Introduction of the submitting organization

Estonian Chamber of Disabled People, celebrating 25 years of work this year, is an independent and professional body in the field of shaping disability policy and public opinon on disability issues. The aim of Estonian Chamber of Disabled People is to increase the standard of life of people with disabilities and chronicle disease patients, inclusion into the society and full realisations of opportunities. The organisation is joining together 48 disability and chronicle disease patient organisations. www.epikoda.ee

At EU level, The Estonian Chamber of Disabled People is represented at:

European Economic and Social Committee; European Disability Forum; European Patient Forum.

We closely co-operate with the Baltic states, Nordic countries and other countries of the world.

People with disabilities play a key role in the work of the the organization – our governing bodies have at least 50% representatives of people with disabilites themselves or family members of a disabled person. The organisation joins together all the different DPO-s in Estonia and the membership is gradually growing.

The shadow report is drawing attention to the shortcomings of the UN CRPD implementation, relying on real life experience of people with disabilities in Estonia and proposing recommendations how to solve the problems.

Drafting the alternative report, the following Civil Society organisations were consulted: All the 48 members of our own network - The Estonian Chamber of Disabled People, Estonian Human Rights Centre, Estonian Union for Child Welfare, Estonian Patients Union and Estonian Agrenska Foundation. With expert opinions the following DPO-s were contributing to the alternative report: Estonian Blind Union, Estonian Deafblind Association, Estonian Association of the Deaf, Estonian Association of Hard of Hearing People, Estonian Autism Society and NGO Accessibility Forum.

The report is based on systematic work – on implemented studies, national strategies, analysis of legal acts and statistics and interviews with leaders of the disability movement, questionnaires and expert opinions.

Background information and statistics

In 2018 there were 1 319 133 inhabitants in Estonia. Average gross monthly wage was 1291 euro and average level of unemployment was 5,2%. At the same time, average old-age pension was 447 euro. At 2017, average life-expectancy for men was 73,7 years and 82,3 years for women.

In 2018 there were 157 900 persons with disabilities in Estonia, what counted for 12% of the population. By age group, most persons with disabilities are in the older age group, over one-third are 55 years old or older. Comparing with 2010, the number of persons with disabilities have increased by almost 25%.

Average benefits for disabled child of non-extensive support need in 2018 was 69 euro per month, in case of more extensive support need was 80 euro per month. Benefit for parent of disabled child was 19 euro per month. The benefits for people with disabilities in emloyment depend on type and severity of the disability and will fall between 16–53 euro per month. Support for people with disabilities of retirement age was in 2018 depending on the severity of the disability and will fall between 12–40 euro per month. The work capacity benefit was in 2018 217 euro and in case of total incapacity for work 318 euro per month. All those benefits are applyied only in case of officially having been evaluated as disabled or with reduced work capacity.

Students with special needs can apply for a scholarship, with a monthly amount between 60–510 euros in 2018.

Contents

Introduction of the submitting organization	1
Article 4 General obligations	3
Article 5 Equality and non-discrimination	5
Article 6 Women with disabilities	6
Article 7 Children with disabilities	8
Article 9 Accessibility	10
Article 12 Equal recognition before the law	12
Article 14 Liberty and security of the person	15
Article 17 Protecting the integrity of the person	18
Article 19 Living independently and being included in the community	19
Article 21 Freedom of expression and opinion, and access to information	22
Article 24 Education	24
Article 25 Health	27
Article 26 Rehabilitation	30
Article 27 Work and employment	34
Article 28 Adequate standard of living and social protection	37
Article 29 Participation in political and public life	40
Article 33 National implementation and monitoring	43

Article 4 General obligations

The Constitution of the Republic of Estonia states that people with disabilities are under special protection of the state and municipalities.¹

The topic of protecting the rights of people with disabilities is directly or indirectly incorporated into several governmental development plans. ^{2 3 4 5 6 7} The only holistic state level strategy on the rights of people with disabilities – Republic of Estonia general concept for disability rights ⁸ Standard rules on securing equal opportunities for people with disabilities – is from May 15th 2001 and is outdated for both content and format.

Governmental action plan 2016–2019 what is wording the main principles of the ruling coalition, is mentioning protection and development of the human rights of people with disabilities on one occasion, addressing the topic of deleting the study loans of parents of severely disabled children.⁹ 10

Simultaneously to drafting the current report, there are three major reforms going on in Estonia: administrative reform¹¹, state reform¹² and work capacity reform¹³. Administrative reform is touching almost all municipalities, aiming at increasing their capacity, state reform should diminish the level of central governance. It's not yet known, how the situation of people with disabilities will change as a result of those reforms.

¹ Constitution of Republic of Estonia (13.08.2015). *State Currier I.* Extract as of January 2018 https://www.riigiteataja.ee/akt/115052015002

² Transport Development Plan 2014–2020. Ministry of Economy and Communication. Extract as of January 2018 https://www.riigiteataja.ee/aktilisa/3210/2201/4001/arengukava.pdf

³ Main principle of Culture Policy until year 2020. Parliament decision, became into force 12.02.2014. Extract as of January 2018 http://www.kul.ee/sites/kulminn/files/kultuur2020.pdf

⁴ Wise parents, nice children, strong society. Development Plan for Children and Families 2012–2020 (2011). Ministry of Social Affairs. Extract as of January 2018 https://www.sm.ee/sites/ default/files/content-editors/Lapsed_ja_pered/laste_ja_perede_arengukava_2012_-_2020.pdf

⁵ Estonian Strategy for Life-long Learning 2020. Ministry of Education and Science. Extract as of January 2018 https://www.hm.ee/sites/default/files/strateegia2020.pdf

⁶ Welfare Development Plan 2016–2023. Ministry of Social Affairs. Extract as of January 2018 https://www.sm.ee/et/heaolu-arengukava-2016-2023

⁷ Competition plan Estonia 2020. State Office of Estonia. Extract as of January 2018 https://riigikantselei.ee/et/konkurentsivoime-kava-eesti-2020

Republic of Estonia general concept for disability rights Standard rules on securing equal opportunities for people with disabilities. Shortened and adapted on UN General Assembly resolution 48/96. Approved by Government of Republic session of May 16, 1995 under agenda point 11. Estonian Chamber of Disabled People. Extract as of January
2018 https://www.valitsus.ee/sites/default/files/content-editors/arengukavad/puuetega_inimeste_vordsete_voimaluste_loomise_standardreeglid.pdf

⁹ Study Support and Loan Act (01.01.2018). *Riigi Teataja State Currier I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/834802?leiaKehtiv

¹⁰ Government of the Republic and DPO-s memorandum on co-operation principles (2012). Tallinn. Extract as of January 2018 http://www.epikoda.ee/wp-content/uploads/2012/03/koost%C3%B6%C3%B6memorandum.pdf

¹¹ Ministry of Finance Administration reform homepage. Extract as of January 2018 https://haldusreform.fin.ee

¹² Government of Republic of Estonia State Reform homepage. Extract as of January 2018 https://www.valitsus.ee/et/riigireform-tegevuskavas

Work capacity reform. Homepage of Estonian Unemployment Office. Extract as of January 2018 https://www.tootukassa.ee/toovoimereform

Some initiatives in the research and development field for introducing universal design principle to design of goods, services, equipment and buildings have been taking place, without yet becoming a systematic approach. In 2012 comprehensive guidelines on universal design Planning and implementing an inclusive living environment for all was elaborated in co-operation with Astangu Vocational Rehabilitation Center, Estonian Union of Architects, Estonian Design Center and Estonian Academy of Arts. ¹⁴

During last decade involving DPO-s into decision making processes have considerably improved.¹⁵ At the same time a trend of formal involvement have occurred, where people with disabilities can express their views during the consultation processes, but their opinion will virtually not always be taken into account.

DPO-s are possessing a lot of specific competences, but participating in the decision making processes is requiring more and more professionalism each year that passes. In seeking to become an equal partner to the state in the involvement process, DPO-s are often experiencing a lack of resources, be it time, legal competence and financial means. ¹⁶

RECOMMENDATIONS

- In co-operation with DPO-s draft a holistic, modern and CRPD driven state level strategy and action plan for protection of the rights of people with disabilities, along with broader consultation with DPO-s.
- Secure for the specialists in the field (architects, interior designers, city- and landscape planners, constructors, service and product designers etc.) education and training on accessibility and universal design.
- Observe Best practice of Involvement into decision making the same way at state and municipal level.
- Support sustainable functioning and development of DPO-s.

¹⁵ Best practice of Involvement into decision making. State Office of Estonia. Extract as of January 2018 https://riigikantselei.ee/et/kaasamise-hea-tava

¹⁴ Falkenberg, V., Kotsjuba, D., Lepik, P.-R., Levald, A., Lillemaa, M., Lubjak, I., Maas, H., Melioranski, R.-H., Mikola, A., Peetsalu, K., Pukk, M., Rummel, K., Vaikla, T.-K., Valk, V. Planning and implementing an inclusive living environment for all (2012). Astangu Vocational Rehabilitation Center. Extract as of January 2018 http://www.astangu.ee/fileadmin/media/PTAK/Koiki_kaasava_elukeskkonna_kavandamine_ja_loomine.pdf

¹⁶ Questionnaire and focus-groups for DPO-s (2016–2017). Estonian Chamber of Disabled People.

Article 5 Equality and non-discrimination

According to the Constitution of Republic of Estonia, everyone is equal before the law. No one may be discriminated against on the basis of nationality, race, colour, sex, language, origin, religion, political or other views, property or social status, or on other grounds.¹

The Constitution is further detailed in the Equal Treatment Act. The legislation is hierarchical, where the widest protection is secured on the grounds of nationality (ethnic origin), race and colour, while the protection is weaker on the grounds of religion or other beliefs, age, disability or sexual orientation. ¹⁷ We have for many years made proposals to amend the legislation, upon which people with disabilities will be provided with a wider protection in cases of discrimination, including in education, social care, health- and social security, while purchasing public goods and services, including availability of housing — making reasonable accommodation a legal requirement also outside the field of employment along with higher and vocational education. During 2015–2018 several proposals for amending the legislation have been made to the Estonian Parliament Riigikogu, but unfortunately the amendments are still due.

RECOMMENDATIONS

- Amend Equal Treatment Act to enable people with disabilities to file claims to equal treatment institution in cases of discrimination.
- Conduct studies and analysis to scientifically map the situation of people with disabilities in all areas of life (including education, employment, health).
- Make public various cases of discrimination of people with disabilities, analysis of the situation, in order to raise awareness.

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¹⁷ Equal Treatment Act (06.05.2017). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/126042017009

Article 6 Women with disabilities

Estonia does not have legislative acts or state policies addressing the situation of women with disabilities. Neither the Gender Equality Act nor other acts addressing the topic of non-discrimination are specifically addressing the situation of women with disabilities in Estonia. Rights of women with disabilities are not covered by state development plans.

Women with disabilities are protected based on disability in employment, vocational training, carrier counselling, providing retraining and continuous education, offering practical work experience, becoming member of an organisation and offering benefits by those organisations.¹⁷

Based on national legislation in Estonia, a women cannot claim discrimination against her to be ended, she can only base that claim upon UN CRPD.

Predominantly it's only the civil society organizations who have been fighting for the rights of women with disabilities.

One of civil society initiatives is the shelter service for women who have been experiencing domestic violence. That service is also assisting women with disabilities. Unfortunately most of the shelters are not accessible for women with mobility impairments. Since 2017 women shelters services are offered based on tender procedures, while the tender requirements are not stating that the services has to be accessible. If a women with mobility impairment is requiring accessible accommodation, it can happen that the service is only offered in another county.

Based on the evaluation of member organizations of the Estonian Chamber of Disabled People, they are possessing certain experience and awareness about multiple discrimination of women with disabilities. As example given, that it is more difficult to find a job for a Russian women, suggesting there might be multiple discrimination, tells that a women can become discriminated based on three different characteristics: gender, disability and nationality. DPO-s are most clearly feeling the vulnerability of women with disabilities at labor market. As well it was highlighted that women with disabilities have greater difficulties in reconciling work and family life.¹⁶

Certainly it is necessary in the Estonian society to raise awareness on that women with disabilities is a vulnerable group, for whom additional measures protecting their rights and avoiding discrimination should be put in place. It has to be stressed that women with disabilities are having equal rights with men, who does not have a disability, and not only with men with disabilities. Also it's not yet fully recognized that women with disabilities can experience multiple discrimination. It's worth mentioning that the term "multiple discrimination" is not used in the Estonian society nor in legislation. As the topic have not been widely discussed in the media, there is generally low level of awareness about rights of women with disabilities and gender equality issues in general. As well, rights of women

with disabilities are not linked to women's rights, what is indicating, that the gender aspect is not really embraced.

As for increased awareness, it's worth mentioning that each year Estonian Women's Union is awarding the Mother of the Year award. The award has been issued since 1998 and in 2018 the award was given to Ms. Signe Falkenberg, a women with mobility impairment, Paralympics movement activist.

RECOMMENDATIONS

- Support implementation of the planned changes of Equal treatment legislation, in order to remove existing barrier from realising fundamental rights and freedoms for women with disabilities.
- Introduced measures which will secure accessibility, including accessibility of accommodation at women's shelters for all women with disabilities who need assistance is all counties of Estonia.
- Conduct studies on execution of rights of women with disabilities in Estonia.
- Improve awareness on equal rights of women with disabilities among people with disabilities themselves and in the society at large.

Article 7 Children with disabilities

On 01.01.2018 there were 13 620 children with dirrerent impairments in Estonia. ¹⁸ For admistrative purposes, there are levels of how intense the support level of those children is. 57% or 7820 are having a high level of support need, 37% or 5007 a moderate level of support need and 6% or 793 a very high level of support need. Divided into type of disability, there has been an increase in all groups, except hearing and visual impairments and mobility impairment. The biggest increase has been among children with speech disorders and intellectual disabilities. ¹⁸

Children with disabilities and their families are also in greater risk of poverty – if among the overall population the level of poverty in 2015 for persons until 18 years of age was 18,5%, the same for children with disabilities was 26,2%. ¹⁹

Children with disabilities are mostly taken care of by their parents (95–97% of cases) most often by mother (90–92%). 11–13% of cases apart from the parents, there are no other persons assisting. Unemployment level of mothers of disabled children (7–9%) is higher than the average of women of 25–54 of age (6,4%). Own evaluation on economic capacity is often lower in cases of households with disabled children than what is the Estonian averages of households with children. ²⁰

There is shared responsibility of state and municipalities on offering social services for children with disabilities in Estonia. While the state is responsible for technical aids and social rehabilitation, municipal level is obliged to secure the child care, support person and social transportation services. ²¹ Financing of the abovementioned three services was considerably increased from the end of 2015 by the support of European Social Fund (ESF). It's not clear how the provision of those services will continue after 2020, when the ESF funding is finished.²²

All municipal level services offered for children with disabilities are not easily available. It was found, that municipal problem is inability to plan the social services and political priorities that are not supporting increased capacity of families with disabled children. Over a third of parents of children with disabilities (33–39%) are stating complicated paperwork as major obstacle. ²⁰

¹⁸ Social Insurance Board homepage. Extract as of December 2018.

¹⁹ Statistics Estonia homepage. Extract as of December 2018.

²⁰ Study on abilities and needs of families with disabled children (2017). Estonian Center for Applied Reasearch Centar and Turu-Uuringute AS /Market-Studies Ltd/.

²¹ Social Welfare Act. (09.12.2015). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/130122015005?leiaKehtiv

²² Overview on usage and preservation of state assets in 2016.–2017. National Auditor-s resume on economic and financial prognosis and issues linked to state assets (2017). National Audit Office of Estonia report to Estonian Parliament.

https://www.riigikontroll.ee/Portals/0/Upload/RVKS2017/RVKS%202017_06.11.2017_LOPP.pdf

Such a fragmented support system, divided into state and municipal level, education, health and social welfare strands is resulting in being too complicated to navigate, needing great deal of time and energy and often resulting in not getting the needed help.²⁰

Responsibility for early noticing and intervention is not determined, meaning that the fact of not noticing issues at an early age might leave the child without timely help. Hence, exercising the rights of children with disabilities in Estonia is linked to parental capacity and is not equally available for all. ¹⁶

Also the aspect of where the child is living is influencing the situation – there are considerable differences between regions on availability of services, but also additional benefits paid by municipalities, in addition to the state level benefit system. ²³

For children with disabilities, transfer from childhood into adult life is often rocky in Estonia and disproportionally dependent on the capacity of the parents. Young adults with intellectual disabilities are experiencing a lack of supportive services for independent living, often staying at their families, receiving care, supervision and being provided for their livelihood for years. ²⁴

RECOMMENDATIONS

- Link services and benefits for children with disabilities into holistic, supportive and capacitating system for family and guardians, backing up children's development needs and securing cross-usage of databases.
- Evaluate the sufficiency of earmarked resources given the local authorities for efficient and regionally equal protection of the rights of children with disabilities.
- Introduce real monitoring system for local authorities' ability to offer assistance for protection of rights of children with disabilities at the local level.
- Establish a state action plan for continuous funding of the support services for children with disabilities after the ESF funding will end, meaning after 2020.
- Evaluate the situation of children with disabilities living at home compared with the ones receiving replacement care services.

²³ Health protection and social welfare (2015) Additional report on UN Convention on the Rights of the Child. The additional views, comments and suggestions of Estonian NGO-s. Tallinn. Extract as of January 2018 http://www.lastekaitseliit.ee/wp-content/uploads/2016/02/%C3%9CRO-LAPSE-%C3%95IGUSTE-KONVENTSIOONI-T%C3%84IENDAV-ARUANNE.pdf

²⁴ Situation of long-term care in Estonia (2017). World Bank study. https://riigikantselei.ee/sites/default/files/content-editors/Failid/hoolduskoormus/estonia ltc report final.pdf

Article 9 Accessibility

Estonian Constitution states that everybody, who is legally staying in Estonia, has the right to move freely and freely select a place of residence and freely receive publicly distributed information. Equal Treatment Act is not treating access barriers to acquisition of goods and services as discrimination, that means people with disabilities cannot put a claim forward for Equal Treatment ombudsman, for evaluation whether the situation might cause discrimination because of disability. ¹⁷

There are great regional disparities in accessibility. At the moment, effective monitoring for accessibility is taking place only where there are active people with disabilities. As a positive example, City of Tallinn has approved its strategic document "Development of Accessibility for City of Tallinn 2016–2022". ²⁵

Adopting the decree on accessibility took over two and half years. Since June 2018 a new decree was adopted, regulating the special needs of people with disabilties in publicly used buildings. During the drafting process for the decree, the opinions and suggesitons of the user groups, for whom accessibility is a daily nescesity, were taken into account. Local authority can moreover, in addition to types of building listed in the decree, define itself more venues which have to be following accessibility criteria.

National Transportation Development Plan 2014–2020 has a goal to secure accessibility for people with mobility impairment, people with visual and hearing impairments to infrastructure and information, though the activities to achieve that goal are not as thorougly planned.

Public Transportation Act enables supporting purchase of vehicles adapted for people with disabilities, but its not a legal obligation. For instance most of the buses serving county routes are inaccessible for wheelchair users. Slightly better is the public transport situation in bigger towns suchs as Tallinn and Pärnu. Best example for accessible city transportation would be Tartu. Train transportation is generally accessible for wheelchair users, ferry transportation within Estonia is accessible partly – compared to ordinary passangers, there are several barriers reaching the smallest islands. ²⁶

According to the Estonian Blind Union, only a few traffic lights are equipped with sound signals. Informing by sound, what is the number of the bus reaching the stop, is not solved. Few guiding signs with embossed script or good contrasts, suitable for people with visual impairments are available in the city environment. Signes in braille are almost entirely absent in city environment. The combination of the abovementioned barriers is making independent movement and orientation for blind people in the city environment almost impossible. ^{16 27}

²⁵ Development of Accessibility for City of Tallinn 2016-2022. Tallinn City Social and Health Department. http://www.tallinn.ee/est/Ligipaasetavus

²⁶ NGO Accessibility Forum expert opinion (2016). Estonian Chamber of Disabled People.

²⁷ Estonian Blind Union expert opinion (2016). Estonian Chamber of Disabled People.

No reliable statistics is available upon accessibility of public spaces and environment. Study on coping ability of inhabitants with disabilities in the City of Tallinn states, that each fourth inhabitant (28%) has problems accessing thier place of residence or encounter barriers moving around inside the place of residence. Also 64% of Tallinn inhabitants with disabilities are encountering physical or mental barriers while moving around in the city environment, while 46% of children with disabilities in Tallinn experience the same. ²⁸ By the opinion of NGO Accessibility Forum, major obstacles exist in access to schools and many voting stations. ²⁶

There is unfortunately no National Accessibility Policy in Estonia. In 2015, National Accessibility Council was formed, where representatives of different ministries, State Real Estate Ltd., local authorities organisations, branch organisations in the construction sector and DPO-s are participating. However, the recommendations of the Accessibility Council are not binding and there are no mechanisms to back up implementation of those recommendations.

RECOMMENDATIONS

- In the framework of the national strategy of protection and development of the rights of people with disabilities, elaborate an accessibility strategy and action plan, addressing accessibility of all groups of people with disabilities.
- Map the level of inaccessible public venues and environment for people with disabilities and introduce measures to make those venues and environment accessible.
- Introduce measures for monitoring accessibility at local level and financing the monitoring.
- Bring the Public Transportation Act into accordance with UN CRPD.
- Secure for relevant specialists (architects, interior architects, city—and landscape planners, constructors, product- and service designes etc.) professional education and training on accessibility and universal design.

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²⁸ Social study on ability to cope for inhabitants with disabilites in Tallinn (2016). Contractor: Office of Tallinn City Government. Saar Poll OÜ. Extract as of January 2018 https://uuringud.tallinnlv.ee/uuring/vaata/2016/Puuetega-tallinlaste-toimetulekut-kasitlev-sotsiaaluuring

Article 12 Equal recognition before the law

Article 12 was ratified by Estonia with a declaration.

The Republic of Estonia interprets Article 12 of the Convention as it does not forbid the restricting of a person's active legal capacity if such need arises from the person's ability to understand and direct his or her actions. As purpose of the declaration, it's stated, that Article 12 should not be interpreted the way that it should prohibit all possibilities for limitations of legal capacity.²⁹

Legal capacity of a physical person is an ability to independently conduct valid actions, whereas full legal capacity is acquired by persons by completion of 18 years of age. Legal capacity of an adult is limited in cases where two aspects simultaneously appear: either mental illness, mental disability or other mental disorder and the person is permanently unable to understand and direct his or her actions. ³⁰

Supreme Court of Estonia has found, that the conditions for evaluating the grounds for limiting legal capacity are sufficiently described in the General Part of the Civil Code Act. ³¹ According to Family Law Act, the legal guardian is legal representative of the person with limited legal capacity and the guardian has the right and obligation to take care of the person and property of the person under legal guardianship. Legal guardianship is set for maximum five years either for taking care of all actions or only some actions. Legal guardian can be a physical person, juridical person or local municipality. Physical persons are preferred, and the personal characteristics and abilities of the person are considered important for making the decision. Secondly juridical persons are preferred and thirdly, local municipalities where the person is living. When deciding upon guardianship, the interpersonal relations of the persons are taken into consideration. Protecting the rights of the person under legal guardianship, the responsibility of the legal guardian is to secure that the person is receiving sufficient amount of health care and social services. In cases the guardianship is set to cover all actions of the person, the person is declared with limited capacity for voting rights and therefore loses the possibility to vote.³²

In Estonia, most often a close relative is set as legal guardians and in cases where there are no close relatives, the local municipality. ³³ For instance, Harju County Court has during 2010–2012 set 78% of legal guardianship to physical persons. ³³ Limited number of juridical persons among legal guardians might be because of legal guardianship is provided free of

²⁹ Proposal for Ratifying UN CRPD Act (2012). (161 SE) Description.

³⁰ General Part of the Civil Code Act (05.04.2011). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/106122010012

³¹ Supreme Court of Estonia Civil Law Chamber 07.12. 2005. decision. http://www.nc.ee/?id=11&tekst=RK/3-2-1-141-05

³² Family Law Act (01.07.2010). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/13330603

Appointing legal guardian for adult with limited legal capacity (2012). Analysis of Case law. Juur. Supreme Court of Estonia, Tartu. https://www.riigikohus.ee/sites/default/files/elfinder/analyysid/2012/eestkostjam22ramine_k2tlinjuur.pdf

charge in Estonia.³⁴ If the legal guardianship is set to be the local municipality, the quality of the service is depending on the knowledge, possibilities and skills of the municipal social worker. ³⁵ Activities of the social workers fulfilling the legal guardianship are often limited to organisational and representative tasks, much less there will be social interaction and provision of personal support to the persons with limited legal capacity.

It's widespread that the persons with limited legal capacity are not involved into decision making processes on their living conditions, opinion of social field professionals and staff of care facilities are more widely used. ³⁶

According to WHO's report, whilst staff of long-term care institutions for adults with psychosocial and intellectual disabilities were friendly to the service users, there was a prevailing attitude that "the staff know better" with regards to organizing a service user's life. Service user knowledge of their rights was simplified. Positively, the WHO's assessment team noted, that all service users had a personal, confidential file with information access for the service users on request, meaning that each service user had the same rights and restrictions on that file as any other Estonian citizen. ³⁷

Although internationally it's widespread, that the legal capacity should be limited only partially, the Estonian County Courts have not always followed those principle and in case law the legal guardianship is often set for all actions. Courts have problems with setting partial limitations to legal capacity, as in such cases the Court needs to find out in a very detailed manner, what the person is able to conduct and what not. Case law is demonstrating, that the Courts are not sufficiently analysing each case, each individual and their capacities. ³⁸ Taking into consideration, that often the Court is setting guardianship to execute all actions, a threat occurs that the real interests and needs of the person under guardianship are not mapped, not taken into consideration, as the decision maker according to the substituted judgement model is the legal guardian alone.

Estonia is utilising the substituted judgment model, that gives the legal guardian the right to decide instead of the person with disabilities. ³⁹ Ratification of the Convention is highlighting the need of moving from the substituted judgment model towards supported decision-making model, what is valuing the autonomy of people with disabilities and their right of making

³⁴ Forstiman, A. (2011). *Setting legal guardianship and implementing it.* Master theses. Tallinn: University of Tallinn Law Academy.

³⁵ Lääts, L. (2015) Legal guardianship of adults with limited legal capacity and human rights through the eyes of municipalities and juridical persons as legal guardians. Bachelor theses. Tartu: University of Tartu.

³⁶ Tsuiman, K. (2015) *Local authority as legal guardians for adults with limited legal capacity in the Pärnu County Court operating circle.* Master theses. Tallinn: University of Tallinn, Institute of Social Work.

³⁷ Survey of Institutions for Adults with Psychosocial and Intellectual Disabilities Report of Findings from Institutional Assessments in Estonia (2018). Word Health Organisation.

³⁸ Štšerbakova, V. (2014) Legal comparison analysis of regulation on transactions with assets belonging to persons under legal guardianship. Master theses. Tallinn: University of Tallinn.

³⁹ Frolik, L. A., Whitton, L. S. (2012). *The UPC Substituted Judgment / Best Interest Standard for Guardian Decisions: a Proposal for Reform.* University of Michigan Journal Law Reform, Vol 45, 739.

own decisions. ⁴⁰ Persons with disabilities can himself/herself decide, but the related aspects and consequences of the decision will be explained by assistive persons, as a result of which one can avoid decisions what will take into account "best concern of the individual". ⁴¹ Full removal of legal capacity on the principle of substituted judgement model is resulting in the individual having fully excluded from deciding over his or her own life and society around him/her.

In conclusion, one can state on the Estonian practice of legal capacity that although the law is highlighting the interest of the person whose legal capacity is limited, the case law tells that implementing legal capacity cases in the above-described manner cannot be considered as supporting the human-rights based approach.

RECOMMENDATIONS

- Establish pre-conditions (legislation, operational voluntary guidelines) for moving from the substituted judgement model towards supported decision-making model.
- Consider withdrawal of the declaration issued when the UN CRPD was ratified.
- Regularly gather and publish data on legal guardianship (including number of legal guardianships set, width of the limitation of legal capacity, timeframe on how long the guardianship lasts and who are the persons appointed as guardians).
- Conduct awareness raising on mental health and intellectual disabilities, promoting the tolerance in the society on participation of people with mental health issues and behavioral problems in our communities.

⁴⁰ The Right to Legal Capacity in Kenya (2014). Budapest: Mental Disability Advocacy Center. http://mdac.info/sites/mdac.info/files/mdac kenya legal capacity 2apr2014.pdf

⁴¹ From Exclusion to Equality: Realizing the rights of persons with disabilities (2007). Handbook for Parlamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol. Geneva: United Nations. http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf

Article 14 Liberty and security of the person

According to the Constitution, everyone has the right to liberty and security of person and deprivation of liberty may happen in the cases and pursuant to a procedure provided by law of a person carrying a communicable disease, patient of a mental disorder, alcohol abuser or drug abuser, who is dangerous to her/himself or others.

Psychiatric assistance is provided based on the Psychiatric Aid Act. Involuntary psychiatric treatment is regulated by Code of Civil Procedure Act deciding on coercive psychiatric teatment is regulated by Code of Criminal Procedure and placement in a care facility is regulated based on Social Welfare Act. Annually, involuntary psychiatric treatment is decided in average 2500-3000 cases and coercive psychiatric treatment in average 130-180. ⁴²

According to Supreme Court of Estonia, placing individuals in guarded facilities is problematic within provisional legal protection. Based on Code of Civil Prodedure Act § 534 point 5 provisional legal protection can be utilized during four days from placement of a person in a guarded facility, without interviewing the involved persons, without appointing a representative and without conducting an evaluation, given that the provisional legal protection is followed by main proceedings. After having interviewed the person, court has the right to prolong the provisional legal protection up to 40 days if needed, if that is clearly nescessary according to psychiatrist or other competent medical doctor. According to Supreme Court of Estonia, it is not according to legislation, if there will be no main proceedings after the 40 days of provisional legal protection, that remaining the only measure enforced. Moreover, Supreme Court of Estonia Chambers are viewing the use of provisional legal protection as the main proceeding as problematic, in particular as there is no requirement for an expert evaluation of the persons condition, what is a prerequisite for determining unhealthy mental condition of a person, according to *Winterwerp* requirements. 43

Supreme Court of Estonia have highlighted serious shortcomings in the legislation of deciding upon involuntary psychiatric treatment and in the enforcement of that legislation. Enforcement is showing, that in general evaluation of the persons condition is not happening prior the involuntary placement in psychiatric hospital, but only after the person have been deprived of his or her liberty. Such practice is according to the Supreme Court of Estonia often not justified, is violating fundamental rights of individuals and is not supporting the aims of Code of Civil Procedure Act and Psychiatric Aid Act. ⁴³

A principle problem according to the Supreme Court of Estonia is that fact, that the state have not established an independent and effective monitoring system to deal with persons with psychiatric problems, what would enable filing timely applications of persons to be placed under involuntary psychiatric treatment. According to Code of Civil Procedure Act § 533

 $^{^{42}}$ Health Statistics in Health Studies database, National Institute for Health Development, stahttp://pxweb.tai.ee/PXWeb2015/pxweb/et/02Haigestumus/02Haigestumus_05Psyyhikahaired/PKH5.px/table/tableViewLayout2/?rxid=90d7592c-2436-4f00-845a-4f93929ac44, Extract as of 16.01.2019

Supreme Court of Estonia case law 19.02.2014 in case nr 3-2-1-155-13 https://www.riigikohus.ee/et/lahendid?asjaNr=3-2-1-155-13 Extract as of 16.01.2019

points 1 and 2, such applications should be filed primarily by municipalities as legal guardians and legal guardians as physical persons. According to Psychiatric Aid Act § 13 point 1, such competence have also been given to doctors of psychiatric hospitals. Content-wise, the state has given the monitoring role to doctors, who cannot independently (as they are treating the patient) be responsible of such a role and are not either responsible of general living situation of the person. ⁴³

Deciding upon person's involuntary treatment depends on wether the person is dangerous to him/herself and/or others. At the same time, the term "dangerous" is not sufficiently defined in the legislation, predominantly its the case law defining it. According to the analysis of Supreme Court of Estonia, dangerousness of a person is in case law described in a too general manner and often placement into involuntary treatment is explained by "poor complience". Mostly dangerousness of a person can consist of a physical threath to his/her and other persons lives or health, including declining towards violence or suicide. The fact, that a person is not able to conduct an independent life does not mean, that the person is a threath to him/heself or others. Lack of social skills can be dangerous if the person in not capable of (re)acquiring social skills. Social Welfare Act is foreseeing several measures for integrating a person into society 45. Introducing other measures, provision of municipal support services play a key role along with ability of the municipality to have an overview, who might need help, be able to timely intervene and provide services what are necessary to avoid futher damage.

Important recent development in the case law have taken place concearning the rights of the person who is undergoing coercive psychiatric treatment. Supreme Court of Estonia have stated, that the mental state of the person have to be evaluated when the decision is made. If the court have doubts, whether the dangerousness of the person have diminised considerably, a new evaluation have to be made and other proof have to be taken into account, including interviewing the person in question, to find out about his/her current mental state. ⁴⁶

RECOMMENDATIONS

- Gather, analyze and publish statistics on use of involuntary treatment, coercive psychiatric treatment and cases of placement in a care facility, prolonging and terminating use of those;
- Elaborate the concept of provision of involuntary treatment, what would derive from the needs of people with psychiatric disorders.
- Elaborate the concept of a new regulation for psychiatric aid, what is describing more detailed the limitations of fundamental rights and the provisions for court

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⁴⁴ Supreme Court of Estonia of 16th May 2007 Analysis on "Placing a person in guarded facility based on Civil Procedure Implementation Act (TsMS) §-s 533-543 foreseen procdures" https://www.riigikohus.ee/sites/default/files/elfinder/analyysid/2007/isiku_paigutamine_kinnisesse_asutusse.pdf
Extract as of 16.01.2019

⁴⁵ Supreme Court of Estonia of 02.03.2007.case law in case nr 3-2-1-145-06 https://www.riigikohus.ee/et/lahendid?asjaNr=3-2-1-145-06

Supreme Court of Estonia of 14.11.2017 case law, case nr 1-16-7102 https://www.riigikohus.ee/et/lahendid?asjaNr=1-16-7102/18 Extract as of 16.01.2019

- psychiatric for providing of both involuntary treatment and coercive psychiatric treatment.
- Elaborate guidelines for courts to secure equal approach for deciding upon coercive psychiatric treatment and involuntary treatment (including the right of being interviewed, right to competent legal protection, right to receive information about own court case).
- Conduct an analysis to find out, if the current regulation, on which the treating doctor/colleague of the treating doctor is evaluating on the need of prolonged hospitalized coercive psychiatric treatment is legal and impartial;
- Secure less restrictive measures used upon persons, developing social community based services (alternative measures):
- Secure that people residing at care facilities are provided accessible health services of high quality, what will exclude illegal restraining measures and giving them medicine against regulations.
- Elaborate practical guidelines with best practices for officials (judges, municipal officers, doctors), who are evaluating the level of dangerousness of persons, deciding upon use of involuntary treatment.⁴⁷

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⁴⁷ http://vatek.ee/wp-content/uploads/2016/04/Vaimse tervise heaolu strateegia 2016-2025 2016.pdf Strategy of Mental Wellbeing 2016-2025

Article 17 Protecting the integrity of the person

A person can be sterilized only based on persons own written application. Sterilization of a person with limited legal capacity is decided by a county court without a claim treatment, based on an application by the legal guardian. ⁴⁸ It has been pointed out, that the Estonian regulation on sterilization of persons with limited legal capacity is not in accordance with international rules, including the CPRD nor with the Constitution of Republic of Estonia, as it is not highlighting the importance of own will while deciding upon sterilization nor is specially defining the cases of people with limited legal capacity. ⁴⁹

There are no state level studies concerning termination of pregnancy and sterilization of people with limited legal capacity. Database for Termination of Pregnancy ⁵⁰ (former Estonian Abortion Registry ⁵¹) is operational, but in not containing data on legal capacity. Counselling on sexual behavior, taking into account needs of intellectually disabled people is not sufficiently available. ¹⁶

RECOMMENDATIONS

• Collect data on termination of pregnancy and sterilization of persons with limited legal capacity and analyze, whether it's in the interest of persons with limited legal capacity to involve courts also in cases of termination of pregnancy, as is the situation in case of sterilization.

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⁴⁸ Termination of pregnancy and Sterilization Act (01.01.2006). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/925400

⁴⁹ Djomin, V. (2016). *Protecting the rights of people with limited legal capacity when deciding upon sterilization*. Master theses. Tallinn: University of Tartu. Extract as of January 2018 https://dspace.ut.ee/bitstream/handle/10062/53510/djomin_ma_2016.pdf?sequence=1&isAllowed=y

⁵⁰ Medical Birth Registry and Termination of Pregnancy Database. National Institute for Health Development. Extract as of January 2018. http://www.tai.ee/et/tegevused/registrid/meditsiiniline-sunniregister-jaraseduskatkestusandmekogu

⁵¹ Allvee, K., Karro, H. (2016) *Estonian Medical Birth Registry 1992–2015*. *Estonian Abortion Registry 1996–2015*. Tallinn: National Institute for Health Development. Extract as of January 2018 https://intra.tai.ee//images/prints/documents/148111070862_ Kogumik%202016%20(EMSR%201992-2015,%20%20AR%201996-2015).pdf

Article 19 Living independently and being included in the community

For DPO-s administration reform impact on provision of social services, their quality and availability is posing questions.

Access for people with disabilities to social services is hindered for different reasons, it can be distance from the service provider, complicated paperwork, long queues for receiving the service or low awareness of existence of the service. As many as a third of adults with disabilities, the cause of not receiving any services is the lack of information or the person has simply not figured out that applying supportive services might improve their quality of life. ¹⁶

Study with DPO-s highlights that public transportation and social transportation is a prerequisite in order to reach other services. In particular at rural areas one of the biggest obstacles is lack of useable and accessible transportation. Partly transportation services are provided by municipal social workers, which is not an acceptable solution due to otherwise heavy workload. Often the vehicle the social worker is using isn't accessible for mobility impaired persons using technical aids. ¹⁶ Local authorities claim not having sufficient funds to offer social transportation of needed amounts or they are not able to find a provider as the prices are low. A similar problem occur when offering personal assistance and support person services.

The state has not sufficiently addressed the aspect that local authorities are having unequal capacities offering necessary services nor do they have sufficient state funding to do so. Equally can unavailability of core services (such as sign language interpretation, transportation, adapted environment) or poorly accessible environment result in not getting the needed services. Services offered by local authorities vary as well by quality, as unlike the state funded serviced (i.e. rehabilitation services), the municipal ones are not subject to minimum quality standards, only should follow voluntary guidelines. Voluntary guidelines are not securing the quality and best result for the user.⁵²

In many studies and reports the aspect of that currently, services provided by local authorities are not meeting the real needs of people with disabilities, be it for availability, amount or content. That means the provided services are not needs-based.⁵³

DPO-s see particularly great risks of exclusion of the Russian speaking population.¹⁶ Separate attention should be paid to elaborate easy to understand materials in Russian and short summaries of legislative acts and decrees in Russian. Such summaries would provide people

Vana, T. (2013) Analysis on quality of social services and recommendations for introducing holistic quality system. Final report of the analysis. Astangu Vocational Rehabilitation Center. Extract as of January 2018 https://www.sm.ee/sites/default/files/content-editors/Ministeerium_kontaktid/ Uuringu_ja_ analuusid/Sotsiaalvaldkond/sotsiaalteenuste_kvaliteet_uuringu_l6pparuanne.pdf

⁵³ Vana, T. (2013) Overview on quality analysis on social services and recommendations for development of the domain. Project description. Astangu Vocational Rehabilitation Center. Extract as of January 2018 http://www.equass.ee/public/kv konverents TriinVana.pdf

with information, what kind of text that is and based on the information seek for more detailed explanations or support. An issue is also unequal level of Russian language knowledge among the specialists. 16

Integration into community is backed up by the support person service, which is based on mapping made in the regions, one of the least available of all services. The service is needed, but provision is not organized well. Support person service development is planned in all counties, there are expectations of doubling of the target group. ⁵⁴

The need for state-funded special care services is considerable greater than the availability. ⁵⁵ For instance by January 1st 2018, service was provided for 5503 individuals, in total at 6879 service seats (some people are using several special care services simultaneously), while the queue was for 1636 service seats. In January 2018, 1927 individuals were receiving 24hours care, in the queue were 599 individuals or one fourth of people in need of help. ⁵⁶ Relatively poor availability of the services is due to insufficient state funding. ⁵⁷

However, Estonia has been focusing on dismantling big service provision units and created smaller, community based units. In 2017 and 2018, open calls for tender were implemented, to reorganize 1200 and establish 200 new service seats. The reorganized and new seats will be available by end of 2020.

What concern transparency of the queues for special care services, those are not always transparent and are not allowing the user to select the provider or time of the service provision. That results in complications planning the lives for people with disabilities themselves and for their family members and guardians, as it's not possible to make prior agreements on when the person is entering service provision.⁵⁸

Above-mentioned aspects result in disproportional burden of care and efforts including into community for families of adults with intellectual disabilities. DPO-s expert evaluation is backed up by World Bank study in 2017, stating that the family is obliged to meet the care burden as local authorities are not offering sufficient services to diminish the burden of care.59

https://www.sm.ee/sites/ default/files/content-editors/eesmargid_ja_tegevused/ Sotsiaalteenuste_ja_toetuste andmeregister STAR/Lisainfo/mak analuus toimetatud.pdf

⁵⁴ Rasu, A. (2017) Developing Social Services in Counties 2016–2020. Analysis. Läänemaa Development Center. Extract as of January 2018

⁵⁵ Special care queues as of 06.10.2017. Social Insurance Board. Extract as of January 2018 https://www.sotsiaalkindlustusamet.ee/sites/default/files/content-editors/Erihoolekanne/ erihoolekande_jarjekorrad_06102017.pdf

⁵⁶ Social Insurance Board (2018). Exchange of letters.

⁵⁷ State actions within organising state provided care for people with psychic special needs. Is the state capable of ensuring nescesary servicres for people with psychic special needs? (2008). Tallinn: National Audit Office of Estonia report to Estonian Parliament. http://rahvatervis.ut.ee/handle/1/1474

⁵⁸ Opinions (2015) Estonian Chamber of Disabled People.

⁵⁹ Reducing the burden of care in Estonia (2017). Interim report, World Bank Group, https://riigikantselei.ee/ sites/default/files/content-editors/Failid/hoolduskoormus/estonia ltc report final.pdf

While reorganizing the special care services, general queues might not shorten drastically as many of the community based seats will be filled with the users coming from currently existing bigger service units or from the priority queue.¹⁶

More positive developments have taken place in 2018, when the state was introducing a service for supporting daily activities for adults of working age with severe and profound intellectual disabilities. As well services for people with autism specter disorders will be enlarged. ⁶⁰ Enlarged service should ease the current shortage of suitable services.

RECOMMENDATIONS

- Evaluate the impact of administration reform on social care system and on equal availability of services at all local authorities, along with securing better availability of social services as a result of the reform.
- Secure equal provision of social transportation services at all local authorities (including accessibility, sufficient amount and flexibility of the service).
- Develop flexible care possibilities, diminishing burden of care of relatives of people with disabilities, as well enabling active participation at labour market and societal life.
- Diminish the risk of Russian speaking people with disabilities becoming marginalised as a result of lack of information.

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⁶⁰ Adults with severe and profound intellectual disabilities will be provided with daycare and weekly care (2017). Ministry of Social Affairs. https://www.sm.ee/et/uudised/raske-ja-sugava-intellektihairega-taisealistele-luuakse-paeva-ja-nadalahoid

Article 21 Freedom of expression and opinion, and access to information

People with hard of hearing are feeling an urgent need for TV sendings and movies with subtitles. Equally, the shortage of speech to text service is felt in education, employment and the field of culture at large. 61–16

Access to information for people with disabilities, in particular access to information concerning rights of people with disabilities, is a challange as the information is fragmented, available at many different bodies and information carriers. In addition to people with visual and hearing impairments, people with intellectual disabilities, as well as people with disabilities not speaking Estonian as their mother tongue are having difficulties.¹⁶

A study conducted in 2015 found out, that only 6% of public sector webpages are living up to the WCAG 2.0 guidelines, more precisely: 28% of governmental bodies and 1% of local authorities have a webpage fulfilling the minimum level A or the recommended level AA. None of the webpages were living up to the highest WCAG 2.0 level AAA ⁶². Local municipalities are in Estonia mayor responsible body for offering required services for people with disabilities. Therefore are inaccessible webpages of local authorities a considerable barrier in acquering information about rights and possibilities for people with disabilities at local level.

Although Language Act accepts Estonian language presented as sign language as a form of presenting state language, sign language is not described in the Social Welfare Act, coming into force since 01.01.2016. As well, in the Social Welfare Act, sign language interpretation isn't listed among social services municipalities have to offer.

Therefore there are no common standards how to offer sign language intrepretation services and availablity of the service is having large regional disparities. The problem is even more serious as there is a shortage of sign language intrepreters. ¹⁶ By opinion of Estonian Deaf Union, access to education provided by sign language and access to information at large is hindered. Elderly deaf people are in even more difficulty situation, as their knowledge of written Estonian is not sufficient to be able to communicate with the authorities and fully participate in the society. ⁶³

University of Tartu has unfortunately closed down provision of University level education of sign-language interpreters, what the deaf community and Estonian disability movement is really regretting.

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⁶¹ Estonian Union of Hard of Hearing expert opinion (2016). Estonian Chamber of Disabled People.

⁶² Accordance of the public sector webpages to WCAG 2.0 guidelines in 2015. (2015). Report of the study. Ministy of Economy and Communication. Extract as of January 2018 https://www.mkm.ee/sites/default/files/wcag aruanne 2015.pdf

⁶³ Estonian Deaf Union-s expert opinion (2016). Estonian Chamber of Disabled People.

Positive development is the transposition into national legislation of the Directive of European Parliament and of the Council on accessibility of the websites and mobile applications of public sector bodies, by amending the Public Information Act. ⁶⁴ ⁶⁵ On the initiative of DPO-s and as a contribution to the Estonian Presidency of the Council of the European Union, Estonian Chamber of Disabled People in co-operation with Government Office of Estonia and European Disability Forum was in October 2017 holding an international conference, focusing on the European Commission directive prososal of the EU Accessibility Act.

As a positive provising it can be highlighted, that since October 2nd 2018, distant signlanguage interpretation is provided via skype 3 days a week for all deaf people who need it.

Recommendation

• Secure sufficient amount of access to sign language intrepretation and speech to text service for people with hearing impairments, including sufficent availablity of sign-language intrepreters and speech to text interpreters.

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⁶⁴ Directive (EU) 2016/2102 of the European Parliament and of the Council of 26 October 2016 on the accessibility of the websites and mobile applications of public sector bodies (2016). Extract as of January 2018 http://eurlex.europa.eu/legal-content/ET/TXT/ELI/?eliuri=eli:dir:2016:2102:oj

⁶⁵ Public Information Act (01.01.2012). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/122032011010

Article 24 Education

Highest level of graduated education being basic education or lower is the case for 3,1% of non-disabled and as high as 9% of people with disabilities in Estonia. ⁶⁶

There are no solid studies on inclusion of children with disabilities into pre-school education. Kindergartens experience a serious shortage of speech therapists, also there is a shortage of other support specialists. 16

Since February 1st 2018 a new Basic Schools and Upper Secondary Schools Act was coming into force, enforcing many changes in the organisation of inclusive basic education. ⁶⁷ DPOs are convinced that the renewed law is contributing to provision of inclusive education for children with moderate disabilities, but is not securing access to inclusive free of charge, quality basic and upper secondary education for disabled children with a high level of support need. State responsibility of providing the special education have been removed from the abovementioned law, resulting in that the state is distancing itself from teaching and financing education, while the municipalities might not be capable of securing that responsibility. One-to-one teaching for children with a high level of support need is currently not sufficiently funded, receiving three and half times less funds than before February 1st 2018, when the previous version of the Basic Schools and Upper Secondary Schools Act was applied. 68

The share of children with disabilities attending special schools have decreased, but involving those children into mainstream schools in mainstream classes has been very slow. Mainstream schools have a shortage of skilled teachers, support teachers and support specialists to make full inclusion a reality. ⁶⁹ ⁷⁰

In Estonia, blind and visually impaired children are acquiring basic education at mainstream schools or special schools. The state is financing adaptation of study materials into braille or electronic format, but the amount and speed of that is not sufficient. At specials schools for visually impaired children, learning Braille, communication and orientation skills are part of the curriculum and financed by state. Mainstream schools do not have the capacity to teach such skills due to lack of knowledge, technical aids, support specialists and support teachers.

67 Basic School and Upper Secondary School Act (2018). Extract as of January 2019 https://www.riigiteataja.ee/akt/13332410?leiaKehtiv

needs and efficiency of the earmarked measures (2016). Final report of study. Centar Centre for Applied Research. Extract as of January 2018 http://www.centar.ee/uus/wpcontent/uploads/2017/01/P%C3%B5hiraport-final.pdf

⁶⁶ Social inclusion of people with disabilities (2014). Tallinn: Statistics Estonia. Extract as of January 2018 http://www.stat.ee/72564

⁶⁸ Opinions on amending the Basic School and Upper Secondary School Act (2017). Estonian Chamber of Disabled People.

⁶⁹ Santiago, P., Levitas, A., Radó, P., Shewbridge, C. OECD Reviews of School Resources Estonia (2016). Extract as https://www.hm.ee/sites/default/files/oecd_reviews_of_school_resources_estonia.pdf

⁷⁰ Räis, M. L., Kallaste, E., Sandre, S.-L. Solutions for education provision for pupils with specials

There are good practices of teaching blind children at mainstream schools thanks to advice acquired from Tallinn Helen School and Tartu Emajõe School. ²⁷

Hearing impaired children are mainly studying at mainstream schools, using hearing aids, what are sufficiently available for children with hearing impairments. ⁶¹

The quality of basic education offered in sign-language has during recent years decreased and one of the reasons is increased use of teaching in multiple level classrooms. State education policy and practical implementation is less and less offering attention to the cultural and linguistic identity of the deaf, promoting primarily the oral teaching methods instead. Teaching children who know sign language, availability of qualified sign language interpreters differ by regions and the state is not compensating schools the cost sufficiently. The state is not sufficiently supporting study materials and adaptation of study methods for deaf pupils. There is no state level motivation package for teachers to convince those acquiring sign language within their further education. ⁶³

Education possibilities for deafblind children, intellectually disabled and visually impaired, as well as for the blind are limited. The law is generally protecting visually impaired pupils, but is not taking into consideration the needs of the blind children with multiple disabilities, for their need for individual study approaches. Study materials for intellectually disabled blind children are completely absent. ⁷¹ ²⁷

In case of transfer from basic school to vocational or regular secondary education, there is much less probability for disabled pupil to successfully graduate from basic school.⁷² If in 2015 98% of all basic school graduates were continuing at the next education level, the same percentage among graduates with disabilities was only 76%.⁷³

Availability of vocational training for disabled learners is regionally different and teachers often does not have sufficient skills for supporting disabled learners.⁷² Also there are not enough dormitories, they are often inaccessible and do not offer support services necessary for disabled learners. ¹⁶

A recent positive change was introduced into provision of vocational education, what is taking into account the severity of special needs of the learner, when calculating the funding per person provided by the state. ⁷⁴ Often however, support person or personal assistant is not available for disabled learners. Possibilities for intellectually disabled in vocational education are narrow, with basically two options: cleaning specialist and

⁷¹ Estonian Deafblind Association expert opinion (2016). Estonian Chamber of Disabled People.

⁷²Räis, M. L., Kallaste, E., Sandre, S.-L. *Solutions for education provision for pupils with specials needs and efficiency of the earmarked measures* (2016). Final report of study. Centar Centre for Applied Research. Extract as of January 2018 http://www.centar.ee/uus/wp-content/uploads/2017/01/P%C3%B5hiraport-final.pdf

⁷³ Results of the working group "Smooth transfer of youth with special needs from general education into vocational training and after graduation into employment" (2016). Ministry of Social Affairs.

⁷⁴ Principles and components of funding vocational education, terms of implementation and guidelines, Government of the Republic Decree. https://www.riigiteataja.ee/akt/129122017026

assistant gardener. ⁷⁵ Disabled learners are often in need of extra time for being able to acquire the skills, what is not backed up by the state funding provisions. There are no study possibilities at the first level of vocational education of the European Framework of Qualifications, what would enable to involve more disabled learners into vocational education. ⁷⁶

Only 20,3% of people with disabilities have higher education, while the same percentage of non-disabled is 32,3%. Particularly high is the gap among women – high education share among women with disabilities is 40% less than among women without disabilities. ⁶⁶

For the study year 2016/17 there were 252 students with disabilities at Estonian higher education providers or 0,5 % of total number. ⁷⁶ Main challenges in the implementation of the Conventions in higher education are access to study materials ja electronic databases for visually impaired students, limited availability of sign language interpretation and speech to text interpretation for students with hearing impairments and insufficient accessibility of the built environment for the mobility impaired. Deaf people using sign language as their mother tongue are only provided 20 hours of sign language interpretation during a month by the state. ⁶³

RECOMMENDATIONS

- As part of a state strategy for protection and development of the rights of people with disabilities, elaborate a strategy and action plan for accessible and inclusive education, securing the right of people with disabilities participating at all levels of education and lifelong learning.
- Restore the responsibility of the state in provision of education for children with extensive special needs, including provision of education for children with complex dependency needs, reintroducing it into the Basic Schools and Upper Secondary Schools Act.
- Organize sustainable training and further training of teachers in special pedagogic, including in the field of typhlo- and surdo- pedagogic.
- Secure sufficient level of support specialists provision, to enable real implementation of inclusive education.
- Improve study possibilities of intellectually disabled and visually impaired students in vocational education.

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⁷⁵ Ministry of Education and Science (2017)

⁷⁶ SA Archimedes (2017).

Article 25 Health

Largely there is no statistics available about real situation of people with disabilities in healthcare. Most studies of healthcare, as well as patient surveys are not providing specific information about patients with disabilities.

Disabled people over 18 years, of working age, who do not have partial or complete incapacity for work, have to live up to the same rules for being insured as all other individuals. That means that in Estonia not all people with disabilities are covered by health insurance and therefore cannot get the expenses covered by Estonian Health Insurance Fund. Its known that the number of people with disabilities who possess full capacity for work were 130 persons by the end of 2017, of which 52 were not working. ⁷⁷

DPO-s have been highlighting as a problem the need for carers for disabled children, as well as for intellectually disabled and mental health patients while receiving medical care at a hospital. Such situations are not regulated in the legislation. ¹⁶

Estonia is still among the states where only a low share of GDP is dedicated to health- and care services. ⁷⁸ Most severe shortcomings within provision of health care for people with or without disabilities are the long queuing for medical treatment. For instance in 2016 35% of all individuals with health issues were, when answering why they were not seeing the doctor, were answering that the reason was long queue to see a specialist. ⁷⁹ Satisfaction among people with disabilities with health services close to the place of residence is today low. ¹⁶

Quality of health service in Estonia is secured and assessed by health service providers, legislation is only offering general guidance. At hospitals, there are no mandatory or voluntary guidelines on how to treat patients with disabilities. Hospitals are not offering supportive (social) services, such as support person for people with disabilities. There have been cases where intellectually disabled people or people with complex dependency needs have not been treated with dignity while hospitalised. ¹⁶

Although availability of free dental care for people with disabilities has improved noticeably from Januari 1st 2019, the availability of general narcosis dental care for people with mental health problems and intellectually disabled is still not sufficient. Such dental care is only provided by very few in Estonia, hence the long queues and one have to travel to another city, what causes help to reach too late and extra costs for people with disabilities. ¹⁶

⁷⁷ Social Insurance Board (2017).

⁷⁸ Development of Estonian Health Care until 2020. Overview on current situation. Ministry of Social Affairs. Extract as of January 2018 https://www.sm.ee/sites/default/files/content-editors/ eesmargid_ja_tegevused/Tervis/tervishoiu arengusuunad 2020.pdf

⁷⁹ Evaluation of Estonian residents on health and health care (2016). Kantar Emor. Extract as of January 2018 http://www.sm.ee/sites/default/files/content-editors/Ministeerium_kontaktid/Uuringu_ja_ analuusid/ Tervisevaldkond/arstiabi_uuringu_aruanne_2016_kantar_emor.pdf

Law of Obligations Act is obliging patients to be informed about the result of medical examinations and health situation, availability and purpose of needed treatment along the risks and outcomes of that treatment. In case of limited legal capacity of the person, such rights are transferred to legal guardian. If the decision of the legal guardian clearly is hurting patient's interest, healthcare provider cannot follow that decision. Patient itself have to be informed about the health care provision and about circumstances around it within what is considered reasonable. ⁸⁰ In real life, cases exist, where the person with limited legal capacity is not involved into decision making processes, but the legal guardian is making the decision based on the principle of substituted decision making. ¹⁶ There is lack of uniform guidelines and understanding, how to involve the person into treatment processes.

Pregnancy of a women with limited legal capacity can be terminated based on her own or her legal guardian's written agreement. If the decision of the legal guardian is contradicting the interest of the women herself, health care professional is acting out of the decision of the women. Health care professional is obliged to explain the women and her legal guardian before termination of pregnancy the nature of the intervention and risks what might occur. It's unclear, how the health professional is finding out about contradicting interests in opinion of the women with limited legal capacity and her legal guardian and on which principles health professional is finding out the wish of the women herself. Therefore there is a risk that rights of women with limited legal capacity are not protected when deciding upon termination of pregnancy.

According to WHO's report, health services and advice available was variable across the facilities. Service users were not always adequately informed about treatments and alternatives; treatments can be discussed with doctors who are not on site. In one site refusal of treatment "was not acceptable", and medications were administered regardless of will. 81

Health Board has stated that health services are not equally available at all care providing units. For instance a widespread behaviour would be to let other individuals consume the medicine if one individual have left the care unit. In addition 4 cases were discovered where psychotropic and neuroleptic medicine were given to clients in care, without doctor's prescription. Premises of many care providing units are inaccessible, therefore care recipients, who are lying in bed, are never brought outdoors. As many as half the care providing units didn't have an alarm button, but there is also a serious lack of personnel, in order to provide good care. ⁸² Moreover, people with disabilities, who are recipients of 24 hours special care, often have their registered place of residence not where the special care is provided, what is posing problems for providing primary health care. ⁸³

Tallinn: Health Board. Extract as of January 2018 http://www.terviseamet.ee/fileadmin/dok/Tervishoid/hooldeasutuste_uuring.pdf

⁸⁰ Law of Obligations Act (27.11.2017). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/117112017040

⁸¹ Survey of Institutions for Adults with Psychosocial and Intellectual Disabilities Report of Findings from Institutional Assessments in Estonia, 2018, Word Health Organisation.

⁸² Provision of health services at care facilities (2017). Summary of a Study.

⁸³ Ambulance of Tartu: 40% of the calls to care homes are justified (2016). *Medical News*, October 27th. Extract as of January 2018

The largest share of people with disabilities in Estonia are individuals of retirement age, who most often require health and social care services at the same time. Unfortunately both for nursing care (health service) and care service (social service), the usability is limited due to long waiting lists and for the care service also because of high co-funding share. There is no countrywide access to permanent nursing care, in particular if the person needs it more than 120 days – for instance until days end.⁸⁴

Issues with accessibility exist in both old and newer health care venues.¹⁶ In many venues of health care providers blind and visually impaired people have difficulties finding their way. ²⁷

RECOMMENDATIONS

- Link the heath care and social services into holistic, disability friendly system backing up disabled patients and secure cross-usage of databases.
- Ensure health insurance coverage by state for all people with disabilities.
- Elaborate voluntary guidelines for treatment of patients with disabilities while providing medical treatment services.
- Improve accessibility of health care units and providers.
- Solve the issues for availability of general narcosis dental care for people with disabilities.

Government Office of Estonia, Extract

⁸⁴ Towards a caring state. Political recommendations for improving the long-term care provision and reducing burden of care of family members in Estonia. Final report of the Task Force on reducing the burden of care (2017).

Article 26 Rehabilitation

In Estonia, rehabilitation service is divided into three strands: medical rehabilitation, social rehabilitation and employment rehabilitation.

Medical rehabilitation, provided by Estonian Health Insurance Fund is focusing on regaining and preserving health or adapting to a disability. Social rehabilitation offered by Social Insurance Board is provided for children with disabilities under 16 years of age, people of pension age and adults of working age, who are not working, are not studying nor have registered as unemployed. Estonian Unemployment Insurance Fund is offering employment rehabilitation for the people with reduced workability, including people with disabilities, who are working, studying, are employers themselves or have registered unemployed.

Within social and employment rehabilitation, services are provided by physiotherapist, occupational therapist, creative therapist, special pedagogist, psychologist and speech therapist. Since 2016, services of a doctor, nurse and peer councelling were added. The same year, lead by Astangu Vocational Rehabilitation Center, 91 peer counselling specialists across Estonia were trained. Autumn 2017 the Chamber of Peer Counselling Specialists was established as an umberalla, with the aim of developing the services. From the beginning of 2016 until the end of 2018, supplying of peer counselling service has slightly risen, but is still not sufficiently available. ⁸⁵ 86

While issuing the permit for service provision, the quality of rehabilitation provision is checked, weather the specialists are qualitied, the health and safety, including fire safety requirements along with accessibility requirements are met. ²¹

Study on coping ability of families of disabled children is showing, that 44% of disabled children at kindergartens and 34% at schools have difficulties accessing rehabilitation services at those education facilities. ²⁰

Earlier years there were long queues recieving rehabilitation services, but since the beginning of 2018, that problem has been solved. At the moment, the availability of rehabilitation services is hampered by uneven distribution of service providers in the Estonian regions. Bigger regions have the possibility to let users choose among several providers while the remote areas have few service providers. Worrying matter is the sustainability of rehabilitation services after the European Social Fund support will end in 2020.

A problem within the rehabilitation field is the ability of people with disabilities and their families to understand and make a distinction, what is medical rehabilitation, social

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Nõmm, A. (2017) Peer counselling service in rehabilitation 2016–2017. Social Insurance Board. Extract as of January 2018 http://media.voog.com/0000/0041/5310/files/Kogemusn%C3%B5ustaja%20teenus%20-%20Airi%20N%C3%B5mm.ppt

⁸⁶ Ministry of Social Affairs, 2019.

rehabilitation and employment rehabilitation. Unnescesary high administrative burden and time-consuming aspect for the persons with disabilities and their families is the constant request for proving the special need and disability, in order to access the services. ⁷⁰ There is a lack of systematic and sustainable holistic view on how the different rehabilitation strands should work best together. The services have siminar content, the aims are difficult to differ between, while the financing is coming from different resources, application procedures differ and the whole organisation is that way confusing. ⁸⁷

As a shortcoming that has been highlighted is, that the percentage of people with disabilities (18% of people with complex dependency needs and 22% of mobility impaired), who most probably need rehabilitation services, are not using those. That is though a worrying fact. ²⁸

Since 2016, there is an additional possibility to participate at social and employment rehabilitation programmes. Rehabilitation programmes aiming at helping people to employment have in Estonia been elaborated in the frames of European Social Fund (ESF) pilot projects since 2009. Programmes tend to create little interest among users, as the programme is connected to a certain service provider, often provided on certain dates and with specific requirements (i.e extra expenses and the need of attending extra hours). People with disabilities prefer services close to their place of residence and using services of a provider chosen by themselves. ⁸⁸ It can be claimed, that rehabilitation programmes are not flexible enough, does not take into account the special need of individuals and therefore are not living up to their aims, what will be to provide a person-centered service.

Looking at technical aids for people with disabilities, those can be either rented or purchased with a personal technical aid card, issued based on a relevant document of proof or an evaluation provided by the rehabilitation team, stating the need for a technical aid. As earlier, the technical aids budget provided by the state, was divided by the Estonian regions, since 2016 there is a joint annual budget and the applicant is not forced to use the provider at his/her place of residence, but can choose among all the providers available in Estonia. The changes have been positive, as more technical aids companies have been established – if in 2014 Social Insurance Board had a contract with 47 companies, in 2018 that number had increased to 97. ⁸⁹

In the new technical aids system, there are price limits for the technical aids, what have resulted in a considerable higher co-funding from the user in case of certain equipment.

⁸⁷ Availability of rehabilitation service. Minutes of the Social Commission of the Estonian Parliament Riigikogu nr 130 (April 17th 2017). Riigikogu. Extract as of January 2018 https://www.riigikogu.ee/tegevus/dokumendiregister/dokument/5265157b-de03-4264-9ac4-97dcaca75789

⁸⁸ Ojala, K. (2017) Programmes of Social Rehabilitation – expectations of the Social Insurance Board. Tartu: Information seminar for rehabilitation service providers. Astangu Vocational Rehabilitation Center. Extract as of January

2018 http://www.astangu.ee/fileadmin/media/Astangu/Dokumendid/RAKK/RAKK teabeseminar 2017/Rehabilitatsiooniprogrammide teabeseminari esitlused

14062017.pdf

⁸⁹ Technical Aids Companies having a contract with Social Insurance Board at 30.11.2018. Extract as of December 2018 https://www.sotsiaalkindlustusamet.ee/sites/default/files/content-editors/Abivahendid/abivahendi ettevotted.xlsx

According to parents of disabled children, one-tenth of the kids in need of technical aids, the equipment is not suitable for the real need of the child.²⁰

The process of applying for a technical aid cannot be considered fair. The person has to proceed through several different stages. Firstly one should recive a document, stating the need for technical aid, thereafter approach the Social Insurance Board, to receive a technical aid card. Only then its possible to approach the company who sells the equipment. Non-electronic cards, only on paper, have posed an administrative burden and unnescesary use of time for people with disabilities.

A serious shortcoming, that has been created by fragmentation of the social and health care system, is the long waiting time to recieve technical aids on discount, when moving from hospitalised care to home based care, as the prerequisit is that the degree of disability or incapacity for work need to be fixed already. An application for evaluation of the degree of disability, while still hospitalised, might take as long as seven weeks and the evaluation on workability can only start when the sickness leave has ended.⁹⁰

Since January 1st 2016, there is a medical equipment and technical aids database in Estonia, what is giving an overview on which equipment, by whom and on what conditions is provided. ⁹¹

By december 2018, only quite limited number of techincal aids were inserted into the database, therfore the database is not fulfilling its role of informing the individuals who are in need for technical aid sufficiently. That means that establishing a market overview on technical aids largely remains on the sholders of people with disabilities themselves and their family members.

As a positive development, since the beginning of 2019, people in residential care can apply for technical aids along the same lines as those who live at home. Additionally legislation amendments have taken place, which enable availablilty of technical aids for certain target groups and are simplifying the processes considerably.

Starting from 2019, the State budget strategy will introduce a principle change for the coming two years, what will enable to secure the techical aid to all individuals who need it. Earlier years there were situations, where availability of techincal aids for certain age groups was restricted, if the funding cealing for that particular group was reached.

RECOMMENDATIONS

⁹⁰ Habicht, A. Estonian Chamber of Disabled People appeal to Ministry of Social Affairs on the availability of technical aids when removed from hospital care into home based care (29.05.2017). http://adr.rik.ee/som/dokument/5109360

⁹¹ Database of Medical Equipment and Technical Aids. Extract as of December 2018 https://msa.sm.ee/

- Elaborate a holistic solution for provision of rehabilitation services, joining medical and social services into one, well-functioning and empowering system, secure crossusage of databases.
- Secure sufficient basic funding of rehabilitation and medical rehabilitation services.
- Improve availability of technical aids for the people moving from hospitalized medical care into medical care at home.
- Transform the paper version of the technical aid card to become an electronic tool.
- Amend the conditions for provision of rehabilitation programmes to become more flexible, in order to increase the usage of the programmes.
- Fix the financing of state level rehabilitation services after the end of the EU Funding post 2020

Article 27 Work and employment

Welfare Development Plan for 2016–2023 highlights people's participation in the labour market and support for long-lasting working life, what at the same time is the main resource for securing ability to cope and wellbeing.⁶

The biggest share of unemployment would be among people with mental health problems and among young intellectually disabled and the lowest among youth with hearing disabilities. ⁹²

One option for reducing the lack of workforce would be better inclusion of people with disabilities into employment. To reach that goal, Estonia was in 2016 gradually introducing a workability reform, what can be considered as one of the biggest reforms in the social field of last decades. Main implementing body of the workability reform is the Estonian Unemployment Insurance Fund.¹³

Barriers, that are hindering the success of the reform would be lack of workplaces to offer, availability of just some type of jobs at rural areas and smaller towns, lack of transportation possibilities, insufficient labor mobility and slower adaptability for change among the employers. ⁹³Also the National Audit Office of Estonia was, while studying the readiness for the reform, highlighting that the willingness of employers to hire a person with lower workability is low – ca. 44% of employers do not consider it possible. Main reason among employers is, that they consider that the skills and qualifications of people with lower workability are not meeting the employer's needs and some of those people lack the routine for work. ⁹⁴

National Audit Office is also highlighting that an important barrier is uneven ability of local authorities to offer social services supporting job-seeking and going to work. One obstacle to hiring people with specials needs could be, that the employer has to offer more assistance and support, as well there might be more people becoming involved, i.e. support person.

The workability reform has not added more national level measures for encouraging employers to hire a part-time employee.

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⁹² Poolakese, A., Lauringson, A. (2016) Transfer from school to working life for youth with special needs and disabilities. Tallinn: Analysis Department of Estonian Unemployment Insurance Fund. Extract as of January 2018 https://www.tootukassa.ee/sites/tootukassa.ee/files/erivajadustega_noorte_
koolilopetajate siirdumine koolist tooturule.pdf

⁹³ Impact study and pre-evaluation of Work Ability Allowance Act (2014). Tallinn: Ministry of Social Affairs. Saar Poll Ltd. Extract as of January 2018 https://www.sm.ee/sites/default/ files/content-editors/Ministeerium_kontaktid/Uuringu_ja_analuusid/Sotsiaalvaldkond/tvk_ semojuanalyys_eessonaga.pdf
⁹⁴ Activities of the state for preparing the work capacity reform (2017). National Audit Office of Estonia. Extract as of January 2018 http://www.riigikontroll.ee/tabid/168/amid/557/ItemId/950/language/et-EE/Default.aspx

Evaluating workability by the new method has been encountering problems with the availability and quality of data in the Health Information System. Unemployment Insurance Fund has in half of the cases had to put forward a separate information claim to the doctor. ⁹⁵ That means the evaluation is taking time and also unfortunately sometimes resulting in unfair evaluation decisions. Lack and varying quality of health data is one of the major reasons why there are many claims for re-evaluation.

Improving the situation of people with disabilities in employment is also a challenge as there is a generally high unemployment rate in some regions, meaning that people with disabilities have to compete with people without disabilities.¹⁶

Within workability reform, Estonian Unemployment Insurance Fund is offering incentives and benefits for people with reduced ability to work and to (potential) employers of those people. ⁹⁶ One incentive, the partial coverage of social tax for the employer, is unfortunately not applied to public sector employers, what is diminishing the competition ability of the people with reduced workability.

According to DPO-s, many shortcomings have appeared providing the labor market services – for instance is transportation to work support not provided for those people with disabilities, who are attending traineeship at the workplace, but cannot use public transportation due to their disabilities. Practicing work, where people with reduced ability to work can try out different occupations and learn relevant skills, should be more in accordance with the real needs of the labor market. Its not useful to practice occupations for which there is no real need at the labor market, as a result of which the person cannot actively participate the labor market anyway.¹⁶

One major reason for inactivity among people with disabilities is a disease or injury⁶⁶, while workability reform is not focusing on preventive measures. National Audit Office is as well on the opinion, that in addition to increasing labour market participation of people with disabilities, avoidance of losing workability by reducing workplace injuries should as well be focused on. ⁹⁴

Simultaneously services provided by local authorities need to be developed – such as transportation, sign language and speech to text interpretation, personal assistance.¹⁶ In order to increase employment of people with disabilities, more attention should be paid supporting transfer of young people with special needs from school to work and from one education level to the next.

One possibility to develop a labour market for all, would be creation of workplaces in sheltered workshops and involve civil society organisations more actively into that task.

35

⁹⁵ Unemployment Insurance Fund homepage. Extract as of January 2018 https://www.tootukassa.ee
⁹⁶ Services for people with reduced workability. Extract as of January 2018 https://www.tootukassa.ee
https://www.tootukassa.ee

A separate issue is salaries of people with disabilities. Even when people with disabilities have a suitable workplace, often the salaries stay very low and wont cover the extra expenses what might occur while going to work. In 2015 the salary of people with reduced workability was 76% of the average salary of other unemployed entering employment. ⁹⁷

RECOMMENDATIONS

- Link the occupational advice and labour market services of the education, employment and social field into one holistic, disability friendly system backing up disabled people and secure cross-usage of databases
- In order to reach the goals of workability reform, support the employers better.
- Bring education and training of people with disabilities better into accordance with labour market expectations.
- Develop supportive services and incentives for intellectually disabled and people with mental health problems in order to improve and facilitate their labor market participation.
- Find a solution and implement the measures for improving the quality of data of the Health Information System.
- Collect data for evaluation of impact and successfulness of the workability for people with disabilities (including data by disability group).

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⁹⁷ Fields of employment and salaries of unemployed with reduced workability compared with other unemployed (2017). Analysis Department of Estonian Unemployment Insurance Fund. Quantitative analysis. Extract as of January 2018 https://www.tootukassa.ee/sites/tootukassa.ee/files/tvr_palgaanaluus.pdf

Article 28 Adequate standard of living and social protection

The level of severe material deprivation of people with disabilities in Estonia is considerably higher than the level of absolute poverty. A reason for that could be a combination of extra costs due to disability and reduced capacity to acquire income through work.⁶

Disability benefit is normally not covering the extra costs due to disabilities and is therefore living up to the expectations only partially. Principles for granting benefits for people with disabilities of working age were changed as of July 1st 2016, resulting in most people with disabilities of working age receiving even slightly smaller benefits. ⁹⁸

For people with disabilities, availability of benefits and services means not only a possibility of alleviating poverty but also a more independent and thus more dignified life. Persons with mobility impairments but with similar health conditions can, in case of inaccessible housing, be quite dependent on external help, while when living in an accessible environment can live fully independently.¹⁶

At the level of local authorities people often experience that they have been deprived of help and treated with repulsive attitude. ¹⁶ There are local authorities, where regulations offering social services are not in accordance with the Estonian constitution. Moreover, the benefits meant to cover for the extra costs due to disabilities are not well enough linked to provision of services what should compensate for that extra cost. ⁹⁹

Unfortunately key factor for getting help from the municipalities is relying on own activeness and capability of the disabled individual or on capable assistance while applying for the services. According to Social Welfare Act, as well as according to the opinion of Chancellor of Justice, the ability to get help should not be dependent on the capacity of the applicant, but on objective evaluation of need for help. ¹⁰⁰

An impediment for providing adequate social protection of people with disabilities is the disproportionally high share of own financing -13% of state level services and 48% of municipality level services 101 -while receiving social services, taking into account the

⁹⁸ Estonian Chamber of Disabled People opinion upon the decree proposal of Minister of Social Protection Rules and procedures for evaluating the degree of disability and providing benefits for people with disabilities of working age (2016).

⁹⁹ Uder, L. (2010) *State activities in supporting people with disabilities and people with reduced capacity for work.* National Audit Office of Estonia. Extract as of January 2018 https://www.riigikontroll.ee/Suhtedavalikkusega/Pressiteated/ tabid/168/ItemId/574/amid/557/language/et-EE/Default.aspx

¹⁰⁰ Social services in cities and municipalities. Chancellor of Justice. 2016. http://www.oiguskantsler.ee/sites/default/files/field_document2/Sotsiaalteenused%20linnades%20ja%20valdades.pdf

¹⁰¹ Initial analysis of modernizing the principles for disability policy and provision of services and benefits for people with disabilities. 2018. Ministry of Social Affairs.

low level of income. Due to low level on pensions and benefits, people with disabilities are not able to pay for the services, often already having difficulties paying the own financing share. ⁵⁴ As an example, considerable reduction in use of social transportation in one of the municipalities can be highlighted, when the service was no longer available without charge. ¹⁰²

Poor accessibility of municipal social housing is as well highlighted as a problem. There should be much better opportunities when choosing housing, suitable for the real needs of the individual. Cases where wheelchairs, rollators and other technical aids are carried up the 5th floor exists.¹⁶

In addition to accessible housing, accessible transportation is also crucial for maintaining adequate standard of living; in particular crucial in the rural areas. Mapping of social services was showing, that the smaller municipalities use most of the total time limit for services just for offering social transportation.⁵⁴

Elderly disabled are often in need of combined social protection measures, to be able to cope with the disability and the barriers caused by age. Although home-based services are considerably cheaper than institutions, offering the first-mentioned by the municipalities is uneven and insufficient. Limited offer of home-based service has resulted in high demand in institutional care, availability of which in Estonia is unfortunately increasingly dependent on costumer-s own income level. For instance only a third of all persons in need of longterm care are receiving it, while most elderly persons are covering that expense by old-age pension, which often is insufficient for even the cheapest care home. 47 000 persons are living with a burden of care, of which 8000 persons are not participating at the labor market and 5000 are working part-time. Lack of unified criteria for municipal service provision, fragmented provision of the services and insufficient funding, as well as political decisions of the municipalities have led to unequal treatment of people with similar needs. Care provider benefits differ from one town to the other, as well does the range of services and the beneficiaries. According to World Bank, burden of care and responsibility of family members is a result of low level of spending on long-term care by the state, being many times less in comparison with most European countries.⁵⁹

From the point of view of a person with disabilities, seeking help, is the disproportional administrative burden as there is no unified database for provision of social services and there is lack of autonomous functioning of the existing databases.

RECOMMENDATIONS

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¹⁰² Uri, A. (2014) *Providing social- and care services for people with disabilities at Estonian local authorities*. Study report. Tallinn: Estonian Patient Advocacy Association. http://www.epey.ee/public/files/KOV_uuring_EPE.pdf

- Create a united and holistic information system or secure cross-usage of databases for providing, applying and monitoring state and municipal level services for people with disabilities.
- Increase disability benefits to cover for the extra expenses due to disability.
- Evaluate the adequacy of resources provided for the municipalities to secure proper protection of rights of people with disabilities in an equal manner in all regions.
- Provide equal, adequate social protection for people with disabilities, deriving from common methods of evaluation of their needs and introduce real monitoring mechanisms of municipal service provision.
- Develop flexible care provision, diminishing the burden of care of relatives and offering then active participation in work life and social life.
- Improve access to housing, including social housing.

Article 29 Participation in political and public life

There is no data available in Estonia on how many people with disabilities are using or can use their voting rights.

For elections to European Parliament, Estonian Parliament Riigikogu and for local elections, the person whose voting rights and rights to be elected have been withdrawn by court order, declaring the person incapable, cannot vote or be elected. ¹⁰³ Voting rights in connection with legal capacity is regulated by Code of Civil Procedure ¹⁰⁴, by which in cases when the court had appointed a legal guardian to execute all areas of life or the responsibilities of the legal guardian are enlarged to all areas, the person under guardianship loses the right to vote.

Whether the person under legal guardianship can vote or not, is depending on the scope of guardianship. Though Estonian case law has interpreted the voting rights and restricting it differently. In some civil law cases its stated, that if the person can independently execute minor transactions, the person should be counted as able to vote, ¹⁰⁵ other case law is focusing on whether the person is understanding the meaning of elections or not, and even in cases where the right of executing minor transactions in remaining, voting rights are not granted.³³

European Court of Human Rights have decided, referring to UN CRPD article 29 in its decision from 2010 that stripping the person of voting rights without individual assessment in court and just because of intellectual disability, what is requiring partial limitation of legal capacity cannot be a rightful cause for limiting voting rights. ¹⁰⁶ Council of Europe Committee of Ministers recommendation from 1999 is stating, that decision on restricting persons legal capacity as a protective measure should automatically not strip the person of voting rights, right to leave a will, capacity to decide upon own health issues ¹⁰⁷ and based on recommendation from 2004, people with mental health issues should be entitled to exercise all their citizen's and political rights. ¹⁰⁸

¹⁰³ Parliament Elections Act (01.01.2017). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/125102016022

Code of Civil Procedure (07.01.2017). *Riigi Teataja I*. Extract as of January 2018 https://www.riigiteataja.ee/akt/128122016022

¹⁰⁵ National Court Civil Collegium 19.04.2017 decision on case no 3-2-1-32-17 p 16. *Riigi Teataja*. Extract as of January 2018 https://www.riigiteataja.ee/kohtulahendid/detailid.html?id=206133329

¹⁰⁶ European Court of Human Rights decision 20.05.2010 case no. 38832/06, Alajos Kiss vs Hungary.

¹⁰⁷ Recommendation R(99)4 of the Committee of Ministers to Member States on principles concerning the legal protection of incapable adults (1999). Council of Europe. Extract as of January 2018 https://www.coe.int/t/dg3/healthbioethic/texts_and_documents/Rec(99)4E.pdf

Recommendation R(2004) 10 of the Committee of Ministers to Member States concerning the protection of the human rights and dignity of persons with mental disorder and its Explanatory Memorandum (2004). Council of Europe. Extract as of January 2018 http://www.coe.int/t/dg3/healthbioethic/Activities/08_Psychiatry_and_human_rights_en/Rec(2004)10%20EM%20E.pdf

In the light of the abovementioned, it's questionable whether the national regulation, what is enabling interpretation of the law in different ways, is in accordance with the principles of UN CRPD and case law of European Court of Human Rights.

UN report from 2015 ensures, that people with disabilities in Estonia can vote despite of their place of residence, i.e. in a care home or hospital, letting the wish to vote be known for the electoral commission. ¹⁰⁹ It's possible to use e-voting ¹¹⁰ solutions and vote at home with an ID-card, if the person does not have abilities to attend the voting station because of disability. E-voting is very widespread in Estonia. However, one cannot be entirely sure if e-voting at care homes is conducted in a rightful and transparent way.

Apart from the mentioned possibilities, there are still serious shortcomings in executing ones voting rights. Problems occur in achieving information about elections – i.e. public statements of politicians, electoral programmes, webpages, printed election materials etc. Published information is often not accessible for people with various disabilities, mostly for people with visual and hearing impairments and intellectual disabilities.

Many voting station are not accessible for people with disabilities in Estonia, for some cases for physical accessibility but more inaccessibility is caused by not providing alternative formats for information. Persons with disabilities have to have the right to decide the way how to vote – whether he or she wants to vote at voting station, by e-voting or asking the voting box to be brought home. Unfortunately often people with disabilities have to accept the possible solution – asking the voting box to be brought home or use e-voting. ¹⁶

¹⁰⁹ UN 28.12.2015 report from page 111 onwards.

¹¹⁰ General description of e-voting. Extract as of January 2018 https://www.valimised.ee/en/internet-voting/internet-voting-estonia

RECOMMENDATIONS:

- Declare illegal the constitutional impediment, upon which a person, who has by court been declared without legal capacity, cannot vote. Provide people with mental health problems and people with intellectual disabilities full right to participate in voting processes based on their abilities.
- Secure people with disabilities access to information and way of voting, despite his or her disability specific characteristics or assistance needs.
- Gather and analyze data on participation of people with disabilities in politics, including participating in elections.

Article 33 National implementation and monitoring

Ministry of Social Affairs is responsible for implementing the convention, being in charge of health, employment and social policy. Each ministry is responsible for the implementation of the Convention in its own field of responsibility. ¹¹¹

Ministry of Social Affairs as responsible body for implementation of the CRPD is posing a risk that securing the rights of people with disabilities is considered as a theme of social care, not reaching all the other areas the Convention is covering. This aspect is hindering more inclusive approach and creation of equal opportunities for all.

When the UN CRPD was ratified, a promise was made to establish a commission at the level of Government of the Republic, for solving disability issues, coordinating, setting strategic goals and priorities, proposed those suggestions to the Government and moreover present annual progress reports on implementation to the Government.¹¹¹ When drafting the current report, almost seven years after the ratification, this commission is yet to be established.

According to the Convention, the state parties should establish a monitoring mechanism, what is in accordance with the Paris principles. Unfortunately establishing of an independent monitoring mechanism was a time-consuming task in Estonia, becoming a reality on January 1st 2019. We are content that as a result of considerable pressure from us, DPO-s, the independent monitoring mechanism was put to Chancellor of Justice Office, who-s responsibility in addition to secure constitutional rights, rule of law, will as well be protecting the rights of people with disabilities.

Monitoring processes should be involving people with disabilities and DPO-s. Estonian Chamber of Disabled People was after the ratification of UN CPRD, during the years 2012–2014 conducting trainings for its member organizations, preparing them for participating in the monitoring of UN CPRD. In 2014 there were individuals and organizations available to contribute into the monitoring processes. For meaningful participation in the monitoring processes, DPO-s need in addition to legal changes also content-wise empowerment, i.e. in a form of continuous trainings in order to improve their abilities to stand for the rights of people with disabilities and provide relevant information upon the situation of people with disabilities for the international organizations. In 2012 and 2013 the Estonian Chamber of Disabled People had earmarked funds for that particular task and in 2014 Praxis Center for Policy Studies was provided 30 thousand euros for that task. Delaying with establishing the monitoring mechanism has caused that the competence among DPO-s have lessened, therefore it has to be raised again. ¹⁶ Unfortunately for 2015, the earmarked state budget funds for CRPD related activities were given to the Gender Equality and Equal Treatment Commissioner office operational grant, without the latter making specific efforts in the

43

¹¹¹ Ratifying the UN CRPD Act 161 SE (21.03.2012).Estonian Parliament Riigikogu. Extract as of January 2018 https://www.riigikogu.ee/tegevus/eelnoud/eelnou/1774015b-86a2-4540-aed8-4ae25d214f16/Puuetega%20inimeste%20õiguste%20konventsiooni%20ratifitseerimise%20seadus

monitoring processes, as the legislative decisions were delayed. By the time the current alternative report is completed, there is no clarity yet how and on which extent people with disabilities and their representatives DPO-s will be involved into the monitoring processes, while the co-operation on drafting the principles have started.

RECOMMENDATIONS

- Establish the focal point for implementing the UN CRPD at the level of the Government of the Republic, enabling taking into account different fields of policy development.
- Establish a commission for promoting, protecting and supporting the monitoring of the UN CPRD implementation, with participation of people with disabilities and DPOs. Secure financing for that commission by state budget.