

From institutions to community living: drivers and barriers of deinstitutionalisation

Case study report: Finland 2018

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INTRODUCTION

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) sets out the right of all persons with disabilities to live independently and be included in the community. Although the CRPD does not specifically mention deinstitutionalisation or address the transition process from institutional to community-based support, the Committee on the rights of persons with disabilities (CRPD Committee) has underlined that it is an essential component of fulfilling Article 19.

Achieving deinstitutionalisation (DI) is not limited to phasing out certain living arrangements. It entails a profound shift from environments characterised by routine and an ‘institutional culture’, to support in the community where persons with disabilities exercise choice and control over their lives. Realising the right to live independently for persons with disabilities therefore stretches beyond closing institutions and requires development of a “range of services in the community [...], which would prevent the need for institutional care”.¹

FRA’s project on the right of persons with disabilities to live independently and be included in the community

To explore how the right to independent living is being fulfilled in the EU, the European Union Agency for Fundamental Rights (FRA) launched a multi-annual research project in 2014. The project incorporates three interrelated activities:

- Mapping types of institutional and community-based services for persons with disabilities in the 28 EU Member States.²
- Developing and applying human rights indicators to help assess progress in fulfilling Article 19 of the CRPD.³
- Conducting fieldwork research in five EU Member States – Bulgaria, Finland, Ireland, Italy and Slovakia – to better understand the drivers and barriers of deinstitutionalisation.

From institutions to community living – commitments, funding and outcomes for people with disabilities

In 2017, FRA published three reports exploring different aspects of the move from institutions towards independent living for persons with disabilities:

- [Part I: commitments and structures](#) highlights the obligations the EU and its Member States have committed to fulfil.
- [Part II: funding and budgeting](#) looks at how funding and budgeting structures can work to turn these commitments into reality.

¹European Expert Group on the Transition from Institutional to Community-based Care (2012), [Common European Guidelines on the Transition from Institutional to Community-based Care](#), p. 27.

²FRA (2017), [Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU](#).

³ Indicators are available at: <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>. The indicators are based on the human rights model developed by the Office of the United Nations High Commissioner for Human Rights (OHCHR). See: UN, OHCHR (2012), [Report on Human rights indicators: A Guide to Measurement and Implementation](#), HR/PUB/12/5.

- [Part III: outcomes for persons with disabilities](#) focuses on the independence and inclusion persons with disabilities experience in their daily lives.

The series complements the Agency's [human rights indicators on Article 19 of the CRPD](#).

Other relevant reports previously published by FRA include:

- [Choice and control: the right to independent living](#)
- [Involuntary placement and involuntary treatment of persons with mental health problems](#)

Reality check? Local-level research on drivers and barriers of deinstitutionalisation

FRA's fieldwork aimed to give actors involved in the deinstitutionalisation process the opportunity to share their knowledge, experiences and perceptions of what drives the process forward, and the barriers that hold it back. It focused in particular on implementation of deinstitutionalisation at the local level, an area little covered by previous research.

The fieldwork was conducted by FRA's in-country research network, FRANET,⁴ in five EU Member States that are at different stages of the deinstitutionalisation process. It was divided into two parts:

- In 2016, interviews and focus groups were conducted in each Member State with various stakeholders from the national and local level (municipalities or cities). The findings led to the identification of one case study locality in each Member State.
- In the first half of 2017, interviews and focus groups took place with a range of stakeholders in the selected case study locality.

This report incorporates findings from both parts of the fieldwork. More information on the research methodology is available in the Annex and the main report presenting the results of the research.⁵

Why this report?

This report presents the findings of FRA's fieldwork research in Finland. Separate national reports capture the results from the four other fieldwork countries.⁶

The report starts by summarising the national context of deinstitutionalisation, including the legal and policy framework and funding, as well as how individuals involved in the deinstitutionalisation process understand some of the key terms and concepts. The rest of the report is structured according to five features emerging from the research as being essential for the deinstitutionalisation

⁴ See: <http://fra.europa.eu/en/research/franet>.

⁵ FRA (2018), *From institutions to community living for persons with disabilities: perspectives from the ground*, Luxembourg, Publications Office.

⁶ The national case study reports are available at: <https://fra.europa.eu/en/country-data/2018/right-independent-living-case-studies>.

process (see table 1). Firstly, the report presents the drivers and barriers of the deinstitutionalisation process in Finland, as experienced by participants in the research. It then looks at what participants believe is needed to make deinstitutionalisation a reality.

A comparative report bringing together the research findings from the five fieldwork countries was published in December 2018.⁷

Table 1: Key features of a successful deinstitutionalisation process

1.	Commitment to deinstitutionalisation
2.	Availability of guidance to support the deinstitutionalisation process
3.	Active cooperation between the people involved in the deinstitutionalisation process
4.	A change in attitudes towards persons with disabilities
5.	Practical organisation of the deinstitutionalisation process

Source: FRA (2018)

⁷ FRA (2018), [From institutions to community living for persons with disabilities: perspectives from the ground](#), Luxembourg, Publications Office.

1. CONTEXT OF DEINSTITUTIONALISATION

In Finland, persons with disabilities typically live in the community, with the exception of persons with intellectual disabilities. 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.

This is reflected in both the legal and policy framework governing deinstitutionalisation efforts, and – by extension – the practitioners' experiences captured in this report. The key policy documents in the area of DI specifically address people with intellectual disabilities (see section 1.1 below). Against this backdrop, participants in this research unsurprisingly noted that those who are in the process of DI are mainly people with intellectual disabilities. Similarly, when talking about living in institutions, participants typically referred to this group of persons with disabilities.

That both the political and practical focus of DI has been on people with intellectual disabilities is reflected in this report. Nevertheless, its findings are relevant to all persons with disabilities, irrespective of their impairment.

The research concentrated specifically on the transition from institutions to community-based support, and focused on people with experience of, or working on, the DI process. As such, it does not cover the situation of persons with disabilities living in the community, even though some of these arrangements may not be in line with the vision of independent living in the community set out in Article 19 of the CRPD. In Finland, for example, a large proportion of people with intellectual disabilities live with their parents well into adulthood.

In Finland, much of the discussion – and policy framework – concerning DI has focused on housing arrangements. Many participants in this research, however, talked about other elements, including healthcare services and the opportunity for people with disabilities to participate in working life, reflecting the wide-ranging changes needed to achieve successful DI. While acknowledging these issues, this report primarily focuses on housing issues.

This research began before Finland ratified the CRPD in 2016; it therefore spans the period immediately before and after Finland's ratification. Many participants reflected on the importance of Finland's acceptance of the CRPD and particularly how efforts to implement the obligations set out in Article 19 of the convention would impact the country's DI process.

1.1 Legal and policy framework for deinstitutionalisation

1.1.1 National legal and policy framework for deinstitutionalisation

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

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.⁸ In addition, specific laws cover services for people with disabilities. They are organised according to the law on disability services and the law on special care for persons with intellectual disabilities,⁹ 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.¹⁰

For persons with intellectual disabilities to get more opportunities 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 2010¹¹ and 2012.¹²

The first Government Resolution established the KEHAS programme.¹³ It aims at the systematic realisation of community-based living with necessary support for 3,600 persons with intellectual disabilities between 2010 and 2015, including enabling them to move out of their childhood homes or institutions. However, according to an assessment of the KEHAS programme, the community-based housing has largely consisted of group homes with places for 15 or more residents and the development of more decentralised housing solutions has been too modest.¹⁴

The second Resolution defines the next steps for the KEHAS programme. Its overall is to finish the DI process by 2020 and to ensure that no one lives in an institution after the year 2020.

The majority of national-level participants as well as a smaller number of local participants in this research highlighted the importance of the **two Government Resolutions, the KEHAS programme and the CRPD**, which entered into force in Finland in 2016,¹⁵ in guiding their work on the DI process.

"The [KEHAS] programme, and the UN disability treaty that's there in the background, because the [KEHAS] programme has been built on it. The UN Convention and its Articles give legitimacy to the [KEHAS] programme." (Representative of national independent living movement)

⁸ The Constitution of Finland ([Suomen perustuslaki](#)) (11.6.1999/731).

⁹ Finland, Act on Services and Assistance for Persons with Disabilities ([Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista/Lag om service och stöd på grund av handikapp](#)) (3.4.1987/380). Act on Special Care for Persons with Intellectual Disabilities ([Laki kehitysvammaisten erityishuollosta/Lag angående specialomsorger om utvecklingsstörda](#)) (23.6.1977/519).

¹⁰ Finland, the Social Welfare Act ([Sosiaalihuoltolaki/Socialvårdslag](#)) (30.12.2014/1301).

¹¹ The resolution was adopted to establish KEHAS ([the Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015](#)).

¹² Finland, Government Resolution on Securing Individual Housing and Services for Persons with Intellectual Disabilities ([Valtioneuvoston periaatepäätös kehitysvammaisten henkilöiden yksilöllisen asumisen ja palvelujen turvaamisesta](#)), 8 November 2012.

¹³ KEHAS (The Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015, [Kehitysvammaisten asumisohjelma](#)).

¹⁴ Karinen et al. (2016) Yksilölliseen ja monimuotoiseen asumiseen: Kehitysvammaisten asumisen ohjelman arviointi asumisratkaisujen osalta. Helsinki. Ympäristöministeriön Raportti 18/2016.

¹⁵ Part 1 of the research was conducted before Finland ratified the CRPD.

“A clear push was the Government resolution adopted in 2010. And when it was further specified in 2012. And we’re reasonably well on schedule. In 2020, we should have finished deinstitutionalisation [process], at least that’s what it says in the documents.” (Representative of Article 33(2) monitoring mechanism)

At the same time, some participants noted some weaknesses related to achieving the goals of the KEHAS programme and the Government resolutions to achieve by 2020. Several participants from local-level authorities suggested that government leadership should have been stronger. In addition, the national-level participants noted that the KEHAS programme did not legally bind municipalities.

There are several important recent reform processes concerning the legislative framework governing services for persons with disabilities. In 2016, the Act on Special Care for Persons with Intellectual Disabilities was reformed.¹⁶ These reforms aim to strengthen the right to self-determination of persons with disabilities. At the local level, service providers in particular identified the recent amendments of the Act as problematic. Some participants fear they could limit the use of certain measures to control challenging behaviour in community settings and therefore increase institutionalisation. This issue is discussed further in section 3.

Secondly, reforms to the social and health care system in Finland (**SOTE reform**) are due to enter into force on 1 January 2020.¹⁷ These reforms encompass the expansion of the administrative social and healthcare areas from the municipalities to the regions (*maakunta*). The reform is expected to safeguard equal services for all by allowing customers greater freedom of choice of services. Disability services will be administrated by the regions and will be governed by the national framework for the DI process in Finland.

1.1.2 Local legal and policy framework for deinstitutionalisation

According to Section 14 of the Social Welfare Act,¹⁸ **municipalities are responsible for arranging social welfare and health services for their residents in Finland**, including services and support based on disability and intellectual disability (disability services). Municipalities are therefore key players in the DI process.

There is **a wide variety of social welfare services which support independent living**, including: home help and home care services, relocation training, personal assistance, transportation services, assistive devices, home modifications and different housing units. In addition, there are work- and daytime activities. The services are provided by the municipality itself or acquired from service providers, the Federation of Municipalities, third sector actors or private companies.

¹⁶ Act on Special Care for Persons with Intellectual Disabilities ([Laki kehitysvammaisten erityishuollosta/ Lag angående specialomsorger om utvecklingsstörda](#)) (23.6.1977/519).

¹⁷ See: <http://alueuudistus.fi/mika-on-sote-uudistus>.

¹⁸ Finland, the Social Welfare Act ([Sosiaalihuoltolaki/Socialvårdslag](#)) (30.12.2014/1301).

According to national-level participants, the **KEHAS programme is a key document also at the local level**, as it is municipalities that are primarily responsible for its implementation. One of the DPO participants stated that the leadership of the national government has helped to involve the local politicians in the municipalities in the DI process. More precisely, the participant reported that the Ministry of the Environment, the Ministry of Social Affairs and Health, and the Association of Finnish Local and Regional Authorities (*Kuntaliitto*) communicated the targets of the KEHAS programme very efficiently to the municipalities.

The case study locality in this research was one of the pilot municipalities in the “At the Centre of Everyday Lives” (*Asuminen Arjen keskiössä -projekt*) project.¹⁹ The project ran from 2012-2014 as part of the KEHAS programme, and was jointly run by the Housing Finance and Development Centre of Finland (*Asumisen rahoitus- ja kehittämiskeskus, ARA*), the Finnish Association on Intellectual and Developmental Disabilities, FAIDD (*Kehitysvammaliitto*), four municipalities, and three joint municipal authorities. The project brought together many different actors in the selected locality to promote DI and independent living of persons with intellectual disabilities, in collaboration with persons with intellectual disabilities. Many participants in this research felt that it was a decisive factor in moving the DI process forward in the case study locality.

1.2 Organisation of deinstitutionalisation

Finnish municipalities are responsible for organising social welfare services, including housing and institutional services for their residents. This autonomy means that municipalities have the right to organise the living arrangements of a resident with a disability in the way it deems appropriate. The services are organised based on the law on disability services,²⁰ 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.²¹

Participants from across all respondent groups, at both the national and local level, emphasised the role of municipalities in implementing DI. The municipality has a key role, but it can buy and acquire services from other producers as well. A range of local actors and service providers play a key role in providing these services. The participants mentioned a number of these actors as being involved in the DI process at different levels, ranging from high-level decision-makers to the staff of the housing units/community-based services, who are closest to the everyday lives of persons with disabilities.

Participants mentioned the following actors as being involved in the DI process: municipalities (different municipal actors such as disability services, health and social services, housing sector and land-use planning department), service-providers (private, public and third sector; such as Aspa Foundation (*Aspa*

¹⁹ See: www.ara.fi/arjenkeskiossa.

²⁰ Finland, The Act on Services and Support Based on Disability (*Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista/Lag om service och stöd på grund av handikapp*) (3.4.1987/380).

The Act on the Special Care of the Persons with Intellectual Disabilities (*Laki kehitysvammaisten erityishuollosta/Lag angående specialomsorger om utvecklingsstörda*) (23.6.1977/519).

²¹ Finland, the Social Welfare Act (*Sosiaalihuoltolaki/Socialvårdslag*) (30.12.2014/1301).

Säätiö), DPOs, especially the Service Foundation for People with an Intellectual Disability (*Kehitysvammaisten palvelusäätiö*) and the Special Care Districts (*erityishuoltopiiri*), the staff of the institutions and housing units, persons with intellectual disabilities, the close relatives of the persons with intellectual disabilities, the Housing Finance and Development Centre of Finland (ARA), and the Slot Machine Association (*Raha-automaattiyhdistys, RAY*).²²

National decision-makers, such as the Finnish Government, and the two Government Resolutions adopted in 2010 and 2012, which gave the impetus for the DI process in many Finnish municipalities, were mentioned across all respondent groups. According to participants, through these resolutions, the Government commits itself to structural reform of services for persons with intellectual disabilities and to developing services that enable people with the most severe disabilities to live in the community. The municipalities are therefore responsible for implementing DI, even though the state governs municipalities through legislation.

Although municipalities are given the responsibility for the implementation of DI, some municipalities have linked with national-level working groups and others have set up their own working groups within their localities. In this process, according to the participants from the case study locality, municipality officers in charge, a representative of a joint municipal federation, DPOs, service providers, and persons with intellectual disabilities form a working group. They discuss together and strive to find the best possible housing solution for persons with disabilities. According to participants from the case study locality, the municipal social worker makes a final decision on the matter.

All participants at the national and local level emphasised the **importance of the municipalities**. However, local authorities hoped for support and guidance from the national level. For example, they want to know the overall situation of DI in the whole country. In addition, they hoped that the financial responsibility could be shared nationally. Some of the national-level participants also said that the government could provide more guidance and support to the municipalities within the framework of the KEHAS programme.

Participants at both the national and local levels identified the **Federations of Municipalities** as one of the key actors in the DI process, because they have been responsible for institutional care of people with intellectual disabilities. They usually operate closely with the municipalities and produce a wide range of customer-oriented special social welfare services, including institutional services and different kinds of housing services, as well as relocation training.

In the case study locality, the Federation of Municipalities is an important actor that cooperates with the social worker(s) of the municipalities and supports the DI process. For example, it has developed relocation training for people with disabilities and for staff members in institutions and the housing units. The Rehabilitation Planner of the Federation of Municipalities in the selected locality is an important actor, who cooperates with the social worker(s) of the

²² Current name "Velkkaus Oy".

municipality and supports them in dealing with housing services for persons with disabilities.

Local officials in the disability services, such as the Director of Disability Services and social workers, are central actors in the DI process in municipalities in general, most participants at both the national and local level highlighted, as they make the decisions about housing services for persons with disabilities. Municipalities may have different ways to arrange housing services in practice. Some municipalities can be much more active than others. For instance, the case study locality could be described as a slightly untypical municipality in its DI efforts. This research showed that it started its DI work very actively and has strived to find new housing solutions. One example of this is the working group which has made concrete plans about the housing for persons with intellectual disabilities.

At the individual level, decisions about DI, such as moving away from an institution or to a housing unit with less support, are made by the **social workers of the municipalities**. The process starts with the drafting of 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 taken into account as much as possible.

Although municipalities are responsible for organising housing for people with disabilities, the **Regional State Administrative Agency** (*Aluehallintovirasto, AVI*) and the **Housing Finance and Development Centre of Finland** (*Asumisen rahoitus- ja kehittämiskeskus, ARA*) are engaged in quality control for the DI process at the local level. They do not approve the replacement of institutions with housing only for special groups. Thus the DI process was further developed in the direction of community-based living, if possible housing in buildings in the city centre where both persons with and without disabilities live.

1.3 Funding for the deinstitutionalisation process

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. 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 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, they felt.

European Structural Investment Funds (ESIF) have not been used to support the transition from institutional to community-based care and support in Finland in the current or previous programming period.²³

²³ See information services of the European Structural Investment Funds (*Rakennerahastotietopalvelu*), which lists all ESIF-funded projects in Finland: [ESIF programme season 2007-2013](#) and [ESIF programme season 2014-2020](#). No projects related to the transition from institutional to community-based care and support were found.

One national policymaker stated that **the KEHAS programme has helped the Ministry of the Environment to direct funding for new housing** through ARA-financing. Plenty of new housing and group homes have been built with ARA-financing of the programme. The participant describes that this would have been more difficult without the KEHAS programme:

"I asked many times from the civil servant in the Ministry that what will be done once the report and proposal [on the housing for persons with intellectual and developmental disabilities] are finished. Is there going to be a programme for this, and he always told me that 'the municipalities will take care of it. Each municipality has the power to decide, and the municipalities will take care of it'. I wasn't satisfied with that, [...] I made the argument that it would be easier for us on the housing side to direct funding, if there was a programme [for this matter]. And that way we could get actors together behind this cause." (National policymaker)

Some participants at the national level also pointed out that financial issues can act as drivers of the DI process. They highlighted that some municipalities have realised that institutional care is very expensive, and that the possibility of financial savings has motivated them to find alternative housing solutions.

However, there is no consensus on this issue among the participants. Many national-level participants pointed out that municipalities have not been interested in this budget saving possibility, despite evidence that community-based services are not more expensive than institutional care. Indeed, one representative of a local authority felt strongly that the more individual the housing solution, the more expensive it is.

1.4 The status of deinstitutionalisation

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 intellectual disabilities lived in institutions.** The situation has changed quite dramatically since then. DI of persons with intellectual disabilities began and the number of customers for 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.²⁴ In the 2010s, the DI process was reactivated by the government resolutions committing to close all institutions by 2020. In 2015 **approximately 1,000 people with intellectual disabilities still lived in institutions.**²⁵ By the end of 2016, this had fallen to 795.²⁶ This indicates 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. The KEHAS programme has supported the development work in the municipalities.

²⁴ STAKES, 2001, Mietola, R. ym. (2013) Kehitysvammaisten ihmisten asumisen tulevaisuus: kansainvälisiä esimerkkejä ja vertailu Suomeen. Helsinki. Ympäristöministeriö.

²⁵ [Yksilölliseen ja monimuotoiseen asumiseen. Kehitysvammaisten asumisen ohjelman arviointi asumisratkaisujen osalta.](#) Ympäristöministeriön raportteja 18/2016.

²⁶ [Tilastoraportti: kotihoito ja sosiaalihuollon laitospaikat ja asumispalvelut 2016.](#)

In Finland, the DI process for the 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. It stood at 131 at the end of 2016.²⁷ In addition to children with intellectual disabilities, children with psychosocial impairments (such as children with autism spectrum disorders) combined with challenging behaviour are placed in institutions. Avoiding the placement of the children with disabilities in institutional care reduces the prevalence of institutional care and housing in the future.

The population of **the case study locality** is about 60,000, making it significantly larger than the average Finnish municipality. It is one of the fastest growing medium-sized cities in Finland, and its population has grown steadily since the 1960s. There has been some consolidation of local government areas by merging neighbouring smaller municipalities with the locality, which partly explains the population growth. The unemployment rate in the case study locality is 12.7 %, which is below the national unemployment rate (14.2 %).²⁸ In this locality, the institution is located far away from the city centre. In this institution area, there is not only the institution but also different housing units.

The case study locality could be described as a **slightly atypical Finnish municipality** in its DI efforts. It started its DI work very actively and has strived to find new housing solutions. The DI process has come a long way, starting with persons with milder intellectual disabilities. The number of residents in institutional care has decreased significantly, and they have established new housing units with 24-hour assistance. When the DI work started in 2010, there were fewer than 50 residents with intellectual disabilities in long-term institutional housing. There are currently approximately 20 persons with severe intellectual disabilities and/or with multiple disabilities in long-term institutional care. The planning for their DI has been prepared.

However, **the transfer to independent living for most of the 20 persons is challenging** due to their intensive care and medical needs. Particularly older persons with severe disabilities, typically born in 1950s or earlier, who have been in institutional care for a long-time are moving into older people's homes instead of community-based housing units. According to many local professionals, the institution has become "a home" for these persons with intellectual disabilities, and requiring them to move away from the institution would not necessarily be a humane solution.

Another significant step in the case study locality was the start of close cooperation between the city and the Federation of Municipalities during the Centre of Everyday Lives-project. After this, DI also meant that people with intellectual disabilities moved from the housing units in the institution area to more independent housing solutions.

At the very beginning of this research, it became clear to the researchers that the Federation of Municipalities in the case study locality is very active when it comes to adopting new ideas and learning from good examples of others. The

²⁷ Ibid.

²⁸ Statistics Finland, [Tilastokeskus. Kuntien avainluvut](https://tilastokeskus.fi/kuntien_avainluvut), downloaded on 27 June 2017.

manager of the Federation of Municipalities stated that their organisation took a big step forward in 2013 when the entire Board of Directors and Management group of the organisation visited Scotland and learned about their promising practices. The general opinion among the leaders of the organisation clearly changed. They started to support independent living for persons with disabilities more strongly than before and started to advance personal budgeting as well.

In short, decreasing institutional care services has in general progressed well in Finland, according to the local participants across respondent groups. The DI process, in the sense of abolishing institutions, is near its completion in the locality. Nevertheless, many participants pointed out that the DI is not just about abolishing institutions and decreasing institutional care, but also entails the construction of new housing, which reflects the principles of independent living in the way services are provided. One participant from a local authority reflected on the importance of avoiding new accommodation which retains an institutional culture:

“Things are definitely going in the right direction, there needs to be deinstitutionalisation and develop, but we need a model, we need to build real homes instead of new institutions.” (Local policymaker)

A large challenge in the case study locality is the “second phase of DI”. This concerns questions such as how to move on from group housing (such as group homes) and institution-like housing units to genuine independent living for persons with intellectual disabilities. Many people with intellectual disabilities have moved from the institution to housing units. These housing units are classed as community-based services, but sometimes have institutional work practices and other institutional features, according to participants. The units are owned by the city, the Federation of Municipalities or private service providers. The Federation of Municipalities also has housing units in the institutional area.

One representative of a local authority suggested that the dismantling of institutions should be in two stages: first, DI of the institutions and later DI of group homes:

“There can't be a jump directly from an institution to fairly independent living. It's a huge change. I think that this group home phase is a necessary phase in this.” (Local policymaker)

2. UNDERSTANDING OF DEINSTITUTIONALISATION AND INDEPENDENT LIVING

2.1 Key terms and concepts

The key terms and concepts in this study are institutional living and independent living. As one of the key aims of the research was to explore how relevant stakeholders understand these key concepts, participants were not provided with a definition of terms such as ‘institution’, ‘community-based service’ or

'independent living'. Rather, all research participants were asked to describe how they understand these terms and concepts.

Two main interconnected issues arose in the data collection regarding the understanding of DI and independent living: the **physical aspect** and the **cultural aspect of DI**.

Understanding deinstitutionalisation as a human rights issue

Throughout the research, participants reflected on the extent to which disability and deinstitutionalisation are viewed as human rights issues. Participants in the peer review meeting, in particular, felt that a human rights-based perspective is essential to achieving successful DI and – ultimately – independent living in the community in line with Article 19 of the CRPD.

- Some participants felt that a human rights-based understanding of disability and DI of persons with disabilities is quite superficial in Finland. Finland's ratification of the CRPD in the summer of 2016 has started, they hoped, to widen the understanding of disability.
- Participants in the peer review meeting in particular highlighted the importance of a holistic vision of DI, which incorporates issues such as education and employment in addition to living arrangements. They felt that this wider conceptualisation needs to come through more strongly in the discourse around DI, and human rights in general.
- Despite many positive developments in recent decades, changing attitudes is still an important goal if independent living in the community is to be realised in Finland.

According to most participants from both the national and local levels, **location** is one of the decisive factors for differentiating institutional from community-based living. In the case study locality, the institution and some housing units, are physically distant from areas where people without disabilities live. Institutions in Finland were traditionally located in a special area exclusively meant for persons with intellectual disabilities. This restricted their choice of living and labelled them as different. This segregation reinforced the idea that persons with intellectual disabilities are not part of society:

"Previously, in the countryside, too, [persons with intellectual disabilities] were in the back room, and when there were visitors they were preferably hidden with the door closed. Now they are brought into society and close to others as they are also normal people and they are part of life. We all have deficiencies, some has one kind and others have other kinds of deficiencies. They are equal members, which is the on-going discussion of society. [...] people started to talk about these things." (Employee of general services)

There are also differences in the provision of **rooms**. In community-based settings, persons with intellectual disabilities have their own rooms that are larger and have private toilet and shower facilities. **Privacy** can be better ensured in a new housing unit, while it was seldom the case in the institution:

"During my student days I went to, we went to see the institution, I visited one ward and I [...] turned around, went outside and I leaned against a tree and cried... And I thought that, no matter how [name of her son] turned out, I will never put him there [...] Somehow it was, there were no curtains, there was nothing there. It was somehow, it was so empty. A lot of people in a small space, there wasn't one's own [room], there were no rooms of your own or things like that. Now there are proper apartments, 'I have my own flat, I lock the door, no one can come there, this is my home'." (Family member of a person with disabilities)

People with disabilities, in particular, thought that the big difference between institutional and community-based living is that in the institutions the staff are present all the time. Many appreciated the difference in the presence and role of staff in community-based settings:

"[The biggest difference between living in an institution and living independently is] the fact that there are staff around 24/7. They are watching over you. When you live alone, there are no staff around anywhere." (Person with a disability)

One participant who previously worked in the institution said that the working conditions in institutional and community-based services are different:

"I worked in the ward [of an institution] for six years and now twenty-four years in non-institutional care. This is more home-like. I think, and I agree with the clients, that life in housing units is totally different. [...] [In the institution] it was more about scheduled activities. Since there were many [...], the wards were bigger when I used to work there. You had to [have] designated hours for specific activities." (Employee of a community-based service)

Even in the community, **institution-like living** is a possibility when the layout of a building is similar to that of an institution: private rooms are located on both sides of a corridor.

When it comes to cultural aspects, there is a clear difference in **support**. In institutions, support is intensive, while in community-based setting much less support is provided and more autonomy and self-determination are secured. One staff member of a community-based service in the case study locality suggests that independent living includes exercising the right of self-determination by persons with intellectual disabilities. She is pleased that, for example, staff members in housing units do less for persons with intellectual disabilities than they used to. She also highlights the impact of greater awareness among persons with intellectual disabilities of their rights on self-determination:

"I could say with regards to self-determination that what I have noticed over the years is that recently it has somehow become more common that the persons with disabilities are familiar with the concept of self-determination and they ask for their rights. [...] They're not just settling

for what's given to them and they are able to say what they want for themselves." (Employee of a community-based service)

People with disabilities in particular recounted certain **rules and practices of the housing units** which they did not like. They experienced **different forms of control**. Some rules, such as the strict curfews, routines and switching off the lights at certain times, were strongly questioned by the participants. Some were of the opinion that many group homes are institution-like in terms of culture and do not represent genuine independent living.

Similarly, when staff members are not sufficiently trained in supporting the independent living of persons with intellectual disabilities, there is a risk that **institution-like behaviour** continues. Most of the participants both in Part 1 and Part 2 of the research felt that sometimes there is no real difference between institutions and housing units, because the approach to providing support remains the same and thus the physical relocation is rather artificial.

Some participants in the case study locality and local service providers suggested that the **needs of some persons with severe intellectual and multiple disabilities** are met well or even better in institutional settings, given their intensive support needs:

"Everything was so easy in the institution. Everything worked. There was a medical doctor, therapists, and everything worked so well there." (Employee of a community-based service)

The same participant continued that DI is not suitable for all residents of the institution. This opinion was based on her experiences of working with **persons with severe intellectual disabilities, such as those with behavioural challenges** who, for example, scream a lot. She said that, as the institution area is away from other settlements, it is safe and allows the clients to go out safely. She argued that **DI is not an appropriate solution for all persons with intellectual disabilities**.

It is noteworthy that no participants at the national level thought that living in an institution was preferable to independent living. Participants who thought that institutional living is better came from the local level and were mainly service providers.

2.2 Impact of deinstitutionalisation

Participants underlined that DI often has a significant impact on those involved in the process, from persons with disabilities to their family members and support staff. They reflected on the impact DI is having both on their own lives, and those of the other stakeholders involved.

In the focus group discussions with **people with disabilities** many stated that, for them, DI means more freedom to make decisions about daily life, as well as greater privacy and independence. For instance, some of the participants emphasised that they now have freedom to smoke and drink alcohol, in contrast

to when they lived in institutions, where drinking was prohibited and they could smoke only a certain number of cigarettes.

One participant with disabilities reported that her life now is more relaxed compared to her time in the supported apartment of a housing unit. There, she felt that the staff monitored her and tried to control her social interactions by, for example, deciding what kinds of friends are decent and acceptable. She said that this happened in a supported apartment, which is deemed community-based housing, but that it is no longer an issue in the housing with lighter support.

The impact of independent living on **parents** of people with disabilities is significant in both positive and negative ways, according to the family members who participated in this research. It takes time for parents to get used to the idea. Especially in the early stages of DI, it was difficult for the parents. At the start, many parents said that their children came to their childhood homes over the weekend. Today, many young people with intellectual disabilities would rather spend time with their friends and do not drop by their childhood homes.

"It was a bit hard at the beginning, because at first he was always coming so that I had to be waiting for him on Friday when he came from [the day time activity centre] and he had his suitcase packed for the weekend. Now on Fridays we go grocery shopping, [as] he very bluntly tells me that he will stay [in his own apartment in the community]. So it has two sides, on one hand it's really wonderful that he likes it there, his friends have surpassed us. It would be horrible if he was always coming [home] and we'd have to almost force him to go back." (Parent of a person with intellectual disabilities)

Many parents still call their children every day and admit that they are overprotective. They are happy at now having their own time, but reported that it was difficult to get used to at first:

"And the thing is precisely that, I myself have the freedom that I haven't had so far, so even that was strange, that from work I didn't have to rush home, that is really strange, like oh my goodness, I can take my time shopping." (Parent of a person with intellectual disabilities)

Some **professional support staff** who had previously worked in the institution in the case study locality continued working in the housing units after the DI process started. Their workplaces changed, as did the working principles, towards a greater focus on participation and self-determination of persons with intellectual disabilities.

Differences in the way services are provided in institutional and community-based services were also highlighted by staff members of services in other localities:

"[T]he biggest difference if you think about institutions, and non-institutional care [is] accepting that the customer is the actor. [...]"

Because in an institution it often happens that the food is there, and someone hands out the food, these days even in an institution you might be allowed to go get your own food, but [...] the customer is simply there. [...] They're not the ones doing and determining it and, participating in cleaning their room, making their bed, doing the laundry, paying the bills, cooking, buying groceries, everything." (Manager of a community-based service)

Some **members of the local community** in the case study locality noted that the impact on their daily life is limited, as they have not yet frequently encountered persons with disabilities. They argued that it takes time to get used to the fact that persons with intellectual disabilities are not any longer hidden. Two members of the community indicated that fear between persons with and without a disability persists. They said that this might be one reason why they do not encounter persons with disabilities so much. However, the overall atmosphere and attitudes in **society** have improved over time and become more inclusive, according to some older participants:

"I remember [...] when I was a child, [disability] was considered scary, we were even afraid that it might be contagious. Really. That was what it was like before, so we have made a lot of progress since then. Of course there's always things to improve on in people's attitudes." (Member of the local community)

3. ESSENTIAL FEATURES OF THE DEINSTITUTIONALISATION PROCESS

Essential features	Key drivers	Key barriers
3.1 Commitment to deinstitutionalisation	<p>3.1.1 Finland is committed to deinstitutionalisation</p> <p>3.1.2 Strong consensus on inclusion and participation</p>	<p>3.1.3 Lack of clear vision and uncertainty due to the on-going SOTE reform</p> <p>3.1.4 Lack of financial resources</p> <p>3.1.5 Legal contradiction</p>
3.2 Availability of guidance to support the deinstitutionalisation process	<p>3.2.1 National-level guidance to the municipalities</p> <p>3.2.2 Relocation Training</p>	<p>3.2.3 Lack of information</p> <p>3.2.4 DI is new for all and takes time</p>
3.3 Active cooperation between the people involved in the deinstitutionalisation process	<p>3.3.1 Coordination working groups for DI at the local level</p>	<p>3.3.2 Lack of coordination and holistic approach between national and local stakeholders</p>
3.4 A change in attitudes towards persons with disabilities	<p>3.4.1 Attitudes of policy makers</p> <p>3.4.2 Positive depictions of persons with intellectual disabilities as citizens</p> <p>3.4.3 Positive attitudes of persons with intellectual disabilities</p>	<p>3.4.4 Reluctance to alter established models of service provision</p> <p>3.4.5 Attitudes of staff members to service provision</p> <p>3.4.6 Negative attitudes of the public</p> <p>3.4.7 Overprotective attitudes of parents</p> <p>3.4.8 Loneliness, passiveness and low self-confidence of persons with intellectual disabilities</p>
3.5 Practical organisation of the deinstitutionalisation process	<p>3.5.1 Adequate support in a housing unit</p> <p>3.5.2 Safe Environment</p>	<p>3.5.3 Lack of services to enable independent living</p> <p>3.5.4 Lack of choice of living arrangements</p> <p>3.5.5 Lack of practical skills in independent living</p> <p>3.5.6 Security risks and fear for safety and security</p>

3.1 Commitment to deinstitutionalisation

Commitment to deinstitutionalisation was not frequently mentioned as a crucial feature of the DI process during the research. Most participants highlighted that disability rights are widely recognised in general in Finland and have gained sufficient support among different stakeholders, including decision makers.

Participants at the national level were most likely to refer to laws and policies as being important drivers of DI, in particular the KEHAS programme. These instruments were much less frequently mentioned by participants at the local level. However, some local actors felt the implementation of DI still lacks clear guidelines.

3.1.1 Driver 1: Finland is committed to deinstitutionalisation

The participants across all respondent groups and localities were **unanimous in the view that Finland is committed to DI**. A timetable for achieving DI for all was set based on the aforementioned national resolutions, ensuring that both the political will and financial resources for making DI a reality are available in different municipalities. Due to the national framework and the ratification of the CRPD in 2016, Finland has put in place national laws and mechanisms supporting the implementation of the CRPD. The national conditions paved the way for municipalities to implement DI. In addition, one participant who is responsible for managing ESIF, felt that Finland's Disability Programme 2010-2015 (*Vammaispoliittinen ohjelma 2010-2015, VAMPO*) is also an important document guiding work on DI.

3.1.2 Driver 2: Strong consensus on inclusion and participation

Participants across all respondent groups underlined that **participation of persons with intellectual** disabilities and those close to them is important as it tends to bring good results. The participants did not mention specific actions, but rather highlighted that it is useful to strengthen and enable participation in both planning of the services (such as new housing) and in the transition process.

Some service providers highlighted that it is extremely important to involve the **close relatives of the persons with intellectual disabilities** in the transition process to mitigate their worries and resistance to the process.

3.1.3 Barrier 1: Lack of clear vision and uncertainty due to the on-going SOTE reform

According to one stakeholder in the case study locality, the locality lacks a clear vision of DI beyond the national resolutions and the CRPD. At the same time, the prospective entry into force of the SOTE reform, if approved, in 2020 creates uncertainty. Some local-level stakeholders, particularly staff of community-based services, suggested that staff working in the institution may feel **uncertain about their future**. One participant who is the instructor responsible for several housing units describes the feelings she has encountered among her employees:

“And we become afraid, when we are talking about the clients leaving and living independently. What happens to us, where do we go, will there be work.” (Manager of a community-based service)

In the case study locality, some participants expressed concern about what happens to disability services and whether the region (*maakunta*) will be able to pay enough attention to each person’s individual needs.

One local official in the case study locality expected the city to have a clear vision of DI so that freedom of choice for persons with intellectual disabilities is secured without compromising their services, even after the forthcoming structural change in 2020 linked to the SOTE reform.

The SOTE reform is expected to bring the opportunity to provide more equal services for all through the principle of freedom of choice. According to one local official in the case study locality, for this to happen there should be a **bigger allocation of funds** for various services.

3.1.4 Barrier 2: Lack of financial resources

Participants across all respondent groups identified **the lack of financial resources as one of the most challenging barriers to DI**. Participants in the case study locality recounted some specific problems. For example, they reflected on how a person with a disability cannot get adequate services, especially for attending to personal needs.

At the national level, participants said that the **difficult economic situation** decreases the willingness of municipalities to improve the housing situation of persons with intellectual disabilities. In their view, many people in the municipalities believe that DI would increase the cost of providing housing and services for persons with disabilities who previously lived in institutional settings.

However, national-level participants felt that community-based services are more affordable for municipalities, because people in institutions often receive higher levels of support than they need. One participant from the national independent living movement argued that even the concept of a 15-place group home is too expensive a model. She said that, in Finland people, view this as the only model, seeing others as too expensive. She found this discussion very perplexing because she thinks that other models could be cheaper. This shows that the issue of cost is not unambiguous.

The views of representatives of local authorities from one locality differed significantly from other participants in both Part 1 and Part 2. These participants emphasised that it is crucial to pay attention to the allocation of resources. They did not refer to lack of resources as a barrier to DI and independent living. Instead, they argued that complaints about a lack of resources are an excuse for not doing anything, such as taking practical actions to support independent living. They felt that lack of imagination and courage in the use of existing resources are barriers to DI: persons involved in the DI process should use their

imagination and have courage to think outside the box when they plan services with the resources that are available.

'Double funding' during the deinstitutionalisation process

The issue of money is never far from the surface in discussions around DI. Research has shown that providing support services in the community can be more cost-effective in the long-run.²⁹ However, 'double funding' to finance both institutional and community-based services simultaneously is necessary during the transition process.³⁰ This allows community-based services to be built up and be in place before institutional services that provide essential support are withdrawn.

One participant at the peer review meeting wondered why two different forms of housing are currently financed at the same time in Finland: institutional housing and community-based housing. In her view, this results in confusion and incurs extra costs in the long run. She strongly recommended to move swiftly to community-based housing.

3.1.5 Barrier 3: Legal contradiction

Service providers at the local level reflected extensively on the provisions on the use of restrictive measures in the Act on Special Care for Persons with Intellectual Disabilities, which was amended in 2016.³¹ In principle, the ban on restrictive measures is widely understood as a starting point for all service provision and decisions concerning the lives of persons with intellectual disabilities. However, it is often hard to implement in practice:

"From the legal perspective we're supposed to provide support for whatever [support needs] is based on [their] intellectual disability. Then there's the right to self-determination, which is understood so that basically everything, or if you want to exaggerate it a little, all the decision-making power is in his own hands. So how do these work together? You have two definitions and they are both based on laws. They're in contradiction with each other." (Employee of a community-based service)

One participant said that the Act prohibits the use of, for example, hygiene overalls in the housing unit. Another participant recounted that they had designed a very functional, individual and stylish overall for a resident but that it is now whether they are allowed to use it, even though it makes the living in the housing unit possible for the person. Participants identified the legislative changes as a barrier, which may result in institutional placements for individuals

²⁹ Conroy, J.W. (2004), *The costs of supporting people with developmental disabilities in institutional versus community settings*, Centre for Outcome Analysis.

³⁰ United Nations General Assembly (2014), *Thematic study on the right of persons with disabilities to live independently and be included in the community: report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/28/37*, 12 December 2014.

³¹ Act on Special Care for Persons with Intellectual Disabilities ([Laki kehitysvammaisten erityishuollosta/ Lag angående specialomsorger om utvecklingsstörda 23.6.1977/519](#)).

who previously have been able to live in housing units thanks to the use of certain restrictive measures.

An employee of a community-based service in the case study locality continued with an example of taking medicine. She felt that if a doctor prescribes medicine for their customer, he or she cannot decide not to take it. Lack of choice for persons with intellectual disabilities is a real problem in different localities, according to many participants across all respondent groups.

Some local-level service providers saw possible incompatibility between the goals of the national framework for DI and the tools available to achieve it in practice. According to the national resolutions, all persons with disabilities are in principle expected to live in the community. However, certain restrictive measures that would – in the view of staff of institutional and community-based services – enable persons with disabilities to live in the community are now prohibited, which results in keeping them in institutions. Such a contradictory situation has confused service providers in the DI process. Sometimes it seems like different impulses guide them from different pieces of legislation.

A second source of confusion relates to the definition of disability. According to some local officials in the case study locality the **ambiguity and different interpretations among stakeholders of the legal definition of persons with disabilities**, as well as the hierarchy of different laws, make some stakeholders feel uncertain about how to accommodate all the needs that customers with disabilities have. For example, one local official in the case study locality stated that, as the definition of disability is ambiguous, the possibility to meet the service needs of each customer with a disability is undermined when customers are divided into different sectors such as services for older persons, disability services, etc.

3.2 Availability of guidance to support the deinstitutionalisation process

Availability of guidance to support the DI process is a driver from two perspectives. Firstly, the municipalities need guidance from the governmental level on how to implement the DI process. Secondly, persons with disabilities need practical guidance in the moving process. Lack of guidance in general, and practical guidance in particular, was the focus of discussion.

3.2.1 Driver 1: National-level guidance to the municipalities

Most participants at the local level felt that government leadership and guidance have helped to involve local politicians in the DI process. Participants said that among the important achievements of the Government Resolutions and the KEHAS programme are the introduction of guidance and government steering to support the municipalities in implementing DI.

In addition, several participants highlighted the role of research in providing guidance to government and other actors. One national-level government official noted that research is important in making DI a reality, as it provides a basis for evidence-based policy making. Several participants suggested that the

government was responsible for both funding such research and ensuring that evidence stemming from it is incorporated in government guidance.

3.2.2 Driver 2: Relocation Training

Relocation training for persons with intellectual disabilities and their families, and for staff members is part of the KEHAS programme. Relocation training was developed to support the DI process and independent living. The case study locality has been very active in terms of **relocation training**: it has both developed training and provided it for its clients, their families and staff. In practice, the training focuses on supporting and preparing the persons with intellectual disabilities, their family members and staff for changes in the person's life after moving to a new housing arrangement.

Most of the local-level participants thought that **relocation training for persons with intellectual disabilities and their families** is one of the most important drivers of the DI process in the case study locality. Many participants mentioned that it is good for persons with disabilities and their families to go through general and practical issues concerning the move. The training sessions bring them security by ensuring a smoother transition process:

"In the past, when I was working in an institution, [...] the resident just moved [to the community]. Of course you gave good information, as much as you could possibly give, but the change was quite sudden for the resident. So now it's really wonderful that we have a relocation coach working for the best of the customer, and we're trying to find a good solution for the customer." (Employee of a community-based service)

A manager of a community-based service highlighted the importance of relocation training for family members:

"Relocation training is in my opinion an essential driver, and I consider it very important... and this is an essential question concerning how the municipality could succeed in this. Without such training [for family members], I am not sure whether I would have joined this process." (Manager of a community-based service)

Participants also discussed what made relocation training successful. A staff member from the case study locality said that the success of the training for persons with intellectual disabilities and their families is largely based on the human "chemistry" between the trainers and trainees as well as their capacities.

Participants at the local level also stated that **it is very important to train staff members**. Those staff members who move from the institution to housing units are trained so that they get used to the idea of DI. According to one local authority, it is sometimes difficult for the staff members to change their work place. They are afraid of what will happen to their jobs and may resist the change. In addition, staff members have to change their views so that their customers can exercise more autonomy. Another staff member working in general services in the case study locality added that training and support are

needed after relocation because relocation is a process that does not end when physically relocated.

One employee of a local service provider reported that her organisation cooperates with the Service Foundation for People with Intellectual Disabilities, and they have set up groups for young persons and their families, and meet with them to get to know their possible future clients in advance of them moving in. This practice is a kind of relocation training:

"A year ago we had a group of nine families of second-year vocational school students, and we discussed the options, not everyone was going to go live independently, but some were, but it was very good. We had meetings for one year, and had discussions around different themes. And we got to know each other, the people who came to live independently in our facility, we got to know them, it was great." (Manager of a community-based service)

3.2.3 Barrier 1: Lack of information

One identified barrier is the **fast DI process** and consequent **lack of information**, which it was hard for parents, children and support staff to come to terms with the new situation. For instance, one person with intellectual disabilities was provided housing in a place, which was not the one his parents thought he would be offered. In contrast, another family experienced that their child was relocated to a "wrong" housing unit where the level of support provided was too high. After a while, the parents realised that the unit was not meant for their child. They were disappointed that they were not informed beforehand of the severity of the other residents' disabilities and their greater support needs. As a result, some residents moved away from the housing unit to another one. More open communication and clearer information are necessary, the parents stated.

Service providers in the case study locality shared similar experiences. According to employees of community-based services in the case study locality, housing units work so independently from one another that communication has not been taking place among them (see also section 3.3.). For instance, they had to prepare relocation of some persons with intellectual disabilities in one week without having much information. Also, information, for example about future users' independent living skills, is usually incomplete in cases where customers move from their childhood home to housing units. One employee working in a housing unit in the case study locality mentioned difficulties she faced with some parents at the beginning of the DI process due to lack of communication and information. She highlighted that one consequence of insufficient communication is unrealistic expectations on behalf of parents about the DI process.

Mixed apartment buildings

In Finland, there are units that are ordinary blocks of rented flats where persons with and without disabilities live together. One such unit in the case study locality accommodates 15 residents with intellectual disabilities and 21

persons without a disability. The first residents moved in in autumn 2016. The housing unit is based on the idea of promoting inclusion. When the unit was about to be opened, the rental home company published stories about the new type of housing in its newsletter. The idea was to familiarise neighbours with housing issues of persons with disabilities through individual stories.

A DPO representative and a person without a disability living in this unit mentioned a case where both the parent and their daughter with an intellectual disability moved into the same building but in different apartments. They viewed this as a very good practice and a successful example of maintaining independence on both sides while keeping the distance close enough for any support need.

This kind of housing may prevent loneliness of the persons with intellectual disabilities. In addition, it can reduce the workload of aging parents. When parents have their own peace and privacy, they will no longer intensively take care of their child, participants felt.

Such housing alternatives should be available in a variety of ways and must answer to the individual needs of people with disabilities, participants stated. Several local stakeholders think that this kind of housing, living together but separately, is worthy of further development in the future.

3.2.4 Barrier 2: DI is new for all and takes time

Most of the parents of persons with disabilities involved in the research felt that **DI takes a long time**. They reported that it took several months for their children to become accustomed to their new accommodation. One family member was concerned that her daughter is not paid enough attention in the housing unit, noting that she wanted to come to the parents' home every weekend. However, the participant believed that DI takes a long time and hopefully her daughter will start to enjoy her life there.

Family members also highlighted that successful DI requires the creation of trusting relationships with staff members and other residents, which can take years to develop. Without prior examples, many employees of community-based services stressed that **DI is about learning by doing**.

"Two-step DI": a stepping stone or a distraction?

'Two step DI' is when people with disabilities first move from the institution to a housing unit (e.g. a group home) with quite intensive support. Then, after some time, they move to more independent living. This two-step approach is common in Finland: an employee of a community-based service estimated that this is the path for about 95 % of persons with intellectual disabilities. Typically, persons with intellectual disabilities first move from childhood homes (or from institutions) to housing units with 24-hour assistance (assisted housing). They then typically move to guided housing (housing with part-time assistance during daytime for people with intellectual disabilities).

Some participants – particularly at the local level – thought that two-step DI increases the likelihood of DI being successful. They felt that moving directly from the institution to living alone is challenging. When time is given for DI, the person learns more about independent living and has the opportunity to develop independent living skills.

However, there was no consensus among the participants. Some wondered why DI cannot be implemented in one step. According to national-level participants, for example, building so many group homes accommodating 15 persons as alternatives to institutions was not necessary. These participants thought that group homes should be just one option. They felt that such housing easily replicates the institutional culture of previous larger institutions. On the other hand, a person with intellectual disabilities considered group homes to be a very good intermediary step when a person is changing from housing with intensive care to a more independent form of housing.

3.3 Active cooperation between the people involved in the deinstitutionalisation process

The issue of cooperation was not one of the topics most frequently mentioned by research participants. Where raised, participants highlighted that cooperation was an important tool in enabling them to understand the ‘big picture’ of the DI process as a whole. However, lack of coordination was mentioned as a barrier by a few authorities in the case study locality. They hoped for an open discussion and a common vision of how services supporting independent living for people with disabilities are offered. Cooperation and coordination, between disability services and home care services in particular, is desirable in their opinion.

3.3.1 Driver 1: Coordination working groups for DI at the local level

The “Centre of Everyday lives” (*Arjen keskiössä*) project was frequently mentioned by participants at both the national and local level.³² Of the seven long-listed localities in this research, three were involved in the project, including the case study locality. The project was carried out as part of the KEHAS-programme. Participants from the case study locality felt that the municipality has actively participated in the project.

Some participants from the case study locality also mentioned the “Working Group on Good Living” in the framework of the project “the Centre of Everyday lives” (see promising practice). The project was the municipality’s own internal project, whose goal was to make concrete plans about housing for persons with intellectual disabilities. These two projects coordinated efforts for a concrete DI process for persons with intellectual disabilities.

³² Asuminen Arjen keskiössä. [Asuntoverkoston yhteiskehittämisen opas](#) (2015).

In addition, one employee of a community-based service in the case study locality mentioned another project, "Citizen's key",³³ led by the Service Foundation for People with an Intellectual Disability (*Kehitysvammaisten Palvelusäätiö*) from 2016 to 2018. This project aims to promote the right to self-determination of persons with intellectual disabilities in housing units. The case study locality was the only municipality in this research involved in the Citizen's key project.

Some staff members reported that it was through participation in the Centre of Everyday lives and/or Working Group on Good Living projects that they started to recognise their specific roles in the DI process:

"There [in the working group], the cooperation picture became clear and [...] well now we have one change going on in [a locality]. There we have been thinking if that housing could be merely for older people or persons with intellectual disabilities." (Manager of a community-based service)

PROMISING PRACTICE: Working group on good living

In the case study locality, the municipality is the key actor in the DI process. One example of how the municipality builds cooperation between different sectors in the city was the 'working group on good living'. It was led and coordinated by a social instructor from the municipality. The working group made concrete plans for the housing of persons with intellectual disabilities, particularly those still in an institution.

The working group convened every month for a year (in 2015 and 2016), with 10 to 30 participants present each time. Members of the working group included persons with intellectual disabilities, their family members, service providers and actors responsible for housing and construction. The task of the working group was to deliberate on how to ensure good quality of life for persons with intellectual disabilities. They focused, for instance, on the following questions: How to ensure a safe living environment, good quality care and up-to-date assistive devices and equipment to support the independent living of persons with intellectual disabilities?

In addition to these specific working groups, the Federation of Municipalities works in collaboration with the city and they have regular discussions on DI. They consult each other when an apartment is available to decide who could move in.

3.3.2 Barrier 1: Lack of coordination and holistic approach between national and local stakeholders

Participants at the local level, in particular, indicate that there is relatively **little cooperation concerning DI between stakeholders** at the national and local levels, as well as between different stakeholders at the local level. They did not

³³ More information on the project is available at: www.kvps.fi/kehittaminen/kotimaiset-projektit/kansalaisuuden-avaimet.

mention such cooperation even when specifically asked about their experiences of coordination with other stakeholders. The national-level participants highlighted some isolated examples of cooperation. For instance, one national-level stakeholder involved in the research emphasised the importance of coordination and gave some examples:

"We discuss continuously with the Association of Finnish Local and Regional Authorities and municipalities. And then there´s the network for the disability actors, an email list, through which we disseminate information. We also have thematic workshops, which are organised online, and where different kinds of people encounter and raise [DI related] issues." (National policymaker)

The fieldwork suggests that many local participants concentrate on their own roles of city planning (managers of services), social services (local officials), and supported employment (general services) and do not feel strong ownership of the DI process as a whole. As such, **a holistic approach is not yet realised**.

Two examples serve to highlight participants' concerns. One professional from the case study locality criticised the lack of coordination and collaboration with regard to the DI process. Another employee working in general services faced difficulties in collaborating with other relevant actors. She encountered problems with different service units when their judgements on customers' services differed due to different understandings of the definition of persons with disabilities. Sometimes persons with disabilities are not provided with services as a result of the sector-specific approach, she said.

The parents participating in the research did not mention other actors, and mostly followed the decisions of the city and their children. This implies that their coordination and information exchange with other stakeholders is fairly limited.

3.4 A change in attitudes towards persons with disabilities

Attitudinal issues were a central focus of discussion during the research. National- and local-level stakeholders mentioned attitudes as both drivers and barriers of the DI process. At the national level, attitudes referred to the political will to offer individual housing options for people with intellectual disabilities. The national stakeholders also talked about attitudes in relation to budget cuts, indicating that the economic situation in the municipalities decreases their willingness to promote DI for persons with intellectual disabilities. At the local level, attitudes emerged in connection with attitudes towards persons with intellectual disabilities and the attitudes of persons with disabilities.

As such, the national stakeholders discuss the challenges from a more general perspective. Local stakeholders, in contrast, talked about the attitude of individuals or groups, such as the staff of services, persons with intellectual disabilities, and their parents. According to many participants at both the national and local levels, the attitude of different stakeholders is often too conservative and/or negative.

3.4.1 Driver 1: Attitudes of policy makers

Both national- and local-level stakeholders mentioned **positive attitudes as a driver of DI**. For instance, one participant from a national human rights body said that it is mainly a question of attitude whether the municipality makes different alternatives available for persons with intellectual disabilities:

“My view is that money is very important, and deinstitutionalisation is not possible without it, but the attitude is even more important. The attitudes of all these different actors.” (Representative of national Article 33(2) mechanism)

The **attitudes of decision-makers, political will and political support** are perceived as the main drivers of the DI process. The participants saw the adoption of the government resolutions and the KEHAS programme, as well as the ratification of the CRPD, as products of the political will to support DI.

It is worth noting that the approach of national stakeholders was naturally more general compared to that of local stakeholders.

3.4.2 Driver 2: Positive depictions of persons with intellectual disabilities as citizens

There are many examples of **positive media images** of persons with intellectual disabilities, such as *Pertti Kurikan Nimipäivät* (a punk rock band whose members are all persons with intellectual disabilities), which participated as the Finnish representative in the Eurovision song contest, and the TV series *Salatut Elämät* (one of the most popular TV programmes in Finland, in which an actress with an intellectual disability plays an important role in). These examples have promoted the understanding that persons with intellectual disabilities are part of society, according to various research participants. Although there are still many taboos about persons with disabilities in general and persons with intellectual disabilities in particular, a positive attitude change has been taking place. Most participants across the respondent groups observed such progress in Finnish society towards marginalised groups, including sexual minorities and persons with disabilities. In their views, this is a clear driver.

3.4.3 Driver 3: Positive attitudes of persons with intellectual disabilities

At the local level, participants highlighted the attitude of persons with disabilities as a key driver. Parents in particular, highlighted that their **children’s wish to live independently was a key factor**.

Local-level participants felt that, today, children with disabilities are taught in their schools to be independent, and automatically think that they will be. Their positive attitude to independence in general and independent living in particular is a key driver, according to their family members.

However, the views of employees of service providers in the case study locality differed from the views of employees of service providers in the other localities participating in the research. Employees of service providers in the case study locality mentioned this as a driver much less frequently. Local-level participants talked about the will of persons with disabilities. They remarked that people with disabilities are used not to having the possibility to express their own will and are accustomed to their subordinated positions. In contrast, an executive authority in the case study locality argued that persons with intellectual disabilities are **open in a good way**, and are ready for changes when they encounter such possibilities. This was reiterated by an employee of general services in the locality, who highlighted that such positive attitudes among persons with intellectual disabilities are accelerated by their participation in employment.

The personal story below shows how the person with intellectual disabilities was ready for change when he got the possibility. In addition, it shows that moving from the institution area to the city centre enables independent mobility.

MIKKO'S STORY: WHAT HAS DEINSTITUTIONALISATION MEANT FOR ME?

Mikko is a 47-year-old man. He lived in an institution in the 1980s. After that he moved into two housing units that were in the institution area. About a year ago, Mikko started to live independently in a housing unit where both persons with and without a disability live.

Mikko remembers the institution where he lived. When he lived in an institution during his childhood, there were many rules. He thinks it is good to make his own decisions. But he thinks that he cannot decide on everything. He did not mention what he cannot decide by himself.

At present, Mikko lives in a housing unit where he can get support 24 hours a day. He eats his breakfast in the common room every day. He often goes to eat his lunch at the common room. Nowadays he also cooks food by himself with the help of the staff at the housing unit. On the day of the second interview, it was a "house day" and he planned to cook soup. The previous day he went grocery shopping and purchased the necessary ingredients for the soup.

Mikko is very active. He goes to the library often. He often borrows music DVDs. He also goes to a church congregation club once a week. He can go to the club by himself because it is close to his home. He is of the opinion that it is better to live in the centre and to live in his own apartment.

Mikko says that the current apartment is better than the previous one in the institutional area. He likes the current living situation very much. When asked what a good living situation is, he answers, "when you can decide things by yourself, then it is a good living situation".

3.4.4 Barrier 1: Reluctance to alter established models of service provision

Some national-level participants felt that **staff members and service providers of institutional services have had an urge to maintain them**, as they are not willing to give up their position and money flows. This reluctance to alter established models of service provision took several forms (see also section 3.4.5 below).

The first is the resistance of staff working in institutions to DI. One local official explained that staff in the institutions are afraid of losing their jobs due to DI. This makes them slow and too careful in moving on DI. Another local official in the case study locality explained that money affects decision-making; service providers do not necessarily want to give up their customers, as it is hard to replace them. Therefore, even if the residents of a housing unit or institution are ready to move out to other housing options with lighter support, the service providers are not willing to let them go.

Employees of community-based services in the case study locality highlighted a second concern: that the **monopoly of the Federation of Municipalities in housing issues of persons with intellectual disabilities** is a barrier for the DI process. Without this, they felt DI would have been much easier. For instance, the process of moving younger persons with intellectual disabilities into housing units from their family homes progresses more easily than the process of moving older persons from the institution to housing units. In the latter case, the institution may have a conflict of interests in promoting DI, as they lose their customers, according to participants. In addition, one employee in the case study locality felt that the monopoly of the Federation meant that people with disabilities in the first instance moved from institutions to the housing units of the Federation, limiting other alternatives.

In the case study locality, however, the most participants felt that the Federation of Municipalities – which provides institutional services – has very actively promoted DI.

3.4.5 Barrier 2: Attitudes of staff members to service provision

Another form of negative attitude are conservative attitudes of staff working in institutions and housing units. Many participants across respondent groups state that institution-like behaviour is often brought into housing units. They claim that **housing unit staff members often treat persons with disabilities as a group and as objects**, not as individuals and subjects. As a result, individually tailored services are hard to get. Even in community-based housing units, institution-like living continues. Persons with intellectual disabilities cannot exercise their self-determination rights, and others tend to make decisions on their behalf. There is a clear attitude problem, most participants felt.

As such, one major barrier to DI is **institutional work practices**. Most participants at the national and local levels said that a “nursing culture” is a

barrier to independent living. It is noteworthy that significantly fewer participants in the case study locality had this view.

Participants at the local level pointed out that institutional work practices and other institutional features are not only typical in institutions, but also in large housing units. National-level stakeholders, local authorities, service providers and persons with disabilities perceived that one of the most significant barriers to the DI process is institutional practices, which are very easily brought from institutions into the housing units. The participants perceive this type of “nursing culture” as a barrier to independent living:

“Looking at the big picture, deinstitutionalisation means going from a culture of institutionalisation more towards a form of living, which respects the disabled person's right to autonomy. And that may actually be the biggest challenge here. The culture of institutionalisation is so embedded in the practice of care. [...] For example, the social welfare for persons with intellectual disabilities in Finland has had an emphasis on nursing culture. Persons with intellectual disabilities have been nursed, treating them as objects. [Therefore] hearing of the person's [wishes] and taking their views into account has not been developed.” (Representative of national Article 33(2) mechanism)

3.4.6 Barrier 3: Negative attitudes of the public

Despite the general positive trend, negative attitudes towards disabilities persist among the public. National-level participants viewed the attitudes of the public as a barrier to DI, in the sense that **segregating attitudes still exist** and persons with disabilities are not wanted as next door neighbours. Two national-level participants pointed out that even public officials may still think that persons with disabilities are not entitled to choose where they want to live, but should settle for anything that is given to them:

“Sometimes when you read the national newspaper and someone there says ‘why can't we just put the disabled somewhere?’ Well, that's the sort of attitude, where the person with disability is only seen as a burden or an item of expenditure.” (National official responsible for institutions)

Fear of the other in the context of persons with and without a disability still remains, some members of the local community in the case study locality highlighted. One member of the local community encouraged persons with intellectual disabilities to use mainstream services to increase encounters between persons with and without a disability, and thereby to deconstruct negative public attitudes. However, it is hard for persons with disabilities to use existing mainstream services for fear of encountering negative attitudes:

“I do believe it's true that, although there was discussion about integration in the 80s already, I would still say that we're still not in a situation where everyone agrees with that. And there's a danger that, I have observed that, persons with disabilities for instance, the library is a pretty familiar place for them, but with regards to all the other services

they tend to be reluctant and I try to encourage them to go, but they won't necessarily, of course they're not accustomed to it and new things can be scary, but it's also because there are those constraints, so I don't think all special services should be cut." (Employee of a community-based service)

Another community member in the case study locality mentioned that the current generation of children is quite tolerant of diversity as they learn about it at school. She implied that **her generation and older persons are still not so tolerant of diversity** and persons with disabilities in the same community.

3.4.7 Barrier 4: Overprotective attitudes of parents

According to many participants across respondent groups, including parents themselves, **parents are overprotective of family members with disabilities**. Prior to DI, service providers contact parents mainly to get essential information about their children with intellectual disabilities. Service providers felt that the information they receive is, at times, not trustworthy, as some parents exaggerate and/or have lower expectations of their children:

"One resident moved to us from home who's now 42, and then [when he moved] he was a little under 40. The first thing that the father said was that it's no use teaching an old dog new tricks, he's not going to learn anything. A month went by, he was doing the laundry, putting the dishes into the dishwasher, hoovering, helping to clean his room, taking out the garbage. They came to visit him. He put the dishes into the dishwasher, the father was asking what he was doing. He's doing his household chores. They were completely shocked. Then, a couple of years ago we heard that he, a 40-year-old man went to the cinema for the first time in his life with us. They'd never taken him there. That tells a lot about the attitudes in the 1970s." (Manager of a community-based service)

Most participants thought that **parents tend to think that the level of support provided at home is necessary for their children**, while staff members often think that persons with intellectual disabilities could be more independent and deal with daily chores by themselves without so much support. Intensive support – often desired by parents – and independent living are a difficult combination to realise in practice, one housing planner and service provider in the case study locality noted:

"The close relatives want [persons with intellectual disabilities] to have an apartment of their own, their own peace [privacy], but from the viewpoint of [having] 24-hour support. That's the kind of contradiction that we can't implement." (Local official responsible for planning housing for persons with disabilities and employee of a community-based service)

A few parents stated that **all persons with intellectual disabilities are bullied at some stage in their lives**. This indicates that overprotection is not selfish behaviour of parents, but has to be understood in a context where tolerance of diversity still needs strengthening, not only for persons with

disabilities but also for other citizens with other characteristics. Many participants understood that parents want to protect their own children.

People with disabilities also described attitudes of parents a barrier to the DI process. They said that parents often have good intentions. However, overprotective parents no longer feel comfortable for persons with disabilities when they are adults. Local authorities and service providers also reported that people with disabilities say that the overprotective attitudes of parents is a barrier to DI. Local authorities thought that people with disabilities would say that they are not allowed to make decisions about their lives, and that someone else, such as family members or staff, decides for them. The local authorities thought that persons with intellectual disabilities feel that they are not taken seriously and are bypassed.

3.4.8 Barrier 5: Loneliness, passiveness and low self-confidence of persons with intellectual disabilities

According to many participants across different respondent groups, one barrier to DI is inadequate housing services that do not address loneliness among people with intellectual disabilities. Many participants expressed concern that one unintended and negative consequence of DI for persons with disabilities is increased loneliness after their physical move to the community. Once living alone, persons with disabilities may not have access to the social networks and companionship present within institutional settings. Family members of persons with intellectual disabilities particularly emphasised this risk.

Parents of people with disabilities, but also some employees of general services in the case study locality, indicated that there is a high risk that persons with intellectual disabilities spend their days within their four walls and become **extremely lonely** when they live independently in their own home. Some participants linked this to the emergence of mental health problems among some persons with disabilities who had been through DI. In some cases, this had resulted into a move back into accommodation with higher levels of support:

“Some [persons with disabilities] have had to return back to a more assisted form of living because of mental health problems. Because they are left alone. They’re lonely. It’s a long wait from four pm until the next morning because they can’t [...] go out alone, they don’t necessarily, even though they have been taught but not everyone has the skills so they’re left alone. They’re lonely.” (Employee of a community-based service)

Some participants, in particular parents of persons with disabilities, linked this to the **overprotectiveness of parents**. Parents are afraid that their children, due to their limited social skills, are lonely when living in the community. Participants across respondent groups and localities indicated that many people with intellectual disabilities find it **difficult to establish social relationships** with other people. They easily remain alone unless someone helps them to make friends. A DPO participant from the case study locality also observed loneliness among persons with intellectual disabilities. Parents said it is very important for employees of housing units to attract and even partially force persons with

disabilities to join available activities with other people. Parents observed that the situation usually improves over time as trust in staff increases.

Some professional participants believe that persons with intellectual disabilities lack experience and, as a consequence, **self-confidence**, even after they have moved into the community. This hampers their full integration in the community and seems to lead to a vicious cycle reinforcing their isolation. The DI process is only the beginning, which makes many participants hope that such a vicious cycle can be gradually overcome.

These factors contributed to some professionals believing that DI is not suitable for persons with more severe impairments because of the risk of loneliness.

Some participants were, however, of a different view. Many service providers, as well as some members of the local community in the case study locality, felt that this is a false argument as it is normal for many persons to spend a lot of time alone. In their opinion, **persons with intellectual disabilities also need to learn to enjoy the time to be alone** rather than be afraid of loneliness:

“Not all that is done has to be together. When we're living together, working together, everything's more or less the same. You don't have to do all your activities in your free time in the common premises, so you can do in your own flat the kinds of things that you like to do.” (Employee of a community-based service)

Promising practice: Civil society organisations working to enhance inclusion

A local chapter of Inclusion Finland KVTL (*Kehitysvammaisten Tukiliitto ry*) coordinates Friend Card (*Ystävänkortti*) activities. The idea is to advance the participation of persons with intellectual disabilities to use general leisure and cultural events and activities in the community with the support of a friend. A friend or support person of a person with intellectual disabilities gets free entry to leisure activities such as the theatre, concerts, cinema, swimming, sports competitions and events, trips and different types of sports and cultural events. All persons with intellectual disabilities are entitled to a Friend Card.

3.5. Practical organisation of the deinstitutionalisation process

Practical organisation of the DI process is the second most frequently discussed element in the Finnish study, although it was raised much less frequently than the issue of attitudes. Given the nature of their positions, local stakeholders in particular have valuable experiences, opinions and advice to share. Accommodating the individual needs of persons with intellectual disabilities in the DI process was the key focus of local stakeholders.

3.5.1. Driver 1: Adequate support in a housing unit

Adequate support in a housing unit was highlighted as a significant driver of independent living by many different participants. They noted a number of ways

in which adequate support – or the perception of adequate support – increased confidence in the DI process among key actors. From the perspective of families of persons with intellectual disabilities, participants noted that provision of adequate support in housing units is crucial for gaining family support for DI, because of the fears around safety of persons with intellectual disabilities in the community. Participants also underscored the importance of adequate support from the perspective of persons with disabilities. Many believed that persons with intellectual disabilities feel secure when sufficient support is available when needed. This is a key driver for a successful DI.

In the opinion of a city official, collaboration among different stakeholders, for instance through the Centre of Everyday Lives project, is an important element for providing adequate support.

ANNA'S STORY: WHAT HAS DEINSTITUTIONALISATION MEANT FOR ME?

Anna is 23 years old. First she moved from her childhood home to a housing unit with 24-hour support. She lived in her own room but shared the kitchen with other residents. The housing unit was located 6 km from the city centre.

One year ago, Anna moved from the housing unit to her current home in the city centre. She lives independently in her own apartment in a building where persons with and without intellectual disabilities live. The staff working in the building provide support to the residents with disabilities. They help Anna whenever she needs support. She eats in the common room every day. She also cooks food at home. In addition, Anna has a good and close relationship with her parents.

Anna thought it was self-evident that she would move out from her home when she started studying and wanted to be independent from her parents. Anna thinks that the first moving process went well with the support of her parents. In comparison to the first move, the second move was harder for Anna. Initially, she did not want to move. She was told that she did not need 24-hour support any longer because she was already quite independent. In the end, Anna agreed to move out and started planning for it.

Anna visited the apartment in the city centre with her parents. Anna explains that they did not visit any other place because it was the only possible option where she could live independently but have access to support whenever necessary.

Anna likes the current apartment because she has her own kitchen, where she can cook by herself. She also likes that she can go food shopping by herself. It is important to her that she can eat when she wants to eat.

One of the biggest differences between the previous and present housing is the timetable. In the housing unit, everyone had to eat at a fixed time. Moreover, the residents had to do different things. For instance, they had to go out every day. Anna likes sports but did not like being pressured to do sport every day.

Another positive difference is that the current kitchen counter is low enough for her; it is adjusted to her height. A standard kitchen counter is too high. In the previous housing unit, friends could not visit the residents at night.

When Anna lived in the housing unit, she was no longer entitled to special transportation for persons with disabilities (invataxi), as she does not have a severe impairment. She had to arrange her own means of transportation. She emphasised that this made it hard for her to go out. Anna has many hobbies, so it is important for her to be able to move from one place to another easily. At present, she can go everywhere by foot as she lives in the city centre.

Today Anna feels good about her house. She thinks that self-confidence helps the relocation process the most. Confidence in the closest people and staff members is also important, she thinks. Anna thinks that it is important for young people to have enough time to gradually get used to new situations.

3.5.2.Driver 2: Safe Environment

Security was mentioned as a major issue by many participants across respondent groups. Participants in the case study locality, including those living in a building where both persons with and without a disability live, felt that residents with intellectual disabilities have a safe environment and supportive atmosphere for their independent living. Such a safe environment is important for DI, residents believe. Such housing arrangements also increase positive attitudes towards people with disabilities, because persons with and without a disability begin to know each other better. They probably help to reduce prejudices and fear for the security more generally.

“The way I see it is that everybody already knows what kind of a place it is when they’re moving in, so only people that certainly accept the disabled groups whatever they may be will end up living here. So it is safe. They surely will greet them and so on.” (Employee of a community-based service)

3.5.3.Barrier 1: Lack of services to enable independent living

Physical relocation is one of the steps in the DI process. Even after physical relocation is completed, however, participants do not consider DI to be completed in terms of achieving independent living, which is the ultimate objective of DI in Finland. A service provider mentioned that “walls are not a problem”, meaning securing plots and real estate, or constructing buildings, is not the real problem. **More important is finding suitable services within the buildings which meet the actual needs of the residents with intellectual disabilities.**

Lack of appropriate services in the community was mentioned by many participants across respondent groups and different levels of governance. Participants spoke about difficulties accessing a range of different types of service, including:

- Healthcare and social services
- Personal assistance services
- Transport
- Discrepancies in service provision between municipalities

The representatives of local public authorities and service providers strongly felt that customers with intellectual disabilities have **difficulty in accessing general healthcare and social services**, especially mental health and psychiatric services. Some parents experience a decrease and deterioration in disability services at home, and note that persons with intellectual disabilities cannot influence these developments.

Several service providers from the case study locality observe that many persons with disabilities are not able to get out of the house as much as they wish. At present, they use home services so that someone else goes shopping for them. **More allocation of personal assistant services** would allow persons with disabilities to go grocery shopping, for instance. Many felt that, while in itself a small service, this is a significant in enabling them to live independently.

One member of the local community in the case study locality expressed that it is sad that persons with disabilities are often in a group as their individual needs are not met due to lack of personal support:

"It somehow makes me sad at times that they have to go as a group. The attendants don't always have the resources to attend to them as individuals even if they wanted to, for instance if they're like "can you come swimming with me?" then the attendant says 'Sorry I don't have time. I'm alone on the night shift.' So they always have to do everything as a group." (Member of the local community)

Another example is **decreasing transportation services**. An employee of a community-based service in the case study locality raises the issue of government budget cuts, which that have led to a decrease in personal services for persons with disabilities. She worries about the transportation service that takes people to their hobbies or elsewhere. If the government keeps cutting, it will isolate persons with intellectual disabilities even more from normal life.

Representatives of local public authorities, service providers and some parents also highlighted challenges related to discrepancies in service provision in different municipalities and across sectors. In the DI process, many participants stated that the quality and quantity of services depends on which municipality customers live in. For instance, the content and length of relocation training depends on the extent to which a municipality is prepared to purchase such services for their residents. Some professionals thought that the case study locality is not purchasing enough relocation training, while providing too much support within the institution.

One employee of general services in the case study locality highlighted the need for a clear definition of persons with disabilities. She said that, at present, **the**

definition is unclear, which leads to contradictory views between workers in different sectors:

"We [in the home care services] might think that this is definitely a person with a disability who sits in his/her wheelchair, but from the perspective of the disability service, suddenly s/he is not a person with a disability".
(Employee of general services)

According to a participant from the case study locality, **some people end up not getting the necessary services**, such as personal assistance, when they are technically categorised under different sectors that do not provide personal assistant services.

3.5.4. Barrier 2: Lack of choice of living arrangements

Many participants across all respondent groups highlighted a **major lack of choice of living arrangements** in general. A large number of participants felt that genuine freedom of choice is not realised, because there are no real alternatives from which to choose and people with disabilities have little previous experience of different types of housing. Participants reported that, in practice, the case study locality often informs persons with disabilities where they will live next without offering an alternative. In principle, persons with intellectual disabilities have the right to choose their place of residence, but in practice they do not have alternatives:

"Lack of choice means that it is informed always only where is the place [to move into] now. [The way how the city promises the place is] more or less take it or leave it. In those cases they don't listen to you. So when the city makes some decision, you just have to live with it."
(Representative of a local disabled persons organisation)

This concern was reflected in the views of other participants in the research. Representatives of local public authorities and staff and managers of local service providers thought that people with disabilities would say the lack of alternatives is one of the main barriers to DI. However, this topic was not raised by people with disabilities themselves.

In contrast, some staff of community-based services who used to work at the institution in the case study locality highlighted the challenges of realising the principle of choice for certain individuals with disabilities, particularly **persons with disabilities who are aggressive and have behavioural problems**. They felt that the potential impact of this behaviour on other residents made it difficult to offer a meaningful choice of living arrangements.

One local-level service provider presented a different view and pointed out that this perception of lack of freedom of choice stems from the **misunderstanding that everything is possible**. In reality, there is a need to balance the freedom of choice of persons with intellectual disabilities and taxpayers' living conditions in general. In practice, there is no possibility to offer full freedom of choice for

persons with intellectual disabilities, as taxpayers similarly cannot afford to get everything they want.

3.5.5. Barrier 3: Lack of practical skills in independent living

Many participants across the respondent groups mention that **persons with intellectual disabilities, their families and staff members in institutions have become used to intensive support**. As a result, a **lack of practical skills needed for independent living** is a challenge for some persons with intellectual disabilities.

Participants particularly highlighted personal hygiene. One service provider in the case study locality said that personal hygiene is something for which persons with intellectual disabilities do not get much support in community-based services. Some are not willing to receive any support for this, even if it is offered. Some service providers observe cases where persons with psychosocial disabilities do not pay much attention to their appearance, hair and odour, which disturbs their activities including employment, for example.

Several parents indicated that the **institution-like habits of support staff members** in the new housing unit are a barrier to DI and to building the skills of their children with intellectual disabilities. Consequently, many participants across respondent groups felt that institutional practices continue to exist as staff usually move from institutions to community-based housing units.

3.5.6. Barrier 4: Security risks and fear for safety and security

Fear for the safety and security of persons with disabilities in the deinstitutionalisation process is one of the major concerns for participants across all respondent groups. Some of the aforementioned barriers, such as insufficient support, negative public attitudes, and overprotectiveness of parents, are linked to this barrier, exacerbating safety and security concerns.

Some staff in housing units in the case study locality think that persons with intellectual disabilities cannot independently and safely walk around the city, where there are big roads and other dangers. The institutional area is, in their view, much safer as it is isolated from the city centre. One employee of a community-based service reported that she was afraid of residents in her current workplace leaving and getting lost, as they now have the freedom to leave. There was no need for such fear in the institution, she said.

Parents of persons with disabilities tend in particular to feel the barrier of insecurity in the DI process. They spoke a lot about their fears when their children live and move alone in the city. One of them described her own fears:

"Of course the thing that always worries me is that when he goes out there alone, something might happen. You read about it every day from somewhere like that and if somebody happens to notice that he's a bit

different, he doesn't know how to defend himself probably." (Parent of a person with disabilities)

Parents' **fears for the safety** of their children were strongly linked to general negative attitudes in the community, uncertainty of service provision, and lack of understanding among city officials and professionals.

3.6. Cross-cutting issues

3.6.1. Impact of different types and degrees of impairment on the deinstitutionalisation process

The research shows that degree of disability plays a major role in the DI process. Participants in all stages of the research underlined the importance of degree of impairment on the DI process and highlighted repeatedly that successfully deinstitutionalising persons with more severe impairments presents a particular challenge.

Most local-level participants agreed that the DI process has gone smoothly so far. This is partly because those taking part in the DI process have milder intellectual disabilities and more limited support needs. They could express their opinions and wishes for their relocation, which facilitated the DI process. Local officials note that those who still live in the institution have severe impairments, have never lived outside the institution, and do not think of alternative living arrangements. The situation will be quite different from those who have already moved out from the institution and requires a sensitive and nuanced approach, several local professionals pointed out. They highlight difficulties in realising independent living, as self-determination rights cannot, they feel, be realised by those whose intellectual capacity is "as low as that of a 6-year-old":

"I've sometimes been thinking whether I would have given my own six-year-old child when he was six full rights to decide upon things. I don't know." (Employee of a community-based service)

In this respect, most employees of community-based services argued that the new law on self-determination is problematic in some respects, especially for certain groups of persons with intellectual disabilities. Service providers feel that implementation of self-determination rights is challenging in practice for those who are expected to live independently in the community and have severe intellectual or psychosocial disabilities and/or challenging behaviour (see section 3.1.5.).

3.6.2. Impact of age on the deinstitutionalisation process

Participants felt that age plays a significant role, with several highlighting major differences in progress towards DI for younger and older people. Younger persons with intellectual disabilities know that they have the right to self-determination and take it for granted that they will not live in institutions but in the community. However, those in their 40s and 50s or older are used to other

persons making decisions for them in institutions. Today older persons with profound intellectual disabilities are moving from institutions to homes for older persons.

4. MEASURES TO ACHIEVE SUCCESSFUL DEINSTITUTIONALISATION

Although participants have many opinions on the DI process, the question of what is needed to make DI a reality was relatively challenging for many to answer. Both national- and local-level participants emphasised the need for a vision of how the dismantling of institutions will be completed. They further stressed that it is important that persons with intellectual disabilities themselves can share their views and wishes and play a central role in the DI process. Some participants emphasised that living independently in the community is a human rights issue. They underlined that we should move away from charity thinking.

National-level participants mentioned that it is important to distribute information about legislation and raise awareness of the benefits and positive impact of the DI process.

Local-level participants emphasised that people with intellectual disabilities should not be treated as a group and should be provided both individually-tailored and diverse forms of housing.

In general, participants across respondent groups found it very hard to specify who they see as responsible for making DI a reality. Local authorities and service providers agreed that DI is much more than just shutting down institutions and diminishing institutional services. It requires the participation and actions of many different actors and sectors. It was pointed out that the Government Resolutions gave a kick-start to the DI process in Finland; forcing municipalities to start taking real action. In that sense, participants felt that municipal actors have a central role in making DI a reality.

4.1. Commitment to deinstitutionalisation

Many participants at both the national and local levels thought that what is needed for the DI process is a **strategy** that enables the network of stakeholders to collaborate smoothly. It is important that an overarching, long-term goal guides all activities to avoid projects being implemented one at a time without a long-term perspective. The municipality should take the leading role in coordinating the collaboration and efforts towards DI.

Concerning implementation of the strategy, local-level participants tend to think that rules and practices could be more flexible to meet residents' individual needs. To that end, **more resources** such as personal assistants financially supported by the city are needed, according to a city official. Currently, each municipality covers the service costs, but this is considered insufficient. A DPO representative from the case study locality also thinks that it should be the **national government that takes care of that responsibility**.

At present, according to a DPO representative who has a child with intellectual disabilities, it is hard for a person with a disability who requires services to move

from one municipality to another. Moving may have implications for their access to the services they currently receive.

Several service providers from the case study locality claim that local services facilitate independent living of persons with intellectual disabilities, which is **the long-term goal of the DI process**. Some think that it would be beneficial if the Act on Services and Assistance for Persons with Disabilities and the Social Welfare Act were complementary in practice, as they are intended to be on paper. Currently, persons with disabilities are sometimes left without services due to a sector-based approach to service provision, rather than a holistic one:

"If we have one organisation for both disability services and social welfare services there is no need to fight for money." (Employee of general services)

A service provider from the case study locality also states that short-term financial costs should not dominate the discourse around the freedom of choice for persons with intellectual disabilities. In her opinion, decisions on alternative housing should not be based only on price. **A long-term perspective** is needed because in the short run DI appears to be a more expensive solution. In the long run, however, it enables these people to live independently, which is cheaper than institutional living. Managers of community-based services feel that this type of long-term thinking is important.

4.2. Availability of guidance to support the deinstitutionalisation process

Many participants at the local level highlighted issues concerning relocation training. Firstly, relocation training is not an automatic service for all persons with intellectual disabilities undergoing DI. One service provider from the case study locality noted that different municipalities have different practices. Ensuring relocation training is available to all persons with intellectual disabilities and their families is strongly supported by local-level participants. Similarly, many participants in the case study locality argued that the quality of relocation training is also important. When the needs of individuals are duly taken into account, it contributes to successful DI, which has not yet been fully realised.

Parents of persons with disabilities, in particular, argue that more training, not only for persons with intellectual disabilities, but also for all stakeholders is needed. This helps everyone to strive for the independent living of persons with intellectual disabilities by sharing relevant information among stakeholders. This is also related to active cooperation between the people involved in the DI process.

4.3. Active cooperation between the people involved in the deinstitutionalisation process

More open dialogue between different stakeholders is recommended by many across all respondent groups, but in different ways. One representative of a local authority suggested that persons with disabilities should be enabled to speak for themselves:

“I think these people [people with disabilities] should be able to talk about this issue themselves, not only us officials or lobbying organisations, I think people with disabilities should be there as well, speaking their minds. Because they have the experience. So whether decisions are made on a national level, or on a regional level, or on a municipal level, it would be nice if people with disabilities could participate in that, so they could say ‘Have you thought about the implications of this decision?’.” (Local policymaker)

Some actors advocate for open dialogue with different actors, both officially and informally, as they feel that enough information is not shared with them. For instance, city officials want their own information-sharing working group incorporating different sectors to clarify the common vision and concrete ways forward towards DI in the locality ; service providers want to discuss first with local officials to come to consensus that DI is the best solution; staff of service providers and parents want open and informal communication to establish trust between them; staff of service providers want an open environment in the workplace to share problems and solve them; and staff of service providers and persons with intellectual disabilities want more opportunities before their relocation to get to know each other.

Another set of comments concern adequate service provision and thus are also linked to the role of the city. One local official recalls that DI is not only about houses but about the environment which enables or hinders independent living. When the goal is to **prevent institutionalisation**, a more holistic approach is needed, many participants at the local level say. Instead of a sectoral approach – such as disability services, child protection, services for older people, etc. – a more holistic approach is recommended by many local-level participants. In their opinion, more holistic budgeting is also needed.

Most participants at both the national and local levels consider it important to put persons with intellectual disabilities at the centre of the DI process. One participant from general services explicitly called for a perspective or paradigm change among all stakeholders, away from a charity-based approach to a human rights-based approach and “more tolerance of diversity in society”.

4.4. A change in attitudes towards persons with disabilities

4.4.1. Positive attitude to persons with intellectual disabilities

All participants share the view that various actors need to change their attitude. Participants discussed positive attitudes among different groups, including:

- The general public, in particular through the media
- Families of persons with disabilities
- Staff of services for persons with disabilities

Most community-based participants consider that **interaction between persons with and without a disability is central to making DI a reality**. In their view, the best form of education is personal contact with persons with

disabilities, because increasing experiential knowledge changes people's attitudes. For instance, in the safe environment of housing units, it is easier for residents with disabilities to build trust:

"Somehow it's probably quite easy to create trust between them and the normal tenants. If I was a family member I would think it easy in a place like this [she talks about the building where live people both with and without disabilities] where there's personnel to trust the other tenants easier and quicker as well compared to a strange apartment building where they live alone and no one knows them. So somehow I think it's quite safe as well." (Employee of a community-based service)

In the case study locality, there are several apartment blocks in which persons without disabilities live alongside people with disabilities with different support needs (see box in section 3.2.3). Residents without intellectual disabilities participating in the research considered it very important to have regular contact in everyday life with persons with intellectual disabilities. They felt that there should be more of these mixed blocks, as regular interactions help to break down stigma.

Local-level participants argued that **information about people with disabilities helps to reduce the fears of people without a disability**. In addition, it can help to reduce societal prejudices when people with disabilities are more visible in society and use the same services as other people. Such information and evidence could be gathered through research, one national-level government official noted.

More **media coverage** of people with disabilities will facilitate positive change, several participants at both the national and local levels felt. One national-level participant emphasised that it is important to distribute information so that persons with disabilities themselves can share their views and wishes:

"Well, probably training and education, improvement of know-how, good examples, and distributing information about them in a way that is easy to understand. There are these kinds of activities. And of course, all actors need to be involved, not only authorities and representative of the DPOs, but as well experts by experience and the persons with disabilities, so that they can share their wishes and views." (National policymaker)

Parents of persons with intellectual disabilities highlighted that **parents have to be trained not to be overprotective**. Parents think they should listen to their children and pay attention to their right to self-determination. Similarly, in the opinion of city officials and the staff of services themselves, staff of service providers need training on changing institution-like practices.

Local-level authorities and service providers, and persons with disabilities, pointed out that it is extremely important to involve the close relatives of persons with intellectual disabilities in the transition process. All sorts of worries and resistance can be mitigated by engaging them in the process. Furthermore, the participants emphasised that the support of loved ones is crucial.

Participants also felt that **staff of community-based services should engage in continual self-reflection** to ensure that they promote autonomy and inclusion, and do not fall back into more 'paternalistic' styles of providing support:

"How do we guarantee that we're having a discussion with ourselves, we're having a discussion with the work community, so that we, the employees, don't create another kind of parallel culture next to the family culture. So that we're not the ones who decide." (Employee of a community-based service)

4.4.2. Positive attitude of persons with intellectual disabilities

Participants across all respondent groups highlighted the importance of **self-determination** by persons with intellectual disabilities in achieving DI. This was mentioned by many participants at the local level especially pertaining to paying attention to individual needs and characteristics and providing more/true freedom of choice. All stakeholders are responsible for achieving this. One manager of a community-based service elaborated that persons with intellectual disabilities need to be encouraged to take risks and learn from their mistakes. In this way they gain new opportunities in their lives on an equal basis with others.

One employee of a community-based service highlighted the positive outcomes associated with promoting self-determination. He mentioned the successful experiences of his residents who started to gain more self-confidence in doing their daily chores when given the time, opportunities and trust in them by employees of the housing unit. In his opinion, the change is slow, but does take place:

"But then if you give them time and space, miracles happen. I've seen it personally. I've been like, do it, do it, I'll come back in a moment. Then it's like ta-da." (Employee of a community-based service)

In addition social networks, including the services of DPOs, can be utilised to increase the self-esteem of persons with intellectual disabilities, participants across different respondent groups said.

4.5. Practical organisation of the deinstitutionalisation process

4.5.1. Adequate and quality support in a housing unit

Most participants across respondent groups believe that **adequate support** in a housing unit is key for successful DI. Bureaucracy and sector-based services should be overcome to ensure necessary and adequate support for persons with intellectual disabilities, bearing in mind that too much support is harmful.

"It is not like a walking device that is always there, but we take a cane away immediately when they walk even a bit, we have to see the support needs so carefully so that they do not become dependent, but the support

is there for them to understand what they have to do, after which they have to do it by themselves.” (Employee of general services)

At the same time, a representative of a DPO from the case study locality continues that persons with intellectual disabilities have to be treated as individuals with different needs, and not as a group. When people start to think about how they want their life to be and apply it also to persons with intellectual disabilities, they finally start to understand this correctly. She continues that this kind of change in perspective is needed to realise **DI in a genuine way** in the housing units. She claims that the difference is that people with disabilities also need support for realising what they want to do, for instance, to go out.

Many professional participants think that increasing personal services, particularly personal assistants and transportation services, would help them to attend to the individual needs of their customers better. Currently, individual needs and rights are not yet widely realised in housing units, even after DI or moving out from childhood homes. Many participants argue that more personalised attention is needed to realise the principle of independent living in practice. Some further recommend **personal budgeting** for persons with disabilities to select and buy suitable services.

A nationwide standard for regular evaluation of service needs is mentioned as a solution by some professionals. In their view, harmonised evaluation of needs has to be secured even after the SOTE reform. Local officials stated that free market competition among service providers is a good means to achieve quality services and freedom of choice for persons with intellectual disabilities.

To solve the problem of **lack of choice**, some local officials state that there should be different types of housing units whose staff members are required to have different skills and competences. Staff who will work for those still living in institutions, who typically have severe disabilities, need to have advanced skills in providing necessary support to their customers. There could be more small housing units, as this would help the situation of DI in general.

4.5.2. Increasing practical skills of persons with intellectual disabilities

Many participants across the respondent groups argue that there should not be more support than the person with a disability needs. Persons with intellectual disabilities should have more autonomy and responsibility concerning their own lives. When offered, such learning experiences become part of their capacity building and rehabilitation, in participants' view. When everything is ready for them, they cannot be creative and build their capacity. However, this takes time.

One local-level service provider argued that persons with disabilities should have a chance to make mistakes just like others:

“Being given the opportunity to fail. So not giving up if they don't succeed right away, but giving them the chance, just like we have become independent and, moved away from home when we were young, at least I

didn't do everything right during the first year." (Employee of a community-based service)

One participant with an intellectual disability suggested that support and assistance in the housing units with 24-hour assistance could be gradually reduced; that way the residents would start to feel more independent and able to make decisions about their own lives. He suggested that support could be first reduced at night.

The personal story below shows that overly extensive support may prevent independent living:

PEKKA'S STORY: WHAT HAS DEINSTITUTIONALISATION MEANT FOR ME?

Pekka is a 54-year-old man with a mild intellectual disability. He has moved many times since he moved out of his family home. He lived with his wife in their own house, but after they divorced Pekka moved into a housing unit in the city centre. He lived in that housing unit for one year. After that he moved into a new housing unit where both persons with and without disabilities live together in the same building. Pekka says that persons with intellectual disabilities live on the first two floors but he lives on the fifth floor, which is meant for persons without a disability.

The motivation for the last move came from the staff members of the city disability service unit. Pekka in fact liked the previous housing very much, but was told that he could live a more independent life if services were not so intensively provided. When the building was ready he went to see it with a staff member from the city. They also visited another alternative housing unit where both persons with intellectual disabilities and older persons live. However, Pekka did not want to move into the latter. He recalls that the decision to move was made by the city and not by himself. He was given the chance to select which apartment was suitable for him within the new housing unit.

Pekka feels that he got enough information about the move from the staff members when he was about to move out from the earlier unit. He still visits the previous housing as he has many friends there. In the new housing, he also became acquainted with nice, new neighbours. He also likes the current apartment, even though it is much smaller than the earlier apartment. He is satisfied with the move and is not willing to move out.

He gets support twice a week. He thinks the support is good because he does not need to pay for it. It is also nice that staff members cook food with him. Staff members do not cook for him but support him to do things independently only when necessary. He likes this. He does not need much support.

Pekka's previous apartment was in the city centre, but the current one is about one kilometre away from the centre. These are the only things that Pekka thinks are worse in comparison with his previous apartment. In the previous housing unit there were many rules. For instance, residents had to be quiet

after 10 pm, and they had to eat at fixed times every day.

Pekka highlights the importance of trust between the staff members and residents. In general, staff members were supportive, in his opinion. He could discuss any matter with them. He has trusted staff members and got good support from them in his life.

At present, Pekka lives quite comfortably and does not plan to move out. He has a new girlfriend to whom he is planning to get engaged. They have not yet planned to live together. Pekka also admits that he wants to be alone for a while as his experience of divorce is still fresh. He is currently very happy with his life.

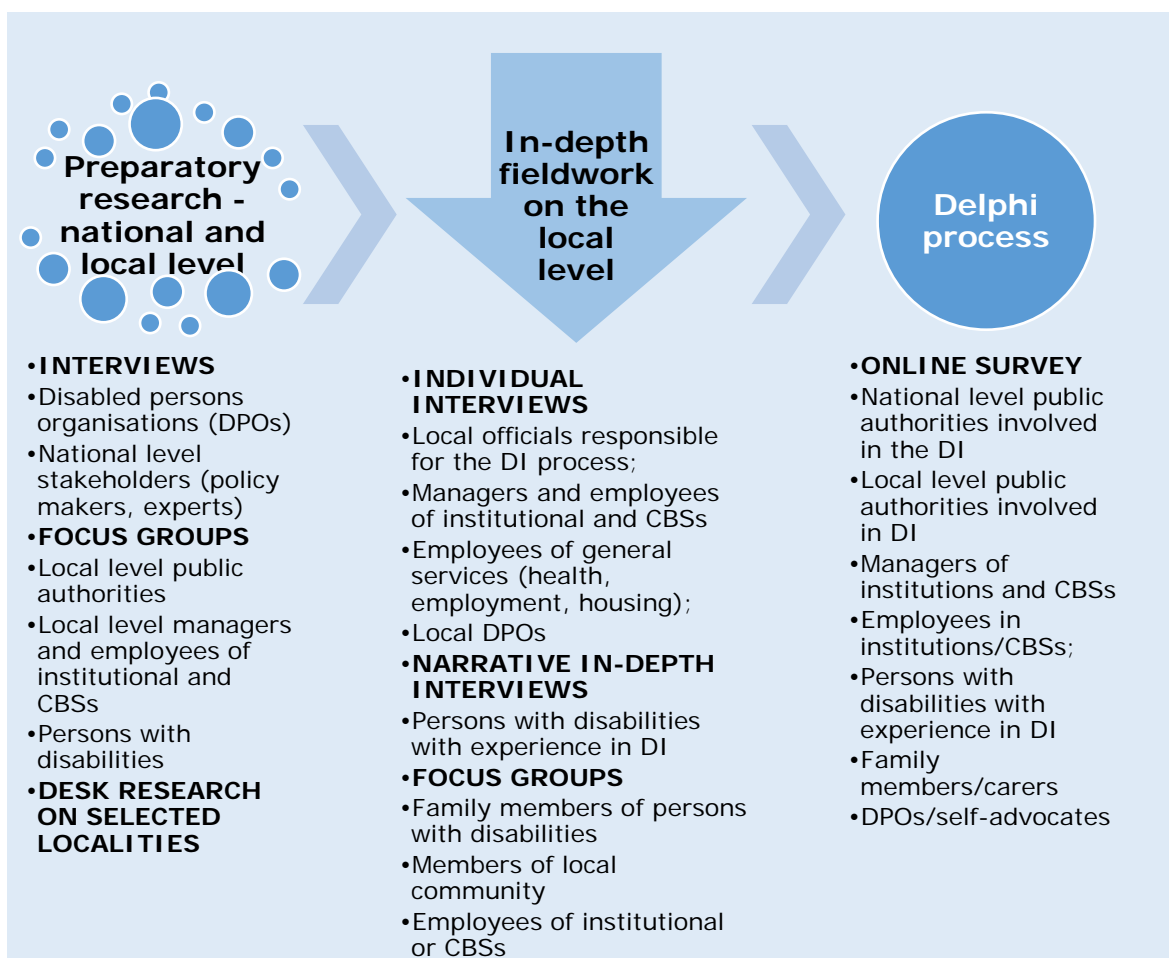
ANNEX: RESEARCH METHODOLOGY

The fieldwork employed several common qualitative research methods to capture the views of a variety of different stakeholders. These included participatory research methodologies enabling full participation of persons with disabilities:

- **Consultation with experts (5 persons)** in conducting research with persons with disabilities.
- Preparatory **semi-structured interviews (7 persons)** with selected national stakeholders to gather contextual information about the status of the national deinstitutionalisation process and to identify key themes to be explored in later interviews.
- **Focus group discussions (58 persons)** to explore differences and commonalities in the experiences and perceptions of groups of participants with similar roles in the deinstitutionalisation process.
- **Face-to-face semi-structured interviews (10 persons)** with individuals involved in the deinstitutionalisation process in the case study locality to gather their views about what works and what does not work regarding policies and practices.
- **Narrative interviews (4 persons)** giving persons with disabilities the opportunity to share their experience of the deinstitutionalisation process and how it affects their lives.

Much more information on the design and methods of the fieldwork research is available in the main report '[From institutions to community living for persons with disabilities: perspectives from the ground](#)'.

Figure 1: Research methods and target groups



Source: FRA (2018)

Inclusion of persons with disabilities

Participatory research principles guided the development of the research design. Particular attention focused on ensuring that persons with disabilities are active participants at all stages of the research.

In preparation for the research, FRA held an international expert meeting with representatives of disabled persons organisations (DPOs) and experts with experience of conducting research with persons with disabilities. This was complemented by a similar process at the national level, where researchers in the fieldwork countries conducted consultations and interviews with national DPOs and experts.

FRA ensured the preparation of easy-read research materials and reasonable accommodation in all activities part of the research.

The names of persons with disabilities telling their personal stories of deinstitutionalisation are pseudonyms.

Delphi process

To validate the results of the fieldwork research at both the national and local levels, FRA carried out a Delphi survey. Delphi is a participatory group communication process which aims to conduct a detailed examination of a specific issue, bringing together a range of stakeholders in a time-efficient way. The process enabled FRA to assess areas of consensus and disagreement between and across stakeholder groups and countries.³⁴

FRA's Delphi survey included almost all those who had participated in the fieldwork. Participants were presented with a summary of the key findings and asked to identify the most important drivers and barriers of the deinstitutionalisation process.

Peer review meeting

In addition, FRA organised in-country peer review meetings in each of the five fieldwork countries between January and February 2018. These meetings allowed a small number of research participants to reflect on the findings emerging from the research.

Discussions at these peer review meetings fed into the revision of the national case study reports and informed the drafting of the main report bringing together the findings from the five countries where the research took place.

³⁴ Hsu, Chia-Chien and Sanford, A., Brian (2007), [The Delphi Technique: Making Sense of Consensus](#), Practical Assessment, Research and Evaluation, No. 10/12; Cuhls, K. (2005) [The Delphi Method](#), Fraunhofer Institute for System and Innovation Research ISI.