

## Case studies on international policy and implementation – Case 3

# Deinstitutionalization of persons with intellectual disabilities in Finland

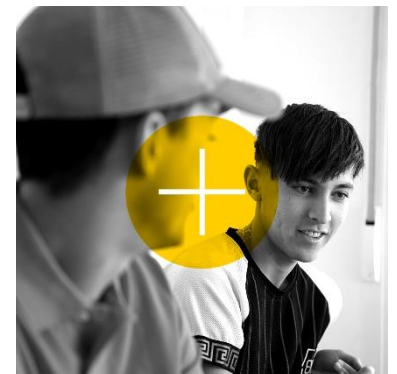
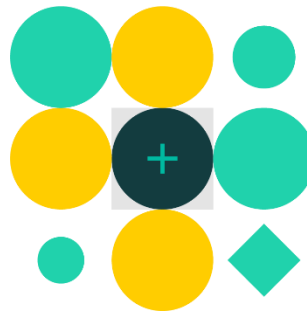
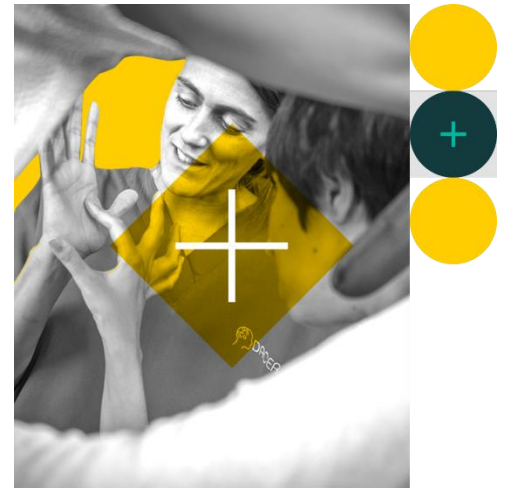


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## Key messages

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Particularly since the claims of the disability movement for inclusion and participation starting in the 70s, Finland has engaged with a series of policy reforms that promote independent living in the community as a human right for persons with disabilities. Accessibility, inclusion and universalism were promoted via legislation, policy, adaptation of the environment and disability services such as personal assistance to persons with disabilities.

- The ratification of CRPD in 2016 has been accelerating the on-going efforts in municipalities that are the main actor to locally implement the deinstitutionalization (DI) in practice.
- The number of residents in institutions (especially those living in institutions for a long-term) steadily decreased over the years. However, the decrease is much higher for the residents aged between 18 and 64 years compared with children and youths with disabilities as well as with people with disabilities over 64. Also, persons with profound intellectual and multiple disabilities, as well as older persons with intellectual disabilities, are among the groups more likely to live in institutions.
- While there is a common policy framework at national level, implementation at local level differs. The conceptual consensus does not translate into an agreement in the practice on the ground. Even some local professionals consider that the institution as “a home” for persons with intellectual disabilities and that requiring them to move away from the institution would not necessarily be a humane solution, generating distress and suffering. Hence, it is important to focus on recognition of the complicated realities at the local level, where disability rights realization takes place with great significance on the lives of persons with disabilities. To enable independent living in the community for persons with disabilities, a general change of attitude is needed within municipal managers, service providers and the community in general.
- In many cases, alternative housing as a result of relocation after DI regenerated micro-institutional settings in supposedly alternative community-based environments. Housing units such as group homes are often for 15 persons with intellectual disabilities or more recreate the cultures of institutions in terms of limiting own decisions, choice, and independence from permanent supervision.
- Often the process of moving to the community does not fully consider the choices and preferences of persons with disability. For persons with disability, organising the transition with foresight is important and relocation training needs to be offered quickly before a housing solution becomes available.
- During the implementation of the Finnish DI strategy, a clash emerged between market-oriented priorities and disability rights realization. The 2016 procurement law promoted the cheapest offer over quality and was heavily contested by citizens.
- Current discussions on the draft Disability Service Act highlight the challenges to change the paradigm into a human rights-based approach by attending individual needs and rights beyond diagnoses. While personal assistant service is foreseen, resistance prevails. Also, the concentration of social service provision to 21 counties plus Helsinki is expected to increase the possibilities of freedom of choice for the users and decrease inequalities among them.



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## Introduction

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In Finland, a group of University of Helsinki students with disabilities started a disability movement in the 1970s and established a cross-disability organization, the Threshold Association, in 1973. The Association has been closely linked with the global disability movement, as one of the central actors. One of its founders, Kalle Könkkölä, became later a member of parliament in 1983, the global chairperson of Disabled People's International in 1993, and further politicized issues around disability as human rights. Organizations of persons with disabilities have been deeply engaged with the government of Finland and developed a partnership relationship.

In 1986, the National Disability Council (VANE) was established under the auspice of the Ministry of Social Affairs and Health. VANE is an official channel to represent voices of persons with disabilities in law making and decision making of the government of Finland. Today it has changed its name to Advisory Board for the Rights of Persons with Disabilities and become the coordination mechanism of the CRPD (Article 33).

The strong Finnish disability movement played a role in building and developing social policy and practice (Ministry for Foreign Affairs of Finland, 2018) that is known as a Nordic welfare model the aim of which is inclusion and universalism (Hellman, Monni and Alanko, 2017). For instance, the disability movement succeeded in gaining subjective rights and persons with severe disabilities became entitled to personal assistants through an amendment of the *Disability Service Law* in 2009. Personal assistance is a significant factor for the agency of persons with disabilities (Sihvola, 2014). Similarly, the Sign Language Act was enacted in 2015 to promote sign language users' opportunities to use their mother tongue.

In this case study, I have taken a closer look at the practice of this process beyond the statistics by listening to experiences of relevant stakeholders and tries to tease out more complicated, evidence-based picture of current Finnish realities around disability rights based on the study conducted in recent years (Tuokkola and Katsui, 2018; Katsui, Valkama and Kröger, 2019).

**The key question to answer in this case study is what the local experiences of deinstitutionalization are, when the global and national policy about deinstitutionalization and independent living is transcended into practice.** This case study shows how the self-determination rights of persons with severe intellectual disabilities can be compromised in practice.

## 1. Policy framework towards deinstitutionalization

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According to the government resolution of 2012, there would be no person with a disability living in an institution by the end of 2020. Until the 1990s, most persons with severe intellectual disabilities lived in institutions (Katsui et al., 2019). In 1995, 3699 persons with disabilities still lived in institutions. The number of residents in institutions (especially those living in institutions for a long-term) steadily decreased over the years as the below table shows.

Table 1: The number of persons with intellectual disabilities living in institutions.

	1995	2000	2005	2010	2015	2016	2017	2018	2019	2020	2021
0–17 yrs	-	208	207	190	194	191	173	176	179	168	172
<i>Of which long-term</i>	-	155	133	122	138	138	110	118	131	129	128
18–64 yrs	-	2.390	1.974	1.588	798	648	494	402	341	321	301
<i>Of which long-term</i>	-	2.332	1.909	1.512	735	583	444	354	288	272	258
Over 65	-	160	165	156	101	81	72	53	36	29	19
<i>Of which long-term</i>	-	157	161	156	96	81	68	49	30	26	17
<b>Total</b>	3699	2.758	2346	1 934	1 093	920	739	631	556	518	492
<i>Of which long-term</i>	-	2.644	2.203	1.790	962	795	622	521	449	427	403

Source: extracted from SOTKANET – statistic database in Finland

The statistical trend tends to present a promising picture about the deinstitutionalization process in Finland. The ratification of CRPD in 2016 has been accelerating the on-going efforts in several municipalities that are the main actor to implement the deinstitutionalization in practice. The action programme 2018–2019 to implement the CRPD (Ministry of Social Affairs and Health, 2018) identifies areas of priority during these years by mentioning responsible duty-bearers. The action programme refers to independent living as an important goal, reiterates the set timeframe of the government resolution to demolish institutions by the end of 2020, and further presents short-term goals for promoting independent living for persons with disabilities. In short, political will and commitment as well as legal development at the national level are drivers for independent living for persons with disabilities. In this process, VANE has been playing a significant role in coordinating dialogue among stakeholders’ representatives such as government officials and OPDs. Consequently, Finland is often cited as a good example of a country committed to the discourse on disability (Ministry for Foreign Affairs of Finland, 2018).

## 2. Hidden realities behind the statistics

The steadily decreasing number of residents with disabilities in institutions disguise the realities. This part focuses firstly on further disaggregated data to understand the deinstitutionalization process better, and secondly on the types of persons with disabilities who still live in institutions. The aforementioned Table 1 shows the number of residents disaggregated by their ages and their lengths of living in the institutions. The table shows that the decrease is much higher for the residents aged between 18 and 64 years compared with children and youths with disabilities as well as with people with disabilities over 64. In fact, the decrease has been minimal for children and youths with



disabilities for the last two decades. The majority of residents who are still in institutions are long-term residents.

In Finland, persons with disabilities typically live in the community, with some exceptions. Persons with profound intellectual and multiple disabilities, as well as older persons with intellectual disabilities, are among the groups more likely to live in institutions (Katsui et al., 2019). This is because the deinstitutionalization started with people with mild intellectual disabilities. Those in the institutions typically have intensive medical care needs and/or were born in the 1950s or earlier, having been in institutional care for a long time (Tuokkola and Katsui, 2018: 13). This means that deinstitutionalization in the near future is going to be much more challenging compared with those who have been already relocated. 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 (Tuokkola and Katsui, 2018: 13). They consider this to be an ethical dilemma, when one is imposed on to be relocated from his/her/their “home”, whereas institutional living is a violation of human rights.

Furthermore, there seems not to be a consensus among stakeholders for deinstitutionalization for all at a local level. Some stakeholders are of the opinion that deinstitutionalization does not fit all. At a local level, several staff members who have worked in institutions and also a family member are particularly of this opinion. To some extent, this is affected by a conflict of interests they experience, as deinstitutionalization implies the threat of unemployment for the institution staff members or more care responsibility for their families. A staff member of a disability service provider also believes that institutions are better for those with intensive care and medical 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. Cited in Tuokkola and Katsui, 2018: 17)

Hence, on the one hand, at the national level, there is seemingly consensus for deinstitutionalization, all of which has been well-observed in the government resolutions and the ratification of the Convention. The personal interviews and consultations confirmed this consensus at the national level among diverse actors including government officials, academics, and representatives of organizations of persons with disabilities. However, on the other hand, consensus has not been reached by local actors in the selected locality of our studies, as was presented above.

When municipalities are responsible for implementing deinstitutionalization in practice, this unreach consensus at the local level does have implications that have an impact on the deinstitutionalization process. In addition, the current austerity measures, administrative reform discussions of the government (so-called “SOTE reform”), and the new Disability Service Act further complicate the deinstitutionalization process, as cost-effective solutions could undermine human rights realization.



### 3. Institution-like practices in alternative living

When it comes to alternative housing as a result of relocation after deinstitutionalization, they are not free from criticism in reality. This is particularly linked with attitude. This part presents another layer of complicated reality, in which physical relocation alone does not necessarily equal independent living.

Many persons with intellectual disabilities who are relocated from institutions and childhood homes often move into assisted housing in community where they receive care 24 hours a day. Guided living means that they get support 12 hours a day without monitoring at night. Supported living means that they get support according to an agreed number of hours, for instance a few times a week (Katsui et al., 2019). Housing units such as group homes are often for 15 persons with intellectual disabilities or more. The statistics in Table 2 correlate with the trends of deinstitutionalization, as steadily increasing numbers of people with intellectual disabilities live in communities.

Table 2: People with intellectual disabilities in group housing alternatives.

Year	2000	2005	2010	2013	2014	2015	2016	2017	2018	2019	2020	2021
Assisted	2.780	4.552	5.876	6.628	6.616	7.728	8.265	8.484	8.664	9.187	9.681	9.165
Guided	1.555	2.061	2.168	2.083	1987	2.006	1.954	1.986	1.859	1.884	1.817	1.766
Supported	553	796	972	1.317	1.274	1.548	1.684	1.880	1.876	2.098	2.235	1.905
All	4.488	7.409	9.016	10.028	9.877	11.282	11.903	12.350	12.399	13.169	13.733	12.836

(Source: extracted from SOTKANET – statistic database in Finland)

The statistics in Table 2 seem to display a promising picture of independent living in Finland. Some interviewees explained differences between institutional living and community living:

*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 person with disabilities. Cited in Tuokkola and Katsui, 2018: 16)

*[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 disability. Cited in Tuokkola and Katsui, 2018: 16)





However, most of the research participants claim that an institution-like culture often continues in relocated housing when resettled from childhood homes and from institutions. This phenomenon is conceptualised as reinstitutionalisation in the process of deinstitutionalisation (Engen et al. 2019).

People with disabilities particularly recounted certain rules and practices of the housing units which they did not like such as different forms of control. Some were forced not to wear certain hats or not to drink any alcohol, while others were forced to switch off the lights at certain times. Various research participants across various levels, especially representatives of OPDs, were of the strong opinion that many group homes are institution-like in terms of culture and do not represent genuine independent living.

In some localities, both institution staff members and residents of the institution were relocated to the same group homes. This relocation was considered to be a way to secure the safety of the residents and to maintain friendships among the residents. At the same time, it shifted the institution-like culture and power relationship between the staff members and the residents to the new housing units. In this way, physical relocation took place, while attitude of both the staff members and the residents did not profoundly change because of the relocation. Municipalities recently started to provide relocation training for persons with intellectual disabilities, their families, and staff members, which is considered to be a driver for the deinstitutionalization 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 community-based service. Cited in Tuokkola and Katsui, 2018: 25)*

Relocation training is primarily to prepare mainly residents and their families for forthcoming change and alleviate their worries and stress. This training is also expected to serve staff members to change their attitude that inform paradigm change to the staff in which persons with disabilities have much greater self-determination right in their lives. However, local experiences have shown that relocation training was not enough according to some professionals in the locality, as the municipality decides on the content and length of relocation training and sometimes does not purchase enough services. When many stakeholders find it hard to change their attitude, any lack of coordinated effort and service have crucial implications for the process of deinstitutionalization.



## 4. Lack of self-determination right

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Many actors across different sectors argue that institutional practices and culture are hard to deconstruct, as human rights-based understanding of disability is still superficial in Finland (Tuokkola and Katsui, 2018: 15).

*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.  
Cited in Tuokkola and Katsui, 2018: 34)

This lack of self-determination right is paramount in numerous examples in the process of deinstitutionalization, one of which is aforementioned institutional practice and culture. Many research participants with various backgrounds highlight that lack of choice was evident when relocation takes place for persons with intellectual disabilities.

*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 local disabled persons organization.  
Cited in Tuokkola and Katsui, 2018: 41)

Many persons with intellectual disabilities are offered housing without any alternative. Lack of coordination among the actors in housing units also lead to a deterioration of relocation practice when relocation training should be quickly prepared and implemented when a room becomes available. As a result, some could not receive the personal assistant service that one was entitled to.

The self-determination right is understood in several ways. On the one hand, as was mentioned above, persons with intellectual disabilities are often restricted from taking "risks" such as drinking alcohol or sleeping less. A popular Finnish punk band consisting of musicians with intellectual disabilities, Pertti Kurikan Nimipäivät, has a number of very depictive songs of their daily lives in Finland. One of them is entitled, "*I always have to (aina mun pitää)*" and the lyrics depict well their repetitive daily lives with a lot of rules. On the other hand, persons with intellectual disabilities do not get much support in personal hygiene in the selected locality of the research, "because of freedom of choice". Some community-based service providers referred to certain cases when their appearance, such as hair and body odour, disrupted their activities including employment. But when a person with an intellectual disability did not want to take medication, he was forced to do so against his will. These are controversial cases when different interests conflict with each other (E.g. Vaughan, 2007), in which local and even individual decisions are made without clear guidelines. Persons with disabilities who are



aggressive and have behavioural difficulties are also mentioned as the target of restrictions in their choices due to “inherent conflicts” (also in England in Muir and Goldblatt, 2011: 629). These are some examples how self-determination rights conflict with other interests or is simply compromised. Consequently, materializing self-determination right of persons with intellectual disabilities at the local level is not straightforward in reality according to most research participants, particularly according to those at the local level.

## 5. Finance and human rights

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Another barrier was the perceived clash between market-oriented priorities and disability rights realization, even though many subjective rights should secure community-based living of persons with other disabilities than intellectual and developmental disabilities. This was articulated as an important turning point in the disability movement in Finland.

In 2016, a procurement law passed and replaced the old law. Consequently, market principles were more strongly visible in decision making concerning public sector procurement after that. In 2018, a demonstration and campaign raised the question to the currently rampant market-oriented practices of disability service providers as well as their relationships with the municipalities that purchase their services. The initiative of citizens, when over 50,000 citizens’ signatures were collected, can launch a Parliamentary process to establish a new law or change a law. This campaign, “Not for sale! (*Ei myytävänä!* in Finnish)”, collected as many as 72,059 signatures and went to the Parliament for discussion.

The main criticism against the status quo was the recent trend of public sector decisions on disability services, including housing services for persons with intellectual disabilities, that started to select the cheapest services over quality ones. Market-oriented competition quite frequently took place, which resulted in discontinuation and/or deterioration of disability services for many persons with disabilities. Therefore, the citizens’ initiative asked for prioritizing quality over other criteria and strongly asserted that this is a human rights issue. The time for the then Parliament was not enough to discuss this, as the government collapsed shortly after that and subsequently a new election took place. This is an illustrative example of neoliberalism that has come to penetrate into the disability rights discourse in Finland and also beyond.

## 6. Concluding remarks

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This evidence in this case study was still only part of the reality of Finland today despite its superficial positive image as a “good” and even “the happiest” country in the world (Helliwell et al., 2019). This case study used several pieces of evidence that such a superficial image is not enough to understand the complex reality. Deinstitutionalization in the form of physical relocation alone is not the panacea for realizing independent living



for persons with intellectual disabilities in Finland. This was rightly pointed out in General Comment Number 5 on Article 19 of the CRPD: “appropriate changes of attitude at all levels and sectors of government, including local authorities, is required.” It continues that creating awareness-raising programme is an important step for the implementation of this Article. Without deconstructing deeply-rooted negative attitudes against persons with disabilities, deinstitutionalization cannot make the differences being sought. Independent living for persons with disabilities, therefore, requires many more interventions beyond deinstitutionalization in Finland and beyond.

Ideological discussion about institution to community-based living is conceptually and politically important for changing the paradigm of disability as a human rights issue. At the national level, the human rights-based approach to disability started to be more widely understood by stakeholders. Yet, it is important to focus on recognition of the more complicated realities at the local level, as disability rights realization takes place at that level that has a great significance on the lives of individuals with disabilities. In fact, Finland is not an exception where negative attitudes in society hinder genuine agency of persons with intellectual disabilities pertaining to their housing and many other areas of their lives.

One of the solutions for the way forward is the forthcoming legal change. Currently, the Parliament has been discussing on the new Disability Service Act that merges two existing laws (the Act on Special Care for People with Intellectual Disabilities 519/1977 and the Disability Services Act 380/1987) into one. The previous two laws take a medical approach to disability: one is meant for persons with intellectual disabilities and the other for those with other disabilities, which is one of the fundamental reasons why these laws are going to be merged into one. The new law is expected to change the paradigm into a human rights-based approach by attending individual needs and rights beyond diagnoses. Most of the services will be subjective rights that are granted based on individual needs regardless of budgetary restrictions of wellbeing service in the counties that will administrate the disability services from 2023 onwards. For instance, personal assistant service was not largely granted to persons with intellectual disabilities in the current law due to their limited capacity to identify and articulate their personal needs. With the new law, a similar service is also available to persons with intellectual disabilities with necessary support to define and articulate personal needs.

Another aspect of this new law is that inequalities will be reduced among service users. Currently, 311 municipalities are responsible for implementing disability policy of the government into practice and for providing disability services with the allocation of national budget as well as local budget. Some decisions and interpretations are different from one municipality to another, which has caused inequalities among persons with disabilities, depending on where they live. From 2023 onwards, the administrative structure for social and health care services change, and bigger regions (wellbeing service counties) are introduced. 21 regions and the City of Helsinki are the administrative units that will be responsible for implementing disability policy of the government and providing disability services into practice. This administrative change is expected to increase the possibilities of freedom of choice for the users and decrease inequalities among them.



2.6 billion EUR are currently used for disability services, and this new law will have an additional budget of 22 million EUR. Some consider this additional budget far too small to cater for all the services promised in the new draft law. The forthcoming law needs to be closely monitored in the implementation, so that the human rights-based approach to disability is materialized not only in policy but also in practice.



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