

LESSON 5

INDEPENDENT LIVING

Article 19 of the CRPD is on the right to live independently and be included in the community. In this part of the course, we learn about independent living which is closely related to the work of social workers today and will be more so in the near future when the CRPD is ratified by the government of Kyrgyzstan.

- This part is meant to learn from experiences of independent living practices in another country. The material below is on Finland.
- If there is any guest lecture possibility, s/he can present good practices and lessons learned from another country.

Content of Lesson 5

- 5.1. Independent Living: An Example of Finland
- 5.2. Sexuality and Disability in Europe
- 5.2. Changed Perception on Disability
- 5.3. Concluding the Training Course

5.1. Independent Living: An Example of Finland

Article 19 of the Convention mentions the importance of the equal rights of all persons with disabilities to live in the community and enjoy their full inclusion and participation in the community:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs (CRPD Article 19).

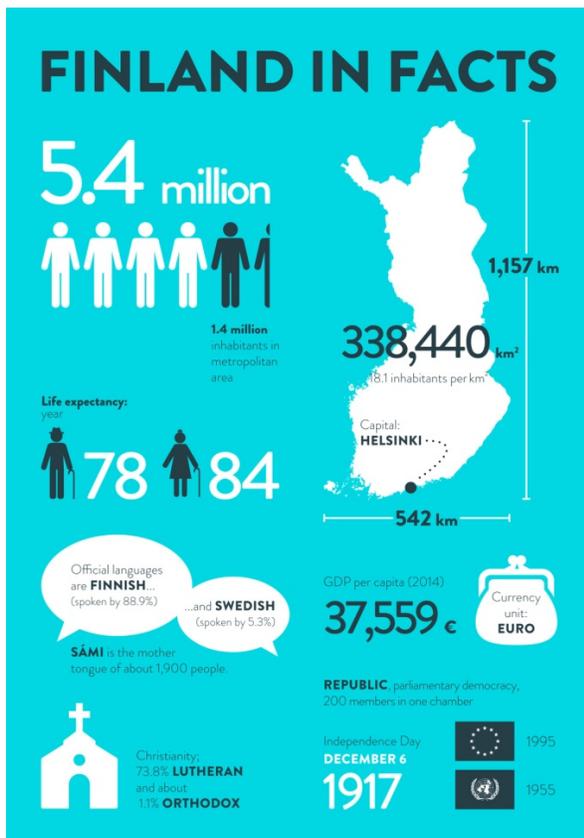
This means in practice that a deinstitutionalization process has been going on in many countries at the same time. Many countries have had the tradition that persons with disabilities have lived in institutions and not in communities. Kyrgyzstan and Finland are not exceptions. This part introduces the case of Finland towards its efforts towards the independent living of persons with disabilities.

- The teacher can ask from the trainees about the living of persons with disabilities in their localities. Do they live in institutions or in communities? Are they part and parcel of the society on an equal basis with others without a disability in communities in cases in which they live in such? The trainees can discuss further why there is the gap between persons with and without a disability.

Finland in Brief¹



Finland is located in the Northern part of Europe between Russia in the east and Sweden in the west. Finland celebrates 100 years of independence in 2017.



Finland has the population of 5.4 million, of which 1.4 million live in the capital area. The life expectancy for men is 78 years and that for women is 84 years.

Helsinki is the capital of Finland.

Finland is the size of 338,440 km², which makes 18.1 inhabitants per km².

Official languages are Finnish and Swedish, that are spoken by 88.9% and 5.3% of the population respectively. Sami is the mother tongue of about 1,900 people.

GDP per capita in 2014 was 37,559 EUR.

Finland is a republic with a parliamentary democracy having 200 members of parliament.

73.8% are Lutheran and 11% Orthodox.

Finland has an extensive Nordic-style welfare system.

¹ The map is from <https://www.findaphd.com/study-abroad/europe/phd-study-in-finland.aspx> and the picture is from <https://finland.fi/facts-stats-and-info/finland-in-facts-2/>

Independent Living

Independent living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives as our non-disabled peers.²

A human rights-based approach is, therefore, manifested in the ideology of independent living.

Deinstitutionalisation Process of Finland

Until the 1990s, the majority of persons with intellectual disabilities lived in institutions in Finland. In 1995, 50 % of the persons with intellectual disabilities had been deinstitutionalised, whereas 5,270 persons still lived in institutions by the end of 1998.³ Today there are about 40,000 people with intellectual disabilities in Finland, that is, 0.7% of the whole population, out of whom approximately 1,000 still lived in institutions in 2015.⁴ This means that there has been an active development work in the localities in order to provide housing solutions for persons with intellectual disabilities, who move out of childhood homes and institutions.

In Finland, persons with disabilities live largely in communities with the exception of persons with intellectual disabilities, some of whom still live in institutions today. The expansion of the DI process to all persons with intellectual disabilities started with advocacy efforts by Finnish DPOs grounded in the Convention on the Rights of Persons with Disabilities (CRPD).

In principle Finland has secured the equality of persons with intellectual disabilities in different ways. The Constitution of Finland⁵ regulates the fundamental rights for everyone. In addition, the services of people with disabilities are organised based on the law on disability services and the law on special care for persons with intellectual disabilities,⁶ when a person with a disability does not get sufficient and suitable services or benefits based on any other law, such as the Social Welfare Act (30.12.2014/1301).⁷

² <https://www.independentliving.org>

³ STAKES, 2001, in Mietola, R. et al. (2013) Kehitysvammaisten ihmisten asumisen tulevaisuus: kansainvälisiä esimerkkejä ja vertailu Suomeen. Helsinki. Ympäristöministeriö.

⁴ Yksilölliseen ja monimuotoiseen asumiseen. Kehitysvammaisten asumisen ohjelman arviointi asumisratkaisujen osalta. Ympäristöministeriön raportteja 18/2016. Available at:

http://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/74911/YMra18_2016.pdf?sequence=1

⁵ The Constitution of Finland (11.6.1999/731), available at: www.finlex.fi/fi/laki/ajantasa/1999/19990731

⁶ Finland, Act on Services and Assistance for Persons with Disabilities (3.4.1987/380), available at: www.finlex.fi/fi/laki/ajantasa/1987/19870380. Act on Special Care for Persons with Intellectual Disabilities (23.6.1977/519), available at: www.finlex.fi/fi/laki/ajantasa/1977/19770519.

⁷ Finland, the Social Welfare Act (30.12.2014/1301), available at: www.finlex.fi/fi/laki/ajantasa/2014/20141301.

In order for persons with intellectual disabilities to get more opportunities for replacing institutional living, the Government has taken measures to promote deinstitutionalisation. Deinstitutionalisation in Finland is framed at the national level by two Government Resolutions on Securing Individual Housing and Services for Persons with Intellectual Disabilities adopted in 2010⁸ and 2012.⁹

The first Government Resolution established a programme,¹⁰ which aims at the systematic realisation of community-based living with necessary support from 2010 to 2015 for 3,600 persons with intellectual disabilities, including enabling them to move out from their childhood homes or from institutions. However, according to an assessment of the programme, the housing has largely consisted of group homes with places for 15 or more residents and the implementation of decentralised housing solutions has been too modest.¹¹

The second Resolution defines the next steps for the programme, the overall goal of which is to finish the deinstitutionalisation process by 2020 and to ensure that no one will live in an institution after the year 2020. Municipalities will be responsible for the DI of all by 2020.

At the individual level, decisions about deinstitutionalisation (such as moving away from an institution or to a housing unit with lighter support) are made by the social workers of the municipalities. The process starts with drafting a service plan for a client with a disability. The legal framework, in particular the Disability Act (1988, revised in 2009) and the Act on Special Care for Persons with Intellectual Disabilities (revised in 2016) requires that the client's thoughts and wishes are heard and are taken into account as much as possible.

Recognised challenges include:

- Negative social attitude
- Institution-like culture in alternative housing
- Lack of coordination and communication among stakeholders, and
- Sufficient services (EU-FRA, forthcoming in 2018)

⁸ The resolution was adopted to establish KEHAS (the Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015.) Available at: www.thl.fi/en/web/vammaispalvelujen-kasikirja/itsenaisen-elaman-tuki/asuminen/kehitysvammaisten-asumisohjelma-kehas.

⁹ Finland, Government Resolution on Securing Individual Housing and Services for Persons with Intellectual Disabilities, 8 November 2012. Available at: <http://julkaisut.valtioneuvosto.fi/handle/10024/71490>.

¹⁰ KEHAS (The Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015). Available at: www.thl.fi/fi/web/vammaispalvelujen-kasikirja/itsenaisen-elaman-tuki/asuminen/kehitysvammaisten-asumisohjelma-kehas

¹¹ Karinen et al. (2016) Yksilölliseen ja monimuotoiseen asumiseen: Kehitysvammaisten asumisen ohjelman arviointi asumisratkaisujen osalta. Helsinki. Ympäristöministeriön Raportti 18/2016.

Social Services for Persons with Disabilities in Finland

As stipulated in the Services and Assistance for the Disabled Act (1987/2008), municipalities are obliged to:

- evaluate the need for services and make a service plan for an individual person with a disability, and
- provide services to support independent living in the community and the functional capacity of the person.

There are several subjective rights for persons with serious disabilities. A person with a severe disability is defined as a person who:

- Due to his/her long-term or progressing disability or illness
- Necessarily and repeatedly
- Needs the assistance of another person
- For daily activities, work, education and hobbies, and
- The limitation is not primarily due to aging.

The disability services for persons with severe disabilities include:

- housing services
- transportation services
- daily activities
- home alterations
- assistive devices at home
- personal assistance

Table 4. Numbers of Disability Service Users in Finland in 2010 and 2013

	2010	2013	Change between 2010-2013 in %
Transport services for seriously disabled people	94 828	102 010	+7,6 %
Personal assistant services	8 985	15 217	+69,3 %
Housing alterations, devices and facilities	9 580	10 322	+7,7 %
Sheltered housing for seriously disabled people	4 310	5 273	+22,3 %

Personal Assistant

Personal assistant (PA) is mentioned in the Article 19 of the Convention. Personal assistance is a service under the Disability Act in Finland. Assistance is provided by another person to a person with a severe disability, either at home or outside the home. Personal assistance is meant for activities that one would do by oneself, but is not able to do because of his/her disability or long-term illness. The purpose of the PA is to assist the persons to act according to his/her own choices. The person him/herself will decide on the kind of assistance, when, where and how to receive it, and who will work as assistants.

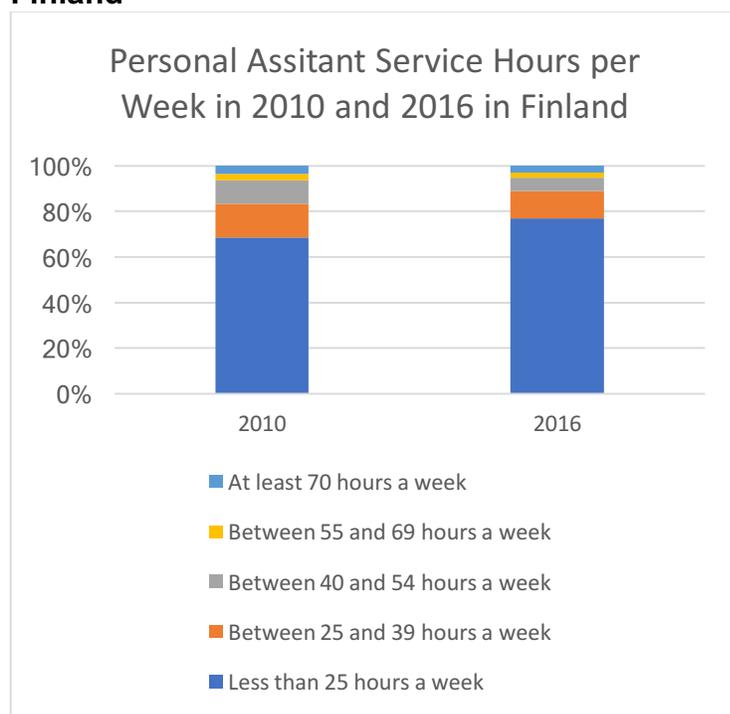
- The teacher can facilitate a discussion on what are the differences between social workers and personal assistants.

Hint: For instance, Kyrgyz social workers go grocery shopping and bring food for their customers. Personal assistants in Finland accompany persons with disabilities to the shop when they want to go to grocery shopping to help reach items that are hard to reach, to carry heavy items, and/or to support cooking with the customers. Persons with disabilities choose what to buy, where to buy, what to cook and how to cook, for instance, and do these chores with the help of personal assistants. The personal assistants support the function that the persons with disabilities would have done by themselves if their function were not limited.

There are three different ways that persons with severe disabilities can use personal assistant services: 1) employer model, 2) voucher model, and 3) assistance service model. The majority of persons with severe disabilities use the first model where they become the employers. In the employer model, the person with a severe disability is the employer of the assistant. The costs caused by this employment relationship are compensated for by the municipality of residence. In the voucher model, the person with a severe disability receives a voucher from the municipality for acquiring the services. In the assistance service model, the municipality acquires assistance services for the person with a severe disability. Finnish DPOs encourage persons with disabilities to use the first employer model and conduct training for persons with disabilities on how to recruit their personal assistants, to train them, and to deal with money as employers, among others. Some of the training of DPOs is financially supported by the local municipalities.

As is clear from the below graph, most of the persons with severe disabilities need less than 25 hours of personal assistant service hours per week. More precisely, 53% of those who receive personal assistant services used less than 10 hours of services per week in 2016.

Graph 1. Personal Assistant Service Hours per Week in 2010 and 2016 in Finland¹²



Identified rooms of improvement of personal assistant services include:

- Need of attitude change both in society and in persons with disabilities
- Need to develop freedom of choice
- Need to secure enough financial resources and salaries for personal assistants

¹² Source of statistics:

https://www.julkari.fi/bitstream/handle/10024/135318/Tr34_17_tilastoraportti.pdf?sequence=3

Formulation of the graph by the authors.

The Case of Kazakhstan

Did you know that Kazakhstan has already introduced personal assistant services for persons with severe disabilities?

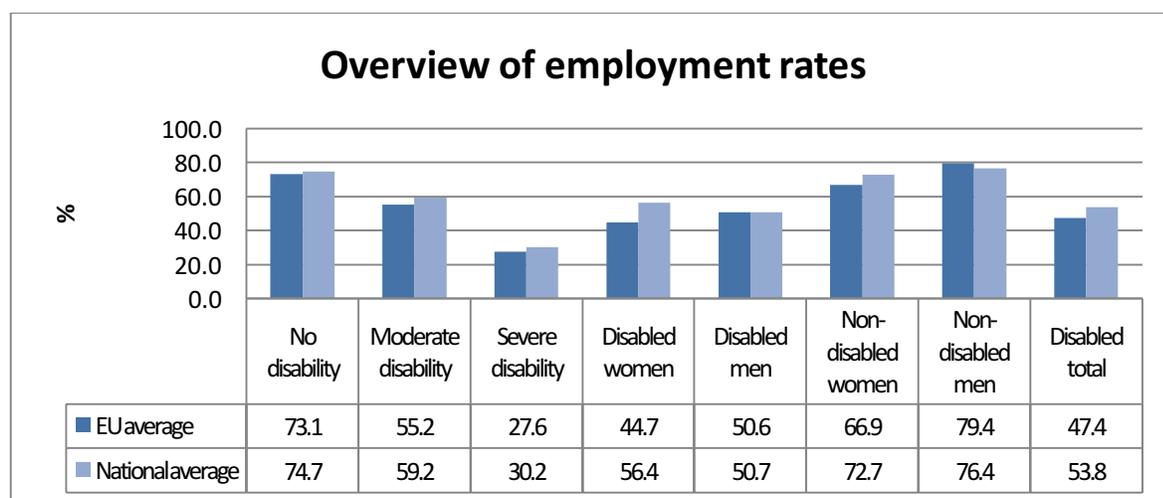
The Kazakh DPOs advocated for the services, as well as transportation services for persons with severe disabilities, and succeeded in gaining the services at the national level with a new law. These services are administrated by DPOs and financially supported by local municipalities.



Employment of Persons with Disabilities in Finland

When it comes to the reality of employment, however, disability services are not enough. There are 70,000 persons with disabilities who are willing to work and who are workable. Only 60% of them are employed, that leaves 40% of them unemployed.¹³

Table 5. Most recent employment data, aged 20-64¹⁴



¹³ THL. (2017) Available at <https://www.thl.fi/fi/web/hyvinvointi-ja-terveyserot/eriarvoisuus/vahemmistot/vammaisuus/tyollistyminen>

¹⁴ Source: EUSILC UDB 2015 – version of October 2017, cited in Valkama, K., Katsui, H., and Kröger, T. (2017) European Semester 2017/2018 Country Fiche on Disability. ANED. Brussels.

The above table shows the EU and Finnish average employment rates of people aged between 20-64, disaggregated by disability, severity of disability, and gender. It is clear that both in EU countries and in Finland, persons with disabilities, especially those with severe disabilities, do not enjoy employment on an equal basis as others without a disability.

Much more changes are needed for both duty-bearers and rights-holders today in Finland.

- The teacher can ask the trainees the following questions:
 - What do the duty-bearers have to do?
 - What do rights-holders have to do?
 - How can social workers contribute to the independent living of persons with disabilities in Kyrgyzstan?

5.2. Sexuality and Disability in Europe

Sexuality is an integral part of everybody's life, including that of persons with disabilities. However, it has often been believed that persons with disabilities are asexual or sexually invisible. Such taboos and myths are very common. As a result, the sexuality of persons with disabilities is too frequently totally ignored in the social protection system in most of the countries around the world. Therefore, many persons with disabilities feel more vulnerable when they deal with their own sexuality, because of negative attitudes, low self-esteem and isolation (please see Lesson 1). Hence, it can be said that the socio-cultural context has been reinforcing the low "sexual self-esteem"¹⁵ of persons with disabilities. Today, in European countries, taboos and myths have been challenged and their sexual rights have gradually begun to be recognized as a natural part of life.

In Article 25 of the UN Convention on the Rights of Persons with Disabilities, it states:

State Parties shall provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, **including in the area of sexual and reproductive health** and population-based public health programmes (emphasis added).

Several European countries have tried to meet the sexuality needs of persons with disabilities with professional sexual assistants who are paid to provide for sexual services

3. Snell Jr, W.E. (1998) "The multidimensional sexual self-concept questionnaire." In Davis, C.M., Yarber, W.L., Bauserman, R. (eds.) Handbook of Sexuality-Related Measures, pp. 521–524. Sage Publications, Thousand Oaks.

for persons with disabilities. Those countries are Germany, Denmark, the Netherlands, Spain and Switzerland.¹⁶ Germany and Denmark made their legal recognition already some 30 years ago. In these countries, sexual assistants go through a training and gain a certificate of competence. In these countries, social workers are responsible for listening to the sexual needs of their clients and connect them to sexual assistants whenever needed.

When an assistant is “passively” helping persons with disabilities to masturbate by changing their positions and placing sex toys in the right places and to support the sex of persons with disabilities and not “actively” practicing sex with the clients, the series of action is defined as sexual assistance. Distinction is made for “active” practice of sex. Currently in countries that do not have sexual assistance services, the job description of social workers and personal assistants does not include sexual assistance. Even in those countries that are more proactive in realizing sexual rights of persons with disabilities, mutual consent between persons with disabilities and sexual assistants is the bottom line for materializing this type of service. The greatest distinctions between sexual assistants and prostitutes lies 1) in the fact that the former voluntarily choose this profession, while prostitutes are often forced into the positions, and 2) that the former aims at providing a sexual aid to the client, while prostitution is for earning money.¹⁷ Ultimately, sexual assistance is for the well-being of persons with disabilities.

Many European countries have either formally or informally started internal discussions on realizing this particular right of persons with disabilities, even though sexual assistants are neither legally recognized nor practiced in many other European countries, including in Finland. Meeting the sexual needs of persons with disabilities is often considered controversial due to the possible abuse on both sides, especially when the line between sexual assistance and prostitution is blurred. In addition to the cultural and social taboos, the ethical dilemma between the rights of persons with disabilities and the rights of support workers, as well as sensitive relationship between them, are among the reasons why sexuality is not taken into account.

- For advanced trainees, they can discuss the realities in Kyrgyzstan and analyse challenges in realizing the sexual rights of persons with disabilities.

¹⁶ Mannino, G., Giunta, S. and La Fiura, G. (2017) Psychodynamics of the Sexual Assistance for Individuals with Disability. *Sexuality and Disability* 35. P. 485-506.

¹⁷ Nina de Vries, a sexual assistant in Switzerland, cited in Mannino, G., Giunta, S. and La Fiura, G. (2017) Psychodynamics of the Sexual Assistance for Individuals with Disability. *Sexuality and Disability* 35. P. 485-506.

5.3. Changed Perception on Disability

Things to prepare:

- The flip chart paper on which the exercise answers were written down on the first day
- A new flip chart paper

At the end of the training, the teacher asks the same question to the trainees: Which words do you think of when you hear “disability”?

- The trainees can orally express which words come to their mind. The teacher can write down those answers on a new flip chart paper.
- After the trainees have exhausted their answers, the teacher encourages the trainees to compare their answers before and after the training course. The trainees are encouraged to discuss the changes made.

5.4. Concluding the Training Course

The teacher summarises the huge perceptual changes that have taken place in the trainees. This perceptual change, based on social and human rights-based approaches to disability among social workers and others working in the field of social protection, is essential to start treating persons with disabilities as equal members of society towards their empowerment and meaningful participation. This perception change is the most important learning that was aimed at in this training course.

Evaluation form to fill

- The teacher asks the trainees to fill in the evaluation survey in the attachment to learn from their feedbacks and experiences.

Certificate to give

- The teacher delivers certificates to the trainees after completion of all the tasks of the module.