of resources and services is worrisome, particularly in rural areas where placement in residential facilities is the only possibility. Also, there is concern about the restriction of the scope of aid for personal autonomy both in relation to people with disabilities who are eligible, as well as in the field of activity for which personal assistance can be utilized (only education and work).

The Associative Movement of Full Inclusion (Plena Inclusion; <http://www.plenainclusion.org/>), on people with intellectual disabilities, is committed to developing the following proposals as a framework for its actions concerning social inclusion:¹³⁶⁰

- Calling for the end of the model of segregated welfare services and promoting its transformation towards a model of supports and services based on the quality of life, full citizenship, adaptation to the needs of the person and inclusion in the community.

¹³⁶⁰ Plena Inclusión (2016). Posicionamiento de Plena inclusión sobre personas con discapacidad intelectual o del desarrollo con grandes necesidades de apoyo. Available at: <http://www.plenainclusion.org/informate/actualidad/noticias/2016/posicionamiento-de-plena-inclusion-sobre-personas-con>.

- Implementing a strict monitoring of compliance with the basic rights established by the UN Convention of rights, developing actions of social complaints and demand of dignified living conditions for all.
- Support families so that all their members can develop their life goals, promoting among them an active role in the vindication of these supports.
- Work with the environment to advance in the coordination and training of a social, health, educational, justice. ... network centred on the person and with technical and ethical competences that ensure good support.
- Promote public policies that favour inclusion and exercise of the rights of all persons and their families.
- Demand the development of systems to collect data on the population with the most significant disabilities or, at least, guarantee that the reality of these people is reflected in the different general and specific surveys on disability.

Ensure that all models and proposals for full inclusion include people with great support needs and their families.¹³⁶¹

Many projects in Spain are carried out by representative entities of people with disabilities as well as other vulnerable groups, thanks to the subsidies granted to 0.7 % of the IRPF (Income Tax Physical Persons). These subsidies are intended to carry out programs to meet social interest purposes. For example, in the 2017 call the total number of beneficiary entities was 2,000, with 5,000 projects financed. Since the 2017 call, 20% of the funds go to eligible activities at the state level and 80 % to the CCAA to subsidize social assistance programs.

For example, for the 2018 call, there is a total of EUR 49,282,767 for state subsidies and EUR 202,688,592.66 for regional grants. In February 2018 the resolution of the call corresponding to the IRPF of 2017 was published. This resolution includes aid for programs of dissemination, awareness and empowerment of people with comprehensive health care needs and grants have been granted for associations of people with physical disabilities, intellectual disabilities, guardianship foundations.

There are also programs to attend to these groups or to carry out investigations in this regard. Half of the state actions receive amounts of less than EUR 40,000 with 12 % of regional projects receiving amounts of less than EUR 10,000. The Table below includes some of the projects funded by the Spanish government throughout the subsidies granted to 0.7 % of the IRPF.

Entity	Program	Amount
Fundacion Cruz Blanca	"We are". Society awareness and empowerment program for dependent, elderly and disabled people)	8.000,00
Confederacion Plena Inclusión España Full Inclusion Confederation - Spain	Social awareness and empowerment for the rights of people with intellectual of developmental disability	125.000,00
CNSE-Confederacion Estatal De Personas Sordas CNSE-State Confederation of Deaf People	Vidasor- Video Assistance and Accompaniment Service for Deaf Seniors	30.374,00
Federacion Nacional Aspaym (Asociación De Paraplejicos Y Grandes Discapacitados Fisicos) Association for People with Spinal Cord Injury (ASPAYM)	Digital Platform for Affordable Housing Management throughout the National Territory	16.000,00
Federacion Nacional Aspaym (Asociación De Paraplejicos Y Grandes Discapacitados Fisicos) Association for People with Spinal Cord Injury (ASPAYM)	Comprehensive care for people with spinal cord injury in accessibility and support products for their social inclusion	32.000,00

¹³⁶¹ Plena Inclusión (2016). Posicionamiento de Plena inclusión sobre personas con discapacidad intelectual o del desarrollo con grandes necesidades de apoyo. Available at :<http://www.plenainclusion.org/informate/actualidad/noticias/2016/posicionamiento-de-plena-inclusion-sobre-personas-con>.

Confederación española de personas con discapacidad física y orgánica Spanish Confederation of People with Physical and Organic Disability	State strategic program of temporary housing services	95.000,00
Confederación Plena Inclusión España Full Inclusion Confederation - Spain	Applied research for the implementation of services focused on people with intellectual or developmental disabilities and their families	550.000,00
Federación Española de Daño Cerebral Spanish Federation of Brain Injury	Social plasticity DCA: Action for the reconstruction of new projects of dignified life and inclusion of people with ACD in the community	20.000,00
Plataforma Representativa Estatal De Personas Con Discapacidad Fisica State Representative Platform for People with Physical Disabilities	State observatory of personal assistance and independent living	60.000,00
Provivienda	Collaboration in health protection policies through the promotion of decent housing	80.000,00
Confederación española de personas con discapacidad física y orgánica Spanish Confederation of People with Physical and Organic Disability	Comprehensive care program for people in centres dependent on IMSERSO through support services for independent living	480.7000,00
Federación Nacional De Asociaciones ALCER (Asociación Para La Ayuda Contra Las Enfermedades Del Riñón) National Federation of Associations ALCER (Association for Help IN Kidney Diseases)	Promotion and training of volunteers for their intervention in the assisted floors program of the National Federation ALCER	7.000,00

One can therefore note a substantial amount of civil society organisations and NGOs in Spain who fill in the void of much needed work in the inclusivity and inclusive operations related to persons with disability. Some examples worth noting are:

AIES (Spain). Its Mission and activities¹³⁶² fall within the scope of this research. It was set up in 1997 by people coming from other NGO's working in the field of disability. Its members gathered more than 25 years of expertise in the social arena and they played important roles at national and international level being the motor of several initiatives in the field of Independent Living, violence and gender issues. They decided to focus exclusively on these three topics in the belief that research has been carried out by disabled women and men themselves in very few occasions. This non-governmental, non-profit, organization, albeit based in Spain, works at an international level. They consider themselves as part of the international Independent Living and Disability Rights Movement. It is 100% run, controlled and represented by disabled people.

The Carmen Pardo-Valcarce Foundation (FCPV)¹³⁶³ The Foundation has been working for the rights of people with intellectual disabilities and their participation in society. Training, employment,

¹³⁶² https://www.independentliving.org/donet/10_asoc_iniciativas_y_estudios_sociales.html

¹³⁶³ <http://www.alapar.org/en/>

integration into the labour market, sport, leisure, clinical and psychological support individual follow-ups, innovation, research and independence allow us to close the loop surrounding the labour force and social participation of people with intellectual disabilities. In 2008, the United Nations included the Foundation in its Business Guide, a list of eighty-five of the world's most reliable Non-Governmental Organisations to form alliances with companies.

Educational Platform Private Foundation (Fundació Privada Plataforma Educativa). This Foundation is a group of social entities, created in 1994 and with 20 years of experience. Over 500 professionals from multiple disciplines work together to promote the quality of life of individuals and groups at risk of social exclusion. The main fields of work are disabilities, infancy, community work, training, labour insertion and cooperation. Educational Platform works with and for people with intellectual disabilities to promote their inclusion and their level of autonomy from an integrated and individualized perspective.¹³⁶⁴

Grup Fundació Ramon Noguera (Grup FRN). This Foundation is a non-profit group of entities based in Girona which aims to guarantee the quality of life of people with intellectual disabilities and their families. The Group consists of three Foundations: Fundació Ramon Noguera (FRN), Fundació Mas Xirgu (FMX) and Fundació Montilivi (FM). Cross services are led and executed by FRN. This entity is the central axis of the Group. FMX is an entity whose objective is the social and labour integration of adults with intellectual disabilities by means of offering a job position in a Special Employment Centre or in a conventional workplace. FM is an entity whose objective is to manage centres and services for adults with intellectual disabilities and children with development disorders.¹³⁶⁵

The Espurna Foundation is also dedicated to the social and labour inclusion of people with intellectual disability.¹³⁶⁶ Espurna focuses her philosophy on the complete development of the person with disabilities. This development starts from the basis that by enhancing capacities, we reduce or reduce disabilities.

These, and other organisations work on public-private partnerships in this field. Other private projects have been implemented in this regard. For example, Fundación Pilares (2017),¹³⁶⁷ a private and NGO, is developing a project for people with disabilities and the elderly to live in their community. The first results of the evaluation (2014-2015) show, among others, improvements in the quality of life, well-being and satisfaction of both the people served and their families' caregivers.

Pallisera et al. (2018)¹³⁶⁸ conducted a qualitative research study on the situation of people with intellectual disabilities with respect to their right to independent living. The authors analyse the

¹³⁶⁴ <http://www.plataformaeducativa.org/portal/>

¹³⁶⁵ <https://grupfrn.cat/>

¹³⁶⁶ <http://www.espurna.org/>

¹³⁶⁷ Rodríguez Rodríguez, P., Ramos Feijóo, C., García Mendoza, A., Dabbagh Rollán, V.O., Mirete Valmala, C., & Castejón Villarejo, P. (2017). La atención en domicilios y comunidad a personas con discapacidad y personas mayores. Guía de innovación según el Modelo AICP. Madrid: Fundación Pilares. Available at: <http://www.fundacionpilares.org/docs/publicaciones/fpilares-guia02-domicilios-comunidad-2017.pdf>.

¹³⁶⁸ Pallisera, M. et al. (2018): "Retos para la vida independiente de las personas con discapacidad intelectual. Un estudio basado en sus opiniones, las de sus familias y las de los profesionales". *Revista Española de Discapacidad*, 6 (1): 7-29. doi: 10.5569/2340-5104.06.01.01. Available at: https://www.cedd.net/redis/index.php/redis/article/view/370/pdf_99.

barriers, supports and challenges that affect the exercise of this right, through 10 focus groups and 22 individual interviews to people with intellectual disabilities, and 5 focus groups with families and 33 individual interviews with professionals. The results of the research highlight the need to guarantee the universality of the right to independent life (it is a right and not a privilege), offer personalised quality support and develop training and awareness-raising actions on rights with the different actors involved. Navas et al. (2017)¹³⁶⁹ published a research on Rights and quality of life of individuals with intellectual disability and extensive support needs. They conclude that disparities observed indicate the urgency of improving the knowledge about the living conditions of people with more significant ID and drive better practices in the provision of supports.

In 2017, the UNCRPD¹³⁷⁰ asked Spain to provide information on efforts, including legislative reforms, to ensure that laws, policies and procedures, mainly those related to the recognition and identification of disability, including the Personal Autonomy Promotion Act, employ a human rights-based approach to disability, and to review the requirements for recognition of dependency and the system for evaluating it in order to bring them into line with the Convention. They also requested Spain describe in detail the funding, the amount of resources used by Autonomous Communities and the proposed measures for making services and economic benefits for personal care available more quickly for accredited persons, making these available to more persons in need of them and guaranteeing equal coverage in all Autonomous Communities irrespective of the place of residence of the persons with disabilities. In addition, Spain should indicate how the generalized system of co-payment by individuals for support services is regulated, and what happens to persons with disabilities who are unable to provide the requisite contribution. Finally, to confirm whether the elimination of co-payment in all Autonomous Communities is envisaged.

The UNCRPD asked as well to explain the measure to guarantee nationwide the recognition of the right of persons with disabilities to choose their place of residence and have access to a range of social services, community support and other services for daily living, including personal assistance on the basis of individual requirements, rather than in pre-determined quantities. Also, to indicate whether it is intended to regulate personal assistance and whether there is any distinction between that system and that of the caretaker.¹³⁷¹

To answer these questions, the report presented by Spain in 2018 on the follow-up of the actions that are being carried out regarding the safeguarding of the rights of persons with disabilities stated in the CRPD, some actions that are being carried out.¹³⁷² For example:

¹³⁶⁹ Navas Macho, P., Verdugo Alonso, M.A., Martínez Torres, S., Sainz Modinos, F., & Aza Hernández, A. (2017). Derechos y calidad de vida en personas con discapacidad intelectual y mayores necesidades de apoyo [Rights and quality of life of individuals with intellectual disability and extensive support needs]. *Siglo Cero*, 48 (4), 7-66. Available at: <http://revistas.usal.es/index.php/0210-1696/article/download/scero2017484766/18532>.

¹³⁷⁰ UN CRPD (2017). List of issues prior to the submission of the combined second and third periodic reports of Spain. Available at: <https://documents->

¹³⁷¹ UN. CRPD. (2017). List of issues prior to the submission of the combined second and third periodic reports of Spain. Available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/107/99/PDF/G1710799.pdf?OpenElement>.

¹³⁷² UN CRPD (2018). Informes periódicos segundo y tercero combinados que España debía presentar en 2018 en virtud del artículo 35 de la Convención. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhslxq2MulDp%2fqMKQ6SGOn0%2fM4rP4Sn04ITU2hnYsbysiJg%2fxfpTWmXHihRhuR7jOTgZj9F0rGUx5uDEEPk8d0jgsBRMI07efi1K3EB%2f1Pr1%2b1>.

- (1) Start-up of a working group to analyse the provision of personal assistance and to propose the modification of the provision of care in the environment and / or the provision of home help.
- (2) Proposal to develop a new type of economic benefit aimed at hiring professional caregiver for people who are currently being treated at home and who either do not have family members or who do not have the availability to take care of themselves living with the beneficiary. It would therefore be a new economic benefit that would allow the dependent to be attended at home, under parameters of professionalism and public control.

It also reports on existing initiatives such as:¹³⁷³

- (1) The one developed in the Community of Madrid. Different types of assistance resources are combined in attention to the physical, family and social situation of the person with disability and the needs that this has derived from their disability and / or dependency.
- (2) Specific resources to avoid the institutionalization of people with disabilities and facilitate their permanence in their community environment. Among them: places in pensions for people with mental illness; the sheltered flats for people with mental illness as well as for people with disabilities; transition flats for independent living; telecare and home help or community social care teams in the case of people with mental illness living in their home.
- (3) The Community of Madrid has an Office of Independent Living (OVI), through which a network of personal assistants is organized to provide assistance and support to people with physical disabilities in situations of dependency and great motivation to have an independent life. Currently serving 72 users (50 % men and 50 % women) who develop an active educational or work life. The work of these personal assistants focuses on assistance and support, following the guidelines and instructions of the user with disabilities, related to facilitating and making possible this training or work activity. Other functions from those who perform home help or personal care.
- (4) In the Autonomous Community of Castile and Leon, there are, among many others, these two ways of promoting independent life: the promotion of personal assistance and the development of a network of integrated housing in the community, all of this as a complement to numerous actions to promote employment among people with disabilities.

The Concluding Observations from the Committee on the above-mentioned report were issued following Spain's hearing scheduled for March 2019.

The consideration from the CRPD of reports submitted by States parties under Article 35 of the Convention and the Concluding observations of the Committee concerning Living independently and being included in the community (Article 19) in Spain, reflect that the Committee was concerned at the lack of resources and services to guarantee the right to live

¹³⁷³ UN CRPD (2018). Informes periódicos segundo y tercero combinados que España debía presentar en 2018 en virtud del artículo 35 de la Convención. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsIxq2MulDp%2fqMKQ6SGOn0%2fM4rP4Sn04ITU2hnYsbysiJg%2fxfpTWmXHihRhuR7jOTgZj9F0rGUx5uDEEPk8d0jgsBRMI07efi1K3EB%2f1Pr1%2b1>.

independently and to be included in the community, in particular in rural areas. It was further concerned that the choice of residence of persons with disabilities was limited by the availability of the necessary services, and that those living in residential institutions are reported to have no alternative to institutionalization. Finally, the Committee was concerned about linking the eligibility of social services to a specific grade of disability. This is still true in Spain.

The Committee encourages Spain to ensure that an adequate level of funding is made available or effectively enable persons with disabilities: to enjoy the freedom to choose their residence on an equal basis with others; to access a full range of in-home, residential and other community services for daily life, including personal assistance; and to also enjoy reasonable accommodation so as to better integrate into their communities.

The Committee is concerned that the law for the promotion of autonomy limits the resources to hire personal assistants only to those persons who have level three disabilities and only for education and work.

The Committee encourages the State to expand resources for personal assistants to all persons with disabilities in accordance with their requirements.

The Committee takes note of the legal regime allowing the institutionalization of persons with disabilities, including persons with intellectual and psychosocial disabilities (“mental illness”). It is concerned at the reported trend of resorting to urgent measures of institutionalization which contain only ex post facto safeguards for the affected individuals. It is equally concerned at the reported abuse of persons with disabilities who are institutionalized in residential centres or psychiatric hospitals.¹³⁷⁴

All the above needs to be taken within the broader perspective of educational initiatives for persons with disability in Spain. The legislative framework governing and guiding the Spanish education system comprises the Spanish Constitution (1978), the Organic Act on the Right to Education (LODE, 1978), the Organic Act on Education (LOE, 2006) and the Act on the Improvement of the Quality of Education 8/2013 of 9 December (LOMCE, 2013) which develops the principles and rights established in it. LOMCE modifies LOE in order to adapt it to the new context.¹³⁷⁵

The Spanish Constitution recognises the right to education as one of the essential rights that public powers must guarantee to every citizen.

The LOMCE offers¹³⁷⁶ the legal framework to provide and assure the right to education. The autonomous communities will be able to regulate the adaptation of this Act to their territories.

¹³⁷⁴ UN CRPD (2011). Consideration of reports submitted by States parties under Article 35 of the Convention. Concluding observations of the Committee on the Rights of Persons with Disabilities. Spain. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhslxq2MulDp%2FqMQ6SGOn0%2FNZ5trZrfgNmKdTjE%2FScMKF96xMrtyzhDx7aguCpqqK4xQVGCY502yRGHBFyeVZXNw00SiVNraxD5auFDv%2FVv2m>.

¹³⁷⁵ <https://www.european-agency.org/country-information/spain/legislation-and-policy>

¹³⁷⁶ At national level.

The Spanish education system, set up in accordance with the values of the Constitution and based on respect for the rights and liberties recognised therein, is inspired by the following principles:

- a) Quality education for all learners, regardless of their condition and circumstances.
- b) Equity that guarantees equal opportunities for full personal development through education, inclusion, rights and equality of opportunities that helps to overcome any kind of discrimination and universal access to education that acts as a compensating factor for personal, cultural, economic and social inequalities, with special emphasis on those derived from disabilities.
- c) The transmission and application of values that favour personal liberty, responsibility, democratic citizenship, solidarity, tolerance, equality, respect and justice and that also help to overcome any type of discrimination.¹³⁷⁷

The state is responsible for education and for offering all pupils free compulsory education from 4 until 16 years of age. The stage from 4 to 6 is not compulsory, while compulsory education goes from 6 to 16 years of age. The Ministry of Education, Culture and Sport is responsible for central administration.

Schools are classified as public schools, private schools and publicly-funded private schools. Public schools are those owned by a public administration. Private schools are those owned by a private person or legal entity. Publicly-funded private schools are private schools which are under the system of legally-established agreements. The provision of the public education service is carried out in public and publicly-funded private schools. Schools have got pedagogic, organisational and management autonomy within the current legislation. They have the autonomy to draw up, approve and execute an education project and a management project, as well as the school's organisational and running procedures.

Provisions for learners with special educational needs are governed by principles of normalisation and inclusion and ensure non-discrimination and real equality in access to the education system and continued attendance, allowing flexibility in the different stages of their education when necessary. The schooling of these learners in special schools or units, which may be extended to the age of 21, will only take place when their needs cannot be met by the special needs provisions available in mainstream schools.

Royal Decree 696/1995, of 28 April,¹³⁷⁸ arranges the education of pupils with special educational needs and establishes the conditions for educational provision for this population. These pupils are educated in mainstream schools and with mainstream curricula; only when it is objectively established that the needs of these pupils cannot be properly met in a mainstream school, is it proposed that they be educated in special schools.

¹³⁷⁷ Act on the Improvement of the Quality of Education 8/2013 of 9 December. Preliminary Title, Chapter I. Principles and Aims of Education. Article 1. Principles.

¹³⁷⁸ Updated with Royal Decree 1/2013, of 29 November, chapter IV

The different stages constituting the Spanish education system are outlined below.

Pre-primary education (0–6 years)

It is organised into two cycles of three years each. The first one (0–3 years) is on a voluntary basis for families, where the purpose is to give educational assistance and attention to early childhood education.

The second one (3–6 years) is voluntary, free and constitutes the first level of school education. Even though it is voluntary, educational authorities are obliged to offer enough places at this level. If there are not enough public places, they must reach agreements with private schools to offer them.

Compulsory education

Basic, compulsory free education comprises primary education and compulsory secondary education, for learners aged 6 to 16 years. It lasts for ten years and is divided into two educational levels:

Primary education (6–12 years)

Comprises six academic years.

Compulsory secondary education (12–16 years)

Comprises four academic years organised into two cycles. The first comprises three academic years and the second, one academic year. Upon passing these two cycles, the pupils receive the Compulsory Secondary Education (CSE) Certificate.

General upper-secondary education level (Bachillerato)

This is a two-year non-compulsory education level, which complements compulsory secondary education. The CSE Certificate is a prerequisite for entering Bachillerato. The theoretical ages for commencement and completion are 16 and 18, respectively.

Specific vocational training

This is a non-compulsory education level. It prepares pupils to work in a specific professional field by providing them with an all-round and practical education that enables them to adapt to the changes affecting their trade, which may take place during their working lives.

There are three levels of specific vocational training:

Basic Vocational Training: It is a second chance for those students who did not get their CSE Certificate.

Intermediate Vocational Training: In order to access it, the student must have at least the CSE Certificate.

Advanced Vocational Training: In order to access it, the student must have at least the

Bachillerato certificate. ¹³⁷⁹

The total budget allocated to education in Spain comes from: public funds, which are provided by state, autonomous and local authorities; private funds, which are provided by families; and, to a lesser extent, private institutions. The public or private nature of the ultimate funding agent, rather than the recipient of the services, is what determines whether spending on education is considered public or private. Some 80% of education expenditure in Spain is financed through public funds, while the remaining 20% comes from private funds. In 2014, Spain devoted 4.39% of its gross domestic product to education. ¹³⁸⁰

Public funds earmarked to finance Spanish education are mainly provided by the Ministry of Education, Culture and Sport, as well as the education authorities of the corresponding autonomous communities. Other ministries and other local and regional authorities also provide funding. Regardless of the authority providing funding, public spending is not earmarked for public education only, but is also allocated to subsidise private establishments and finance learner scholarships and grants.

Education funding comes from the following sources:

- National budget, which includes the Ministry budget
- Autonomous communities.
- The Budget for Special Education covers the following items:

Staff expenses

Operational expenses

Furniture and inventoried equipment expenses

Expenses for alterations

Grants to non-governmental organisations

Grants to private schools with an educational co-operation with the Ministry

School canteens

Hostels located inside schools

Financial support for mainstream schools with inclusion of pupils with special educational needs

School transportation

New building improvement

Removing physical architectural barriers.

The autonomous communities finance special education in a similar way. As with the Organic Act on Education (LOE), the Act on the Improvement of the Quality of Education (LOMCE, 2013) focuses attention on learners with specific educational support needs. This concept covers learners who require additional educational support because of special educational needs, specific learning difficulties, attention deficit hyperactivity disorder, high intellectual capacity, late entry to the education system or due to personal circumstances or past school records. ¹³⁸¹

The LOMCE (2013) regulates and governs special education within general education and asserts the incorporation of special education into the mainstream system. It also highlights the concept of special educational needs (SEN). Pupils with SEN can attend mainstream or special

¹³⁷⁹ <https://www.european-agency.org/country-information/spain/legislation-and-policy>

¹³⁸⁰ According to the National Sheets on Education Budget in Europe 2014. Eurydice – Facts and Figures.

¹³⁸¹ <https://www.european-agency.org/country-information/spain/assessment-within-inclusive-education-systems>

schools. This Act also establishes that pupils with SEN should attend mainstream schools and programmes, by adapting such programmes to each pupil's individual capacities. Their schooling in special education units or establishments, or combined schooling, will only take place when pupils' needs cannot be met in mainstream schools. This situation will be periodically revised in order to promote, if possible, increased inclusion.

According to the LOMCE (2013), special education is understood as a combination of material and human resources available to the education system to meet the needs (whether temporary or permanent) that pupils may have. In this sense, the education system must have the necessary resources so that pupils with special educational needs may achieve the general goals set for all pupils. The principle of normalisation, with the aim of promoting school inclusion, underlies this Act and the Organic Act on Education.

The LOMCE stipulates that, in the case of pupils with special educational needs, the identification and evaluation of their needs will be carried out, as early as possible, by teams of professionals with different qualifications, and in the way education administrative authorities determine. These professionals will establish performance plans with regard to each pupil's educational needs. At the end of each year, the evaluation team will assess the extent to which the objectives set out in the plan have been achieved. This will facilitate the introduction of the necessary adaptations and changes in the intervention plans, including the most suitable type of schooling according to learners' educational needs, so as to facilitate, whenever possible, their access to a better inclusive system.

The education administrative authorities are responsible for the early childhood schooling of children with SEN and the development of programmes to facilitate schooling in primary and compulsory secondary education mainstream schools.

The education administrative authorities are also responsible for the schooling of learners with SEN after compulsory education, and for making the necessary adaptations of the exams, as stated by law, when required.¹³⁸²

But what about employment for persons with disabilities in Spain? There are a series of Special Employment Centres in Spain. There are almost 700,000 people working in these centres and get the opportunity to work for mainstream companies as subcontractors. This system allows disabled people to spend more time in non-sheltered employment and encourages them to make the move on a more permanent basis. The centres get bonuses on their social security contributions and many of those that work there find positions in the public sector.¹³⁸³

Support is also available for disabled workers who want to become self-employed. There are a number of organisations which help workers to create their own businesses. A case in point refers to ONCE. This is the Spanish organisation for the blind and other disabled persons and they offer advice in areas such as management and accounting. Training is also available for those who have been out of work for a long time and who want to find work or establish their own business. There are government incentives for those with mobility problems who wish to establish their own business and organisations such as ONCE are able to offer advice on this too.

¹³⁸² Ibid.

¹³⁸³ <http://www.expatsfocus.com/expatriate-spain-disability>

Another unusual example was published in a paper entitled 'Inclusion in the Workforce for Students with Intellectual Disabilities: A Case Study of a Spanish Postsecondary Education Program.'¹³⁸⁴ In this paper, one notes the efforts done by the Autonomous University of Madrid (UAM), which is the first Spanish university to provide training to young people with intellectual disabilities (ID) in the university environment. This qualifies them for inclusion in the workforce.

In this practice brief, there is a full description of the UAM-Prodis Patronage Chair program, a successful model used at Spanish universities within the European Higher Education convention framework, which addresses the inclusion and occupational training of young people with ID in order to help them obtain employment. The report reviews the special educational system for young people with ID in Spain. They report outcome data for students with ID who completed the program at UAM during its first four years of implementation. These outcomes indicate that the UAM-Prodis Patronage Chair program has become one of the main strategies to achieve independent living and community integration of people with ID through a postsecondary education option.¹³⁸⁵

Furthermore, aiming to boost open labour market inclusion, Spain increased progressively the scope of its Supported Employment Programme and introduced, for the first time, a legal definition in a country where employment of persons with high support needs in sheltered workshops is the norm.¹³⁸⁶

In Spain, national legislation has given authorisation for non-profit employment intermediation agencies to facilitate the integration of persons from disadvantaged groups in employment. There is a wide range of private organisation, to a large extent non-profit entities, that render specialised activation and training services. The services of entities are instrumental for political objectives related to the promotion of the employment of persons with disabilities.

Therefore, they receive funding from regional and national budget. There has been a reform in Spain that introduced an outcome-based allocation of funding for employment integration projects. This reform has an objective to enforce impact-oriented competition between service providers. The emphasis is placed on giving regional autonomy in delivering active labour market policies. There is a common national strategy for employment activation, but regions have a freedom to choose different measures and systems to achieve the common objectives.

Thus, placement and activation services are decentralised to regional level. However, local level activities remain dependant on the regional level. Decentralisation gives more flexibility to regional authorities, but this means that differences exist between regions. In order to create a connection between regions, a Strategy for Employment Activation has a provision setting up a best-practice programme, which is a means for transferring good practices between regions.¹³⁸⁷

Royal Decree No. 870/2007 provides a framework for supported employment as well as a general financial budget from the state to autonomous communities to support this employment scheme. The definition of supported employment in legislation emphasizes the employment in

¹³⁸⁴ <https://thinkcollege.net/resource/program-descriptions/inclusion-workforce-students-intellectual-disabilities-case-study>

¹³⁸⁵ Ibid.

¹³⁸⁶ The Royal Decree 870/2007 on Rules for Supported employment

¹³⁸⁷ https://www.path-ways.eu/wp-content/uploads/country_report_es.pdf

the open labour market.¹³⁸⁸ Regional governments are tasked to put in place measures facilitating the professional integration of persons with difficulties in entering the labour force, in line with the principles of supported employment.

Such measures are different across regions. For example, the Bureau of Employment in Diversity of Catalonia¹³⁸⁹ is the responsible agency for the allocation of “subsidies for the realization of comprehensive services for guidance, assistance and support for the inclusion of people with disabilities and/or mental illness”.¹³⁹⁰ This subsidy can last for 1 year for each participant. In addition, the Barcelona Provincial Council supports the Network of Specialised Employment Offices,¹³⁹¹ which is a network of 16 local employment offices specialised in the employment (re-integration) of persons with mental health conditions.

The offices handle the job placement task. In 2014, 393 people were put in employment through the network, with approximately half of them being placed in the open labour market jobs. When working with persons with mental health problems, some specialised employment intermediation entities follow the IPS methodology to supported employment. Catalonia, for instance, participated in the IPS programme led by the Dartmouth University in the US.

Protections and privileges:

- Greater flexibility and possibility to hire employers on temporary contracts and training contracts. In the time of economic crisis this gives more flexibility to employers. The maximum age for applying a training contract has been extended from 21 to 25 up to 31 years. Employers get a 100% deduction in their employer contributions for these types of contracts. The cost of training workers with these contracts is assumed by the state for companies with less than 50 workers.
- Under the Law 13/1982, employer is obliged to adopt appropriate measures, according to the needs of each specific situation in order to enable disabled people to have access to employment, to do a job, to advance in a profession and to undergo training, unless such measures would entail an excessive burden for the employer.
- The Law 51/2003 imposes a duty to provide reasonable accommodation. Employment support through Social enterprises or social cooperatives Under the Law 44/2007, cooperatives can take up the tasks of job placement intermediaries. Companies created by patients' initiatives are, however, limited in scope and difficult to operate in Spain. This is something to be developed.¹³⁹²

Sheltered work in Spain is provided through Special Employment Centres, where the majority of workforce is made up by persons with disabilities. These centres are regulated by the Royal Decree 2273/1985 and the Royal Decree 469/2006. Some sheltered centres are subcontracted by non-sheltered businesses, who can fulfil their quota requirements by outsourcing from sheltered workshops. Such centres are known as the “work enclaves” and are intended to encourage the transition to the open labour market. These enclaves are regulated by the Royal Decree 290/2004.

¹³⁸⁸ Ibid. Pg. 4.

¹³⁸⁹ Subdirecció General d'Ocupació en la Diversitat

¹³⁹⁰ Subvencions per a la realització dels serveis integrals d'orientació, acompanyament i suport a la inserció de les persones amb discapacitat i/o malaltia mental, SIOAS

¹³⁹¹ Oficines Tècniques Laborals, OTL

¹³⁹² https://www.path-ways.eu/wp-content/uploads/country_report_es.pdf

There are no additional benefits paid for participation in vocational rehabilitation and training programmes. However, there is flexibility in combining benefits with work. In Spain, a distinction is made between temporary and permanent disability. A temporary disability benefit is a daily allowance to cover the loss of income caused by a worker's illness, an accident or an occupational disease. The benefit can be paid for a period of 365 days (extendable by another 180 days) in a case of a non-work related illness or accident, and for a period of 6 months (renewable for another 6 months) in a case of an occupational disease.

Permanent disability benefits and rules on their compatibility with employment vary depending on the degree of disability:¹³⁹³

- Partial permanent disability benefit is paid when the worker's normal performance is impaired by 33% or more, but she/he can carry out the basic tasks of their normal job. This benefit is a lump-sum compensation made in a single payment in an amount that equals to 24 months of the base pension used to calculate the subsidy for the temporary disability from which the permanent disability is derived. It is compatible with any type of employment activity and income level.
- Total permanent disability benefit is paid when the worker cannot carry out basic tasks of the normal profession, but can do another job. The benefit consists of a lifetime monthly pension that, under exceptional circumstances, may be substituted for a lump-sum payment, when the beneficiary is under the age of 60. The benefit is compatible with the salary the worker may receive in the same or another company under a condition that the duties are not the same as those that led to the total permanent disability.
- Absolute permanent disability benefit is paid when a worker is completely disqualified from any profession. The benefit amounts to 100% of the base rate and is compatible with profit or non-profit activities that are in line with the individual's degree of disability and that do not represent a change in the ability to work for the purpose of reviews.
- Severe disability benefit is paid when a worker is completely disqualified from any profession and also requires assistance from another person to carry out daily basic activities. The benefit amount to 100% of the base rate and is compatible with profit or non-profit activities that are in line with the individual's degree of disability and that do not represent a change in the ability to work for the purpose of reviews.

The types of financial incentives and subsidies paid to employers with an aim of promoting the employment of persons in disadvantaged situation vary across autonomous regions. In general, employers can receive different financial benefits depending on the type of a contract offered to a person with a disability. Permanent contract:

- A benefit for covering the cost of social security costs per worker ranging from EUR 4,500 to EUR 6,300 per year for full-time contracts, depending on the severity of disability, age and sex. For part-time contracts the amount is based on agreed days of work;
- A subsidy of EUR 3,907 for hiring a person with a disability on full-time basis; For part-time contracts the amount is proportional to agreed days of work;

¹³⁹³ Ibid. Page 7.

- A deduction of EUR 6,000 euros from the full amount of the corporate tax per person, under a condition that the recruitment of a person with a disability leads to an increase of the average number of persons with disabilities in the labour force.
- A grant for job adaptation up to EUR 901.52. Temporary contracts (from 12 months to 3 years):
- A benefit for covering the cost of social security costs per worker ranging from EUR 3,500 to EUR 4,700 per year for full-time contracts, depending on the severity of disability, age and sex. For part-time contracts the amount proportional to the agreed working hours;
- A grant for job adaptation up to EUR 901.52. Training contract (from 6 months to 2 years):
- A 50% benefit for covering the cost of social security costs for graduates under a condition that 6 years have passed since the completion of their studies. ¹³⁹⁴

Apart from these financial benefits, under the Law 30/2007, preference in granting public contracts is given to companies that comply with the legal quota of 2% of people with disabilities in their workforce. Non-financial incentives for employers to recruit/retain persons with NCDs an example of the non-financial measures encouraging employers to recruit persons at risks of social exclusion can be seen in the activities of the Incorpora programme, supported by La Caixa Foundation. ¹³⁹⁵ The programme offers companies the opportunity to acquire a socially active attitude through the promotion of corporate social responsibility. Incorpora works in a close partnership with businesses and provides them with business advice and full support the recruitment and integration process. The emphasis is made on the advantages of hiring persons at risk of exclusion in terms of an improved company image, reduced absenteeism, retaining of talents, and a positive societal impact.

Job placement services to persons at the risk of exclusion from the labour market may be provided by non-profit organisations supporting these groups of people. For example, Parc Sanitari Sant Joan de Deu, headquartered in Sant Boi de Llobregat, ¹³⁹⁶ provides job placement services for people of working age with a mental health condition who are motivated to join the labour market but face difficulties in the integration process. Job placement services assist job-seekers in preparing job applications, looking for vacancies, providing guidance and creating a job search strategy. Jobseekers receive individualised support but can also participate in support groups, where they can share experiences with other service users.

Another example is the Adecco Foundation, a non-profit arm of the employment agency Adecco that is focused on people who for various reasons face difficulties in finding employment. For all users, the foundation provides access to a job vacancy database, allows registering CVs, and provides assistance in vocational training. In addition to this, it participates in research and development projects aimed at creating assistive technologies facilitating the employment of

¹³⁹⁴ https://www.path-ways.eu/wp-content/uploads/country_report_es.pdf

¹³⁹⁵ www.incorpora.org

¹³⁹⁶ <https://www.pssjd.org/>

persons with disabilities. The foundation has been created as a result of social responsibility assumed by Adecco. Job placement services targeted to specific needs of persons with specific health conditions may be rendered through organisations of such patients. ¹³⁹⁷

The Spanish Association against Cancer (AECC) has a job placement programme for persons with cancer who require employment support and are registered as jobseekers at the Employment Service of their Autonomous Community. The services are focused towards guidance, training and mediation through the development of personal aspects for the occupation, through the promotion and enhancement of individual skills, training, information and advice. In addition, awareness of entrepreneurship and society as a whole is intended to help facilitate the employment of those affected. ¹³⁹⁸

Various services offered to persons at the risk of exclusion from the labour market include:

- Pre-labour services (servicio prelaboral) are social care services to help people with severe mental conditions who are unable to directly access and integrate into work. For this reason they require a vocational rehabilitation process that prepares them for obtaining a job. It involves basic skills necessary for work as well as training for families. Pre-labour services are mainly offered by NGOs.
- Targeted legal, psychological, training advice and guidance – e.g. the Spanish Group of Cancer Patients (Grupo Español de Pacientes con Cáncer, GEPAC) offers its users services such as legal advice on matters relating to access to employment, education and training; psychological counselling; help in finding jobs and getting interviews; training and empowerment for socio-professional reintegration.
- Occupational rehabilitation services – e.g. Fundación Manantial's Centres for Occupational Rehabilitation develop occupational rehabilitation programmes aimed at helping persons with mental issues to acquire or regain skills needed for work integration. ¹³⁹⁹

¹³⁹⁷ <https://fundacionadecco.org/>

¹³⁹⁸ <https://www.vallhebron.com/en/list-of-organisations/spanish-association-against-cancer-aecc>

¹³⁹⁹ https://www.path-ways.eu/wp-content/uploads/country_report_es.pdf

Sweden

In Sweden accommodation with special service is offered to people with disabilities, who need more extensive support than what can be provided in ordinary housing.

Special accommodation for adults provided under the Law of special support and services for persons with certain disabilities (the Swedish acronym, LSS)¹⁴⁰⁰ is provided as housing with special service or other specially adapted housing for adults with certain kind of disabilities.¹⁴⁰¹

The municipality is responsible for arranging the special accommodation. Group residence and service housing are the most common forms. Group residence is a small-scale housing (for three to five persons) with staff around the clock.

Service housing consists of a number of apartments where the residents have access to shared service and permanent staff. Accommodation for children provided under LSS is provided as accommodation in family homes or in homes with special services for children or young people with certain kind of disabilities.

Special accommodation for adults provided under the Social Service Act (the Swedish acronym, SoL),¹⁴⁰² is provided in group residences with staff around the clock, similar to group residences provided under LSS. Special accommodation provided under SoL is foremost provided to people with psychiatric disabilities with extensive care and supervision needs that extend over much of the day.

Housing support provided under SoL¹⁴⁰³ is a personalized support to cope with daily life in the home, in the community or in contacts with authorities. The purpose of housing support is to give people with mental disabilities a better quality of life and security in everyday life and an independent life.

Personal assistance provided under the LSS¹⁴⁰⁴ can be granted to people with extensive and long-term disabilities who need support in their daily life. The purpose of personal assistance is to enable people with disabilities to live a life as others in the community.

One should now look at current related figures:¹⁴⁰⁵

¹⁴⁰⁰ Sweden, The Act on support and service for certain functional impairments, 1993:387 (lagen (1993:387) om stöd och service till vissa funktionshindrade (LSS), available at: www.notisum.se/rnp/sls/lag/19930387.HTM.

¹⁴⁰¹ Types of disabilities are intellectual disabilities, autism spectrum disorders and severe (multiple) disabilities.

¹⁴⁰² Sweden, The Social Security Act (Socialtjänstlagen, SOL), 2001: 453, available at: www.notisum.se/rnp/sls/lag/20010453.htm.

¹⁴⁰³ Sweden, The Social Security Act (Socialtjänstlagen, SOL), 2001: 453, available at: www.notisum.se/rnp/sls/lag/20010453.htm.

¹⁴⁰⁴ Sweden, The Act on support and service for certain functional impairments, 1993:387 (lagen (1993:387) om stöd och service till vissa funktionshindrade (LSS), available at: www.notisum.se/rnp/sls/lag/19930387.HTM.

¹⁴⁰⁵ The statistics presented in the table is retrieved from <https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20874/2018-2-18.pdf> and <https://www.forsakringskassan.se/statistik/funktions%C2%ADnedsattning/assistansersattning>.

TYPE OF SERVICE	Children (boy/girl)	Adults, (men/women)	Adults 65+ (men/women)	Total (figures from 2013/2014/2015)
Special accommodation/ Residential care provided under SoL (<i>Särskilt boende enl SoL</i>) ¹⁴⁰⁶	20 (15/5)	4 260 (2 500/ 1 760)		4 280 (4 100/ 4 100/ 4 100)
Special accommodation/ Residential care provided under LSS ¹⁴⁰⁷ (<i>Särskilt boende enl LSS</i>) ¹⁴⁰⁸	1 000 (630/370)	23 490 (13 750/ 9 740)	3620 (1950/ 1670)	Children 1 000 (1 100/ 1 030/ 1 000)
				Adults 27 110 (25 000/ 25 840/ 26 500)
Housing support (Boendestöd enl SoL) ¹⁴⁰⁹	190 (100/90)	22 310 (10 740/ 11 570)		22 500 (ca 19 000/ 20 000/ 21 500)
Personal assistance according to LSS ¹⁴¹⁰	1 310 (790/ 520)	2 560 (1 320/ 1 240)	720 (360/ 360)	4 590 (3900/ 4 090/ 4 300)
Personal assistance (assistance allowances from the Social insurance agency (SIA)) ¹⁴¹¹				15 691 (16 142/ 16 158/ 15 866)

The number of people with the special accommodation according to SoL has, for several years, been around 4 100 people, but in recent years there has been an increase to almost 4 300 people. If this is a trend break or a temporary change is not yet known.

Special accommodation with service for adults has increased over the past decade, and since 2013 it has increased by 8 %. Between 2015 and 2016, 1 916 new decisions were taken regarding special accommodation according to LSS, which corresponds to 8 % of all with decisions of special accommodation. However, special accommodation that has been granted to children and young people have decreased in number, although the decline has stopped in recent years. Since 2013, special accommodation for children has decreased by 10 %.

¹⁴⁰⁶ Sweden, The Social Security Act (Socialtjänstlagen, SOL), 2001: 453, available at: www.notisum.se/rnp/sls/lag/20010453.htm.

¹⁴⁰⁷ The Law regulating Support and Service to Persons with Certain Functional Disabilities (LSS).

¹⁴⁰⁸ Sweden, The Act on support and service for certain functional impairments, 1993:387 (lagen (1993:387) om stöd och service till vissa funktionshindrade (LSS)), available at: www.notisum.se/rnp/sls/lag/19930387.HTM.

¹⁴⁰⁹ Sweden, The Social Security Act (Socialtjänstlagen, SOL), 2001: 453, available at: www.notisum.se/rnp/sls/lag/20010453.htm.

¹⁴¹⁰ Sweden, The Act on support and service for certain functional impairments, 1993:387 (lagen (1993:387) om stöd och service till vissa funktionshindrade (LSS)), available at: www.notisum.se/rnp/sls/lag/19930387.HTM.

¹⁴¹¹ Assistance allowance can be granted to persons with significant and long-term disabilities. The compensation, which is administered by the Swedish Social Insurance Agency, shall be used to pay personal assistants. The statistics presented in the table is retrieved from <https://www.forsakringskassan.se/statistik/funktions%C2%ADnedsattning/assistansersattning>.

The population increase and the increase in diagnoses within the autism spectrum are, according to the National Board of Health and Welfare, two of the explanations for the increase in special accommodation according to both to LSS and to SoL. Another conceivable reason may be that the persons who have had the assistance allowance withdrawn instead are granted special accommodation according to SoL or LSS.

Types of Service. ¹⁴¹²

TYPE OF SERVICE	Billions of SEK 2014	Total (Figures from 2013 2014 2015)	Change 2012-2016		From EU Funds*
			Billions	%	
Special accommodation/ Residential care according to SoL (Särskilt boende enl SoL) ¹⁴¹³ (fixed price calculated at the 2016 price level)	4.9	4.9 (4.3/ 4.4/ 4.5)	0.7	17.8	
Special accommodation/ Residential care according to LSS for adults (Särskilt boende enl LSS) ¹⁴¹⁴ (fixed price calculated at the 2016 price level)	25.2	26.9 (24.2/ 24.8/ 24.7)	3.5	16	
Special accommodation/ Residential care for children according to LSS (Särskilt boende enl LSS) ¹⁴¹⁵ (fixed price calculated at the 2016 price level)	1.7	1.7 (1.7/ 1.6/ 1.6)	-0.1	-5.0	
Housing support (Boendestöd enl SoL) ¹⁴¹⁶ (fixed price calculated at the 2016 price level)	6.1	6.1 (5.6/ 5.5/ 5.6)	1.3	26.2	

¹⁴¹² The statistics presented is presented in <https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20874/2018-2-18.pdf> and Social Insurance Report 2017:4 <https://www.forsakringskassan.se/wps/wcm/connect/d603e099-7176-4471-898f-33c55a4ccd39/socialforsakringsrapport-2017-04.pdf?MOD=AJPERES&CVID=>

¹⁴¹³ Sweden, The Social Security Act (Socialtjänstlagen, SOL), 2001: 453, available at: www.notisum.se/rnp/sls/lag/20010453.htm.

¹⁴¹⁴ Sweden, The Act on support and service for certain functional impairments, 1993:387 (lagen (1993:387) om stöd och service till vissa funktionshindrade (LSS), available at: www.notisum.se/rnp/sls/lag/19930387.HTM.

¹⁴¹⁵ Sweden, The Act on support and service for certain functional impairments, 1993:387 (lagen (1993:387) om stöd och service till vissa funktionshindrade (LSS), available at: www.notisum.se/rnp/sls/lag/19930387.HTM.

¹⁴¹⁶ Sweden, The Social Security Act (Socialtjänstlagen, SOL), 2001: 453, available at: www.notisum.se/rnp/sls/lag/20010453.htm.

Personal assistance according to LSS ¹⁴¹⁷ (fixed price calculated at the 2016 price level)	10.5	10.5 (9.4/ 9.5/ 9.5)	1.3	14.6	
Personal assistance (assistance compensation from the Social insurance agency) (calculated at current prices)	26	26 (22/ 24/ 25)	4,5	17.6	

During 2012–2016, the municipalities' total costs for efforts to persons with disabilities increased by 7.7 % in fixed prices, corresponding to SEK 13.8 billion. During the same period, municipalities' costs for efforts according to SoL increased with 18.6 %, corresponding to SEK 2.1 billion, where housing support accounted for the largest increase, with SEK 1.3 billion.

Costs for LSS have also increased and between 2012 – 2016 the municipalities' costs for efforts according to LSS increased by 12.5 %, corresponding to SEK 5.6 billion. The cost of housing with special service for adults had the strongest development with an increase of 16%. The increase in costs between 2015 and 2016, SEK 2.1 billion, was particularly large.

Between 2012 and 2016, municipalities' costs for personal assistance increased by almost 15%. The increase between 2015 and 2016 is particularly clear with 11 %, corresponding to SEK 1 billion. The number of persons with personal assistance also increased significantly between these two years.

The national board of health and welfare points to several reasons to this development.¹⁴¹⁸ One contributing factor is probably withdrawals within the personal assistance allowance (paid by the Social insurance agency), and that many assistance users were instead granted special accommodation according to LSS or housing support according to SoL. Since 2015, the withdrawals of personal assistance allowances have increased significantly in number.¹⁴¹⁹

National reform programme ¹⁴²⁰

In the NRP it is stated that “The objective of disability policy is, proceeding on the basis of the UN Convention on the Rights of Persons with Disabilities, to attain equal standards of living and full inclusion in society for people with disabilities, in a society based on diversity.” (P.30) In the further text,¹⁴²¹ however, there is nothing about independent living, special accommodation or community-based living, but the focus is on inclusion in education and labour market for people with disabilities in society.

¹⁴¹⁷ Sweden, The Act on support and service for certain functional impairments, 1993:387 (lagen (1993:387) om stöd och service till vissa funktionshindrade (LSS), available at: www.notisum.se/rnp/sls/lag/19930387.HTM.

¹⁴¹⁸ <https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20874/2018-2-18.pdf>.

¹⁴¹⁹ <https://www.disability-europe.net/search?searchword=sweden&searchphrase=all>

¹⁴²⁰ <https://www.government.se/49bfaf/contentassets/8c870068125e4941aada4f4dad740b4e/swedens-national-reform-programme-2018.pdf>.

¹⁴²¹ The document has been searched through, using the phrases “disability”, “independent”, “living”, “community” and parts concerning disability read through.

Agenda 2030

The Swedish Government expresses in the Action plan¹⁴²² for Agenda 2030 that “equality, gender equality and respect for human rights are central to create sustainable welfare. The differences that exist in living conditions between individuals and groups should be levelled. Sweden should be a vivid and sustainable democracy, which is characterized by participation and where the opportunities for influence are equal.”

Partnership Agreement with the European Commission

There is no mentioning of disability, independent living or community-based living in the agreement.¹⁴²³

Operational programs for ESIF

In the operational programs¹⁴²⁴ for ESIF concerning Sweden there is no reference to independent living, concerning special accommodation or community-based living for persons with disabilities.

National disability strategy

The national goal for the disability policy is, with the UN Convention on the Rights of Persons with disability as a starting point, achieving equality in living conditions and full participation in society for people with disabilities. However, in the bill¹⁴²⁵ that forms the basis of the objectives, there is only a short paragraph on special accommodation for people with disabilities. The paragraph is about additional costs for individuals who received the special accommodation or accommodation with special service for adults with disabilities, according to the LSS. The Government intends to review the issue of how individuals, who have received this kind of accommodation, should avoid getting extra costs due to their disabilities. No mention is made in the bill on transition from institutional care (special accommodation) to community-based living or vice versa.

The law of special support and services to persons with certain disabilities (LSS)¹⁴²⁶

Special accommodation for adults provided under 9 § 9 LSS is relative well described in the proposals for LSS,¹⁴²⁷ even if the LSS does not regulate in detail how the accommodation should be organized. An accommodation with special service can be designed as a group home or a service home. For both types of accommodation, the law states that the housing must be of good standard, that it is the individual's permanent home and that it does not have an institutional character.

¹⁴²² <https://www.regeringen.se/49e20a/contentassets/60a67ba0ec8a4f27b04cc4098fa6f9fa/handlingsplan-agenda-2030.pdf>.

¹⁴²³ The document has been searched through, using the phrases “disability”, “independent”, “living” and “community”.

¹⁴²⁴ I have read the operational programs for ESF, <http://ec.europa.eu/esf/main.jsp?catId=576&langId=en>, and for Community-led local Development - ERDF/ESF, <http://ec.europa.eu/esf/main.jsp?catId=576&langId=en>.

¹⁴²⁵ https://www.regeringen.se/49aa12/contentassets/0571a7504d49428292a6ab114e4b0263/nationellt-mal-och-inriktning-for-funktionshinderspolitiken-prop-2016-17_188.pdf.

¹⁴²⁶ https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387.

Review of LSS and personal assistance¹⁴²⁸

The state-initiated investigation "Opportunity to live like others - New law on support and service for some people with disabilities" includes an in-depth analysis of how LSS relates to other laws and areas, how the law is applied in practice and which other factors that are decisive for people with disabilities to be able to live like others. The review takes its point of departure from "that efforts according to LSS should be the means to achieve the disability policy goals so that the individual has the opportunity to live as others." (p.18)

The winding-up of nursing homes for people with developmental disabilities is described and the review notes that all nursing homes have now been closed down. The review points to that ordinary housing with a professional support as an alternative to institutional care has been expanded over a period of twenty years.

Investigation of LSS¹⁴²⁹

A recent investigation in 2018 has reviewed the personal assistance allowance and parts of the Act of LSS. The purpose is to create a long-term sustainable financial development of the personal assistance allowance and to make the services provided under the LSS more cost-effective. The legislation should promote equality in living conditions and full participation in society. In Chapter 5, on housing, the investigation expresses that "everyone should have the right to choose how to live, where to live and where" (p.203).

According to The European Expert Group on the Transition from Institutional to Community-based Care (EEG) defines independent living "as people being able to make choices and decisions as to where they live, who they live with and how they organise their daily life. This requires:

- accessibility of the built environment;
- accessible transport;
- availability of technical aids;
- accessibility of information and communication;
- access to personal assistance, as well as life and job coaching; and
- access to community-based services."¹⁴³⁰

Some of the documents cover all these areas but only the LSS-bill, the reviews and investigation of LSS, and the National disability policy covers the housing situation in more detail.

The review of LSS,¹⁴³¹ in 2008, notes that all nursing homes for people with developmental disabilities have closed, which is in line with an overall target of independent living in the community, that the LSS- legislation should provide opportunities for.

¹⁴²⁸ <https://www.regeringen.se/49b6a7/contentassets/9d5346ef7a024b3ab9fa8efc61b11b35/volym-1-mojlighet-att-leva-som-andra-hela-dokumentet-sou-200877>.

¹⁴²⁹ https://www.regeringen.se/48dbb0/contentassets/573c64721c9a43388b756b953d7c4d24/oversyn-av-insatser-enligt-lss-och-assistansersattningen-sou_2018_88.pdf.

¹⁴³⁰ <https://deinstitutionalisation.com/terminology/>.

¹⁴³¹ <https://www.regeringen.se/49b6a7/contentassets/9d5346ef7a024b3ab9fa8efc61b11b35/volym-1-mojlighet-att-leva-som-andra-hela-dokumentet-sou-200877>.

There is no detailed action plan in the most recent LSS-investigation¹⁴³² concerning community-living or housing/special accommodation. The investigation describes (briefly) a line of action: "In order to meet the needs that exist today, there needs to be an adjustment of the support that is linked to the housing with increased opportunities in support of anyone who wants to choose a housing entirely on their own and do not have right to personal assistance. Today, such support is mainly outside LSS in the form of e.g. housing support and help in home (hemtjänst) according to the Social Services Act. We believe that there should be more choice in LSS/ .../when it comes to how you want to live, in a housing with special service or with support in ordinary housing".

The investigation also points to risks of institutionalization in accommodation with special service as there are "risks with an increased number of people in such housing, co-location with some other activities and reduced opportunities to own activities" and that these risks "must be taken seriously and be counteracted". How and when these risks should be counteracted, and by whom, is not specified in the investigation.

In the National disability policy however, housing is described from a financial point of view, where an equal economic situation for persons with disabilities (which may influence the standards of living) is the focus, not equivalence in the actual living situation. The starting point should therefore be that additional costs, because of disability, should be compensated or prevented". The planned approach expressed in the National disability policy is that the Government intends to review this economic issue.

The bills and investigations concerning persons with disabilities mentioned above, have used disability organizations to get opinions from people with disabilities, through a referral procedure.

However, the involvement has been criticised by the representatives of the disability organizations, as they experience lack of impact in the process, as described by one of the representatives in the recent LSS investigation:¹⁴³³ "We have been two experts in the investigation who represented the target group to which the investigation relates. Given the diversity that exists within the LSS with groups that have completely different needs, the investigation should involve more representatives from the disability movement. There is a wide range of skills and experiences that should be better used in the investigation. The user perspective has also not been clear in the investigation's work and proposals."

The state-initiated investigation "Opportunity to live like others - New law on support and service for some people with disabilities",¹⁴³⁴ from 2008, notes that all nursing homes (institutional care) have been closed, and by that is the de-institutional phase for people with (developmental) disabilities finished. Instead, people with disabilities have been given the opportunity for personal assistance in their own homes, according to LSS, or the different accommodation alternatives, described below:

¹⁴³² https://assistanskoll.se/_up/LSS-utredningen.pdf.

¹⁴³³ https://assistanskoll.se/_up/LSS-utredningen.pdf.

¹⁴³⁴ <https://www.regeringen.se/49b6a7/contentassets/9d5346ef7a024b3ab9fa8efc61b11b35/volym-1-mojlighet-att-leva-som-andra-hela-dokumentet-sou-200877>.

Accommodation with special service, according to SoL,¹⁴³⁵ is offered to people who, due to physical, psychological or other reasons, need more extensive support than what can be provided in ordinary housing. The special accommodation offers individually adapted support, service and nursing.

Accommodation for children according to § 9 8 LSS is provided as accommodation in family homes or in homes with special services for children or young people with certain kind of disabilities. The efforts are given to children or young people who for various reasons cannot live with their parents.

Special accommodation for adults according to § 9 9 LSS is provided as housing with special service or other specially adapted housing for adults with certain kind of disabilities. Group accommodation and service housing are the most common forms. A group accommodation is a housing alternative for people with an extensive supervisory and nursing need, where support can be given at all times of the day by a permanent staffing. In group accommodation, only three to five persons should normally live (the National Board of Health and Welfare's regulations and general advice [SOSFS 2002: 9]. Service housing consists of a number of apartments where the residents have access to shared service and permanent staff. Other specially adapted housing for adults does not include support by staff and not nursing.

Reviews show that personal assistance has provided opportunities for an improved living situation for many people with extensive disabilities as they have been given opportunities to move from institutions and special housing with different degrees of service to ordinary accommodation with personal assistance. Standards of living today are not significantly different between the beneficiaries of personal assistance and the population in general.¹⁴³⁶ An aim of personal assistance is that people with disabilities should have the power over their own life and the SIA noted in a review¹⁴³⁷ that a majority of the personal assistance - users feel they have control over their assistance and feel safe and secure with it, and that many people with the support of personal assistance experience independence to a greater extent than in alternative forms of support.

Reviews also show that personal assistance has given opportunities to social life and work. A review¹⁴³⁸ of the users' view of the quality of personal assistance shows that the assistance allowance contributes to the opportunity of having a meaningful employment for eight out of ten people with assistance and contributes to opportunities for social contacts and activities for nine out of ten people. However, there are differences between men and women where more men than women believe that the assistance allowance is a prerequisite for their opportunities to study or work.

¹⁴³⁵ https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453.

¹⁴³⁶ <https://www.regeringen.se/49b6a7/contentassets/9d5346ef7a024b3ab9fa8efc61b11b35/volym-1-mojlighet-att-leva-som-andra-hela-dokumentet-sou-200877>.

¹⁴³⁷ https://www.forsakringskassan.se/wps/wcm/connect/332d7f4e-1c6d-418c-8395-6800ae1bf351/socialforsakringsrapport_2014_08.pdf?MOD=AJPERES.

Studies show that the personal assistance has meant a lot to relatives and not least to parents to children with disabilities.¹⁴³⁹ It has improved their opportunities for gainful employment and thus their financial conditions

Although the personal assistance increases opportunities for independence and a life like that of others, studies¹⁴⁴⁰ show that everyday life with personal assistance is a complex phenomenon in which assistance users are faced with various dilemmas in their quest to decide on their everyday life and daily support. And despite the right to choose and design their assistance according to their own needs, the informants are faced with situations that challenge their power and control over everyday life.

In their concluding observations, the UN Committee wrote, concerning article 19, that “The Committee is concerned that State-funded personal assistance has been withdrawn for a number of people since 2010 due to a revised interpretation of “basic needs” and “other personal needs”, and that persons who still receive assistance have experienced sharp cutbacks, the reasons for which are unknown or only seemingly justified. It is further concerned at the reported number of positive decisions under the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments that are not executed. The Committee recommends that the State party ensure that personal assistance programmes provide sufficient and fair financial assistance to ensure that a person can live independently in the community.”

The perceived worry was also underlined in the comments of the Council of Europe Commissioner for Human Rights who expresses concern in his country visit report,¹⁴⁴¹ of a trend towards re-institutionalisation. The report writes “As a result of the decrease in state-funded personal assistance, a trend towards re-institutionalisation has been reported, which is of special concern to the Commissioner. Children have apparently been particularly affected/.../municipalities have difficulties in finding adequate replacement for those who have been denied state-funded personal assistance, occasioning an increase of short-term stays in homes for children with disabilities/.../. The Commissioner is concerned that Sweden is implementing retrogressive measures in the area of state-funded personal assistance. He calls on the authorities to closely monitor the impact of the decrease in state-funded personal assistance in terms of access to rights, in particular access to education and employment; resort to congregated settings; and re-medicalisation of the approach to disability/..../Finally, the Commissioner draws the attention of the Swedish authorities to his predecessor’s Issue Paper(¹⁴⁴²) on the right of people with disabilities to live independently and be included in the community, which contains indicators and guiding questions to help member states to monitor their progress towards full compliance with this right”

¹⁴³⁹ Socialstyrelsen (2008), Personlig assistans enligt LASS ur ett samhällsekonomiskt perspektiv.

¹⁴⁴⁰ <http://su.diva-portal.org/smash/get/diva2:849156/FULLTEXT01.pdf>.

¹⁴⁴¹ <https://rm.coe.int/commdh-2018-4-report-on-the-visit-to-sweden-from-2-to-6-october-2017-b/16807893f8>.

¹⁴⁴² Council of Europe Commissioner for Human Rights, Issue Paper “The right of people with

In the reporting cycle II-III (2018) on the ratification of international Human Rights treaties the Committee on the Rights of Persons with Disabilities addressed a list of issues prior to submission of the combined second and third periodic reports of Sweden.¹⁴⁴³ Concerning article 19 in the CRPD the Committee wanted Sweden to “provide information about:

- a) Measures taken to ensure that personal assistance programmes provide persons with disabilities with sufficient financial assistance to allow them to live independently in the community, and the criteria to be eligible for personal assistance;
- b) Measures taken to provide persons with disabilities with the opportunity to choose their place of residence, and where and with whom they want to live, on an equal basis with non-disabled persons;
- c) Measures taken to ensure that decisions granting individual support are implemented promptly by the municipalities;
- d) The number and percentage of persons with disabilities who have received personal assistance benefits since 2014, disaggregated by year, sex, age, type of impairment and municipality of residence.”

There are no recommendations concerning Sweden and article 19, in other relevant documents in the OHCHR treaty bodies’ database¹⁴⁴⁴ or in the European Committee on Social Rights country factsheet.¹⁴⁴⁵

In the report “Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU”¹⁴⁴⁶ by The European Union Agency for Fundamental Rights (FRA), Sweden is just mentioned in a few sentences and the report does not point to any concerns about Sweden.

The Disability movement in Sweden is indeed a vital force. Swedish organisations for people with disabilities have been influencing policymaking for over 50 years. They will certainly continue to be watchdogs on this and other salient factors related to persons with intellectual disabilities. Most of these organisations belong to the Swedish Disability Federation (Handikappförbunden), an umbrella body designed to influence official policy. The federation is an active member of the European Disability Forum (EDF)¹⁴⁴⁷, an independent NGO that represents the interests of 80 million Europeans with disabilities throughout Europe.

The organisations help shape public opinion by presenting their members’ demands and proposing improvements. In 2015, about 65 organisations for people with disabilities received

¹⁴⁴³ List of issues prior to reporting. Downloaded 20190212 on
https://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=SWE&Lan

¹⁴⁴⁴ The researcher searched for the most recent concluding observations, with the key-words
”disability” and “independent living”, on the website

<https://www.ohchr.org/en/countries/enacaregion/pages/seindex.aspx>.

¹⁴⁴⁵<https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016804928a3>.

¹⁴⁴⁶ <https://fra.europa.eu/en/country-data/2017/country-studies-project-right-independent-living->

state grants amounting to more than SEK 183 million (EUR 20 million/USD 22 million) to help them pursue their activities. Most are organised on the basis of their members' disabilities. Many have special youth sections, and some focus specifically on children and families. ¹⁴⁴⁸

To conclude, Sweden has had a very positive development since the LSS and SoL legislation were introduced in the 90`s and the 80`s respectively, as they have meant that persons with disabilities have been given opportunities for independent living in ordinary homes. Especially personal assistance has been central to development of independent living as it will enable people with disabilities to live a life as others in the society and not being forced into institutions.

As shown above, there is, however, a worrying development in Sweden with an increasing proportion of people with disabilities who have lost the right to personal assistance. This entails an increased risk of institutionalization, which figures show signs of. Especially for children the National Board of Health points to a worrying development where children with disabilities are not given the opportunity to live together with their parents.

With regards to educational opportunities for persons with disabilities, the Swedish educational system ¹⁴⁴⁹ is decentralised and managed by overall goals and rules. All decisions concerning the implementation of the Education Act and the curriculum are made within the local self-governing municipalities. There is therefore great variation among the municipalities. ¹⁴⁵⁰

Under the Ministry of Education and Research ¹⁴⁵¹ there are three national agencies:

Swedish National Agency for Education

Swedish Schools Inspectorate

National Agency for Special Needs Education and Schools. ¹⁴⁵²

The Government gave the Swedish National Agency for Education, the Swedish Schools Inspectorate, the National Agency for Special Needs Education and Schools and the Swedish Institute for Educational Research a new assignment in 2020. The assignment is based on the school commission results and has three aims:

- Building a quality framework. Gathering knowledge about crucial factors for effective school development in order to increase quality and equality in schools. The quality framework builds on three main priorities: Raising achievement, quality in teaching and equity in education.
- Developing monitoring mechanisms. Identifying milestones and indicators that can be used for monitoring and that will form the basis of system analysis.
- Providing content for dialogue. The authorities should analyse and summarise critical success factors for school development and make suggestions on what should be included in a future dialogue between the government and school principals.

¹⁴⁴⁸ <https://zeroproject.org/report/swedish-disability-federationhandikappforbunden-on-26-reasonable-accommodation/>

¹⁴⁴⁹ https://www.skolverket.se/download/18.35e3960816b708a596c6fe4/1567407297288/SVUS_eng.pdf

¹⁴⁵⁰ Source: IECE Country Survey Questionnaire, p. 16.

¹⁴⁵¹ <https://www.government.se/government-of-sweden/ministry-of-education-and-research/>

According to the Swedish Education Act, ¹⁴⁵³ the basic principle guiding all Swedish education, from childcare to the transition period, is access to equivalent education for all. This means that pupils in need of special support should not be treated differently or defined as a group that is any different from other pupils. Their rights are not stated separately, but the obligation for schools to attend to all pupils' needs is emphasised. Social services, schools and healthcare are obliged to collaborate for children at risk. The social services have main responsibility for ensuring that the collaboration is enacted (stipulated in the Social Services Act, the Health and Medical Services Act and the Police Act). ¹⁴⁵⁴

Children with learning disabilities can attend compulsory schools for pupils with learning disabilities as an alternative to mainstream compulsory schools. Deaf or blind pupils can attend special schools. An action plan of provision must be drawn up for pupils in need of special support in compulsory schools. The school head is responsible for investigating pupils' needs before setting up the action plans. Teachers usually draw up the plans, in consultation with learners, their parents and specialist support teachers. The plans, which identify needs and provisions to meet them, are continuously evaluated. Progress and changes of solutions are possible. ¹⁴⁵⁵

Pupils in need of special support have the right to specialist provision. All education corresponds as far as possible to the national curricula, but with an emphasis on meeting individual learning needs. In a few circumstances, this provision is offered in special settings. Three national and five regional state-run special schools are available for pupils with visual impairment combined with additional disabilities (MDVI), deafness or hearing impairment combined with learning disabilities, or severe speech and language disorders.

All pupils have the right to choose their school – whether municipal or independent – as long as the school can demonstrate that it can meet the pupils' educational needs.

The United Nations (UN) Convention on the Rights of the Child was incorporated into Swedish law on 1 January 2020. ¹⁴⁵⁶ A number of measures for the induction process and other legislative proposals to strengthen the rights of the child in Swedish legislation were introduced.

The curricula for pre-primary, compulsory and upper-secondary education are partly consistent in order to make them homogenous. There is a special curriculum for pupils with learning disabilities. The National Agency for Education decides on the syllabi for special schools and schools for pupils with learning disabilities.

The curricula state the leading values, tasks and goals for the activities, but do not state how to reach them. The organisation of childcare and school activities is the responsibility of the local authorities who should therefore ensure learners and schools can reach the goals and follow the curricula. Pedagogical staff in each unit are responsible for the pedagogical means and specific organisation of the operation.

¹⁴⁵³ Skollagen 2010:800, 4 §

¹⁴⁵⁴ Source: IECE Country Survey Questionnaire, p. 15.

¹⁴⁵⁵ Skollagen 2010:800, 9 §.

¹⁴⁵⁶ <https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2016/03/sou-201619/>

The Curriculum for the Pre-school Lpfö 18, revised in 2019, covers the following areas: ¹⁴⁵⁷

Norms and values
Development and learning
Influence of the child
Pre-school and home
Co-operation with recreation centres.

The Curriculum for the compulsory school, pre-school class and the recreation centre (2018) covers: ¹⁴⁵⁸

Norms and values
Knowledge
Responsibility and influence of pupils
School and home
Transition and co-operation
The school and the surrounding world
Assessment and grades
Responsibility of the school head.

The Curriculum for the upper-secondary school (available in English) covers: ¹⁴⁵⁹

Knowledge
Norms and values
Responsibility and influence of pupils
Educational choices – employment and social life
Assessment and grades
Responsibility of the head.

All childcare, pre-primary activities, leisure time activities, compulsory education and upper-secondary education are incorporated under the National Agency for Education.

The Education Act states that children are entitled to Early Childhood Education and Care (ECEC) from the age of 1 to 7 if their parents work, study or are unemployed. ECEC is a separate school form and its activities are regarded as education and teaching. Teaching takes place under the supervision of pre-school teachers, but there may also be other staff who promote the child's development and learning.

ECEC is regulated by the Education Act and the curriculum. Activities should be based on individual needs. Children in need of special support should receive care related to their needs.

¹⁴⁶⁰

¹⁴⁵⁷ <https://www.skolverket.se/publikationsserier/styrdokument/2019/curriculum-for-the-preschool-lpfo-18?id=4049>

¹⁴⁵⁸ <https://www.skolverket.se/publikationsserier/styrdokument/2018/curriculum-for-the-compulsory-school-preschool-class-and-school-age-educare-revised-2018?id=3984>

¹⁴⁵⁹ <https://www.skolverket.se/publikationsserier/styrdokument/2013/curriculum-for-the-upper-secondary-school?id=2975>

¹⁴⁶⁰ Skollagen 2010:800, 3–7 §.

The nine-year basic compulsory school level is for all children between 7 and 16 years of age, but children can start school at the age of 6. It includes compulsory schools, compulsory schools for learning disabilities, Sami schools and special schools. The municipalities also have a duty to organise pre-primary activities from the age of 5. In most municipalities, these activities are integrated into the compulsory school.

Six-year-olds have the right to start compulsory school if their parents wish. A law introduced in 2018 stipulates obligatory school for all children at six years of age. Children with learning disabilities can attend the compulsory school for pupils with learning disabilities as an alternative to the mainstream compulsory school.

The compulsory school for pupils with learning disabilities consists of nine years of schooling. Within the school there is a special orientation called the training school. This is intended for pupils who lack knowledge in all or parts of compulsory schooling for pupils with learning disabilities in some subjects. Children who, due to a functional impairment or for other special reasons, cannot attend mainstream compulsory school or compulsory school for pupils with learning disabilities can attend special schools if they:

- are deaf and blind or have visual impairments and other functional impairments;
- are deaf or hearing impaired or have a severe speech disorder.

Upper-secondary schools – gymnasiet – are not compulsory, but almost all pupils attend. Schools are free of charge and there are no fees for educational materials, food or healthcare. Upper-secondary school pupils have the same right to special support as compulsory school pupils.

For pupils in need of special support, technical aid is available from the regional counties and the state provides adapted teaching materials. Schools and teachers consult local resource centres, which in turn consult the Swedish National Agency for Special Needs Education and Schools.

Upper-secondary pupils can choose from 18 national programmes, according to their interests. Most pupils with disabilities attend these national programmes. Pupils who are deaf or have hearing disabilities can attend special upper-secondary schools. Pupils with physical disabilities also have this opportunity.

Upper-secondary school for individuals with learning disabilities (USSILD) is a free, voluntary school. Young people with developmental disorders or acquired brain injuries can choose to attend it once they have completed compulsory school for pupils with learning disabilities. USSILD consists of national programmes, individual programmes and programmes that diverge from the national programme structure.

There are nine national USSILD programmes in total. Each programme spans four years and consists of USSILD foundation subjects, programme-specific subjects, more in-depth programme-specific courses and assessed coursework.

Pupils who are not eligible to apply to a national upper-secondary school programme can follow one of five introductory programmes that provide individually-adapted education to meet their needs and offer clear educational alternatives. The introductory programmes are intended to help pupils establish themselves in the labour market and to serve as the best possible foundation for continued education. Each school is responsible for setting up an individual study

plan for these pupils. The pupil's local municipality is responsible for offering the introductory programmes.

Pupils in compulsory schools for pupils with learning disabilities have the right to work introductions or an individual alternative, if the pupil wishes to take a particular programme and the municipality feels they have the prerequisites for it. After the learner has completed education in an introductory programme, the school head is responsible for issuing a school-leaving certificate that shows the education the learner has received.

It is the duty of the municipalities to offer upper-secondary education for all pupils, including those with severe learning disabilities.

From 1 January 2017, the Discrimination Act introduced new active measures against discrimination. The measures apply to pre-primary and compulsory education and other activities regulated under the Education Act. The measures form part of discrimination law. The active measures against discrimination in Chapter 3 of the Discrimination Act stipulate actions against seven types of discrimination:

Gender
Gender identity or gender expression
Ethnicity
Religion or other beliefs
Disability
Sexual orientation
Age.

One form of disability discrimination is lack of accessibility. Lack of accessibility means an activity does not take reasonable measures to ensure that a person with disabilities is in a comparable situation with a non-disabled person.

Lack of accessibility was introduced in the Discrimination Act 2015 due to Sweden's commitment to comply with the UN Convention on the Rights of Persons with Disabilities. The Convention was adopted by the UN General Assembly in 2006 and has applied in Sweden since 2009.

Employers and schools now have greater responsibility to work with prevention and promotion to combat discrimination and work for equal rights and opportunities. The new law will help schools and pre-schools to prevent discrimination more effectively with the participation of learners and professionals. The work will therefore be active and affect the mind-set of the participants.¹⁴⁶¹

Local authorities are bound by law to provide a number of basic services, of which childcare and pre-primary, compulsory and upper-secondary education are a major part. Municipalities can use collected taxes and state funding for the services and systems that are deemed best for their respective areas. About 15% of the total municipality budget is based on state grants (general and targeted).¹⁴⁶²

¹⁴⁶¹ Source: Legislation Updates 2017, pp. 28–29.

¹⁴⁶² Source: Financing of Inclusive Education – Sweden country report, p. 9.

Many municipalities delegate budgets directly to individual schools. An amount of money is granted and follows each pupil to the school they choose, whether municipal or independent. A school that receives grants from the municipality is not entitled to collect school fees.

The responsibility for personal assistance and assistance benefit is divided between the municipality and the Social Insurance Administration in central government. The Social Insurance Administration makes decisions about assistance benefit for people who need personal assistance for their basic needs for more than 20 hours a week. If a person needs assistance for 20 hours per week or less, the municipality makes the decision. During schooling, it is usually the municipality that is responsible for allocating resources for assistance based on local conditions and needs. ¹⁴⁶³

Through the National Agency for Special Needs Education and Schools, the state offers special needs support, education in special schools, accessible teaching materials and government funding. The National Agency runs three national and five regional special schools. The national schools cater for pupils with:

- visual impairment combined with additional disabilities (MDVI);
- deafness or hearing impairment combined with learning disabilities;
- severe speech and language disorders.

Technical aid is accounted for by the regional counties.

All principals in the school system must systematically and continuously plan, monitor and develop education at their level. The planning, monitoring and development of education must also be carried out at pre-school and school unit levels. Principals are responsible for carrying out quality assurance at the units. Systematic quality assurance must be documented. ¹⁴⁶⁴

Analysis and follow-up are critical elements that need to be prioritised in the development and improvement of operations. The Swedish Association of Local Authorities and Regions (SALAR), which advocates at local government level, has developed a quick guide, Open Comparisons, to support and provide tools for school development. Open Comparisons aims to encourage municipalities to analyse and compare results and learn from each other in order to improve quality and streamline operations. As a method, Open Comparisons is based on the idea that benchmarking drives development. Open Comparisons stands for a selection of key figures presented together to promote improvements that benefit the citizens.

The following are targeted grants from the state relevant to the discussion:

- State grants for higher education in special education 2020: to enable teachers and pre-school teachers to study for a special teacher or special education degree at university level.
- State grants for strengthening staff competences regarding student health and special education in 2020: to enable schools to hire staff or to educate staff on matters regarding student health or special education.

¹⁴⁶³ Source: Financing of Inclusive Education – Sweden country report, pp. 17–18.

¹⁴⁶⁴ Education Act, Chapter 4, 3–4 §.

- State grant for learning about special education pedagogy 2019/20: to develop teacher competences in special education pedagogy. It aims to give them greater ability to meet the different needs of students.
- State grant for the teacher campaign 2020: The government grant will make it easier for teachers to supplement their competence and expertise with courses within the Teacher Lift. The purpose is for the students to get a better teaching. ¹⁴⁶⁵

Childcare is financed by locally collected tax revenues, state grants and parental fees. There are no separate funds for special education. Municipalities decide upon allocations in the same way for all childcare, and parental fees vary. In 2011, parental fees accounted for about 17% of ceiling for pre-primary fees set at about 1–3% of the family's income, depending on how many the municipal total costs.

Pre-primary school fees are linked to family income and the number of hours the child attends. Since 2001, municipalities can adopt the system of maximum fee. This means that there is a children the family has.

Since January 2003, all children of four and five years of age are offered at least 525 hours of free schooling per year. The provision is mandatory for the municipalities, but children participate on a voluntary basis.

Municipalities are responsible for educational provision and the education system is financed with locally collected tax revenues. There are no separate state funds for special education. Each school is provided with a sum of money based on the number of pupils in the school. The school is responsible for allocating those means in a way that meets all individual needs. Schools can apply to the municipality for additional funding based on the individual needs of a pupil. Pupils and their parents are not usually charged for teaching materials, school meals, health services and transport.

Many municipalities have resource centres that offer pedagogical support to schools and teachers.

Upper-secondary education is free of charge. Municipalities are responsible for educational provision and the education system is financed with locally collected tax revenues. Financial assistance from the state, in the form of personal subsidies and loans, is available to adults attending most post-compulsory education. ¹⁴⁶⁶

The local municipalities are independent in terms of organisation. There are different ways to identify and investigate individual needs for special support. In the Education Act, every school must have a pupil health team under the head teacher. These teams work with prevention, intervention and compensation for pupils with educational needs. Health services and psychologists are available for pupils, parents and childcare and school staff to consult. There are regular health checks for all children.

¹⁴⁶⁵ Source: Swedish National Agency for Education.

¹⁴⁶⁶ <https://www.european-agency.org/country-information/sweden/financing-of-inclusive-education-systems>

Parents approve longer-term or more detailed investigations by psychologists or medical staff. This is not the case for pedagogical investigations.

Parents or guardians must be offered a forum for consultation in order to influence their child's education. Each pre-primary and school unit shall contain one or more forums for consultation with learners and guardians. Within these forums, learners and guardians must be informed of proposals and given an opportunity to comment before decisions are made. The head is responsible for forums for consultation and information and for ensuring that consultation obligations are fulfilled.

Municipal childcare, pre-primary activities, compulsory schooling, after-school centres and youth centres are often part of the same organisation with a common school board. Often, several of these activities are integrated, with staff organising joint work together. This facilitates a complete view of each pupil. It is common practice to provide for the pupils' needs in close co-operation with their parents. The Education Act ¹⁴⁶⁷ states the importance of parents' participation in planning pupils' education.

The new grading scale has six levels: A–F. For each subject and course there are knowledge requirements (standards) for grades A, C and E. Grades A–E are pass results, while F is the non-pass result. The rating serves to express the extent to which a pupil has attained the knowledge for each subject and course. If the pupil has been absent frequently and a grade cannot be awarded as it is impossible to assess their knowledge, then the symbol (-) is inserted in the grade records. However, grades F and (-) should not be used in the compulsory or upper-secondary schools for pupils with learning disabilities.

The Swedish Schools Inspectorate scrutinises schools and assesses applications to run independent schools. People contact the Swedish Schools Inspectorate if they believe that a school has done something wrong. The objective is good education in a safe environment. ¹⁴⁶⁸ In years 3, 5 and 9, learners undertake national compulsory tests in maths, English, Swedish and Swedish as a second language. Additional tests are given in years 6 and 9 in one subject from biology, physics and chemistry and one from geography, history, religion and social studies. These tests are the basis for individual evaluations, school plans and national comparisons.

Grades are awarded in years 6, 7 and 8 in compulsory school. In the eighth year, a term grade is awarded at the end of the autumn and spring terms. In the ninth year, a term grade is awarded at the end of the autumn term and a final grade at the end of the spring term. The final grade is used for applications to upper-secondary school. ¹⁴⁶⁹

After the compulsory dose of education, persons with disabilities are aided and assisted in their needs and challenges to face the open job market. The state is responsible for helping people to find and keep jobs through its labour market agencies. Employers who hire people whose work

¹⁴⁶⁷ https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/skollag-2010800_sfs-2010-800

¹⁴⁶⁸ <https://skolinspektionen.se/en/About-Skolinspektionen/The-activities-of-the-School-Inspectorate/>

¹⁴⁶⁹ <https://www.skolverket.se/undervisning/grundskolan/betyg-i-grundskolan/satta-betyg-i-grundskolan>

capacity is limited are sometimes entitled to wage subsidies. The state-owned services and goods provider Samhall offers people with disabilities meaningful employment that furthers their personal development. People with disabilities can also receive various types of financial assistance from the Swedish Social Insurance Agency.¹⁴⁷⁰

People with disabilities can apply for municipal grants so they can have their accommodation modified. This may involve having doorsteps removed, support rails mounted, doorways widened, automatic door openers fitted, or special elevators installed. Such grants cover all types of disabilities, including mobility disability, impaired vision, mental disorders and allergies. The first such grant was made available on a trial basis in 1959, and was introduced formally in 1963.

Anyone in need of extra support may live in group housing, where staff provide 24-hour assistance. Group housing usually comprises a number of apartments with a range of common amenities. Another alternative is the serviced flat; people can live completely independently but are able to call for assistance at any time. The family home is another option, enabling children with functional disabilities to live with a family other than their own during certain periods.

The work of the Swedish Agency for Participation is to ensure that disability policy will have an impact in all corners of society.¹⁴⁷¹

They work on the premise that everyone is entitled to full participation in society, regardless of functional ability. They do this by:

- monitoring and analysing developments
- proposing methods, guidelines and guidance
- disseminating knowledge
- initiating research and other development work, and
- providing support and proposing measures to government.

Employers who hire workers with reduced working capacity are eligible for the wage subsidy scheme funded by the Public Employment Services. This also applies to currently employed workers who acquire a disability. The subsidy amounts to a set percentage based on the full salary and is subjected to a time limit of four years. In special cases the duration may be extended to support the employer into retaining the disabled employee.

As part of the Technical Aid and Adaptation scheme, the employer receives a grant to adjust the workplace while the disabled employee receives funding to acquire personal technical aids. The scheme is made available to newly hired disabled employees as part of the wage subsidy scheme by the Public Employment Services, and to existing employees who acquire a disability by the Public Insurance Office.¹⁴⁷²

Employers who hire disabled employees who require assistance are supported through one of 2 Personal Assistance schemes. The first scheme offers the funds to cover the appointment of an existing employee to assist the disabled worker. The second option concerns disabled workers who require assistance in both their personal and professional lives: they are eligible for

¹⁴⁷⁰ <https://sweden.se/society/swedens-disability-policy/>

¹⁴⁷¹ <http://www.mfd.se/other-languages/english/>

¹⁴⁷² <http://www.euroblind.org/convention/article-27--work-and-employment/nr/136>

a specific allowance to cover the hire of a personal assistant who will provide them with the necessary support in both their private and job related tasks.

The main legislations concerning the measures to support disabled workers in Sweden are SFS 2000:630 and SFS 2000:628. These measures are mainly administered by the Public Employment Services.

The 1977 Act on Environment in Working Life (AML), amended in 2008, states that both public and private sector employers must take the necessary measures to improve working conditions. The provisions include risk prevention and the adjustment of the workplace based on each worker's needs, including disabled workers.

The Developing Employment scheme targets a better job inclusion for disabled workers. Arrangements are available to provide the disabled worker with specific training, if required, and other tailored adjustments when starting a new job. The scheme provides a wage subsidy to the employer and personal support to both the employer and employee for up to a year.

As part of the Technical Aid and Adaptation scheme, the disabled employee may receive an allowance for personal technical aid and the employer may receive funding to adjust the workplace. The scheme is available for new hired disabled employees as part of the wage subsidy scheme and it is paid for the Public Employment Services. For existing employees who acquire a disability or in the case of on-going employment without wage subsidy the scheme is paid for by the entity referred to as the Public Insurance Office.¹⁴⁷³

Disabled workers who require personal assistance may receive it in 2 ways. The first scheme offers the funds to cover the appointment of an existing employee to assist the disabled employee. The second option concerns disabled workers who require assistance in both their personal and professional lives. They are eligible for a specific allowance to cover the hire of a personal assistant who will provide them with the necessary support in both their private and job related tasks.

The Swedish supported employment programme is known as Special Introduction and Follow-Up Support (SIUS). The programme begins with personal support provided to the job seeker by a SIUS Consultant. The consultant also performs outplacement and then offers guidance to both employee and employer during the introduction and adaptation period.

The Safety Employment scheme concerns those disabled people who are not able to compete on the open labour job market because of a reduced working capacity. The scheme is somewhat similar to a supported employment plan in that it applies to ordinary workplaces and enables employers to receive high levels of personal assistance, support and wage subsidies.

A specific subsidy is available for sheltered employment in the public sector. It concerns workers whose working capacity is severely reduced by a functional disability.

¹⁴⁷³ <http://www.mfd.se/other-languages/english/>

Supported employment in Sweden is by far the jewel in the crown of Swedish empowerment to persons with disabilities, including and specifically persons with intellectual disabilities. Generally acknowledged as a positive Nordic trait, the truth is slightly different.

“It is like the priming work you do before painting a wall. If it is performed badly, or if you have chosen the wrong colour, it will stay with you throughout the entire process,” as Johanna Gustafsson from the Örebro university told one of the many seminars held during the 2018 INKO conference. The situation in the different countries can be crudely summed up like this: Sweden has the largest projects, Norway has come the furthest with the education while the term Supported Employment is nearly unknown in Denmark – despite the fact there are a few projects running in some municipalities. In Finland an upcoming welfare and province reform has overshadowed all other debate, and in Iceland the method is being used in the capital only.

“It is now 25 years since I went to Sweden and taught the method to the first job coaches there,” said Grete Wangen from the Oslo Metropolitan university. She is also the leader of SENO, Supported Employment Norge.

As early as in 1992, the Norwegian employment service began a three year long trial called *Arbeid med bistand* (Jobs with support), which was inspired by Supported Employment. This was later made a permanent measure within the employment service, mainly in social enterprises.¹⁴⁷⁴

In Sweden a similar yet considerably more comprehensive project was established, called SIUS, *Särskilt introduktions- och uppföljningsstöd* (Special introduction and follow-up support).

“The last time I checked, there were 927 SIUS consultants within the employment service, and if you add just over 1,000 working in the municipalities there are 2,000 consultants working with Supported Employment,” said Bertil Johansson, who has been involved from the very beginning and who now heads the Swedish organisation, SFSE.

He and other conference participants underlined that there are many variations of Supported Employment. Not all have it as a goal to create salaried jobs, and some are more focused of the training. Sometimes there is also a need for more – there are programmes for Supported Living and Supported Leisure. Since the form varies and the projects are often not permanent measures but limited in time, there have been few scientific evaluations of the projects.

“There is also the risk that the method is being tailored to the organisation and not the other way around. But we cannot simply blame the system. This is also about our belief in the individual. Are we really working with those who need SE, or are we using resources on those who would manage on their own?” said Bertil Johansson.¹⁴⁷⁵

Sweden stands out for its comprehensive statutory protection of employees against arbitrary or unjustified dismissal consisting in the Employment Protection Act No. 80 of 1982 (widely referred to by the initials LAS), which represents a further development of original legislation dating from 1974. When first introduced, on the basis of tripartite negotiations, trade unions feared that the

¹⁴⁷⁴ <http://www.nordiclabourjournal.org/i-fokus/in-focus-2018/working-environments/article.2018-10-15.1253121543>

¹⁴⁷⁵ Ibid.

high standards of workers' rights, which formerly were agreed on in collective agreements, would be quickly weakened by politicians. However, with the time passing by, the LAS acted to uphold a standard of employment protection. With decreasing collective bargaining power, the act can be expected to gain even more importance. In 2007, the act was amended and flexibility measures, such as the possibility to make short-term contracts, were introduced in its article 5.

¹⁴⁷⁶

Employers' obligations under the Swedish Employment Protection Act No. 80 of 1982 seem to be the key for achieving the OECD's top disability employment rate. Most importantly, 50% of disabled persons with reduced ability to work are employed, which is significantly higher compared to countries such as Denmark, where that rate is as low as 26%. Indeed, persons with disabilities in Sweden enjoy the same rights in employment protection as their non-disabled counterparts, as lesser capability because of age, illness or acquired disability is not an objective ground for dismissal and employers must make all reasonable efforts to retain the worker.

At present, changes to article 22 on collective redundancies (which possibly affects article 23) are in the pipeline. Beyond the act's standards for accommodations which must be provided by employers, specific guidance on reasonable accommodation and employers' incentives for workplace adaptation are needed.

Indeed a success story, with a track record of numbers and statistics to support such a statement: In 2010, Sweden's employment rate of persons with health problems or disability was at 62%, the highest in the entire OECD.

In addition, around 50% of persons with disabilities and reduced ability to work are in employment – a situation, which is significantly different from other countries such as Denmark, where only 26% of disabled persons with reduced ability to work are being employed.

In 2009, 75% of Swedish employees with reduced ability to work reported that they required adaptation of their working conditions, such as adapted work duties, work rates, working time, aids etc, and the absolute majority stated that they received the help needed. In the last decade, these numbers have increased progressively. ¹⁴⁷⁷

¹⁴⁷⁶ <https://zeroproject.org/policy/sweden/>

¹⁴⁷⁷ Ibid.

Perception Survey Analysis

In order to ensure that the extensive research carried out in this document is tallied and buttressed by real-time feedback on the ground within the various countries and jurisdictions of the European Union, this project also sent a perception survey to two key elements who could enlighten the project as to what actual, streamlined needs are within the European Union.

The first survey was sent to various non-governmental organisations, associations, social enterprises and foundations throughout Europe who deal, directly and/or indirectly, with the welfare, inclusivity and employment assistance of persons with intellectual disabilities. In fact, the survey stated that:

'The objective of this initiative is to create a set of modules which will assist persons of an intellectual disability to engage in independent living. This will be achieved by focusing on the current need to enhance communication, literacy and numeracy skills of persons with an intellectual disability so that they will have the means to be fully integrated within the social and economic national frameworks and also to be able to realize their inherent rights for independent living.'¹⁴⁷⁸

Whilst the first survey was thus sent to the service providers, the second survey was sent – again throughout Europe - to the service users themselves: persons with intellectual disabilities who, by means of the various initiatives of the service providers, are already being assisted in procuring or enhancing the desired skill sets which is so essential for their societal needs.¹⁴⁷⁹

¹⁴⁷⁸ Please refer to the enclosed first survey immediately after this text.

¹⁴⁷⁹ Please refer to the enclosed second survey immediately after this text.



Erasmus+

ENHANCING SOCIAL AND ECONOMIC INCLUSION THROUGH INDEPENDENT LIVING



6 Participating countries:

Malta (MFOPD), **Belgium** (GTB), **Finland** (Vates-Säätiö), **Greece** (Idryma Prostatias Aprosarmoston Paidon I Theotokos), **Sweden** (Stiftelsen Activa / Örebro Län), **United Kingdom** (Northern Ireland – Orchardville Society)

Project Reference: 2017-1-MT01-KA204-026971

Start: 01-09-2017 - **End:** 31-12-2020

Coordinator:

Malta Federation Organisations Persons with Disabilities

Hal Caprat Complex, No 1 Niche,

Braille Street,

St Venera, Malta

<http://www.mfopd.org>, email: info@mfopd.org

Organisation type:

Non-governmental organisation/association/social enterprise

The objective of this initiative is to create a set of modules which will assist persons of An intellectual disability to engage in independent living. This will be achieved by Focusing on the current need to enhance communication, literacy and numeracy skills of persons with an intellectual disability so that they will have the means to be fully integrated within the social and economic national frameworks and also to be able to realize their inherent rights for independent living.

Your assistance in helping us out with this questionnaire would be greatly appreciated.

Questionnaire for Service Providers

Please select which statement mainly describes your organization?

Supported Employment Organization

Yes/No

Government funded Employment Service

Yes/No

Public sector Health & Social Care Organization

Yes/No

Other (Please specify) _____

Does your organization directly support people with Learning Disabilities? Yes/No

What type of support do you offer? (Please select from menu – you can choose more than one)

Training/Vocational Services	Yes/No
Employment Services	Yes/No
Supported Housing	Yes/No
Community Projects	Yes/No
Social Enterprises	Yes/No
Other/s (please specify)	Yes/No

If you directly offer training please tell us about the courses you deliver including the name, duration, level and accrediting body if applicable. Training has been grouped into 5 areas, please state if not applicable

Literacy Skills	Yes/No
Numeracy Skills	Yes/No
Social Skills	Yes/No
Communication Skills	Yes/No
Independent Living Skills	Yes/No

What percentage of persons with learning disability who participate in these programs complete your program?

All of them, 100%	Yes/No
More than 50% of them	Yes/No
Less than 50% of them	Yes/No

If the answer to the above is not 100%, what are the main reasons for non-completion?

Is any of the above training offered elsewhere within your area, ex. college, other service providers?

Yes/No

If Yes, please provide details of any training offered elsewhere that you know of including name, duration, level and accreditation body:

Are there any gaps in training provision you have identified for persons with learning disabilities within your organization/ geographic area? What would you add?

Please select from the list below what training areas you think would encourage independent living skills:

Functional Literacy (e.g reading transport timetables, signage, reading instructions, identifying letters & logos etc)

Yes/No

Money Management (e.g budgeting, using banks, cost of goods and services, saving)

Yes/No

Independent Travel Training (e.g using buses, trains, walking safely, personal safety)

Yes/No

Healthy Eating (e.g basic cookery, balanced diet, food groups)

Yes/No

Domestic Housekeeping (e.g laundry, cleaning, tidying, cooking, shopping)

Yes/No

Communication (e.g verbal and non-verbal communication, listening skills)

Yes/No

Social Skills (e.g team building, resilience, appropriate behaviour, confidence building)

Yes/No

Employability Skills (e.g interview skills, job search, CV development, careers awareness)

Yes/No

Other/s (please state):

Please state what you think are the biggest challenges people with learning disability need to overcome to become more independent?

Lack of training opportunities in the area

Yes/No

Literacy skills

Yes/No

Money Management skills

Yes/No

Confidence

Yes/No

Attitudes of others eg parents/carers, employers, service providers, general public

Yes/No

Personal safety concerns

Yes/No

Lack of funding to deliver programs

Yes/No

Other/s, please specify:

How many people per annum does your organization support?

How many of them do you believe would actually desire to participate in a functional academic skills and/or communication skills program?

Please state which country your organization operates in:

Please state if your organization is mostly or partially run by state funds or EU funds:

This part of the Questionnaire is optional:

If you would like to be kept informed about the progress of the project and the training tools that are developed please state your contact details:

We would appreciate your organisation's name, address and contact information.

The answers that you have supplied in this project will be treated with the strictest confidentiality and only the result of the survey will be published, not the individual answers sent in by the organizations such as yours.

Thank you for completing the survey!



ENHANCING SOCIAL AND ECONOMIC INCLUSION THROUGH INDEPENDENT LIVING



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Your assistance in helping us out with this questionnaire would be greatly appreciated.

Questionnaire for Service Users

Please tick which of the following best describes where you live:

I live with my family (or relatives) and I am dependent on them	
I live with my family (or relatives) and am independent for most activities	
I live in supported housing	
I live independently with little support	
Other	

What is your age range?

18 – 30	
30 – 40	
40+	

What type of daily activities do you take part in (please tick yes or no from the list)?

Vocational Education & Training Day program	Yes/No
Work Experience	Yes/No
Paid Employment	Yes/No
Volunteering	Yes/No
Training Courses	Yes/No
Community Activities	Yes/No
Arts and Crafts	Yes/No
Leisure/Social Activities ex. swimming, gym, playing sport etc.	Yes/No

Others: _____

Rate your Skills in the Following Tasks (Poor, Average and/or Good)

TASK	POOR	AVERAGE	GOOD
Reading a paragraph			
Writing a note			
Using numbers			
Calculating			
Using pocket money			
Using a timetable, following the clock			
Using technology: mobile, computer, Hoover, washing machine etc.			
Communicating with friends and family			
Communicating with people in the community			

How often do you engage in the following?

TASK	Daily	Weekly	Monthly	Never
Read a book / magazine				
Read letters and correspondence from family				
Read labels, social signs, shopping lists, recipes, housekeeping bills				
Write				
Use a mobile phone				
Use a computer				
Send Emails or text messages				
Use money				

**In a literacy skill training program, it would be important for you to learn about:
(You can choose more than one)**

READING:

Reading a book / magazine / newspaper	
Reading instructions (e.g. a recipe, how to make something, game rules)	
Reading Medication	
Reading transport timetables and signs	
Reading social signs & logos	
Reading a TV or cinema program	
Reading a weather report / map	
Reading a menu, a catalogue, or other index	
Reading information relating to public services	

WRITING:

Filling in a form	
Taking a message	
Writing lists (e.g. for shopping, things to do)	
Writing an email	
Using social media networks	

**In a numeracy skill training program, it would be important for you to learn about:
(You can chose more than one)**

Measurements (length, height)	
Measurements (distance) and orientation to space	
Weights (for cooking and shopping)	
Reading the time	
Time orientation (date, month, seasons)	
Planning time and using a diary/planner/agenda	
Money calculations	
Money management	
Budgeting	
Using banks	
Paying bills	
Shopping	
Shopping on-line	
Reading temperature, ex. a thermometer	

In a communication skill training program, it would be important for you to learn about:

(You can choose more than one)

Non-Verbal Communication	
Listening Skills	
Understanding instructions	
How to start a conversation	
How to keep a conversation going	
Using a phone	
Talking with strangers	
Working in a team	
Expressing feeling and thoughts	
Giving instructions or explanations	

Which learning modality helps you learn better? (You can choose more than one)

Visual (seeing, watching a model)	
Auditory (listening)	
Verbal (talking)	
Practical (tactile, manipulating objects, doing the task)	

Service Providers – Analysis of Questionnaire

In order to ensure that this project has a holistic grasp of the experiences of service providers throughout Europe, a number of surveys were distributed to established NGOs, foundations, not for profit entities and other representatives of civil society who are duly registered as offering services to persons with disabilities in their respective jurisdictions.

The partner organisations forming part of this project were entrusted in zoning in on specific countries and executing the necessary translations of the survey in order to receive as accurate a sample as possible.

Salient features of the Questionnaire for Service Providers are as follows:

- The questionnaire was translated into eight languages, including English, French, Italian, German, Flemish, Swedish, Finnish and Greek.
- 142 entities from twenty five different countries and jurisdictions replied, including the jurisdictions of England, Northern Ireland, Wales, Scotland, Malta, Italy, Sicily, Belgium, Germany, Austria, Spain, Portugal, Finland, Norway, France, Bulgaria, Sweden, Denmark, Greece, Albania, Macedonia, Serbia, Romania, Cyprus and Latvia. This underlines the fact that the survey was widely and properly distributed throughout Europe's main service providers in order to ensure that the feedback received would tally with the thoughts and initiatives of the major service providers irrespective of the zone of operations within Europe.
- 46 entities (32.39%) of the respondents identified themselves as a supported employment organisation. 37 entities (26.06%) identified themselves as a government funded employment service. 23 entities (16.20%) identified themselves as a public sector health and social care organisation. 36 entities (25.35%) did not identify themselves with any of the above labelling exercise, with the overall majority of these (91.67%) describing themselves as either a national or regional representative organisation (or federation) representing persons with disabilities.
- From the 142 service providers answering the questionnaire, 136 of these (95.77%) stated that their organisation directly supports persons with learning disabilities.
- The questionnaire asked the service providers to identify five specific types of support services which they offer, with an option of inserting additional types of support not mentioned. In order of precedence, the feedback was as follows:

Training and Vocational Services	(82.4%)
Community Projects	(80.6%)
Employment Services	(69.8%)
Advocacy and Representation	(61.5%)
Social Enterprises	(51.7%)
Supported Housing	(24.6%)

- When asked what courses do their particular organisation offer to persons with learning disabilities, those who did offer such courses answered in the following fashion:
 - 43.38% offer all five listed skill inductions, namely Literacy Skills, Numeracy Skills, Social Skills, Communication Skills and Independent Living Skills.
 - 36.03% offer only (sometimes limited) skill inductions in Social Skills and Independent Living Skills.
 - 20.59% offer skill inductions in Literacy, Numeracy and Communication Skills.
 - 16.91% also mentioned additional skill building inductions, mostly (listed as per order of preference) related to mechanical skills related to sheltered employment, mechanical skills related to specific hobbies and pastimes (pottery, gardening etc) and sessions related to moral/religious induction (mostly when the entity in question is church owned).
- Only 21.32% of respondents stated that they ensure a participation completion rate of 100% of their respective service users. 55.15% stated that more than half of their service users complete their programs, whilst 23.53% of the respondents stated that less than half their service users finish their programs. When analysing the main reasons cited for the service users not achieving a 100% participation completion, a number of reasons were recurring (and listed here in order of frequency):
 - Pressure from the service users' immediate family to halt induction;
 - Distance and logistical problems;
 - Enrollment in other initiatives by the service users;
 - Illness and/or the need for therapy outside the domain of the service giver;
 - Indifference and lack of initiative by the service users.
- The majority of respondents (57.35%) confirmed that any or all of the above training is indeed offered elsewhere within their area. When it came to service providers who described themselves as either a national or regional representative organisation (or federation) representing persons with disabilities, the amount shot up to nearly a hundred percent reply (96.77%). Names of other organisations were given as examples of examples of centres offering such services in the vicinity of the respondents. These mostly fell into the categories already mentioned in the questionnaire, but which were not contacted for the purposes of this research. A small amount of respondents who furnished names of such centres offering such training within their area fell under the category of an educational institution, mostly government or state financed (18.2%).
- The questionnaire respondents were explicitly asked to identify gaps in the training provisions for persons with learning disabilities within their organisation and/or area. The feedback (in order of frequency) was as follows:
 - Training is mostly done without a proper curriculum;
 - Training is not hands-on, mostly theoretical and not really helpful in real life;
 - Training does not have a sense of continuity and a KPI ¹⁴⁸⁰ structure;
 - Training has no coherent end assessment if the service user is ready to face independent living and societal integration at the end of the sessions;

¹⁴⁸⁰ Key Performance Index

- Training depends on the zeal and integrity of the instructors, mostly on voluntary and/or part-time basis;
 - Training is looked upon as a means of 'parking' the service user by his/her family instead of an essential prerequisite for societal integration and independent living.
- When specifically asked which training areas do the respondents think would encourage living skills, their answers (in order of preference) were as follows:

Employability Skills
Social Skills
Money Management
Communication
Functional Literacy
Sports and/or hobbies and/or Pastimes ¹⁴⁸¹
Independent Travel Training
Domestic Housekeeping
Healthy Eating

The above replies underline the fact that there is indeed a huge shortfall of training areas on offer which really and truly create a holistic solution for persons with intellectual disabilities to enjoy a truly independent living (note the last three training areas – the absence of such induction will never truly create an independent living environment for the service users).

- The respondents were asked to state their take on what they regard as the biggest challenges that people with learning disabilities need to overcome in order to become more independent. Their feedback (in order of preference) was as follows:

Lack of funding to deliver programs;
Economic Restraints suffered by the Service User (Poverty Line);¹⁴⁸²
Attitude of Others;
Confidence;
Lack of Training Opportunities in the Area;
Personal Safety Concerns;
Money Management Skills;
Literacy Skills.

- The questionnaire asked the respondents how many persons annually their organisation supports. 19.85% of respondents declared an annual carrying capacity of not more than fifty persons. 57.35% of respondents declared an annual carrying capacity of between fifty and one hundred persons. 22.79% of respondents confirmed an annual carrying capacity of more than one hundred persons.

¹⁴⁸¹ This training area was not suggested by the questionnaire itself but was mentioned frequently by the service user respondents: indeed more frequently than other training areas suggested by the questionnaire.

¹⁴⁸² This factor was not suggested by the questionnaire itself but the vast majority of the respondents who inputted extra factors for this particular question stated that the bulk of their clients come from economically challenged households, with their intellectual disabilities being furthermore enhanced due to their financial, stratificational and social grouping within society.

- The absolute majority (87.64%) of respondents stated that they believe that their service users would actually desire to participate in a functional academic and/or communication skills program.
- The absolute majority of respondents (94.2%) stated that their organisation is mostly or partially run by state and/or EU funds.

Service Users – Analysis of Questionnaire

In order to ensure that this project has a holistic grasp of the actual needs of service users throughout Europe, a number of questionnaires were distributed to service users who reside and/or participate in the initiatives of established NGOs, foundations, not for profit entities and other representatives of civil society who are duly registered as offering services to persons with disabilities in their respective jurisdictions.

The partner organisations forming part of this project were entrusted in zoning in on specific countries and executing the necessary translations of the survey in order to receive as accurate a sample as possible.

Salient features of the Questionnaire for Service Users ¹⁴⁸³ are as follows:

- The questionnaire was translated into nine languages, including English, French, Italian, German, Flemish, Swedish, Finnish, Maltese and Greek.
- 856 persons from twenty five different countries and jurisdictions replied, including the jurisdictions of England, Northern Ireland, Wales, Scotland, Malta, Italy, Sicily, Belgium, Germany, Austria, Spain, Portugal, Finland, Norway, France, Bulgaria, Sweden, Denmark, Greece, Albania, Macedonia, Serbia, Romania, Cyprus and Latvia. This underlines the fact that the survey was widely and properly distributed throughout Europe's main service providers in order to ensure that the feedback received would tally with the thoughts and initiatives of the actual service users irrespective of the zone of operations within Europe.
- It is imperative to note that during the compilation and extrapolation period of the questionnaire analysis, questionnaires emanating from the same organisation had evident similarities in the replies submitted, suggesting to the researchers that the questionnaire was debated as a group and thus some answers project a group 'decision' instead of an individual opinion.
- 381 service users (44.51%) live with their family or relatives and are dependent on them. 86 service users (10.05%) live with their family or relatives but are independent for most activities. 269 service users (31.43%) live in supported housing. 64 service users (7.48%) live independently with little support. 56 service users (6.54%) were listed in the 'others' category.
- 42.41% of respondents were aged from forty years of age and over; 33.76% were aged between thirty to forty years; 23.81% were aged between eighteen and thirty years of age.

¹⁴⁸³ All service users were targeted to be persons with intellectual disabilities.

- When asked which daily activities did they take part in, the responses were as follows (in order of preferential mention):

Arts and Crafts
 Work Experience
 Leisure and Social Activities
 Community Activities
 Training Courses
 Volunteering
 Paid Employment
 Vocational Education and Training Day Programs
 Others ¹⁴⁸⁴

The results of this particular question continues to reinforce the findings of Question Number 6 in the Service Providers' questionnaire where the Service Providers were asked to give the main reasons for non-completion of programs as a percentage from their service users. ¹⁴⁸⁵

- When specifically asked to rate their own skills in a number of tasks, the results were as follows:

Task	Poor	Average	Good
Reading a Paragraph	39.4%	42.8%	17.8%
Writing a Note	22.7%	38.6%	38.7%
Using Numbers	36.2%	40.1%	23.7%
Calculating	41.5%	29.7%	28.8%
Using Pocket Money	37.0%	31.4%	31.6%
Using a Timetable; Following the Clock	29.4%	41.8%	28.8%
Using Technology ¹⁴⁸⁶	38.9%	44.4%	16.7%
Communicating with Friends and Family	12.6%	28.3%	59.1%
Communicating with People in Community	26.4%	37.1%	36.5%

¹⁴⁸⁴ A sizeable chunk of activities mentioned in others (31.46%) referred to various activities related to religious initiatives; mostly coming from two sets of service users – persons with intellectual disabilities who attend church run institutions and persons with intellectual disabilities who live with their families within the community but attend various church-organised initiatives.

¹⁴⁸⁵ The feedback (in order of frequency) for Question 6 was as follows:

Training is mostly done without a proper curriculum;

Training is not hands-on, mostly theoretical and not really helpful in real life;

Training does not have a sense of continuity and a KPI structure;

Training has no coherent end assessment if the service user is ready to face independent living and societal integration at the end of the sessions;

Training depends on the zeal and integrity of the instructors, mostly on voluntary and/or part-time basis;

Training is looked upon as a means of 'parking' the service user by his/her family instead of an essential prerequisite for societal integration and independent living.

The fact that subject matter with no real direct financial/employment injection in the lives of the service users scored so highly in the answers to this question re-affirms and underlines the reasons mentioned in this footnote given by the service providers.

¹⁴⁸⁶ The Questionnaire gave specific examples of technology: mobile, computer, Hoover, washing machine etc.

- When specifically asked to quantify their engagement in the following tasks, the results were as follows:

Task	Daily	Weekly	Monthly	Never
Read Book/Magazine	10.8%	26.4%	32.2%	30.6%
Read letters/correspondence from Family	6.9%	40.5%	31.8%	20.8%
Write	26%	31.2%	31.6%	11.2%
Use a mobile phone	48.2%	10.6%	21.5%	19.7%
Use a computer	12.6%	28.4%	30.1%	28.9%
Send Emails/Text Messages	26.8%	31.4%	28.4%	13.4%
Use Money	22.3%	28.6%	31.5%	17.6%

- The service users were asked what they deem to be important to learn in a literacy skill training program. Their replies (in order of preference and frequency) were as follows:

Reading Instruction (ex. A recipe, how to make something, game rules);
 Reading a book/magazine/newspaper;
 Reading medication;
 Reading information relating to public services;
 Reading transport timetables and signs;
 Reading social signs and logos;¹⁴⁸⁷
 Reading a menu, a catalogue or other index;
 Reading a weather report/map;
 Reading a TV or cinema program

- When it came to writing, their choice of what they deemed to be important to learn were as follows (in order of preference and frequency):

Using social media networks;
 Writing lists (ex. For shopping, things to do etc);
 Writing an email;
 Taking a message;
 Filling in a form

- The service users were also asked what would be important for them to learn about in a numeracy skill training program. Their answers (in order of preference and frequency) were as follows:

Shopping;
 Money calculation;
 Planning time and using a diary/planner/agenda;
 Using banks;
 Money management;
 Budgeting;
 Shopping on-line;

¹⁴⁸⁷ The two choices of Reading social signs & logos and Reading a menu, a catalogue, or other index scored the same frequency points in the answers submitted by the service users; thus both these topics placed 6th in preference overall.

Weights (for cooking and shopping);
Measurements (length, height);
Reading temperature, ex. A thermometer;
Paying bills;
Measurements (distance) and orientation to space;
Reading the time;
Time Orientation (date, month, seasons)

Such a pattern of preference and frequency underlines the fact that the interviewed service users, albeit benefiting from a basic form of skill training program within the institution that they attend (irrespective of country/jurisdiction), are somewhat lacking – generally speaking - in being inducted in comprehensive, hands-on training programs which enhance their needed life skills for independent living and societal inclusion.

- The service users were also asked to pinpoint what would be important for them to learn about in a communication skill training program. Their replies (in order of frequency and preference) were as follows: ¹⁴⁸⁸

Working in a team;
Giving instructions and explanations;
How to keep a conversation going;
Expressing feeling and thoughts;
Talking with strangers;
Non-verbal communication;
Understanding instructions;
How to start a conversation;
Using a phone;
Listening skills

- Finally, the service users were asked which learning modality they think will help them learn better. Their replies (in order of frequency and preference) were as follows:

Practical (tactile, manipulating objects, doing the task)
Visual (seeing, watching a model)
Verbal (talking)
Auditory (listening)

¹⁴⁸⁸ Again, these answers buttress the replies given in the previous question and the service users' General need for a comprehensive, hands-on training programs which enhance their needed life skills for independent living and societal inclusion.