**ANED 2018-19 Task 1.2**

**Living independently and being included in the community**

Country: Finland

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# PART A – Factual information and statistical data

# Current situation and direction of travel

## Numbers and proportions of disabled children and adults residing in institutional care or community-based settings

### Current figures

In Finland, persons with disabilities typically live in the community, with some exceptions. Persons with severe intellectual disabilities and multiple disabilities, as well as older persons with disabilities, are among the groups most likely to live in institutions. It is estimated that there are about 40,000 persons with intellectual disabilities in Finland, which amounts to around 0.7% of the total population. Until the 1990s, the majority of persons with severe intellectual disabilities lived in institutions.For instance, according to the archive record of the Finnish Association on Intellectual and Developmental Disabilities, in 1979 there were about 3,500 persons with intellectual disabilities living in institutions.The situation has changed quite dramatically since then. Deinstitutionalisation (DI) of persons with intellectual disabilities began and the number of users of housing services in the community started to grow. Between the 1980s and 2000s, the change took place quickly; since the 2000s, however, research shows that the speed of change has slowed down.[[1]](#footnote-1)

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 1995 | 2000 | 2005 | 2010 | 2013 | 2014 | 2015 | 2016 | 2017 |
| 0-17 yrs | - | 208 | 207 | 190 | 194 | 175 | 194 | 191 | 173 |
| Of which long-term | - | 155 | 133 | 122 | 128 | 114 | 138 | 138 | 110 |
| 18-64 yrs | - | 2 390 | 1 974 | 1 588 | 1 117 | 933 | 798 | 648 | 494 |
| Of which long-term | - | 2 332 | 1 909 | 1 512 | 1 054 | 875 | 735 | 583 | 444 |
| Over 64 | - | 160 | 165 | 156 | 153 | 133 | 101 | 81 | 72 |
| Of which long-term | - | 157 | 161 | 156 | 149 | 128 | 96 | 81 | 68 |
| Total | 3 699 | 2 758 | 2 346 | 1 934 | 1 464 | 1 241 | 1 093 | 920 | 739 |
| Of which long-term | - | 2 644 | 2 203 | 1 790 | 1 331 | 1 117 | 962 | 795 | 622 |

*Table 1. The number of persons with intellectual disabilities living in institutions.[[2]](#footnote-2)*

Table 1 above illustrates the number of persons with intellectual disabilities living in institutions in Finland. A person is categorized as a long-term user when an administrative decision has been made about his/her long-term care. Long-term care also refers to disabled people who have been in institutional care over 90 days.

### Trend since 2013

In the 2010s, the DI process was reactivated by government resolutions committed to close all institutions by 2020. In 2015, 1093people with intellectual disabilities still lived in institutions.[[3]](#footnote-3) By the end of 2017, this had fallen to 739.[[4]](#footnote-4) In other words, there has been steady progress in the DI process for adults with intellectual disabilities.

In Finland, however, the DI process for children with disabilities has not progressed as well as for adults. The number of children with intellectual disabilities under the age of 18 in institutions has not decreased as planned. In 2015 it was 194 and at the end of 2017 still 173.[[5]](#footnote-5) In addition to children with intellectual disabilities, children with psychosocial disabilities (such as children with autism spectrum disorders) combined with challenging behaviour are placed in institutions.[[6]](#footnote-6)

It is challenging to deinstitutionalize those adults and children who are still in institutions today, because the deinstitutionalization process started with those with milder disabilities. Those in the institutions typically have intensive medical care needs and/or were born in the 1950s or earlier, having been in institutional care for a long time.[[7]](#footnote-7)

Moreover, the “second phase of DI” concerns questions such as how people with intellectual disabilities could move on from group housing (such as group homes) and institution-like housing units to genuine independent living in communities. Many people with intellectual disabilities have moved from the institution to specific housing units for disabled people. These housing units are regarded as community-based services, but sometimes they have institutional work practices and other institutional features.[[8]](#footnote-8) These housing units are mostly meant for 15 people or more.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Year | 2000 | 2005 | 2010 | 2013 | 2014 | 2015 | 2016 | 2017 |
| Assisted | 2 780 | 4 552 | 5 876 | 6 628 | 6 616 | 7 728 | 8 265 | 8 484 |
| Guided | 1 555 | 2 061 | 2 168 | 2 083 | 1 987 | 2 006 | 1 954 | 1 986 |
| Supported | 553 | 796 | 972 | 1 317 | 1 274 | 1 548 | 1 684 | 1 880 |
| All | 4 488 | 7 409 | 9 016 | 10 028 | 9 877 | 11 282 | 11 903 | 1 2350 |

*Table 2. People with intellectual disabilities in different group housing alternatives at the end of the year.*

When deinstitutionalized, in Finland persons with intellectual disabilities have three possible ways of living in communities. Assisted living in the community means that persons with intellectual disabilities receive support 24 hours a day. Guided living means that they get support 12 hours a day without night-time monitoring. Supported living means that they get support according to agreed number of hours, for instance a few times a week. The above table 2 shows the clear trend that the number of persons with assisted living has been growing constantly as deinstitutionalization process has been progressing. In addition, people in supported living have been increasing steadily though more slowly than those in assisted living. People living in assisted living have 24/7 supervision and support which makes the transition either from childhood home or institution feel more safe and easier.

## Overall spending on institutional care versus services for support for living independently and being included in the community, including information about proportion/amount of funding provided from EU funds

### Current figures

The National Institute for Health and Welfare (THL) provides statistical information on welfare and health in Finland in the SOTKAnet database. This information is also available from Statistics Finland.[[9]](#footnote-9) User-specific data on care received during the year and census data on all users receiving care at the end of the year are gathered from residential homes for older people, institutions for people with intellectual disabilities, institutions for substance abusers, and 24-hour housing services for older people and disabled people. Concerning housing services for disabled people, only the costs of institutional care were reported until 2014. Since 2015 the expenditures for assisted living have been reported in the statistics, as well (see Table 3).

The Housing Finance and Development Centre of Finland (ARA) grants investment subsidies for the construction, basic improvement and acquisition of housing intended for persons with intellectual disabilities. As well, the Funding Centre for Social Welfare and Health Organisations (STEA, formerly known as RAY) grants funding for the acquisition of housing to persons with intellectual disabilities. The investment subsidies granted by ARA for persons with intellectual disabilities have focused primarily on group homes for 15 or more residents. The subsidy for groups homes can be 50 % of the total cost but in normal housing the investment subsidy for individual rental apartments is only 10 %. The challenge is that not enough decentralised housing solutions have been provided and that the services related to housing have not been developed sufficiently with new housing production.

Some examples have been calculated by ARA to compare the costs in different forms of housing for the user as well as the municipality.[[10]](#footnote-10)

EU funds are not used in this area.

### Trend since 2013

The decrease of spending for institutions and a corresponding increase of expenditures for community living are observable clear trends (Table 3). In 2016 the resources spent in assisted living were over five times those spent in institutional care.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 2012 | 2013 | 2014 | 2015 | 2016 |
| Institutional care | EUR 168 M | EUR 164 M | EUR 157 M | EUR 153 M | EUR 135 M |
| 24/7 assisted living | - | - | - | EUR 666 M | EUR 698 M |
| Total | - | - | - | EUR 819 M | EUR 833 M |

*Table 3. Expenditures for institutional care and assisted living for disabled people[[11]](#footnote-11) [[12]](#footnote-12) [[13]](#footnote-13) [[14]](#footnote-14)*

When it comes to cost of services and financial support provided pursuant to the Act on Services and Assistance for the Disabled, that are central to independent living of persons with disabilities in communities, there is similarly observable clear trend of increase (Table 4).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 2013 | 2014 | 2015 | 2016 | 2017 |
| Total costs | EUR 513 M | EUR 563 M | EUR 619 M | EUR 644 M | EUR 659 M |

*Table 4. Total costs of services and financial support for services and assistance for persons with disabilities[[15]](#footnote-15)*

# Government commitments on living independently and being included in the community including the transition from institutional care to community-based living

## In which document(s) are government commitments and plans concerning support for independent living in the community set out?

In principle, Finland has secured the equality of persons with intellectual disabilities in different ways. The Constitution of Finland regulates the fundamental rights of everyone.[[16]](#footnote-16) In addition, specific laws cover services for people with disabilities. They are organised according to the Act on Services and Assistance for Persons with Disabilities and the Act on Special Care for Persons with Intellectual Disabilities,[[17]](#footnote-17) which apply 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.[[18]](#footnote-18)

In order to support persons with intellectual disabilities to leave institutional settings, the Government has taken measures to promote DI. DI in Finland is framed at the national level by **two Government Resolutions** on Securing Individual Housing and Services for Persons with Intellectual Disabilities (*Valtioneuvoston periaatepäätökset kehitysvammaisten henkilöiden yksilöllisen asumisen ja palvelujen turvaamisesta*) adopted in 2010[[19]](#footnote-19) and 2012[[20]](#footnote-20).

The first Government Resolution established the KEHAS programme.[[21]](#footnote-21) It aimed at bringing about community-based living with necessary support for 3,600 persons with intellectual disabilities between 2010 and 2015, enabling them to move out of their childhood homes or institutions. However, according to an assessment of the KEHAS programme, the new community-based housing has largely consisted of group homes with places for 15 or more residents while the development of more decentralised housing solutions has been too modest.[[22]](#footnote-22)

The second Resolution defined the next steps for the KEHAS programme. Its overall aim is to finish the DI process by 2020 and to ensure that no one lives in an institution after the year 2020. The provision and organization of services for people with disabilities is the responsibility of the municipalities that have a lot of autonomy. Many local authorities as well as special care districts and social and health care joint municipalities (that both represent collaboration of neighbouring municipalities) have made detailed plans for DI.[[23]](#footnote-23) The localization of the implementation of DI is one reason why the state level documents are quite general, leaving more options to take the local needs and characteristics into consideration.

The **CRPD** entered into force in Finland in 2016,[[24]](#footnote-24) guiding now the DI process together with the European Disability Strategy 2017-2023. For instance, some domestic laws were revised to comply with the Convention, while political will has been upheld by the European Disability Strategy.[[25]](#footnote-25) The Home Municipality Act (Kotikuntalaki 201/1994) stipulated support for independent living in the community of residence but restricted the freedom of mobility of persons with disabilities to move to another municipality where better services may be available. As this restriction was considered not to comply with the Convention, the law was revised (1377-1378/2010) and enacted in 2011 to allow mobility of persons with disabilities to seek for better services in another municipality. In such a case, the home municipality pays for the services.

The inter-Ministerial action plan of the Finnish Government for 2018-2019 includes some targets related to DI, which will be introduced more in detail in the following section 2.2.

## What are the aims and objectives of relevant strategies, including relevant targets and milestones? Are they linked to ESIF?

As mentioned, the second Government Resolution on Securing Individual Housing and Services for Persons with Intellectual Disabilities from 2012 aims to ensure that no disabled person lives in an institution after the year 2020.

In the Action Plan[[26]](#footnote-26) of the Finnish Government for the implementation of the CRPD in 2018-2019, several actions (number 30-38) are relevant to independent living of persons with disabilities. They are listed below with identified responsible duty-bearers:

1. Investigating the good practices for supported decision-making together with disability organisations.

*Responsible bodies: Ministry of Social Affairs and Health and Ministry of Justice*

1. Ensuring that the special needs of persons with disabilities and the obligations pursuant to the UNCRPD are taken into account in the preparation and later implementation of the legislation concerning the right of self-determination.

*Responsible body: Ministry of Social Affairs and Health*

1. Ensuring that the new disability legislation and its implementation take into account obligations pursuant to the UNCRPD.

*Responsible body: Ministry of Social Affairs and Health*

1. Organising a follow-up meeting for the KEHAS programme with an aim to promote the abolition of institutional housing and development of individual housing solutions pursuant to the UNCRPD. Contributing to ensuring that enough different housing solutions that fulfil the needs of persons with disabilities are available, particularly as part of the ordinary housing stock.

*Responsible bodies: Ministry of Social Affairs and Health and Ministry of the Environment*

1. Utilising the results of a survey on the equality of housing for persons with intellectual disabilities in improving their living arrangements.

*Responsible body: Ministry of the Environment*

1. Specifying the instructions for personal assistance through the Handbook on Disability Services, for instance. Collaborating with experts from disability organisations in this matter.

*Responsible body: Ministry of Social Affairs and Health*

1. Supporting the implementation by counties: Ensuring that the special needs of persons with disabilities are taken into account and individual solutions are realised.

*Responsible body: Ministry of Social Affairs and Health*

1. Specifying the application instructions for social welfare and disability services to ensure that the privacy of persons with disabilities is respected and their convictions taken into account when appointing assisting and nursing staff.

*Responsible body: Ministry of Social Affairs and Health*

1. Raising awareness of the application of the Act on Public Procurement and Concession Contracts to ensure the implementation of the right of persons with disabilities to independent living, necessary services and the right of self-determination.

*Responsible bodies: Ministry of Economic Affairs and Employment and Ministry of Social Affairs and Health*

The Action Plan mentions that one of the milestones is the forthcoming Disability Service Act. A disability legislation reform has been pending for several years already. The new legislation, which would replace both the current Disability Services Act and the Act on Special Care for People with Intellectual Disabilities was intended to be brought before the Parliament in the end of September 2018. The new legislation was expected to enter into force in 2021.[[27]](#footnote-27) However, the process has been delayed and the new act will not be introduced to the Parliament before the parliamentary election in April 2019.

As well, legislation on the right of self-determination is currently under preparation. Amendments and appendices necessary for the UNCRPD concerning restrictions to the right of self-determination were made to the Act on Special Care for People with Intellectual Disabilities (519/1977) in the summer of 2016. The future regional government, health and social services (SOTE) reform also affects the lives of persons with disabilities. The national legislation continues to exclude supported decision-making; indeed, developing this is a challenge for the coming years.

The European Disability Strategy 2010-2020 has also been implicitly impacting on the strategy of the Finnish government. European Structural Investment Funds (ESIF) have not been used to support the transition costs from institutional to community-based care and support in Finland. The ESIF, however, has funded some development projects regarding employment of persons with disabilities as well as their social inclusion, which can indirectly be seen to support independent living:

* [S20607: KELPO: pathways to working life of developmentally disabled people](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S20607);
* [S20701: Administration of labour market activity resources for development project ‘KELPO - a path for mentally disabled persons to a working life’](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S20701);
* [S20659: Effectiveness and indicators of occupational health activities](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S20659);
* [S20578: Occupational wellbeing at all ages](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S20578);
* [S20784: Work ability coordination pilots for better employment of people with work incapacities](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S20784);
* [S20752: Strengthening participation and preventing marginalization in social work processes of disability services](https://www.ulapland.fi/FI/Kotisivut/VamO-hanke);
* [S21288: TOGETHER - Finding individual work paths](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S21288);
* [S21306: We, You, They! – Working ability or welfare to everyone!](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S21306);
* [S20864: Woman of her own life - Improving the career management skills of women with disabilities;](https://www.tuas.fi/en/research-and-development/projects/woman-her-own-advancing-working-life-skills-women-/)
* [S20874: THE KEY TO CITIZENSHIP: participation, self-determination, freedom of choice and support through personal budgeting](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S20874);
* [S20865: Satakunto project](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S20865);
* [S20851: Develop the Social Rehabilitation in Kainuu](https://www.eura2014.fi/rrtiepa/projekti.php?projektikoodi=S20851).

In the project ‘Strengthening participation and preventing marginalization in social work processes of disability services’ the purpose is to strengthen the processes of social work in disability services.[[28]](#footnote-28) The main aim is to promote the service users’ participation. The project also aims to recognize and develop the expertise needed in social work in disability services. The long-term objectives are to ensure that processes are working well, services for disabled people are adequate and that equality has been reached nationwide.

In the project ‘THE KEY TO CITIZENSHIP: participation, self-determination, freedom of choice, and support through personal budgeting’ the purpose is to create a pilot model of personal budgeting in collaboration with relevant actors including cities, colleges, and companies.

## Please summarise the planned approach and the actions to be taken in relevant strategies

The approach of the Action Plan of the Finnish Government for the implementation of the CRPD in 2018-2019 (pages 38-41) is summarized as follows:

The housing solutions should always be based on individual need, and the inclusion of persons with disabilities and their close relatives must be at the focus of the implementation of the housing solutions.

Adequate and high-quality services are also an essential element of the implementation of independent living.

For securing independent living of persons with disabilities in communities, legal changes are under process, as presented above.

Concrete actions are left for the municipalities to decide upon and to implement at the community level.

## What budgetary commitments are made to support these strategies, both for domestic and EU funds?

Both institutional and community-based services are funded from the **budgets of municipalities**. In addition to municipal tax revenues, municipalities receive state subsidies for the provision of social and health care services such as the KEHAS Deinstitutionalisation programme that will be mentioned below in section 3.2. This aims to ensure that all citizens can access a certain level of basic services irrespective of their place of residence. Despite this, many participants at both the national and local levels have felt that there are significant differences in the quality and quantity of services between different municipalities. In small and rural municipalities, the range of alternative services is much more limited than in cities.[[29]](#footnote-29) In chapter 3.2 are some relevant projects presented.

ARA has granted investment subsidies in 2005-2016 for 4,105 apartments for persons with disabilities and subsided their construction with EUR 234 million.[[30]](#footnote-30) Table 5 illustrates the number of apartments built and ARA investment subsidies granted in 2010-2017.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 |
| New apartments | 405 | 408 | 415 | 412 | 524 | 313 | 311 | 408 |
| Reconstruction | 38 | 72 | 10 | 39 | 20 | 35 | 27 | 18 |
| Investment subsidy mil € | 28,9 | 27,1 | 30,4 | 27,7 | 36,5 | 20,0 | 30,7 | 23,7 |

*Table 5. ARA investment subsidies for apartments for disabled persons in 2010-2017.[[31]](#footnote-31)*

In Finland, the provision of many essential care and housing services for disabled people are outsourced to for-profit or non-profit providers under procurement. The contract period usually lasts for 3 or 5 years. The procurement process has often led to a change of provider, which has led to occasions where the staff working in care and housing units has changed several times. In some occasions, disabled people have been forced to move due to the procurement process. Such changes have had deep negative effects on the everyday lives of many disabled people in Finland. This situation had led to a campaign “Ei myytävänä” (“Not for sale”) in order to have the Section 9 of the Public Procurement Act changed. The initiative was signed by over 72,000 people and is going to be debated in the Parliament before the parliamentary election in April 2019. According to the initiative, paragraph 16 of the Act should include the following statement: "This law does not apply to the procurement of those services, which are essential for the everyday life of people with disabilities.” The Government of Finland has already budgeted EUR 300,000 to be used during 2019 in educating municipal decision-makers to fully ensure the rights of persons with intellectual disabilities when tendering housing and care services according to the Procurement Act.[[32]](#footnote-32) It has also been argued that the problem is not the lack of procurement knowledge in the municipalities. In any case, the legislation should be changed as currently a person with an intellectual disability is not considered as a party of interest in procurement of housing and care services and therefore has no legal protection.[[33]](#footnote-33)

EU funds have not been used for covering the implementation costs of deinstitutionalisation. EU FRA commissioned a case study on the DI process to compile evidence and experiences of relevant stakeholders both at the national and local levels.

## What is the (official) involvement of persons with disabilities and/or their representative organisations in the development of the strategies and plans

The extension of the DI process to all persons with intellectual disabilities started with **advocacy efforts by disabled persons’ organisations (DPOs)** grounded in the CRPD.

DPOs were closely involved into the preparation of the 2018-2019 Action Plan through VANE, the Advisory Board for the Rights of Persons with Disabilities. VANE’s current general secretary is a woman with a disability, and its vice chairperson and 5 members are representatives of the Finnish Disability Forum. It is hosted by the Ministry of Social Affairs and Health.

Disability Rights Committee (Vammaisten ihmisoikeuskomitea) operates as a permanent division under the Human Rights Delegation and was set up based on the Article 33 of CRPD. The Committee includes representatives of DPOs and closely works with the Parliamentary Ombudsman and the Human Rights Centre to promote and monitor the implementation of the CRPD.

The international disability coordination group is hosted by the Ministry for Foreign Affairs being a more informal forum composed of various governmental and non-governmental stakeholders. DPOs are well represented in this forum, too, to regularly and openly exchange timely information on disability rights.

# Implementation and monitoring

## Summary of relevant calls for proposals

Despite our efforts, we have not heard of any specific funding calls for proposals concerning the transition from institutional care to community-based living in Finland. However, certain projects have been funded, see below 3.2.

## Summary of relevant projects funded

Project 1: KEHAS Programme 2010–2015

In 2010–2015 Finland implemented a housing programme for persons with intellectual disabilities. The intention was to create individual housing for such persons moving from either an institution or their childhood home. This includes an accessible and well-functioning dwelling in an ordinary residential environment and sufficient, individual services and support. The purpose was that no person with an intellectual disability should live in an institution after 2020. During the programme, approximately 3,400 dwellings were produced, the use of institutional care decreased more rapidly than before, and the number of long-term residents in institutions for people with intellectual disabilities declined.[[34]](#footnote-34)

Project 2: The Centre of Everyday Lives Project 2012–2014[[35]](#footnote-35)

In 2012–2014 the Association of Persons with Intellectual and Developmental Disabilities was commissioned by ARA to implement this project. It focused on living environments in communities, promoting participation of persons with intellectual disabilities by meeting their individual needs. Prior to the project, housing alternatives and services around them were rather standardised, focusing on intensive support, around the country, which did not meet individual needs of persons with intellectual disabilities. In order to promote independent living of persons with intellectual disabilities, services are reconsidered to be arranged nearby with a suitable amount of, instead of excessive, support. This required coordination of housing, disability service and other relevant stakeholders to deal with the new situation of DI. Based on the pilot projects of this project, a guidebook was created for municipalities to establish a supported housing network and to make decisions in collaboration with persons with intellectual disabilities.

Project 3: Finland’s Disability Policy Programme 2010-2015 (Vammaispoliittinen ohjelma 2010-2015, VAMPO)

Finland's Disability Policy Programme 2010-2015 and its measures aimed to safeguard a just position in society for persons with disabilities and to outline the development paths through which to pursue sustainable and responsible disability policy. According to the evaluation of the implementation of the programme, most measures were completed as planned. Consequently, a positive trend is clearly visible especially in cultural and sports services, education and international cooperation. The programme also strengthened the attention paid to the rights of persons with disabilities in all administrative sectors and it increased cross-administrative cooperation on disability issues.[[36]](#footnote-36) By the end of the term, over 100 goals out of 122 were achieved.

Project 4: Citizen’s Keys (kansalaisuuden avaimet) 2016-2018[[37]](#footnote-37)

In 2016-2018 the Service Foundation for People with an Intellectual Disability (*Kehi-tysvammaisten Palvelusäätiö*) was funded by Veikkaus, a Finnish gaming company owned by the Finnish state, to run a project that tried to promote the realisation of the self-determination right of persons with intellectual disabilities living in housing units. The activities included training and peer support meetings to strengthen the right to self-determination for persons with intellectual disabilities.

## Overview of other relevant measures since 2013

In 2016, the Act on Special Care for Persons with Intellectual Disabilities (Kehitysvammalaki) was revised in order to ensure the right to self-determination. Currently, the government is renewing the legislation regulating disability services as well as demolishing the special district system/institutions.

THL has published a working paper “Disability-related information and information needs – an analysis of data production activities of the National Institute for Health and Welfare”.[[38]](#footnote-38) The working paper illustrates the information needs associated with disability and describes the possibilities to obtain information on disability and the situations of persons with disabilities through the information production activities of the National Institute for Health and Welfare. The paper considers ideas for developing the current database to ensure optimal responsiveness to relevant information needs.

The National Supervisory Authority for Welfare and Health (Valvira) has a national supervisory programme that is updated every year. In 2019 children and young people with intellectual disabilities is a specific object for supervision.[[39]](#footnote-39) In 2017 self-determination in services for people with intellectual disabilities was the object for supervision.

## Monitoring mechanisms and approaches

### Monitoring mechanism(s)

The Ministry of Social Affairs and Health as well as the Ministry for Foreign Affairs are the focal points of the national monitoring mechanism of the CRPD.

The Action Programme for the implementation of the CRPD is the official governmental plan that stipulates monitoring to be coordinated by the Advisory Board for the Rights of Persons with Disabilities (VANE). VANE is the national coordination mechanism.

An independent mechanism is the Disability Rights Committee that operates as a permanent division under the Human Rights Delegation and was set up based on the Article 33 of CRPD. The Committee works closely with the Parliamentary Ombudsman and the Human Rights Centre to promote in monitoring the implementation of the CRPD. They are the key independent human rights institutions in Finland.

These are the structures established for the Article 33 of the Convention and monitor the overall development of disability rights.

When it comes to monitoring of the DI process, the Ministry of Social Affairs and Health and the Ministry of Environment are the most relevant stakeholders.

### Measurement and data collection

The Action Plan of the Finnish Government for the implementation of the CRPD in 2018-2019 defines the responsible Ministry/Ministries for each action. The responsible party has to set indicators for their objectives by the end of the term. This has not been completed at the time of writing this report, which might be problematic as the time is running out.

Institutional care is highly regulated and therefore the number of people with intellectual disabilities in institutions is reported in the official statistics, SOTKAnet, as mentioned in chapter 1.2.1.

The Ministry of Environment has evaluated the DI process and published reports[[40]](#footnote-40) on its progress and ideas for further development. The data is collected with different methods, depending on the research questions.

# Impact and outcomes

## Progress against explicit targets and milestones

Over the last decade there has been an observable decrease in the number of residents with disabilities in institutions. Accordingly, an increasing number of persons with intellectual disabilities live in communities. The progress during the last few years, however, has been stagnating. The objective of reaching full deinstitutionalisation of persons with disabilities by 2020 is at risk. At a time of planned major changes in social and health services, disability services and local administrative structures (brought by the general SOTE reform), the future of the DI process remains uncertain.

## What is replacing institutional care?

### At the point that persons with disabilities are being moved out of institutional care facilities, what types of accommodation and support are they being moved into?

Across the country, people often first move into a group home for persons with disabilities where they learn independent living skills. Subsequently, genuine community-based living with an apartment of your own should ideally follow. Disabled people moving out of institutions often start with relatively intensive support and typically are thought to reduce the amount of support gradually, as they become more independent. This two-step model has been the basis for the implementation of DI in Finland. The approach is disputed, however, as many representatives of DPOs are against it, being concerned that group homes might uphold institutional practices and that in order to really reach Independent Living, a one-step process would be better, disabled people moving directly from institutions to normal or supported housing. Many professionals, family members and persons with disabilities at the grassroot level nevertheless think that a two-step process is more realistic. Moreover, currently institutions, group homes and community-based living co-exist, which brings additional financial burdens to municipalities many of which are, in general, in a difficult economic situation.[[41]](#footnote-41) According to SOTKAnet statistics, 2/3 of housing alternatives for persons with intellectual disabilities are group homes.[[42]](#footnote-42)

### What services, supports and measures are being developed and instituted to build long-term support for the right to live independently and to be included in the community?

Many kinds of disability services are available based on the needs of persons with disabilities. Persons with severe disabilities have legally enforceable rights to transportation services, assisted living, day time activities, personal assistance, renovation of homes and assistive devices that are to be used at home. In addition, night-time monitoring, assistive devices, relocation training and other services are available when needs are recognised, and municipalities have enough budget to cover the service costs.

The primary law for social services is the Social Welfare Act (Sosiaalihuoltolaki [1301/2014](http://www.finlex.fi/fi/laki/ajantasa/2014/20141301)), which covers needs of the general population, including persons with disabilities. If that is not enough to secure necessary support, then special laws such as the Disability Service Act (Vammaispalvelulaki [380/1987](http://www.finlex.fi/fi/laki/smur/1987/19870380)) and the Act on Special Care for Persons with Intellectual Disabilities (Kehitysvammalaki 519/1977) are applied.

## Satisfaction levels among persons with disabilities

The aforementioned study commissioned by the EUFRA reveals mixed experiences of persons with disabilities who have gone through the DI process. A specific critique has been that DI took place too quickly for interviewed persons with disabilities and their families without enough freedom of choice regarding where to live.[[43]](#footnote-43) Initially it was particularly the parents who felt that their children with intellectual disabilities cannot live in communities with lesser amount of services available in housing units. However, both persons with disabilities and their families gradually have changed their attitude towards independent living and started to be satisfied with the DI after a while when they got used to the idea.

However, those who still live in institutions have large medical and care needs and little or no experience of living in communities. For them, moving out from the institution seems too difficult, according especially to professionals and families.[[44]](#footnote-44)

A national survey of people with disabilities and those closest to them is also discussed in 5.3 below.

# PART B – Critique and evaluation

# Observations and recommendations of official bodies

## Observations by the UN Committee on the Rights of Persons with Disabilities on Article 19

After the ratification of the CRPD in June 2016, the Finnish government is overdue to submit its first state report. Therefore, there are yet no observations made by the Committee on the situation of Finland pertaining to Article 19.

## Recent observations by other official European and international bodies

The UN Universal Periodic Review Report 2017 of Finland refers to “promoting rights of persons with disabilities” on pages 12-13 and mentions the KEHAS programme and the VAMPO Disability Policy Programme as satisfactory.

## Observations and recommendations by national human rights bodies

VANE, the Advisory Board for the Rights of Persons with Disabilities, is a coordination body for the implementation and monitoring of the CRPD. VANE conducted an on-line survey among people with disabilities in autumn 2017 to understand the daily realisation of disability rights. The survey was answered by 577 persons with disabilities or their families, their representative organizations and members of disability councils. The survey answers were compiled into a report.[[45]](#footnote-45) According to the results of the survey, the majority of people (54 %, N=312) thought that the freedom of choice for persons with disabilities pertaining to their right to live in a place and live with a person of their choice is currently poorly realised in practice. A similar result was found also for concerning the availability of necessary services for enabling their independent living in communities. Independent living was identified in the report as a priority area. It further pointed out the needs for more information dissemination and that the strengthening of the decision making opportunities of disabled people on their own lives and societal issues, and the availability and accessibility of responsive services for individuals are the necessary preconditions for the realisation of disability rights.

## Observations and recommendations by national or regional/devolved Parliaments and assemblies

The office of the Non-Discrimination Ombudsman produces an annual report, which has since 2014 included an independent chapter on the rights of persons with disabilities. In 2016, the office conducted a survey and compiled a report entitled “’My disability makes me a second-class citizen’: A report on the discrimination experienced by the disabled in everyday life.”[[46]](#footnote-46) [[47]](#footnote-47) Similarly, in 2015 the Human Rights Centre wrote an open letter[[48]](#footnote-48) upon the request of the UN Special Rapporteur on the Rights of Persons with Disabilities, concerning the rights of persons with disabilities to social protection. The letter was based on the findings of the Ombudsman from 2014 and highlighted the widely spread discrimination practices against persons with disabilities in Finland.

# Views and perspectives of civil society including DPOs

## UNCRPD civil society shadow and alternative reports

As the ratification of the CRPD by the Finnish government took place only in June 2016, and as the country report is unfortunately overdue and not submitted yet to the Committee, shadow and alternative reports have not been published yet.

At present, both the Finnish Disability Forum and the Human Rights Centre are preparing their respective shadow and alternative reports. In 2018, they have conducted an on-line survey responded by about 2,000 persons with disabilities about their experiences. Both parties use the data for writing their reports. It is expected that more stakeholders will prepare their shadow reports when it is more timely.

## ‘Grey literature’ at the national level

The Ministry of Environment commissioned the Finnish Association of Persons with Intellectual and Developmental Disabilities to conduct a study regarding future housing solutions for persons with intellectual disabilities. The research was conducted by this NGO, but its researchers are academics. This report[[49]](#footnote-49) was published in 2013 and it compares the rather institution-like housing options available in Finland to housing alternatives in other European countries. The report makes the following recommendations for making independent living possible for persons with intellectual disabilities:

* Relocation and housing for people with developmental disabilities are planned so well that crisis situations do not arise.
* Personal assistance is used to support the independent living of people with intellectual disabilities for coping with daily activities.
* Personal budgeting can be used for housing, whereby the size of the budget is set according to the individual needs.
* The set housing quality standard[[50]](#footnote-50) should be extended to cover all housings. The size of the new apartments is at least 45-50 square meters. New dwellings will be built as part of a normal housing area.
* The renovation of housing contributes to the integration of persons with disabilities into the community. The use of individual apartments, both owned and rental ones, need to be considerably increased.
* The maximum number of persons living in group homes should be less than ten. The apartment is at least 35 square meters in size, including a kitchen area and bathroom. A bigger living spaces and smaller common and staff spaces are recommended.

## Pan-European and international civil society organisations

Finland is not directly mentioned in any recent reports published by ENIL, Inclusion Europe or Community Living for Europe.

# Academic research

EUFRA conducted a European-wide research on independent living of persons with disabilities around Article 19 of the CRPD. It commissioned in 2016 the Institute for Human Rights, Åbo Akademi University to conduct a case study on independent living of persons with disabilities in Finland. Finland was selected as one of the five case countries and its deinstitutionalisation process was investigated at the local level in 2017-2018. The following materials on the research findings are available:

* The report ‘[From institutions to community living for persons with disabilities: perspectives from the ground](http://fra.europa.eu/en/publication/2018/independent-living-reality)’ bringing together findings from the fieldwork across the five countries.
* A [summary of the report](http://fra.europa.eu/en/publication/2018/independent-living-reality-summary) in English, Bulgarian, Finnish, Italian and Slovakian.
* [National case study reports](http://fra.europa.eu/en/country-data/2018/right-independent-living-case-studies) presenting the findings from the five countries where fieldwork took place in English and the respective national language.
* [Easy read national case study reports](http://fra.europa.eu/en/country-data/2018/right-independent-living-case-studies-easy-read) in English and the respective national language.
* An [infographic](http://fra.europa.eu/en/publications-and-resources/infographics/5-success-factors-road-independent-living-people)presenting the five essential features of successful deinstitutionalisation.
* A webpage highlighting the [personal deinstitutionalisation stories](http://fra.europa.eu/en/publication/2018/independent-living-reality/stories) of some of the people with disabilities who participated in the research.
* A [video](http://fra.europa.eu/en/video/2018/independent-living-people-disabilities)highlighting some of the main findings of the research.

According to the Finnish country report, attitudes are one of the biggest barriers for independent living of persons with disabilities in Finland. The report recommends the following:

* Fostering positive attitude of both persons with and without a disability through interaction, information dissemination, media coverage, and training among others.
* Freedom of choice for a housing unit or in an apartment with adequate and quality support through personal budgeting when applicable.
* Commitment of the government to the DI in terms of clear strategy and allocation of enough resources in a long-term perspective.
* Relocation training and practical guidance to all stakeholders.
* More open dialogue and active cooperation of all stakeholders in the DI process with a more holistic approach.

# PART C – Key points

# Positive developments, including promising practice examples

One of the clear, positive developments is the commitment of the government to close institutions for persons with disabilities by 2020. This is a clear goal, which has been translated into deinstitutionalization practices at the local level. The statistics show that deinstitutionalization has been proceeding accordingly until recently, though there are still some people in institutions. However, at the moment the process is stagnating due to the expected major changes in legislation, administration, financing and organization of social and health care in general and disability services in particular.

As for legal development, laws have been either amended in conjunction with the ratification of the Convention or are in the process of amendment or renewal for stipulating independent living of disabled persons, paying attention to individual needs.

Positive attitudes have also been facilitating the deinstitutionalization process and independent living of persons with intellectual disabilities. The general public has gradually started to change its attitude, while persons with intellectual disabilities, particularly those of younger generations, have started to take it for granted that they shall also enjoy independent living in the community. This general attitude change is an enabling factor for the promotion of independent living.

# Negative developments including examples of poor practice

The fact that an increasing number of for-profit actors have entered into the housing and care sector of persons with disabilities has brought some negative implications, due to the introduction of competitive procurement of disability services. Currently the “Ei myytävänä (Not for sale)” campaign is strongly addressing this problem to ensure human rights of disabled persons rather than prioritising low expenditures of services.

There has also been a lot of uncertainty about forthcoming major legal and administrative changes that will affect disability services. The SOTE reform, which would move the responsibility for social and health care from local authorities to regional authorities and bring a substantial change in the funding system and a major boost for marketisation of care, through the adoption of a customer choice model, has been a key project of the current Government (2015–2019). At the time of finalising this report only one and half months are left of the current Government’s term, as parliamentary elections will be organised in Finland 14 April 2019. However, it is still uncertain whether the Government will manage to legislate the reform, due to lengthy political debates and widespread criticisms of the planned reform. As well, a reform of disability services has been under preparation for years but it seems now that this reform will not be legislated before the elections, which means a further delay for it. Overall, for a long time there has been a substantial lack of information concerning the future of social and health care in general and disability services in particular, which has in recent years considerably slowed down the implementation of DI in Finland.

Another observation has been made on the “neoinstitutionalisation” in the form of group homes that maintain institutional culture and practices even after deinstitutionalisation. Especially when the staff of institutions and long-term residents of institutions are relocated to alternative forms of housing, they tend to maintain their institutional culture. Moreover, it has been observed that there have not been enough alternative housing options for persons with disabilities to freely choose from. The physical relocation to the community, therefore, is often not quite enough to declare deinstitutionalisation.

# Recommendations

As the biggest barrier for independent living in Finland are negative attitudes of both persons with and without disabilities[[51]](#footnote-51), awareness raising and training are important strategies for promoting independent living of persons with disabilities. So far no significant awareness raising work has been conducted or budgeted by the government. There is a strong need for a government initiative for a nation-wide awareness raising campaign and targeted trainings for different stakeholders.

The legal change supporting independent living of persons with disabilities has been on progress but it has taken a longer time than expected. Under the circumstances where the SOTE reform has been predominating the political discourse in the field of social and health care issues, independent living of persons with disabilities and other vulnerable groups has been overshadowed. This should be changed and IL brought again in focus. The current policy trend that has promoted marketisation of social and health care has also brought major problems in disability services. Genuine freedom of choice needs to be in place for different disability services but following the market principle should not lead to degradation of the quality of disability services. Furthermore, it is necessary to highlight that, in addition to specific disability services, mainstream services should also be designed so that they are accessible to persons with disabilities on an equal basis.

There is a significant lack of data on independent living in Finland, partly due to the privacy law restricting data collection and disaggregation by disability. More systematic, holistic and longitudinal research is needed on the process of deinstitutionalisation towards independent living of persons with disabilities, with a special focus on those with severe intellectual and multiple disabilities.

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