



Interdisciplinary Disability Studies

DISABILITY, HAPPINESS AND THE WELFARE STATE

FINLAND AND THE NORDIC MODEL

Edited by
Hisayo Katsui and Matti T. Laitinen



ROUTLEDGE


Disability, Happiness and the Welfare State

This book looks at disability as an evolving social phenomenon. Disability is created through the interaction between persons with impairments and their environment.

Exploring these experiences of persons with disabilities and discussing universality and particularity in our understanding of assumed development and normalcy, it takes Finland, which has been chosen repeatedly as the happiest country in the world as its case-study. Using disability as a critical lens helps to demystify Finland that has the positive reputation of a Welfare State. By identifying different kinds of discrimination against persons with disabilities as well as successful examples of disability inclusion, it shows that when looking Finland from the perspective of persons with disabilities, inequality and poverty have been collective experiences of too many of them.

It will be of interest to all scholars and students of disability studies, sociology, social policy, social work, political science, health and well-being studies and Nordic studies more broadly.

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Finland and the Nordic Model

Edited by Hisayo Katsui and
Matti T. Laitinen



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Contents

<i>List of figures</i>	<i>vii</i>
<i>List of tables</i>	<i>viii</i>
<i>List of contributors</i>	<i>ix</i>
Introduction	1
HISAYO KATSUI AND MATTI T. LAITINEN	
1 The sense of difference: Disability and loneliness as emotional and social isolation	12
MERJA TARVAINEN	
2 ‘Disability is so invisible at the University’: Disability inclusion/exclusion experiences of students with disabilities at the University of Helsinki	28
HISAYO KATSUI, MATTI T. LAITINEN, IRA KUOSMANEN, MILLA TENGSTRÖM AND MAIJA LINDSTRÖM	
3 Being independently dependent: Experiences at the intersection of disability and old age in Finland	48
SALLA ERA AND TEPPO KRÖGER	
4 One step backward? Exploring the outcomes of the COVID-19 pandemic for persons with intellectual disabilities in supported and service housing	68
SONJA MIETTINEN	
5 The state of inclusion in the state of inclusion? Inclusion as principled practice in Finnish basic education	83
JUHO HONKASILTA, PÄIVI PIHLAJA AND HENRI PESONEN	

6	Media representations of disability MARJAANA HAKALA AND HISAYO KATSUI	111
7	Reforming disability services to balance rights and needs STINA SJÖBLOM AND PÄIVI NURMI-KOIKKALAINEN	139
8	Employment, the Finnish disability pension system, and self-determination of people with intellectual and developmental disabilities LOTTA-KAISA MUSTONEN AND HISAYO KATSUI	158
9	The happiness of having a hobby: Inclusion of persons with disabilities in leisure activities EERO SAUKKONEN, JENNI VALMARI AND REETTA MIETOLA	179
10	Spiral of progress: Disability activists' perception of the societal and political position of disabled people in Finland PEKKA KOSKINEN, AARNO KAUPPILA AND REETTA MIETOLA	200
11	'Second Class Citizens': Challenges with truth and reconciliation process of deaf people and the sign language community in Finland MAIJA KOIVISTO AND HISAYO KATSUI	215
12	Examining cooperation-based advocacy between government and disability activists in transnational advocacy networks MINA C. MOJTAHEDI AND HISAYO KATSUI	234
	Concluding remarks HISAYO KATSUI	256
	<i>Index</i>	267

Figures

2.1	Completion of tertiary or equivalent education (aged 30–34 and 30–39)	29
6.1	The key elements of and main differences between the models and approaches to disability	119
11.1	Internalized oppression and vicious circle	221

Tables

3.1	Background information of the participants	54
6.1	Operationalization of theoretical framework	120
6.2	Current media representations of disability according to the data	124
6.3	Recommendations for media representations of disability according to the data	128
7.1	Documents included in the study	144
7.2	Categories and themes emerging in the analysis	149
8.1	Characteristics of study participants	163
8.2	Motives behind wanting to work	165
8.3	Pension experiences and decisions of study participants	169
12.1	Summary of three modalities of advocacy	247

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Introduction

Hisayo Katsui and Matti T. Laitinen

The aim of this book

Finland has often been among the top countries in international ratings for stability, freedom, public safety equality, environment, information technology and health. In addition to that, Finland has regularly been named as one of the top Organisation for Economic Co-operation and Development (OECD) countries in education. Finnish students have performed well in the Programme for International Student Assessment (PISA) studies. PISA assesses the learning outcome of students aged 15 in mathematics, science and reading literacy. In PISA 2000 studies, Finland showed the highest reading literacy performance in the OECD. Lately Finland has also been ranked *the happiest country in the world* for six consecutive years, 2018–2023, by the United Nations World Happiness Reports.

The success of Finland in international rankings has been a somewhat puzzling experience for academics like us in the field of disability studies. On the one hand, we are happy that Finland is doing well. On the other hand, looking at Finland from the perspective of persons with disabilities, we know that it is not so straightforward, as inequality and poverty have been the collective experiences of too many of them (Pohjalainen, 2021; Katsui, 2020; Vesala and Vartio, 2019; Hoffren, 2017; Katsui et al., 2023). That is, these glorious images of Finland do not truly reflect the reality of many Finnish persons with disabilities.

We cannot, of course, deny that success in such country comparisons has increased international attention to the Finnish approach. We have noticed that international researchers and readership have been interested in the reality of persons with disabilities in Finland due to the overly positive image created by them. We have received a number of enquiries asking for information about good practices in the Finnish disability sector, as they often take for granted that Finnish persons with disabilities are doing well in such a country which has also been traditionally perceived as a Nordic *Welfare State*. This book will respond to these growing needs for information. Our aim in this book is to open up opportunities for critical analysis, learning and understanding of Finland from the pertinent perspective of disabilities. Our

goal is to go beyond simply drawing on statistical averages that provide only a superficial view of the reality in Finland today.

In this book, we and the other authors will scrutinize the reality of persons with disabilities in Finland. We will explicate the phenomenon of disability as a cutting edge to understand our Finnish society. The main objectives are to investigate disability with a critical lens and thereby demystify Finland. We also try to identify different kinds of mechanisms that work against persons with disabilities as well as present possible solutions. We pinpoint the challenges of exclusion and discrimination directed towards persons with disabilities even in “the happiest country in the world” and show how disability inclusion might work in practice.

Theoretical frameworks

As we want to critically analyse Finnish society from the perspective of disabilities, disability studies is the most appropriate academic disciplinary foundation for this book. Disability studies was born in the struggle of persons with disabilities in the 1970s and 1980s in the United Kingdom (UK) (Barton and Oliver, 1997) and the United States (US). In the wake of the disability movement in the 1960s and 1970s being established simultaneously at around the same time in different geographical locations (Könkkölä and Sjövall, 1993), persons with disabilities started to politicize their realities such as oppression, poverty, medicalized bodies and institution practices (Barton and Oliver, 1997). The development of a social model of disability (Oliver, 1990) based on the criticism against the positivistic medical model of disability was central. This coincides with the time when other social movements were formed that paid attention to differences and vulnerable minority groups. The disability movement was one of such social movements to seek equal rights with others (Katsui, 2005). Disability activists and scholars started to question missing voices and to promote the perspectives of persons with disabilities in global and national discourses. As disability studies was born within the disability movement, both the research process and findings have been politically oriented. The aim has been to contribute to social transformation and to provide equal opportunities for persons with or without disabilities in the UK and the US.

In Nordic countries, disability studies came slightly later than in the UK and the US. In the 1960s and 1970s, normalization was introduced as a strong foundation for the disability policy (see Nirje, 1969). In principle, persons with disabilities were considered to live a normal life and should have the same rights. When human rights frameworks including principles such as equality and citizenship became central in conjunction with the Nordic Welfare State policies (Traustadóttir, 2004), the disability movement advocated for independent living against institutions and top-down medically oriented decisions (Tøssebro et al., 2012). Along with the changes, disability research has been deeply intertwined with disability policy, reform and

services particularly concerning what works and largely lacked theoretical perspectives (Gutavsson, 2004). It is finally in the 1990s, disability studies in Nordic countries including Finland started to flourish with theories of *Nordic relational approaches to disability*. In 1992, the Nordic research association on intellectual disabilities (Föreningen forskning om utvecklingsstörning i Norden, FUN) was established, which was then transformed into the current Nordic Network of Disability Research in 1997 to encompass wider disabilities. In 1999, the first issue of the Scandinavian Journal of Disability Research was published. In the process, the historically strong research on disability policy, reform and services encountered disability studies in the UK and other countries, which started to diversify the Nordic approaches to disability. Traustadottir (2004) describes that the Nordic approaches are not a single theory but a family of ideas around the perception that there is a person-environment mismatch. In the Nordic approaches to disability, disability is seen as relational, contextual and relative (Traustadottir, 2004; Tøssebro, 2004). In this way, environmental factors started to be more explicitly scrutinized.

In Finland, education, particularly special and inclusive education, has been a strong focus together with studies on disability policy and services such as social work. Although the history of disability studies is not particularly long also in Finland, it has as an academic discipline made a significant impact on the global and local discourses on disability in the recent past. It has done this by strengthening the disability movement with scientific evidence and new knowledge from previously marginalized disability perspectives. Yet, in the keynote speech at the Nordic Network of Disability Research Conference in 2013, Kalle Könkkölä, then leading Finnish and global disability activist, pointed out that the Nordic and Finnish disability research remained distant from the concerns of many persons with disabilities.

Many theoretical developments have taken place in disability studies that point to the need for more nuanced approaches to disabilities (see Shakespeare, 2018; Katsui, 2020). This is a necessary process as the more a social movement matures, the more polarization takes place within that movement (Pleyers, 2010). In the disability movement context, a split between articulate and empowered disability activists and the many persons with disabilities who do not have easy access to the mainstream has been taking place (Lorenzo and Coleridge, 2019:236). Katsui and Chalklen (2020) summarize criticisms against the conventional social model. One of the first criticisms against the gender-neutral approach to disability was made internally by women with disabilities who were inspired by feminism (e.g. Thomas, 1993; Morris, 1991). The lack of an ethical approach in the social model was also pointed out (Vehmas and Watson, 2013). Moreover, individual accounts were also highlighted in the relational approach to disability of critical realist disability studies scholars (Shakespeare, 2018: 158). Furthermore, critical disability studies started to pay attention to the construction of categories and the role of culture (e.g. McRuer, 2006; Goodley, 2012). Also noted was

the increasing pressure from a neoliberalizing state that tried to delegitimize disability movements and their collective agency (Soldatic, 2019:28).

Today, disability-related theoretical frameworks have become more diversified. Similarly, Nordic approaches to disability have been much more diversified beyond the reformer's perspective to serve the Welfare States (Gutavsson, 2004). Many more academic disciplines are represented beyond education and social work, for instance. Much more nuanced approaches to disabilities are increasingly necessary to understand the multifaceted phenomenon of disability in the Welfare States.

In the Nordic Network of Disability Studies Conference in 2023 in Reykjavik, Iceland, a session entitled, "Revisiting a Nordic Approach to Disability" was held. It was led by Hisayo Katsui (Helsinki University), Marianne Hedlund (Norwegian University of Technology and Science) and Kristina Engwall (Uppsala University). In the session, Welfare States were discussed not any longer as a supreme framework reducing inequalities (see Kvist et al., 2012) but as a fragile system encountering challenges of new public management, marketization, austerity measures, lack of understanding of disability rights, re-medicalization of social problems and re-institutionalization, to name a few. Much more critical investigation of the Welfare States from the point of view of disability is needed.

Based on the development of disability discourse and theories, including criticisms against them, we, the authors, are increasingly interested not merely in persons with disabilities but also in the interaction and relationships between persons with disabilities and their local and global environment (Shakespeare, 2018). We take a *non-reductionist approach* (Shakespeare, 2006:55–56) with multiple theoretical frameworks *beyond the medical-social-human rights axis*. We try to understand disability as a social phenomenon that is embodied (Wilkerson, 2015; Rohleder et al., 2019) due to a number of social mechanisms as well as the impairment effect. In this process, we also try to deepen our understanding of normality in Finnish society as its counterpart concept of disability and question the very idea of normality from the critical disability perspective.

In the era of the United Nations Convention, disabilities have been increasingly mentioned in international and national laws and policies including most recently the responses to COVID-19 (see e.g. United Nations [UN], 2020). Now that 186 countries have ratified the Convention, many countries are in need of learning from good practices and the lessons learned from other countries. As stipulated in Article 32 of the Convention on International Cooperation, information and knowledge exchange is more than necessary in our society today. We take a critical view of the status quo in Finland even after the ratification of the Convention in 2016. The initial state report was submitted to the Committee of the Convention in 2019, pointing out many significant gaps in the operationalization of the human rights-based approach across different sectors (The Finnish Government, 2019). Many aspects of life in Finland in social, political, economic and other environments

still prevent persons with disabilities from enjoying equal human rights with others without disability. In order to understand the phenomenon of disability in Finland, this book critically scrutinizes these anomalies with the help of theories and key concepts primarily derived from disability studies and other relevant disciplines such as social policy, law, education, youth studies and deaf studies.

Guiding readers to the Finnish context

The 1960s marked a period of fundamental structural change in Finnish society. It was also a period of many important legal reforms connected to the construction of the Finnish Welfare State. Structural change was brought about by economic liberalization, industrialization and the rapid mechanization of agriculture, and it resulted in massive migration from eastern and northern Finland to the cities in southern Finland. In addition, many Finns moved to Sweden (Leppälä, 2013). In 1945, 70 per cent of the Finnish population lived in rural areas, and almost 60 per cent were employed in agriculture and forestry. Following the great migration of 1960–1975, half of the population lived in cities and 32 per cent were employed in industry and construction. Whereas the demise of agrarian labour took place over a period of 80 years in Norway, and over 50 years in Sweden, it happened within 20 years in Finland (Simola et al., 2017). In the history of Finnish disability policy, the 1960s can be characterized as a decade that extended the rehabilitation ideal. It can also be viewed as a period which saw the diminishing importance of economic gain with rehabilitation extending to groups which had not previously qualified because they were perceived as unprofitable targets. Thus, the discussion on extending rehabilitation to new groups not only marks a period of expanding policy but is also an indication of the normative changes in Finnish social welfare (Leppälä, 2013).

The independent living movement of persons with disabilities, along with other social movements, started during the 1960s in the US (Martinez, 2003) and quickly spread to other countries including Finland. In the independent living philosophy, self-representation, equal opportunities and self-determination were central principles at a time when persons with disabilities still largely lacked agency within the predominantly medical approach to disability in society (Oliver, 1996). In several parts of the world, persons with disabilities simultaneously started to organize themselves to eventually form the global disability movement (Könkkölä and Sjövall, 1993; Katsui, 2005). As a part of this development, a group of Finnish students with disabilities founded the Threshold Association in 1973. It became a new kind of actor in Finnish disability politics. The members of the Threshold Association identified themselves as disability activists. Whereas other Finnish disability organizations provided services for persons with disabilities, the Threshold Association profiled itself as an expert on disability issues, influencing officials

and other authorities to consider the needs of people with disabilities when making decisions (Laitinen, Marsh and Pietilä, 2014).

The late beginning and rapid change of Finnish society led to some unusual consequences in the building of disability services (Saloviita, 2013:44). When, for example, the construction of residential care homes for persons with physical disabilities took place during the 1980s, the ideals and values of the disability movement and society had already moved away from the institutional model of service provision towards independent living. However, there was still much to fight for. It was not until 1979, for example, that the training officer of the Threshold Association, Gunilla Sjövall, became the first person in Finland with a disability to have a personal assistant (Sjövall, 1983).

Gradually, the Threshold Association and other organizations of persons with disabilities became more engaged with the Finnish government and developed a partnership relationship. In 1986, the National Disability Council (VANE) was established under the auspices of the Ministry of Social Affairs and Health. VANE is an official channel that represents the voices of persons with disabilities in the law-making and decision-making of the Finnish government. Today it has changed its name to the Advisory Board for the Rights of Persons with Disabilities and has become the coordination mechanism of the Convention on the Rights of Persons with Disabilities (CRPD) (Article 33).

In 1987, the Disability Service Act replaced the decades-old Social Welfare for the Invalids Act (Leppälä, 2016). The new act included solutions concerning transportation, interpretation, adjustment training, sheltered housing, assistive technologies and personal assistance. In Finland, many persons with disabilities consider that the Disability Service Act was the beginning of the construction of the Finnish Welfare State for persons with disabilities. At the same time, the conception of disability as a minority status with citizenship became more common in Finland.

Everything went well in the beginning, but the economic depression put a stop to beneficial developments in 1991. The depression created a general “consciousness of crisis” that made even the most radical cuts and savings acceptable and easy to realize without significant political resistance (Simola et al., 2017). For this reason, the process of constructing the Welfare State from the viewpoint of persons with disabilities remained unfinished, and the 1990s was a decade of significant cuts and savings regarding disability services.

During the 2000s and 2010s, the Finnish understanding of disability essentially transformed from a socio-political problem to a human rights issue. Politicians as well as local authorities have gradually accepted that the fulfilment of disabled people’s rights requires the removal of obstacles and discriminatory practices. The United Nations Convention on the Rights of Persons with Disabilities (2006), which came *into force* in Finland in 2016, has speeded up this development.

There have also been some other concrete improvements in the 2000s and 2010s. The Finnish disability movement succeeded in gaining subjective rights and persons with severe disabilities became entitled to personal assistants through an amendment of the aforementioned Disability Service Law in 2009. Similarly, the Sign Language Act was enacted in 2015 to promote opportunities for sign language users to use their mother tongue.

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, Valkama and Kröger, 2019). In 1995, 3,699 persons with disabilities still lived in institutions, while by 2021, the number had decreased steadily to 403 (Sotkanet, 2023). More and more persons with intellectual disabilities are in communities but often in group homes with the support of disability services. The statistical trend presents a promising picture of the deinstitutionalization process in Finland. The ratification of CRPD in 2016 has accelerated the ongoing efforts in several municipalities, which in practice are the main actors to implement deinstitutionalization.

In 2020–2021, the system of personal budgeting is still in its piloting phase in Finland (THL, 2020). Personal budgeting is a participatory approach in arranging social and health services for persons with disabilities. They will have the freedom to choose between services. In principle, this is in line with the politics of disability rights. However, the other side of the coin is that this will increase the marketization of disability services (Eriksson, 2014).

Over the last few governments, Finland has undergone a social and health service reform (SOTE reform). The five key objectives of the future SOTE centres programme are:

- 1 To improve equal access to, timing and continuity of services
- 2 To shift the focus of activities from heavy services to preventive and proactive work
- 3 To improve service quality and effectiveness
- 4 To ensure the multidisciplinary and interoperable nature of services
- 5 To curb the growth of expenditure.

The first county election that will affect this reform took place in early 2023, after which the new Disability Service Act will enter into force in January 2025. The SOTE reform is significant for the disability sector because it encompasses the revision of the Disability Service Act. The two existing acts, the Disability Services Act 380/1987 and the Act on Special Care for People with Intellectual Disabilities 519/1977, will merge into one act. This revised act is expected to ensure disability services based on individual support needs beyond impairment categories (Katsui, Kröger and Valkama, 2018). We are at the crossroads. We need in particular to pay close attention to the aforementioned fifth goal so that self-determination rights will not be compromised, and equal opportunities for persons with disabilities are

provided. This book will present timely and critical arguments at this conjunction of change with the following structure after this Introduction chapter. The book starts by focusing on the experiences of persons with disabilities, which leads the readers to the core of the book's theme. Subsequently, the book chapters are dedicated to studies investigating environmental and contextual barriers against equal opportunities for persons with disabilities. The book then introduces three papers on activism and advocacy that include internationally new modalities to aim for transformation.

The authors and contents of the book

The book is divided into three sections on (I) living with disability, (II) disabling barriers and public policies and (III) activism and advocacy as listed below:

- I Living with disability
 - 1 The sense of difference: disability and loneliness as emotional and social isolation
 - 2 “Disability is so invisible at the University” – Disability Inclusion/Exclusion Experiences of Students with Disabilities at the University of Helsinki
 - 3 Being independently dependent: Experiences at the intersection of disability and old age in Finland
 - 4 One step backwards? Exploring the outcomes of the COVID-19 pandemic for persons with intellectual disabilities in supported and service housing
- II Disabling barriers and public policies
 - 5 The state of inclusion in the state of inclusion? Inclusion as principled practice in Finnish basic education
 - 6 Media representations of disability
 - 7 Balancing universal rights and individual needs when organizing disability services
 - 8 Employment, the Finnish disability pension system and self-determination of people with intellectual and developmental disabilities
 - 9 The happiness of having a hobby: inclusion of persons with disabilities in leisure activities
- III Activism and advocacy
 - 10 Spiral of progress: disability activists' perception of the societal and political position of disabled people in Finland
 - 11 Truth and Reconciliation Process of Deaf People and the Sign Language Community in Finland
 - 12 Examining cooperation-based advocacy between government and disability activists in transnational advocacy networks

Even though the thematic areas are diverse, we identify similar challenges against persons with disabilities in different contexts. Based on the chapters

with practical examples, including those that deal with policy implications and the grassroots level, assumed normalcy is reflected upon and discussed. Hence, we are contributing to the theorizing and demystifying of Finnish society by means of the new and critical perspective of disability with rich empirical data.

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1 The sense of difference

Disability and loneliness as emotional and social isolation

Merja Tarvainen

Introduction

Loneliness has been studied widely in Finland, but studies on loneliness and disability have been somewhat scarce, especially lived experiences among people with disabilities. Self-narratives about loneliness, for example, have remained rather unexplored, and qualitative aspects of loneliness and disability are relatively understudied. Additionally, studies that problematise the relationship between disability and loneliness are still missing (Tarvainen 2021). This study acknowledges loneliness as both social and emotional isolation (e.g., Weiss 1973; Rokach 2004; Tiilikainen 2019) in relation to the available conditions of belonging (e.g., Sønderby 2013; Shiovitz-Ezra, Shemesh, and McDonnell-Naughton 2018; Burholt, Windle, and Morgan 2017; Tiilikainen 2019; Rokach 2019, 1–20). By using the model of narrative circulation (MNC) (Hänninen 1999, 2004) as its methodological point of departure, the study investigates loneliness and disability in Finland through three different data sets that are available for research use at the Finnish Social Science Data Archive (FSD). The research question is as follows: How do the narrators disclose the relationship between loneliness and disability?¹

Loneliness may touch everyone potentially at times, but the conditions of loneliness are not equal for all (e.g., Rokach 2019, xii–xiii; Burholt, Windle, and Morgan 2017; Parsons and Platt 2020; Jones 2013). Juho Saari (2016, 9), who has widely studied loneliness in Finland, notes that Eurostat surveys and World Happiness Reports have shown Finland as the happiest country in the world, as measures of quality of life as well as social cohesion and trust among citizens and between citizens and the state are high. However, these statistics and surveys do not reveal the distinctions between different groups of people or their subjective experiences. As a result, experiences of loneliness need to be studied further (Saari 2016). Even though loneliness has been extensively studied in Finland during the 21st century (see, e.g., Saari 2016, 20–25; Tiilikainen 2019), qualitative studies on loneliness and disability are still rare (see Tarvainen 2021).

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Structural inequalities feed loneliness (Saari 2016; see also Tiilikainen 2019, 192). These inequalities have recently been addressed in loneliness studies (e.g., Shiovitz-Ezra, Shemesh, and McDonnell-Naughton 2018; Tiilikainen 2019) and have been connected to disability (Tarvainen 2021). Loneliness has many faces, but loneliness stemming from structural inequalities can have negative consequences for identity and agency (e.g., Saari 2016; see also Jones 2013; Burholt, Windle, and Morgan 2017). Disability studies have recognised that such phenomena as regards to disability are usually linked with ableism, which treats disability as unwanted (bodily) difference (Campbell 2009; Garland-Thomson 2002, 2009). People with disabilities tend to internalise ableist sentiments into their own life story (Campbell 2009, 16–29; Tarvainen 2019). According to Saari (2016), internalised structural inequalities tend to have negative consequences for health and well-being.

Recently, the COVID-19 pandemic had revealed various inequalities: some of them relate to the given conditions, but they may illustrate also experiences that are shared under different times. According to a survey focused on users of personal assistance service in Finland, for instance, the challenging times caused by the pandemic have increased feelings of loneliness (Nurmi-Koikkalainen, Korhonen, and Väre 2021, 8). The survey also revealed that people who live alone reported more feelings of loneliness (Nurmi-Koikkalainen, Korhonen, and Väre 2021, 5). Desired but unfulfilled social relationships are one source of experiencing loneliness and social isolation. Additionally, attitudinal barriers as regards to disability can cause loneliness (Tuokkola and Katsui 2018, 21; see also Tarvainen 2021). Kati Tuokkola and Hisayo Katsui (2018) studied deinstitutionalisation in Finland and noticed that social distance, including negative attitudes and prejudices, can lead to loneliness among people with intellectual disabilities and thus hamper real inclusion (Tuokkola and Katsui 2018, 21, 36, *passim*).

Studies on loneliness have been widely conducted in psychology (see Saari 2016) and also the social science (see, e.g., Sønderby 2013; Rokach 2004) both in Finland and elsewhere. Studies on loneliness and disability have increased during the past years; they have been investigated recently as regards to the following aspects: social support and well-being in working-age adults (Emerson et al. 2021b), health (Emerson et al. 2021a), the life course (Tarvainen 2021), everyday exclusion (Olsen 2018) and disabling barriers that feed social isolation and emotional loneliness (Macdonald et al. 2018). This study investigates disability and loneliness as emotional and social isolation.

The next section introduces this study's approach to loneliness as social and emotional isolation. The methodological premises and practices of the study are then discussed, followed by the findings and a discussion concerning loneliness and sense of difference in social and emotional configurations. Finally, the chapter concludes with some closing remarks on disability and loneliness as emotional and social isolation.

Loneliness and disability in social and emotional configurations

Loneliness may be approached with different theoretical underpinnings that may emphasise different points, for instance, existential, interactional, individual aspects or structural aspects (see Perlman and Peplau 1982; Sønderyb 2013). Loneliness differs from solitude: loneliness refers to not being appreciated in social and emotional configurations, while solitude is being alone but not feeling lonely (e.g., Weiss 1973; Rokach 2004, 29–31; Stauffer 2015; Tiilikainen 2019).

One of the well-established outlooks is to approach loneliness by distinguishing emotional and social isolation (e.g., Weiss 1973; Rokach 2004). This analytical distinction helps to understand subtle signs of loneliness, and its consequences even though social and emotional aspects tend to be intertwined in practice. Robert S. Weiss (1973) takes the example of childhood and argues that emotional isolation is like a child's longing for their parent, while social isolation is feeling disconnected from peers (see also Tiilikainen 2019; Rokach 2004). In sum, emotional isolation is about longing for a meaningful other, and social isolation concerns disconnectedness from desired social relationships. Together, emotional isolation and social isolation are linked with the sense of belonging as well as the conditions of belonging (e.g., Burholt, Windle, and Morgan 2017; Sønderyb 2013; Morrison and Smith 2018, 20–21; Rokach 2019, 1–20). According to Ami Rokach (2019, 1), the sense of belonging as 'being part of the larger community and having a special someone who cares deeply about us' is fundamental. Such a definition summarises the conditions against which both emotional isolation and social isolation are interpreted: to be without someone close (emotional isolation) and to be socially excluded (social isolation). Social connectedness is built through shared values and respect (Rokach 2019, 3–5), whereas ableism causes disability to be seen as unwanted (bodily) difference (Campbell 2009), which affects the conditions of belonging in many ways.

Conditions of belonging have begun to be discussed in the recent research on loneliness and disability (Tarvainen 2021; Emerson et al. 2021a–b) and in wider loneliness studies (e.g., Rokach 2019, 1–20; Tiilikainen 2019; Sønderyb 2013; Shiovitz-Ezra, Shemesh, and McDonnell-Naughton 2018). Moreover, loneliness is about both social relationships and 'group expectations', which affect how social relationships are or may be built (Morrison and Smith 2018, 20; see also McNay 2008). Social and emotional configurations affect us, as the conditions of belonging are influenced through social and emotional configurations (Burkitt 2014; Stauffer 2015, 2, 4; Hviid Jacobsen 2019, 3). Emotions matter at both the individual and structural levels (Hviid Jacobsen 2019, 3; see also Burkitt 2014). Yet emotions are experienced through everyday life (e.g., Hviid Jacobsen 2019; Misztal 2019).

Moreover, loneliness may be hard to verbalise and may even be considered a stigma (e.g., Rokach 2012, 2019). The available narrative conditions make

stories of loneliness and disability difficult to tell and receive (Tarvainen 2021). Therefore, the conditions of living and telling need to be appreciated in order to approach lived experiences of loneliness and disability. Loneliness among people with disabilities is not a uniform but a multifaceted phenomenon that is linked with conditions of belonging in society as well as an individual's personal path through their life course (Tarvainen 2021). By drawing on loneliness studies that consider loneliness as emotional and social isolation as well as focusing on the conditions of belonging, this chapter explores disability in relation to emotional and social isolation.

Data and method: Stories of loneliness and disability in Finland

The methodological basis of this study is the MNC proposed by Vilma Hänninen (1999, 2004). According to the MNC, people construct their 'inner story' for themselves and share 'told stories' with others in relation to the cultural stock of stories, which provides resources to interpret events. Yet the cultural stock of stories is remodified through the storytelling. Additionally, the MNC appreciates a 'lived story', which refers to living in relation to the available material and discursive conditions (Hänninen 1999; 2004). Some stories are more feasible to tell than others (Smith and Sparkes 2008). Disability narratives are dominated by ableist narratives that people have to negotiate with as they narrate disability. Such oppressive but dominant narratives can be resisted, but people have few narrative resources when discussing disability (Tarvainen 2019).

This study's data were collected through three different data sets available for research use at the FSD. The first data set is FSD3066 Support Networks of Families with Special Needs Children 2014, in which four families were interviewed. A mother was interviewed in three cases, and in the fourth, both a mother and a father participated in the interview (Nysted 2015). The interviewed parents' ages were between 40 and 69 at the time of the interview (Nysted 2015). The data were collected for the interviewer's master thesis (FSD3066 n.d.). According to the available information, the sampling method was 'non-probability: purposive' (FSD3066 n.d), because the interviewer knew one interviewed family prior to the interview, and the other interviewees were found through 'snowball sampling', i.e., someone informed the interviewer about other possible interviewees (FSD3066 n.d.).

The second data set, FSD2512 Daily Life and Autonomy of Disabled People 2007, consists of 25 interviews of people with disabilities (Eriksson 2010). The interviews are available as transcriptions. The data were collected in 'various residential care units around Finland' that were informed prior to this by an email (FSD2512 n.d.). According to the available information, the interviews were conducted in the units that responded to the call (FSD2512 n.d.). The third data set, FSD3040 Life of Disabled Persons in Finland 2013–2014, comprises 11 written life story texts (Finnish Literature Society (SKS)

and Threshold Association: Life of Disabled Persons in Finland 2013–2014, from here on SKS and Kynnys 2017). The call was made available on the SKS website and was circulated through its respondent network and disability policy organisations as well as other relevant voluntary organisations (FSD3040 n.d.). The selection of the participants was based upon their availability (FSD3040 n.d.; FSD2512 n.d.) and willingness to participate in the given study. The SKS and Kynnys (2017) data are part of a larger data set, which is archived in the SKS archive (see, e.g., Tarvainen 2021; 2019). This smaller part is available through the FSD. In this study, I have used only the data set that is available at the FSD. All but one of the accounts in the data sets were in Finnish. I translated the other accounts from Finnish to English. I reference the data in accordance with the FSD guidelines.

I read the data carefully several times. Then I focused more precisely on the accounts of loneliness: explicit expressions of loneliness, emotional and social isolation. I summarised all accounts in which loneliness was discussed. Loneliness was discussed in all (four) interviews in the Support Networks of Families with Special Needs Children 2014 data set (Nysted 2015). In the Daily Life and Autonomy of Disabled People 2007 data set (Eriksson 2010), 16 of the 25 participants discussed loneliness. In that data set, information about participants' age was not available in any case, but as it was, it was mostly around 40 regarding these 16 of 25 participants but ranged from 20 to around 60 at the time of interview. Eight of these narrators identified as female and eight as male (Eriksson 2010). Additionally, nine narrators wrote about emotional and social isolation in the SKS and Kynnys (2017) life story collection. In this corpus, information about participants' age or gender was not available in any case, but as it was, the range varied from around 20 to around 55 at the time of participation. All these 9 of 11 narrators in the life story corpus were female. In sum, 29 of 40 participants discussed social and emotional isolation, even though loneliness was not a main theme in the data collections. However, the participants discussed both social and emotional isolation in every data set. Social support was also a theme in both interview data sets (Nysted 2015; Eriksson 2010).

I soon realised that the accounts of loneliness resonated with the available narrative resources of loneliness. Loneliness was depicted as emotional and social isolation. In almost every account, loneliness was narrated in relation to disability but not in all, which reminds us that not all experiences of loneliness among people with disabilities necessarily link with disability. I began to organise the accounts and realised that they resonated with the available cultural narrative resources of loneliness as emotional and social isolation. Yet the conditions of belonging were also discussed. Therefore, I acknowledged emotional and social isolation as the available narrative resources. I read the accounts by employing thematic narrative analysis to examine loneliness through different data sets (Riessman 2008, 53–76). I first located the key thematic elements in each account. They discussed not only emotional and social isolation but also the conditions of (un)belonging. I read every account

and all accounts together in relation to the MNC; I considered the available narrative resources and the conditions of living with and telling about loneliness and disability. The aim was to understand each account individually and together with others as regards to the narrative circulation.

The accounts were in a dialogue with the existing resources of narrativising loneliness in relation to disability. However, the accounts also revealed how loneliness and disability were entwined in a 'lived story' (Hänninen 1999: 2004) in everyday life as regards to social relations as well as material and discursive conditions. Moreover, the accounts of emotional and social isolation revealed experiences of disability as unwanted difference and discussed conditions of (un)belonging. The main themes related to experiences of difference regarding close emotional attachment, mainly in the childhood family, and differences regarding social relationships.

Disability and loneliness as emotional and social isolation

Emotional isolation: Relational shame and emotional detachment

'There was nobody in the family, nobody that I could trust on and turn to' (SKS and Kynnys 2017, 05), a participant of the life story collection wrote. Other participants shared similar experiences. Emotional isolation was narrated as detachment from a meaningful other or a lack of emotionally meaningful relationship.

In many cases, a key experience of loneliness as emotional isolation was located in childhood. Many participants discussed loneliness in terms of unwanted separation from their family. Parents of children with disabilities, for instance, thought about separation of children with disabilities from their parents and family when they were in the hospital (Nysted 2015, 1 and 2), for instance, as follows: 'Those little ones on their own there, and the nurses did not have time to stay with them...' (Nysted 2015, 2). One participant of the life story collection shared a somewhat similar experience but from a different perspective: 'I do not remember anything about my time in the hospital'. The narrator continued that the hospital personnel did not want 'parents or other relatives visit there so to avoid the pain of separation' (SKS and Kynnys 2017, 09). In this latter case, the reasoning was based on avoiding the expected pain of separation. However, in many cases, loneliness among children or in relation to childhood was discussed as emotional isolation from meaningful people in their lives. Experiencing loneliness at a hospital or at another institution for children was talked about in several accounts. Loneliness was experienced as longing for family members and for their home. A narrator who had to spend time in a hospital discussed the following: 'I was deeply homesick and I used to just stay still and look out the window' (SKS and Kynnys 2017, 10). A mother of a child with a disability explained that situations in which a child with disabilities has to move from home to another place can be emotionally demanding: 'I guess a [child] with

disabilities may suffer from such situations, as it fosters a sense that nobody cares about him or her' (Nysted 2015, 4).

Some participants discussed emotional isolation that they felt as the result of unwanted separation from their family as a child. One participant from the life story data revealed that she participated in a camp for children with disabilities. She enjoyed the stay even though she felt the camp's duration was too long for a little child 'to be separated from her family' (SKS and Kynnys 2017, 05). She recalled how 'nobody came to see me' (SKS and Kynnys 2017, 05), and she was told that her family would come, but they did not and she 'cried bitterly' (SKS and Kynnys 2017, 05). Afterwards, she was told that her parent was not able to 'see all those children with disabilities as her own child was one of them' (SKS and Kynnys 2017, 05). The account emphasises isolation regarding both family separation and emotional detachment, as illustrated in a case of the cancelled visit.

Another female participant explained how her family became 'tense' and even 'exhausted' due to her disability when she was young (SKS and Kynnys 2017, 01). Disability is interpreted here as a relational matter that affects social and emotional relationships in a family. A mother discussed siblings of children with disabilities' point of view and how they 'may experience these things ... feelings of shame or things like that' (Nysted 2015, 4). Shame or more precisely relational shame regarding disability was discussed in many other accounts.

Another narrator disclosed how she felt ashamed due to her 'difference', and she thought that her mother 'was even more ashamed due to my disabledness and joint impact of [shame] cast a shadow over my life all the time' (SKS and Kynnys 2017, 05). The narrator discussed she sometimes felt her mother 'was unable to love her': 'Sometimes I felt she really hated me, but maybe she felt guilty and that made her bitter' (SKS and Kynnys 2017, 05).

In this case, the narrator felt that her parent 'was not able to love her' because of the feelings of guilt and bitterness she had, which the daughter felt originated from her disability.

In some accounts, emotional isolation did not explicitly relate to disability. Another participant in the life story data told about how her parents had died when she was somewhat young: 'I was so deeply lonely. ... [A person] said kind words to me about my mother, but it could not heal my longing' (SKS and Kynnys 2017, 07). An older male interviewee spoke about the loneliness he felt after his mother passed away: 'Your mother was an important person for you?', the interviewer asks, and he responds briefly: 'Yes, indeed' (Eriksson 2010, 22). Emotional isolation may concern the loss of a meaningful other that is not necessarily linked with disability. All experiences of loneliness in a life course of people with disabilities do not necessarily relate to their specific disability.

Additionally, emotional isolation is also experienced among adults regarding longing for a meaningful other and close emotional attachment. A male participant from the interview data shared the following:

I have never had a [close] relationship. I do not think that I would have, but I never had ... I wish I would find, find a person, to be friends with [at least], but ... it would be nice to live with someone.

(Eriksson 2010, 05)

Some participants reflected upon the term a ‘person with disabilities’ and argued that disability is often seen as ‘incompleteness’ (e.g., SKS and Kynnys 2017, 07), as something that is not ‘normal’. One of the narrators expressed their feelings about this topic through a poem, wherein they describe disability as ‘incompleteness’:

an incomplete person, often overlooked; s/he feels but is not seen. The heart goes on, it still believes, everything, even as a weak, angry ... Painful moments, evil words. Love? Does it exist at all?

(SKS and Kynnys 2017, 06)

The poem shows how disability is considered unwanted difference and interpreted against ‘normal’ (see also, e.g., Ahlvik-Harju 2016): incompleteness that is constructed in social and emotional configurations. The poem continues and concludes as follows: ‘the best thing is a loving family. Many friends, happy moments too. I have feelings, even though [I am considered] incomplete’ (SKS and Kynnys 2017, 06).

In some cases, emotional isolation and social isolation were entwined in practice, and life seemed lonely. A young male participant discussed his contradictory experiences of loneliness: ‘I am always so lonely ... I am used to be lonely ... all of my life’ (Eriksson 2010, 21). However, he did have friends all around Finland but felt ‘sorry’ that he had ‘not visited them any longer’ (Eriksson 2010, 21). Another interviewee touched on the same topic: ‘I have learnt to live a lonely life’ (Eriksson 2010, 03). Not only does emotional isolation shape experiences of loneliness but so too does social isolation.

Social isolation: An experience of difference in ableist terms

In the data, social isolation was discussed regarding different life events, but peer-relationships in childhood and youth were mentioned in many cases. School greatly affects children’s lives (Rokach 2019, 144). In these accounts, social isolation was disclosed as regards to school, friendships and other social relationships. Additionally, social isolation was mentioned regarding experiences of difference, especially regarding being stared at in social situations (see also Garland-Thomson 2002).

When I was a small kid, I went to a playschool, I was among able-bodied peers, but just one accepted me as I was, others did not. ... It was because of my difference. ... I was bullied because of it [difference]. ... When I

started comprehensive school, the feeling of difference became somewhat more established: I felt that I was different from other able-bodied people. (Eriksson 2010, 05)

In this account, the participant tells about the lived social exclusion, and bullying, they experienced at school among peers (see also Rokach 2004) due to their disability. Another participant added the following about being treated differently: ‘I hated my prosthesis when I was a youth ... I did not want to have it and be different from other people’ (SKS and Kynnys 2017, 05). Many narrators discussed their disability in relation to the difference linked to social and emotional configurations. In many cases, a sense of difference was an embodied experience of loneliness. As one participant explained: ‘When I was young, I felt that people stared at me because I limped strongly; sometimes it troubled me. They may have felt sorry for me, too’ (SKS and Kynnys 2017, 09). The participant tied her experience of difference to her disability in her youth and told that as an adult, she has not faced such things. As young people construct their identity, the existing attitudes on disability strongly affect them. Additionally, people ‘stared at her’, and she received unwanted social attention due to her body.

Some participants reflected the experience of being different and its lived meaning in depth:

People with disabilities as well as older people exist on margins of society, not as an integral part. You face rough, even offensive behaviour and receive inappropriate support. As regards to [health care and social] services, these people do not meet a client-driven approach but patronising treatment. People talk to us as if they were speaking to a child (SKS and Kynnys 2017, 07)

A middle-aged participant said that some decades ago she felt that people with disabilities were treated as ‘second-class citizens’ (Eriksson 2010, 01). Similarly, another participant said that in the past, she had to deal with attitudinal barriers that prevented her from participating in different events. She thought that ‘upbringing’ affects us and our attitudes (Eriksson 2010, 03). However, some participants reported that things had not changed at all: ‘... if you think about nowadays, I would say that it is second class, considering minor, more like insignificant and those able-bodied, those are highlighted’ (Eriksson 2010, 19). According to the participant, people with disabilities are still treated as second-class citizens against the able-bodied ideal.

Additionally, participants also discussed their experiences of social isolation regarding acquired disability. One participant told that she had lost all of her social relationships since she acquired her disability: ‘Friendships and other social relationships broke down after the [accident]’ (SKS and Kynnys 2017, 08). This participant did not explain why these social relationships

broke down specifically; however, she did believe it had something to do with her acquired disability.

Some of the participants said they had resisted social isolation, but feelings of being different still bothered them sometimes. Some parents of children with disabilities, for instance, disclosed that they had consciously resisted social isolation in relation to disability. As one mother shared: '[W]e have not given any space for social isolation. We are somewhat active people. We move, and we go everywhere' (Nysted 2015, 2). Such experiences reveal how disability is considered something that can at least potentially lead to being socially isolated from social relationships and environments.

One mother said that her family lived an active life and participated in different activities in society. However, she continued:

I don't know whether it makes sense to say ... Some people are staring at [us], adults, children are staring at us. ... Some may want to glimpse in order to know, but well, adults stare how [her child] walks

(Nysted 2015, 2)

Being stared at is an experience that was shared in data sets. One participant mentioned that she felt shame and being different in her childhood. She would hide 'under the table' or 'stayed still without taking a step' when somebody visited her family when she was a child (SKS and Kynnys 2017, 05).

A mother of a child with a disability discussed feeling like an outsider: '... you diminish yourself in such situations' (Nysted 2015, 3). Interviews of parents of children with disabilities revealed that they felt disconnected from social relationships: '[If] we as parents ... have to go somewhere ... one of us ... [goes, and] the other stays at home' (Nysted 2015, 1). Moreover, social support from others may be hard to receive in some cases, as one of the participants discussed it is difficult to make friends with Finns and that is 'the problem here ...' (Nysted 2015, 1). Another parent said the following:

Normality totally disappeared. I really do not know whether it was about [disability] or my own wish... to isolate socially, but we could not access anything with [our child].

(Nysted 2015, 4)

The mother discussed how her sense of 'normal' disappeared but was not sure whether it was due to disability or her own wish to isolate from her social contacts; soon she realised her 'only' friends were 'families with disabled persons' (Nysted 2015, 4). Others reported something similar: '... Yes, friends are mostly somehow connected with intellectual disability. Or at least I feel so' (Eriksson 2010, 13). Moreover, sharing lived experiences in everyday life and having even some 'routines together' (Nysted 2015, 1) were considered meaningful social interaction, but they were not easy to find. Experiences of social isolation reflected the lived sense of difference due to ableism.

Discussion: Loneliness and feeling different in social and emotional configurations

This chapter aimed to explore disability and loneliness as emotional and social isolation. More precisely, the aim was to explore how the participants discussed the relationship between loneliness and disability. By drawing on loneliness studies that consider loneliness as emotional and social isolation as well as focusing on the conditions of belonging, this chapter explored disability in relation to emotional and social isolation.

Participants understood loneliness as emotional and social isolation. Emotional isolation was narrated as a sense of detachment and shame. Most but not all the experiences of emotional isolation were about childhood and involved situations in which children with disabilities were separated from their family or sensed emotional detachment in their family relationships (see also Jones 2013; Margalit 2010, 284; Rokach 2004). Emotional isolation was also understood relationally and discussed as relating to shame, which hampered emotional attachment (see also Rokach 2004). However, all experiences of emotional isolation were not connected with disability. The loneliness experienced by people with disabilities does not always stem from their disability. Additionally, loneliness was understood as a longing for personal and emotionally meaningful relationship as an adult (Rokach 2004, 2019). Accounts of emotional isolation disclosed shame and longing for love – to be loved and to be recognised by a meaningful other (see also Rokach 2004, 34–45). Feeling different was narrated as the link between loneliness and disability.

Correspondingly, experiences of difference were key points as regards to social isolation, which was narrated as the sense of being socially ‘different’ due to disability. It was revealed as unwanted social attention, for instance, in which a disabled person’s body was stared at and considered ‘different’. Such staring differs from common ways of looking at somebody in social conditions (Garland-Thomson 2002, 56; 2009). It instead relates to ableist practice and performance, in which disability is considered unwanted bodily difference (Garland-Thomson 2002, 57, *passim*). Additionally, this study illustrated how the disability of a family member affected not only the individual but also the individual’s family in terms of society viewed them. Many participants discussed shame as a relational matter in the given social and emotional configurations. Loneliness as social and emotional isolation was related to disabling conditions of living and telling (see also Jones 2013). Narratives are crucial to understand both the ‘performance’ of agency and the interplay between agency and structural conditions (e.g., McNay 2008, 96–125, *passim*; Tarvainen 2019).

Profound, long-lasting loneliness diminishes agency. Loneliness is experienced in relation to time (e.g., Tiilikainen 2019; Rokach 2004), and through the life course, it can be situational or more long-lasting (Tiilikainen 2019, 17–30). Experiencing loneliness through the whole life course is rare,

but those feelings resonate in other situations (e.g., Tiilikainen 2019). As Jill Stauffer (2015, 2) argues, it ‘may be devastating’ for a young person to feel like an outsider, but if the person has ‘aged well’, they may restory and reinterpret these biographical events. From a narrative perspective, such restorying may offer new outlooks to interpret events in a life course. Sharing one’s story is a means of interconnecting with others. Sharing a story demands both telling and receiving the story, which calls for adequate resources to do both (Tarvainen 2019; Smith and Sparkes 2008). Inadequate narrative resources may limit people’s opportunities to access the circulation of narratives, share their stories as they want and thus to be recognised in the circulation of narratives (see also Stauffer 2015; Tarvainen 2019). Additionally, this reveals an interplay of structural inequalities regarding loneliness from a narrative perspective. If narrative resources and the access to shared circulation of narratives are inaccessible and inadequate, it deeply affects the conditions of living and telling (see also Stauffer 2015, 1–2, *passim*).

Many narrators disclosed their experiences about being stared at. Staring is seen as an act of othering (see also Jones 2013). Disability as unwanted bodily difference was discussed in the accounts of emotional and social isolation. Social isolation was about being stared at in social relationships and environments, and emotional isolation was about not being seen as a person (see also Misztal 2019; Jones 2013), which is linked with recognition. We need to be seen by others in order to be recognised but being stared at feeds a sense of difference (Garland-Thomson 2009; McNay 2008). Additionally, the sense of difference due to disabling conditions, prejudices and other socially generated issues was experienced as a relational matter in the family narratives (see also Jones 2013).

Emotions affect conditions of belonging (Burkitt 2014, 168, *passim*). Moreover, being unrecognised in emotional and social configurations can make someone feel that their dignity has been overlooked (Misztal 2019, 51–54; see also Ahlvik-Harju 2016, 71–84). In these data sets, the participants narrated about feeling as if they were ‘second-class citizens’ because of their disability. Barbara A. Misztal (2019, 43–44) argues that emotions matter as regards to ‘the usage of human dignity as a principle in everyday life to indicate a certain type of treatment’. From a classic sociological point of view, dignity in practice concerns both discursive and material conditions, and in many cases of everyday life, dignity is discussed in relation to ‘respect, recognition and human rights’ (Misztal 2019, 47–48; see also Ahlvik-Harju 2016).

Altogether, accounts of disability and emotional and social isolation discussed disability in relation to the available ableist narrative, which affects the conditions of living and telling. Structural inequalities, especially internalised ones, tend to cause feelings of loneliness, especially as social isolation (see also, e.g., Saari 2016). Some participants chose to resist these oppressive conditions. Additionally, the cultural stock of stories provides still somewhat limited resources for discussing the relationship between disability and loneliness (see also Tarvainen 2021). This creates a paradox as

more information is needed in order to critically scrutinise loneliness and disability. Since ableist narratives on disability dominate in the circulation of narratives, the conditions of living and telling disability are inaccessible, incomplete and oppressive. Moreover, all experiences of loneliness in the life course of people with disabilities are not linked with disability. Loneliness may occur in many ways in a life course of people with disabilities; this calls for further studies as regards to loneliness and disability in the life course.

Similar experiences about loneliness and disability were shared in all the data sets. Yet, the data sets draw on different time periods, which may be both a strength and a limitation. By focusing on a fixed time-bound period, experiences can be looked at in greater depth. However, as similar experiences were told through different data sets as regards to different time periods, it signals responses to disability in social and emotional configurations in different times. All the data sets were collected during the 21st century, and thus, the moment of telling is important to notice regarding sense-making about disability in society (see Tarvainen 2019). Moreover, there are not much available qualitative data about loneliness and disability. Other conditions of belonging as well as family relationships and the meaning of a family regarding experiences of loneliness and disability need further studying (see also Rokach 2019, 143–145).

Additionally, it needs to be appreciated that disability and loneliness are not easy to narrate, as both may bear a social stigma, and together they may be interpreted in a stigmatising framework (see Tarvainen 2021). Therefore, it is important to note that loneliness as social and emotional isolation was discussed in all the data sets even though it was not the main theme of data collection. Moreover, it is crucial to re-construct the cultural stock of stories regarding loneliness and disability. It matters for the critical scrutiny of the available narratives of disability and loneliness that diverse stories about loneliness and disability enter the circulation.

Conclusion

This study suggests that narrative accessibility matters for understanding the complex configurations of disability and loneliness. Further studies on disability and loneliness with various methodological approaches are much needed (see also, e.g., Tarvainen 2021; Teittinen 2015; Emerson et al. 2021a). As loneliness is also a political matter (e.g., Saari 2016), it needs to be further studied as regards to disability.

This study explored disability and loneliness as emotional and social isolation. The relationship between disability and loneliness is complex and entails different aspects in social relations and individual life trajectories (see also Tarvainen 2021). Therefore, more empirical studies focusing specifically on disability in relation to the life course, conditions of belonging and social relationships are needed.

Note

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2 ‘Disability is so invisible at the University’

Disability inclusion/exclusion experiences of students with disabilities at the University of Helsinki

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Introduction

In this chapter, we discuss the inclusion and exclusion experiences of students with disabilities in higher education. The chapter is linked to Chapter 5 dealing with inclusive education before higher education. Given the findings of the previous chapter, it is not surprising that reality is unfortunately far from equal for students with disabilities in higher education institutions.

Many studies and statistics have verified that the level of education of persons with disabilities is considerably lower than that of the rest of the population in Finland. For example, in 2019, the Social Insurance Institution of Finland (KELA) granted financial support for vocational rehabilitation to a total of 1455 higher education students with disabilities, which is about 1 per cent of all students studying at universities and polytechnics (Nori, Lyytinen, Juusola, Kohtamäki and Kivistö 2021: 13). However, in most statistics, the number of students with disabilities is significantly higher. The latest European Union Statistics on Income and Living Conditions (EU-SILC) statistics show clear differences between youths with and without disabilities in terms of whether they have completed tertiary or equivalent education (Figure 2.1).

The Finnish nation-wide representative Health 2011 survey data revealed that only 23 per cent of persons with limited functionalities had completed higher education, while the ratio of the respondents without functional defects was 40 per cent (Nurmi-Koikkalainen et al. 2017: 40). According to the latest registry of the Finnish Federation of the Visually Impaired, 21 per cent of persons with visual impairments have completed higher education in comparison with 34 per cent of the general population (Ojamo and Tolkkinen 2020: 14). This is a serious problem, because higher education is a matter of great importance to people with disabilities in terms of promoting their employment, social inclusion, and participation.

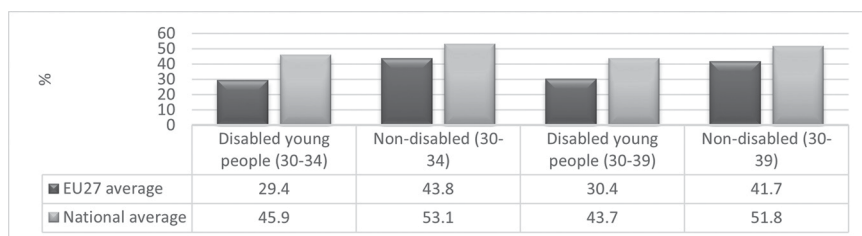


Figure 2.1 Completion of tertiary or equivalent education (aged 30–34 and 30–39).

Source: EU-SILC 2020 Released April 2022 cited in Katsui and Valkama (2023).

When we talk about inclusive education, we often only talk about it in the context of compulsory education (Vaahtera and Honkasilta 2022). In higher education, the belief that students who fit in are highly functional and competitive, which underpins neoliberalist ideology, has a negative impact on many students with disabilities, particularly on their mental health (da Silva Goncalves and Ikävalko 2022). Unfortunately, this is also the case in the Finnish context (Nieminen 2022a), in the so-called happiest country in the world. This chapter describes the experiences of students with disabilities in higher education using empirical data collected at the University of Helsinki.

The structure of the chapter is as follows: first, we introduce the theoretical framework through a literature review. Second, we present the methodological choices, followed by the study findings based on the empirical data. After this, we discuss the university environment using the key theoretical framework of crip theory and embodiment. We conclude that the underlying value on which the university is based makes it a disabling place.

Theoretical background – Crip theory and embodiment

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) has strongly affected how disability is understood in Finland (Finnish Institute for Health and Welfare, THL 2022). Article 24 of the UN CRPD with Disabilities declares the right of persons with disabilities to education without discrimination. Section 6 of the Constitution of Finland also states that no one, without an acceptable reason, shall be treated differently from other persons on the grounds of sex, age, origin, language, religion, conviction, opinion, health, disability, or other reason that concerns their person. It is worth noting that the prohibition of discrimination does not extend to positive discrimination, which is when particular groups of people are supported with special measures if, without them, they are at risk of falling into a less favourable position. The Non-Discrimination Act (1325/2014) makes the promotion of equality obligatory in education. The Act also

renders reasonable adjustments obligatory, and refusal of these is classed as discrimination.

In their survey study (N=1525 persons with disabilities) on the implementation of the CRPD, Vesala and Vartio (2018: 16) found that in terms of reasonable accommodation, 8 per cent of the persons with disabilities whom they studied encountered discrimination during the admission process, and 10.6 per cent during schooling. The same study found that 5 per cent encountered discrimination that violated their language and communication rights. A total of 11.3 per cent felt that poverty had disturbed their education (*ibid.*18). In addition, attitudes in society created significant barriers. As many as 26.9 per cent directly or indirectly felt that even their right to life was questioned (*ibid.*14). During the last two years, 15.4 per cent had experienced physical violence, 56.3 per cent psychological violence, 9.2 per cent sexual violence, and 24.8 per cent other kinds of harassment and violence (*ibid.*16). When these study findings are combined with insufficient personal assistant services (43.1 per cent) or transportation services (41.4 per cent), a lack of assistive devices (23.0 per cent) (*ibid.*19), and rehabilitation services (44.7 per cent) (*ibid.*20), equal opportunities for higher education among persons with disabilities are far from reality in Finland.

Many Finnish reports and the literature have discussed the reasons for this and shown different statistics. It has been pointed out that children and youths with disabilities are often advised to take work incapacity pension rather than continue to higher education (Heini and Klemetti 2018: 18; please see also Chapter 8). Accessibility varies greatly in higher education (Saavutettavuuskriteeristö 2019). The accessibility plan for higher education and higher education institutions is based on the Programme of Prime Minister Marin's Government. However, unlike other Nordic countries, Finland has not earmarked financial resources for accessibility to higher education. It is currently up to each institution to decide on its accessibility (Kyröläinen 2021: 8). Furthermore, in the Non-discrimination Ombudsman's study (2016), over 51.4 per cent of respondents claimed that attitudes towards persons with disabilities in general in Finland are poor or very poor. The same percentage, 51.4 per cent of respondents, reported that these attitudes were also poor or very poor in education institutions. The same study reported discrimination against persons with disabilities in Finland and revealed how higher education students with disabilities find it difficult to move on to employment. Those who experienced discrimination in moving from higher education to employment comprised 16.7 per cent, whereas the proportion of those who experienced it moving from secondary education to employment was 4.1 per cent. Sixty-two per cent of respondents had experienced discrimination in the last 12 months. However, only 40 per cent knew where to turn when they encountered discrimination. Consequently, only a minority of those who experienced discrimination made any claims. Moreover, 28.8 per cent of the respondents said that they did not believe anything would change even if they made a claim. These previous Finnish studies, however,

have lacked detailed empirical accounts of the experiences of discrimination, which is one of the aims of the current study.

A study conducted in 2018 identified the challenges faced by students with disabilities in higher education. These included unsuitable teaching methods, poor teaching quality, rigid teaching timeframes and assignments, and excessively demanding teaching (Lehto et al. 2019: 30). Many argued that lectures and courses were not planned properly to accommodate the needs of students with disabilities, including accessibility (ibid.34). Students with disabilities and those with learning difficulties have to use a great deal of their energy to arrange practical issues (such as disability services provided by the public sector – e.g., personal assistants and transportation), which leaves less resources for them to concentrate on their studies. At present, many have to deal alone with their difficulties in managing practical arrangements as well as their studies. Accessibility requires knowledge, capacity, and financial resources, but even just an open attitude towards accommodating different needs would bring about huge changes (Lehto et al. 2019: 161). Nieminen (2022b) similarly argues that university, especially its exams and assessments, is predominantly designed for ‘the ideal, able student’, which makes students with various disabilities see themselves through medical categories, as marginalized, and as others.

Against these general background conditions in Finnish universities, in 2022, the University of Helsinki launched a thematic year of Disability Inclusion and a new strategic plan for 2021–2030 (University of Helsinki 2021). Inclusivity is claimed to be one of the four core values and foundations of our University. However, according to the survey on equality conducted by the University’s student union in the spring of 2021, as many as 9 per cent of the respondents answered that equality in the University was ‘very poor’ (2 per cent) or ‘poor’ (7 per cent) (Niemi 2021). To the question, ‘Which aspect does the University need to pay particular attention to?’, accessibility (saavutettavuus/esteettömyys) was the most frequent (40 per cent) out of the responses related to diverse aspects of equality and diversity. The latest *Diskurssi* magazine for University students majoring in social research discusses this very issue and explains how the needs of students with disabilities are undermined by many kinds of structural barriers (Ilmola and Lindström 2021). This chapter elaborates on the experiences of students with disabilities at the University of Helsinki through three research methods.

Our study is theoretically oriented towards critical disability studies, which understands disability as something beyond the so-called social model of disability and as interaction between the person with disabilities and the wider context (see, e.g., Goodley 2013; Shakespeare 2018). We are particularly interested in crip theory (McRuer 2006), according to which McRuer (2006: 57) argues that disability is ‘On me, not in me’, that is

ways of seeing, questions about when and where looking inside the body works in tandem with the relations of looking shaped by global movements

for social and economic justice and when and where looking inside the body works against those relations.

(McRuer 2006: 41–42)

McRuer (2006) calls this *crip theory*. The *crip experience* is when experiences deviate from socially constructed norms, namely the experiences of people without a disability. He argues that the *crip experience* is essential for countering neoliberalism and accessing alternative ways of being. Another theoretical key concept is *embodiment*. Disability, including the *crip experience*, is embodied, and thus, people with disabilities are individualized as ‘others’ and normalized as invisible (Katsui and Mesiäislehto 2022). We deliberately use *embodiment* as an analytical tool to understand the students’ *crip experiences* in the following. We used these theoretical frameworks to analyse the dataset.

Methodology

Finnish higher education institutions are all publicly funded. This particular university is one of the largest universities in Finland with over 30,000 students and 8000 faculty members with 11 faculties. The objective of this study was to understand the embodied, *crip experiences* of students with disabilities at the University by asking the following key research questions:

- How do University of Helsinki students with disabilities experience disability inclusion/exclusion at the University?
- What are the implications of their experiences for the promotion of disability inclusion at the University of Helsinki and beyond?

The study was based on three datasets: (1) the qualitative answers of 11 students with disabilities evaluating equality at the University of Helsinki in student barometer studies, (2) group interviews of 10 students with disabilities at the University of Helsinki, and (3) 30 students’ reflections on the topic in their lecture journals in one of the disability studies’ courses at the University of Helsinki. The first dataset was from the student barometer study. Otus Foundation periodically conducts survey studies directed to all students in higher education in Finland, the last of which was in 2022. During the preparation period of the study, [Laitinen and Katsui] contacted the Foundation and began collaboration. We gave the Foundation our input into their questionnaire, particularly concerning the disability, equality, and non-discrimination questions. The data were collected between February 9 and March 9, 2022. A total of 5323 Finnish students in higher education institutions, including both universities and colleges, responded to the survey. The dataset was first pseudonymised by the Foundation and then shared with [Laitinen and Katsui]. For this book chapter, we utilize the responses to the open-ended questions

of those who identified themselves as students with disabilities (N=11) at the University of Helsinki from among the 5323 students who responded.

The second dataset was based on the primary data from the conducted interviews. In March 2022, we conducted group interviews of students with disabilities at the University of Helsinki. The invitations were sent to the University's student associations; student groups in social sciences, humanities, medicine, and dental medicine; disability groups of political parties; students taking disability studies; and also directly to students with disabilities in the authors' networks. The invitation was in three languages: Finnish, Swedish, and English. The information was also shared in the aforementioned Disability Inclusion thematic year's webinars held at the University in January and March. Twelve students with different types of disabilities volunteered to participate in the study, of which ten students were able to actually join the group interviews. The types of disabilities include learning difficulties, neurodiversity, mental health conditions, physical and sensory disabilities. Due to the high probability of identification, we will not disclose more detailed personal information for the following interview citations. Three group interviews were conducted to accommodate as many students as possible on three time slots, one of which was dedicated to Swedish-speaking students with disabilities. Questions included (1) what kind of a place the University is from the perspective of a student with disabilities? (2) what kind of experiences you have regarding accessibility in our teaching? (3) what is implemented well in the University in terms of accessibility? (4) what are the most urgent needs of improvement in terms of accessibility of the University? In addition, attitude and belongingness were also spontaneously discussed. The interviews lasted between 1 hour and 1 hour and 45 minutes and were attended by two to five students per group. All the interviews took place on Zoom and were recorded with permission. The interviews were transcribed by three research assistants who themselves are university students with disabilities. When the transcription was ready, the recorded digital data were destroyed.

The third dataset consisted of the lecture journals of 30 university students with and without disabilities who were taking disability studies in January to February 2022. The disability experiences at the University were the central theme of one lecture. After this lecture, the students submitted their lecture journals about their learning. Many expressed their own disability-related experiences and/or those of their close friends with disabilities. Before the submission of the journals, they were informed of this study and the use of their content in this chapter, without their names or any other identifiable information.

The three datasets were thematically analysed together with *crip theory* and the key concept of *embodiment*. We selected illustrative interviews or written citations of the students' experiences at the University. These citations contained no details that enabled the research participants' identification. Other ethical issues were also considered carefully throughout the study. Participation in the study was voluntary and based on informed consent.

The participants were also informed that this chapter would contribute to increasing our knowledge of the experiences of students with disabilities in higher education and thereby to positive changes in the University's structures and systems. They were able to select what information they wanted to share with the researchers. The transcriptions of the interviews were then saved without identifiable information. The first author of this article thematically analysed the data. During the data analysis process, Kuosmanen, Tengström and Lindström (students with disabilities) made comments on the further analysis by first and second authors. The final version of this article will be shared with the research participants when published.

Findings: Students' experiences

This part is divided into three themes: (1) *crip* experiences, (2) coping strategies, and (3) the psychosocial impact of *crip* experiences. We first present when and how *crip* experiences take place. Then we analyse the coping strategies. The *crip* experiences and coping strategies explain how these experiences are embodied through the psychosocial impact.

Crip experiences

The *crip* experiences of students with disabilities begin from the *entrance examination*. According to the UN CRPD, reasonable accommodation is a right for applicants with disabilities at the University, but this is quite a new practice, for instance, extending the examination time for some students with disabilities to accommodate their disability-specific needs. The University failed to arrange reasonable accommodation measures for some of the interviewed students even though they were promised, as a result of which one candidate failed the examination. Only the following year were the promised arrangements made, and this person passed the examination. Another student described herself as 'a UFO creature', as everything related to the entrance examination was in Finnish, although her mother tongue was sign language.

For instance, Finnish (language) is so strongly central in the entrance examination, and this shows that it's meant for certain people. Who wants to be the only deaf student at University? Who wants to come to University and be a UFO creature? (group interview).

Many students also described *physical environment barriers* as a source of *crip* and disabling experiences.

The campus in the city center is so hilly. All those thresholds, narrow elevators (...) and it's difficult to open the elevators [sigh] (group interview).

There were stairs and the lecturer was contacted, but ... the response was something along the lines of, "Unfortunately we don't have any other

spaces available in which to hold the class.” The student [with disability and a classmate] was unable to attend a mandatory course due to their disability’ (lecture journal).

The University is an extremely inaccessible place for students and disability is hated. Inaccessibility has impacted me throughout the course of my studies (student barometer).

I have to study remotely because the university is not obstacle-free (student barometer).

A few students felt that *distance learning* had improved the accessibility of their studies in comparison with the disabling barriers at the University. However, as seen in the second response, distance-teaching experiences may also contain contradictory elements as both the impairment and the disabling barriers are interacting.

For a person with hearing limitations, distance learning on Zoom, for example, and the lecture recordings, have significantly improved the accessibility of studies and learning (student barometer).

I have social anxiety ... it’s simply too challenging to be in a place [physically] on the one hand. On the other hand, it’s challenging to concentrate on the content in distance teaching (group interview).

In all the three datasets, *student activities organized by student organizations* were particularly criticized for not paying sufficient attention to accessibility in the physical environment and access to information. Social skills are important for student activities, and they exhaust students with neurological disabilities. Many students find that activities are meant for a ‘homogenous group of people’ and are not inclusive of them.

I’m not part of any student organizations and their activities because they’re not really inclusive. Those organizations are not inclusive (group interview).

Sometimes teaching materials, but especially student union materials, have a lot of accessibility challenges. Fonts, colours, etc., they are really hard to read (student barometer).

In all the three datasets, reasonable accommodation, which is stipulated in the UN Convention as the human right of persons with disabilities, is not systematically operationalized in the practices of the University. It is not really known to either teachers or students. When a student has *visible impairments*, the teacher understands their needs better than those of persons whose impairments are invisible, such as neurodevelopmental impairments.

It's easier to ask for flexibility for the needs related to my so-called physical reason (...) when it's about other reasons like mental issues, I've had anxiety, very bad anxiety, then it's another story (group interview).

Some students claimed it was easier when they had a medical diagnosis. However, many found there was no test in English to diagnose dyslexia or Attention Deficit Hyperactivity Disorder (ADHD) (student barometer), which made the lives of international students with possible disabilities even harder, as the intersection of the international background and disability have been hardly paid sufficient attention to at the university. ADHD and mental health were specifically reported as invisible disabilities in all three datasets.

I'm worried that individual arrangements don't really come to fruition. I'm afraid I won't graduate because of my mental health. I don't feel I have the same opportunities to study (student barometer).

Symptoms of autism spectrum are ignored. For example, the language of learning materials is often confusing or poorly structured, and the course guidelines are scattered (student barometer).

According to our data, *reasonable accommodation measures* are not systematic; they are sporadic and greatly depend on individual teachers and their attitudes.

Ableism in particular needs to be addressed better! Accessibility needs to be taken into account in teaching arrangements, events, etc. (e.g., based on inquiry) (student barometer).

It depends so much on the teachers, how they react. When they are welcoming, then I'm somehow encouraged to ask more in a way (group interview).

The teacher did it [the teaching] so that everyone could be part of it and it was so crazy how much it varies [from one teacher to another] and the fact that one teacher can do it turns down all the excuses the other teachers make for not being able to make the accommodations (group interview).

When some individual teachers can accommodate needs, there is *pressure to be grateful* for such arrangements.

There are exceptional cases and friendly teachers, but when I need some individualized arrangement then I always somehow have to be super, super grateful, though I think it should be normal, and somehow I live in a strange fear (group interview).

There are interested and understanding individual teachers at the University, but *many teachers are simply ignorant and lack the capacity* to meet the

disability-related needs of the students. Equality is too often understood without taking into account disability-related needs.

Very often I've heard comments that reasonable accommodation is against equality, and isn't possible because of a lack of teacher resources or for many other reasons (lecture journal).

Some professors said that it's equality for all that they [the students] do everything in the same manner in the same conditions, and do not understand what equality or accessibility really is (group interview).

One teacher has been strict. If you can't come [to class], then you fail the course. This happened to me a few times. I couldn't help it that I had a doctor's appointment at the same time [as a class] and I really had to go to the doctor (group interview).

The teaching staff don't take dyslexia or neurodiversity into account. For example, expressing negative feelings towards studies is seen as a weakness and is unwelcome (student barometer).

Many of the students found it difficult to meet the *expectations of pace* and scheduling. According to them, teachers' attitudes varied when students with disabilities asked for extra time to complete examinations or to submit their essays or other assignments.

Extra time for an exam is now perhaps something that is somehow understood, it's like a normal thing to admit, but then if you ask for something like extra time for a task then it's like... I've experienced that it's really awkward (group interview).

Teachers attitudes have varied; some teachers say it's going well and no problem, and then other teachers want to know exactly why I return an assignment late and then they might reprimand me for it as this [laughs] causes extra effort for others and it would be good if I could do it in that timeframe, and it's just that I'm so sorry, but I'm not able to do it, but I can't do that (group interview).

Coping strategies

This sporadic operationalization of reasonable accommodation is challenging for both the teachers and students. The teachers have insufficient capacity and *struggle alone*, and the students also struggle alone in their studies.

The teachers are also alone with these students [and their needs for accommodation], and would like to, maybe, want to care about their needs but

don't know how to. Sometimes it's just attitude: this is how it is, period. But other times I feel that teachers may be willing to do more but, but they can't (group interview).

I always have to send the same email and the answers are always different, and this is so tough (group interview).

Not only teachers but also some *students with disabilities do not know that accommodation is their right*.

When I entered University, I didn't know I could ask for individualized arrangements [laugh] and this information came to me in the course of the disability studies. (...) I have an illness that has impacted my life so much and I maybe didn't think about this from such a perspective, (...) the perspective of disability studies, this has been very, very beneficial for me personally (...) I woke up and aha, it shouldn't be so difficult!' (group interview).

For a mental health condition, you can ask and get individual arrangements. And I, I heard this like only three months ago. I think this is so insane in a way, that it wasn't made clear to me earlier, as nobody mentioned it before. And this is the very reason that many fail their studies (group interview).

The student barometer results also underlined the mixed experiences of students when encountering discrimination and harassment: some made official reports to designated persons and tried to resolve the situation, sometimes obtaining results, sometimes not, while others remained silent. Discussions might have taken place but could very well be 'superficial' (student barometer) and 'not useful' (student barometer). An anonymous complaint mechanism has been useful and helpful for some who have reported incidences (student barometer).

Recently, *study psychologists (study-related counsellors)* have been employed to support students with diverse needs. *Equality advisors* have also been appointed at the University to deal with equality, diversity, and inclusion issues, in which both teachers and students struggle alone. This system was established as a coping strategy by the University. Unfortunately, it has not worked for many, as the queue has been long, especially during the pandemic, and students have not received the support in a timely manner.

At times, I've wondered whether or not it's easier to just keep struggling without any support, because sometimes it feels like it takes so much more work than what you get from it. (...) practical problems, like it took so many months before I could even get the support and it was a project that didn't go anywhere (group interview).

Many friends told me that maybe I could go to the students' psychologist who could help me and support me in my studies. But then when I tried to

book an appointment or to visit them, it was impossible, and I just gave up [the idea] (group interview).

It's sad that I didn't know even that there was such a system (group interview).

Nowadays one person is responsible for counselling my studies and I can complete them individually [with individual accommodation]. Otherwise, it's been impossible to get any flexibility or adaptations (study barometer).

Some of the students said that *stigma* brought with it shame, discomfort, or discrimination. It prevented students from disclosing their disability-related needs to teachers and other personnel at the university. This was primarily due to the fear of prejudice or discrimination during their studies and in employment in the future.

It was also not nice to see how much stigma was attached to having sign language interpreters there (group interview).

Because of my illness, even though it's not a mental health problem, it involves a stigma and everything... it's really hard to know how to approach it, and I think if I'm honest, they think that if I can't cope with it, maybe I shouldn't [laugh] be here at the University (group interview).

I haven't asked for extra time or other [support] because of my anxiety or emotional problems, I've felt a bit of ashamed of them. But for the physical reasons, I've had the courage to say it, and this has been a relief (group interview).

When the aforementioned systematic support of the University was not accessible or available, some, although not everyone, received support from their classmates. The importance of peer support by peer students with disabilities was also mentioned. Most students with disabilities manage their studies thanks to *support from individual and external friends*, as well as from their families.

I had a classmate who happened to be in the same group. She wrote a message asking how I was doing (group interview).

How much does busy, competitive time affect this? How much can other students be motivated to help us when our studies are primarily based on competition? You have to think, shall I use my time for others or for myself? This competition and busy time issue is manifested in, for instance, group tasks or small daily situations in the classroom. Is it worth selecting a partner who needs more help and support? Is it worth taking the risk when it's about your grade? (group interview).

It's so important that students who are in the same situation can ponder these issues together and receive peer support, and celebrate together when studies go well, etc. (group interview).

The psychosocial impact of crimp experiences

Consequently, students with disabilities are too often left alone to deal with their studies, and their needs are not met. They feel pressured to *survive alone and give up* challenging the disabling structure of the University.

If the teacher says like [in a negative manner] that he has to drop my grade because I submitted my assignment late, then in a way, I can't bring this issue to the surface, that I have this illness, and I somehow want to survive (group interview).

I got tired of being the only one who raises the disability issue all the time. It's so hard and I, I can't take it anymore (group interview).

When I need individual arrangements and accommodation, it's very, very stressful, as it remains only my responsibility in a way, and there's no collective practice, and you never know how it will turn out and contacting someone for each course demands a lot of extra work, and, and, somehow OK, what shall I tell them about my health condition, when I don't want to tell them everything but then I have to, so that the teacher understands? There are so many things (group interview).

Many of the students argued that 'the University is the most inaccessible place in society' (group interview) and analysed this university context and their crimp experiences in *the wider, societal culture of ableism*.

Disability is so invisible at the University. There is often no information, because people [at the University] don't think about accessibility (...) I once raised the issue of accessibility in an event or on Instagram, "Hey, add some information, alt text for persons with visual disabilities, blind students." And then I was asked, "Well, are there any people with visual disabilities or blind students?" And I thought, "Of course, there are!" How could they think like that, that there are no blind students? (group interview).

I think the whole study culture and then the practices and everything, somehow the starting point is that students do not have disabilities, and [they are] "normal" people (group interview).

In my studies, sure I've been super alone. I feel that everybody else's studies are moving on well and then everybody asks about my courses and my Master's thesis and I'm not going as fast and am still at Bachelor level, and then I try to somehow make a joke but I don't feel good or funny because

other people don't understand why I can't complete these courses, or I actually feel so proud of completing one course and having succeeded in it, and then others laugh at me and have completed many courses during the same time. Then I feel: what's wrong with me? (group interview).

It's so contradictory at the moment, how somehow Helsinki University claims that inclusivity is one of its values but then the whole institution is guided from the top on a fully neoliberal foundation (group interview).

The university culture pressures students to be 'effective', 'competitive', and 'successful'. Many feel like 'others', 'strange', 'different', 'ashamed', 'slow', and 'excluded'. This culture is profoundly based on the ableism of Finnish society, which leads to *psychosocial impact* through crip experiences. This topic was extensively discussed, especially in the group interviews.

As I get older, I'm becoming more introvert, I perhaps suffer alone and don't show it outwards (...) It's very hard for me to distinguish, as it is in a way a permanent strange feeling, and it's hard to differentiate between what other people think and what I think reflects other people's thinking (group interview).

I feel that these experiences are somehow too much and define me in relation to my studies (group interview).

I feel so terrible when I feel I'm too demanding [for reasonable accommodation] (group interview).

I often think what's socially acceptable and how not to disturb others (group interview).

These students' experiences reveal the disabling culture of the University, in which individual students struggle alone with limited support from individual classmates and teachers and no accessible, functioning, available support system. The psychosocial impact is embodied and too often negatively affects their mental health.

Discussing the University experiences in the Finnish context

The students who participated in this study have been through many kinds of crip experiences on different occasions at the University and during their student lives. Many participants shared crip experiences in relation to time in particular, feeling that they were too slow (see Ljuslinder Ellis and Vikström 2020; Isaac 2020). According to Sheppard (2020: 39), crip time is a developing understanding of how disabled persons are orientated to and move in/through time, and also how ableist expectations of 'normal' orientations and timespans are part of the construction of disability.

Disabled persons are not only too slow but also too fast, too uncontrolled, too reliant, too different, too much, and also, not enough. In Sheppard's (2020: 43) study, pacing was

the activity of scheduling a daily life, particularly rest and low-activity periods, to either reduce the likelihood of a period of high pain or fatigue from occurring, or to enable them to do other higher-energy tasks and, significantly, to conceal the impact of those high-energy tasks as much as possible.

This is because the University is part of society in general, and part of a disabling society in particular. In fact, the study participants argued that their *crip* experiences at University were much stronger than in society in general as will be discussed shortly.

McRuer (2006: 72) argues that 'locations where disability identities emerge will always be interrogated and transformable' and 'sustaining our understanding that who we are or might be can only have meaning in relation to who we are not (yet)'. McRuer's *crip* theory and identity observation are useful for understanding the complex, multi-layered experiences of the students with disabilities in this study. The difficult physical, information-related, and attitudinal environment in society in general is already a disadvantage for these students, for instance, ice and snow in the winter (group interviews; lecture journals; Tunström and Löfving 2020). Internalized oppression or ableism (see Katsui 2005; Campbell 2009) is often already a part of the students' experiences before entering University and unfortunately continues or even strengthens at University. In addition, many students with disabilities have reduced functionality due to their disabling environment, and not only due to their disabilities. They have to use their time and energy to arrange their disability services or accessible materials with a number of stakeholders and service providers, and this is too frequently unrecognized by University faculty members.

If you have a chronic illness or are seriously ill, there are so many kinds of bureaucracy, you can't imagine. KELA (The Social Insurance Institution of Finland), specialized health care professionals, many forms to fill, all the time something to do, and then, then, it takes so much time that it's hard to predict how much time and energy will be left for me to arrange my studies (group interview).

In this conjunction, it is interesting to compare the study findings of Kosunen (2021) on the views of university teachers and university leadership in Finnish universities. The leadership recognizes that accessibility issues are aptly taken into account in their strategies and believes in the capacity of the faculty members to realize accessibility in practice (ibid.138–148). The overall impression of the university teachers is that they have been taking good care of their teaching and have been giving individualized support based

on individual needs. To the statement, ‘In the process of teaching curriculum planning, accessibility is taken into account...’, 13.5 per cent answered ‘poorly’ and 16.7 per cent ‘rather poorly’ (ibid.130). To the statement, ‘I discuss accessibility with my boss’, 26.0 per cent answered ‘poorly’ and 10.4 per cent ‘rather poorly’ (ibid.128). This indicates a clear gap between policy and practice at Finnish universities, which was also the experience of the study participants, as mentioned above. The disabling environment in society and its impact, the disabling academic environment, and the disability-related vulnerability of the students are clearly unrecognized by many members of the University community. A good question is *why is the University such a place for students with disabilities?*

Taylor and Shallish (2019a,b: 1201) have suggested that the focus on merit in higher education undermines meaningful participation and positive recognition of persons with disabilities. The success of individuals – students and academic personnel – is understood to be due to their natural talents and hard work, rather than because they resemble the normed archetype fitness for higher education. Taylor and Shallish (2019a,b: 1202) call this the logic of bio-meritocracy and argue that it operates pervasively within higher education. According to this model of thinking, the marginalization of persons with disabilities within the academy is not arbitrary, unintended, or accidental; it is tied to the maintenance of able-bodied and able-minded supremacy (Taylor and Shallish 2019a,b: 1202). Therefore, it is in fact natural that many students with disabilities encounter *crip* experiences and *crip* time in the university context. The situation is further complicated by the fact that in academia, research continues to have priority over teaching (Moilanen, Nikkola and Rähkä 2008).

Concluding remarks

The present study findings imply that the university is not as inclusive as it should be. Students with disabilities experience barriers in physical, social, and pedagogical environments at universities and in student organizations. Many students with disabilities do not know their rights and do not know whom to turn to in their own educational institution with accessibility issues. Reasonable accommodation measures appear to be unsystematic. Instead, they seem to be sporadic and to depend very much on individual teachers who do not always have sufficient capacity and end up struggling alone. Meanwhile, students also struggle alone in their studies.

This study did not aim to generalize the experiences of students with diverse disabilities but to listen to their accounts of *crip* experiences in their own words in the three datasets. Obviously, it is impossible to cover all the diverse realities and experiences in the space of one book chapter. We are particularly conscious of the different needs of students with different impairments and health conditions which also intersect with other characteristics at different times and in different contexts. Students with learning difficulties but no

medical diagnosis also encounter crip experiences at the University. The triangulation of different data collection methods, as well as diversity among the studied students' backgrounds, enabled us to reach some of the complex realities in the light of crip theory. Much more detailed and comprehensive studies are needed to carefully elaborate on these impairment-specific and individual differences in different environments.

The COVID-19 pandemic hit the University and its community members hard, including students with disabilities. The sudden shift from contact teaching to distance learning (see Fagerholm, Casi and Katsui 2021) created a compassionate environment for both teachers and students. This was unprecedented. In fact, the University leadership instructed teachers to be kind to themselves and their students during the time of the pandemic, as all of us were overstretching ourselves. For instance, before the pandemic, students were required to be present for almost all contact teaching in order to pass the courses. This rule was temporarily suspended for online teaching. Many lectures were digitally video-recorded for the students to watch at a convenient time. Many teachers have been more flexible and understanding of the mental health and other health conditions of their students during distance teaching in the last two years. It is a widely known social phenomenon that all the restrictions have negatively impacted the mental health of many people, especially that of young students around the globe, also in Finland (UNESCO 2020; Holzer et al. 2021). The COVID-19 pandemic has been an additional burden for many research participants, but for others it has offered opportunities. At the time of writing this chapter, we are going through the transition period from distance teaching to hybrid teaching, so that all students with and without health conditions are equally accommodated both on campus and online. This peculiar situation has forced us to stop and come up with alternative pedagogical solutions to genuinely accommodate the diverse needs of students. The time is not yet ripe to profoundly analyse the impact of the pandemic and the transition period. But it provides us with a great opportunity to reconsider the University culture that has excluded many groups and individuals as others. However, regardless of the pandemic, surely it is high time to make our University culture inclusive.

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3 Being independently dependent

Experiences at the intersection of disability and old age in Finland

Salla Era and Teppo Kröger

Introduction

In this chapter, we discuss the situation of older persons with disabilities in Finland from the viewpoint of personal experiences, focusing on in/dependence. Older persons with disabilities tend to be overlooked in both disability and ageing policies while there is little bridging between these policies, and it has been suggested that one reason for this is conceptual issues (Leahy 2018). We want to go deeper into these conceptual issues: the very concept of disability has different meanings, which may impact the intersection (Era, Katsui and Kröger, forthcoming). Close to the conceptualisation of disability lies the notion of in/dependence, which is discussed widely in both ageing and disability domains. In this chapter, we analyse texts written by older persons with disabilities in Finland with a focus on in/dependence. We ask *how in/dependence is displayed in the accounts of older persons with disabilities, and how they negotiate different meanings of in/dependence*.

In the following sections, we will first introduce the situation of older persons with disabilities in Finland and elsewhere, after which we will briefly discuss what we mean by in/dependence and its related concepts. Then we move on to describe our analysis, briefly looking at the data and methods, and to our findings around reflections of dependency. Finally, we will discuss the findings and their contribution to the research on the nexus of disability and old age.

Ageing and disability in Finland

The population is ageing rapidly, both in Finland and worldwide. Along with the general population, also persons with disabilities are living longer (Freedman 2014; LaPlante 2014). Population-based calculations of Statistics Finland predict that the number of people aged 75+ will double from 2010 to 2040, increasing by 108 per cent in this period (Tilastokeskus 2022). Disability, on the other hand, is more common in the older than the younger population (Jönson and Taghizadeh Larsson 2009). In EU countries, on average, 17 per cent of 16–64-year-olds reported disabilities in 2018, whereas

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the share of reported disability was 47.8 per cent among people over the age of 65 (Grammenos 2021, 16).

Around 3.3 per cent of Finland's population used disability services in 2020 (THL, 2022). In Finland, the proportion of older persons who use disability services is noteworthy: a report by the six largest municipalities in Finland – Helsinki, Espoo, Tampere, Vantaa, Oulu, and Turku – indicates that in 2021 the share of persons over the age of 65 among the users of disability services was 59.2 per cent (Kuusikko 2022).

As the above statistics indicate, older persons report more disabilities than the younger population, and older persons are a major user group of disability services. Even though there is such overlap between old age and disability, older persons with disabilities tend to be overlooked in the service systems of many countries, and often on the system level, the services are organised separately for older persons and persons with disabilities (e.g., Jönson and Taghizadeh Larsson 2009; Leahy 2018; Priestley and Rabiee 2002). This is applicable in Finland as well: older persons with disabilities are often seen as 'just old' rather than 'disabled' (Era 2021; Hoppania, Mäki-Petäjä-Leinonen and Nikumaa 2017). Acquiring impairments in older age is considered to be the norm of an ageing body and part of so-called normal ageing, reasoning which has been used in arguments supporting the exclusion of older persons with disabilities from disability services (Era 2021; Priestley 2006).

Formally, services for older persons and disability services are in Finland organised separately by different specific pieces of legislation. However, Finland's disability service legislation was recently reformed, and the situation for older persons with disabilities has changed as well. The most important discussion during the reform process from the viewpoint of older persons with disabilities has been around an age-related restriction that has been suggested to be applied to disability legislation on multiple occasions.

Disability services in Finland are organised according to the Act on Disability Services and Assistance (*Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista*, 1987; 2023) and the Act on Intellectual Disabilities (*Laki kehitysvammaisten erityishuollosta*, 1977), in addition to general legislation guiding social services (for example, the Social Welfare Act [*Sosiaalihuoltolaki*, 2014]). The new legislation was planned to come into force in October 2023, but after the new government was formed in the summer of 2023, the implementation has been postponed. In addition, the new government has reopened the already approved Act in order to specify its scope in a way that would ensure sufficiently low expenditure. One proposed way of specifying the scope was, once again, to impose an age-related restriction. At the time of finalising this chapter in December 2023, the new Act is planned to come into effect in January 2025, but the contents of the Act and its implementation are yet to be seen.

In the previous Disability Services and Assistance Act (1987), there were no age-related restrictions, except for personal assistance, a legal right to which was added to the Act in 2008. At that time, persons whose impairments

were the result of health decline related to advanced age were made ineligible for personal assistance. As there was no chronological age limit, this restriction left room for interpretation. This age-related restriction and other age-related confusions in the application of the Act have spawned many correction requests to higher governing and legal bodies that have had to clarify the practices (for example, Korkein hallinto-oikeus 2012: 60). The suggested age-related restriction in the disability legislation reform followed along the lines of the restriction in personal assistance, and discussion around it often referred to the experiences of personal assistance.

Before its (first) finalisation in 2023, the reform had been ongoing for many years. Regarding older persons with disabilities, the debate on age-related restrictions has been essential. In the discussion around the reform, understandings varied concerning what disability really is and whether age-related disabilities should be included (Era 2021). In a draft Act in 2017, persons whose impairments had originated, worsened, or increased because of old age or from deterioration due to old age were suggested to be made ineligible. In the 2018 government proposal, there was no age-related restriction, but the next draft proposal in 2022 introduced it again.

The draft of the new Act in 2022 suggested the same as the one in 2017: extending the beforementioned restriction to all disability services, including transportation services and home adaptations. This draft was introduced for public consultation in February 2022 and the government proposal was given to the Parliament in autumn 2022. However, the Constitutional Law Committee of the Parliament concluded that age-related restrictions were against the Constitution, and they were thus removed from the proposal. Instead of the age-related restriction, the scope of application of the Act now states that it will be applied if the person does not get required individual services according to any other law. The modified proposal was accepted in Parliament in the beginning of 2023. However, as mentioned, the Act has been now reopened by the new government, and there is no certainty of how its contents will change. The Act is planned to come into force in October 2024.

In Finland, the specific law that directs older persons' services is the Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons (*Laki ikääntyneen väestön toimintakyvyn tukemisesta sekä iäkkäiden sosiaali- ja terveystalvveluista*, 2012, henceforth, the Older Persons' Services Act). The Older Persons' Services Act was introduced to tackle the gaps found in older persons' services at the time. However, it has been argued that it has had very little effect on the deficiencies of older persons' services (Hoppania 2015). Kröger, Van Aerschot, and Mathew Puthenparambil (2019) have stated that the Finnish long-term care system fails to fulfil the Nordic ambition for universalism, that is, to provide care to all older people who need it.

Although the legislation and services on the system level are separate, older persons with disabilities can acquire services according to disability

legislation (the Act on Disability Services and Assistance and the Act on Intellectual Disabilities) as well as the Older Persons' Services Act, as there are no chronological age limits in either. This was the case also with the previous disability legislation, but in practice the implementation of the Disability Services and Assistance Act by local authorities was varied. Before the disability legislation reform, Hoppania, Mäki-Petäjä-Leinonen, and Nikumaa (2017) identified weaknesses in the services regarding older persons with dementia and suggested that older persons with dementia ought to be accommodated in the disability framework and legislation instead of the Older Persons' Services Act. In their view, older persons with dementia remain in an unequal position compared to other people with different diseases or disabilities (*ibid.*). Even though the previous Disability Services and Assistance Act did not specify which disabilities were included in its realm, and only personal assistance had an age-related restriction, in practice, dementia in old age was often excluded. Other age-correlated disabilities faced the same issues.

The legislations regarding older persons and persons with disabilities differ in many ways, both with the previous and the reformed disability legislation: the Older Persons' Services Act does not provide specific rights to services but rather aims to ensure that services meet local needs and certain quality standards, whereas the Act on Disability Services and Assistance provides for enforceable legal rights (*i.e.* subjective rights) to a list of services. The most used disability service among older persons is transportation service (61 per cent of the service users were aged 65+ in 2020), whereas, for example, personal assistance (37 per cent) and service housing (35 per cent) are used more rarely by older people. However, it needs to be noted that personal assistance is the one disability service that previously has had an age-related restriction and the usage per cent of older persons might increase if the age-related restriction is lifted in 2025.

In sum, at the moment, there are no age-related restrictions in the Finnish disability legislation (except in personal assistance), and older persons with disabilities are included in both disability services and older persons' services. Although there is no general age-related limit, there has been support for such a restriction throughout the disability legislation reform process. Additionally, in practice, there has earlier been a tendency to exclude older people from disability services and provide them services only according to the Social Welfare Act (Hoppania, Mäki-Petäjä-Leinonen and Nikumaa, 2017) and/or the Older Persons' Services Act. However, the new disability legislation points clearer towards the inclusion of older persons with disabilities, and it remains to be seen how this translates into practice.

As noted earlier, the aim to exclude older persons with disabilities from disability services is not limited to the Finnish context but takes place in other countries as well (Jönson and Taghizadeh Larsson 2009; Mastin and Priestley 2011; Gibbons 2016; Leahy 2018). It has been suggested that one reason for such an exclusion is conceptual issues and especially the lack of the association

of the concept of disability with ageing (Leahy 2018). Molton and Ordway (2019) have suggested that disability studies and ageing research often speak different languages, as the conceptualisation of disability varies drastically between these two fields, and this can be a barrier to cross-network communication. There seems to be conceptual confusion at the intersection of disability and old age in research and in general discussion (Era et al. 2020; Era, Katsui and Kröger, forthcoming).

Conceptual gaps and bridges in the nexus of disability and old age

According to Priestley (2006, 85), disability and ageing both tend to be approached through health and functioning, whereas Molton and Ordway (2019, 55) point out that even within the nexus of disability and ageing there are divisions: the study of disability is scarce in ageing studies, and the same goes for ageing in the study of persons with disability. Yoshizaki-Gibbons (2018) has noted the same regarding critical disability studies and critical gerontology, with the former focusing on impairment/disability and the latter on old age. In ageing research, the health and functioning type approach to disability in old age seems to be mostly related to *disability with ageing*, whereas the more socially oriented conceptualisations intrinsic to disability studies often regard *ageing with disability* (Era, Katsui and Kröger, forthcoming). Accordingly, it seems that in disability studies, research in the nexus of disability and ageing focuses on persons ageing with disability whereas ageing research looks at older persons ageing into disability or acquiring disability with ageing. This difference in approach and concepts can further the division between ageing and disability research and respective policies.

In addition to conceptual issues surrounding the very concept of disability, there are conceptual differences concerning the use of the notion of in/dependence in the ageing and disability fields. In many parts of the world, self-sufficiency and independence are often portrayed as the preconditions of an ideal human being, and dependency is easily considered a failure (Kittay 2011). Therefore, those cast as ‘dependent’ are assumed to want to change that. According to Fine and Glendinning (2005, 602), ‘[autonomy and independence are] commonly promoted as the antithesis of dependency and, moreover, as unproblematic and universally desirable goals’.

The disability movement – and specifically the Independent Living (IL) movement – has challenged these assumptions with the argument that independence does not mean doing things by oneself physically, but rather that assistance makes independence possible (Barnes and Mercer 2006; Kittay 2011; Pearson 2013). Making independent decisions on how, when, where, and by whom the assistance is provided is independence rather than dependency, being ‘independently dependent’, as the activists of the IL movement call it (Barnes and Mercer 2006, 31). Looking at disability from within feminist care ethics, Kittay (2011, 51) has raised this notion’s risk of promoting

independence as the only way to dignified life and portraying dependence as ‘denigration of the person’. Similarly, Kelly notes (2013, 792) ‘[t]he IL movement revises common definitions of independence but it still maintains it as an important, if not paramount, social value’.

Even though there are differences in the conceptualisation of in/dependence, both disability studies and feminist care ethics have theorised (although with different premises and frameworks) that there is no independence without dependency: every human being is dependent at some point in their lives, and we all need others to be independent. It is a web of connections rather than a dichotomous, one-way flow of assistance. This conceptualisation of independence is concretely reflected in disability strategies in Finland as well as in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that Finland has ratified.

However, the conceptualisation of in/dependence can be different when viewed from the ageing sphere. For example, Phillips, Ajrouch, and Hillcoat-Nallétamby (2010, 131) have defined independence in the following way: ‘[independence is a] sense or state of physical, psychological and spiritual autonomy, self-identity, self-respect, control and degree of functional capacity’. This definition includes physical, psychological, and spiritual autonomy as well as functional capacity – the independence conceptualised in disability studies refrains from referring to similar requirements related to physical or psychological capacities.

Whereas in the disability field ‘Independent Living’ often refers to the ideology where individual autonomy can be achieved relationally, in the ageing field, ‘independent living’ or ‘living independently’ usually refers to the housing situations of older persons: living alone at home has been seen as a marker of independence (Portacolone 2011). Within housing for older persons, living independently often means living alone (or with a partner) in one’s home and not in any type of assisted living facility. According to Portacolone (2011), often the literature regarding independence has been closely related to studies on ‘ageing independently’ and supporting the ‘independent living’ of older persons. However, ageing research has argued for a broader conceptualisation of independence, for example, ‘relative independence’ (Hillcoat-Nallétamby 2014) as independence with intersecting dependency and independence (Secker et al. 2003).

As discussed above, ‘independence’, when used in an ageing context, typically means something rather different than in the disability field. Also, professionals’ views can differ from those of older persons or persons with disabilities. Writing in a disability context, Reindal (1999) has noted that professionals tend to view independence through self-care activities and therefore have a different meaning for independence than disabled people. Older persons’ services do not have the same kind of movement and involvement of activism as disability services do – and this can be expected to be reflected also in the professional understanding of in/dependence.

Data and methods

We collected 24 written accounts, gathered through Penna, which is a written data gathering website governed by the Finnish Social Science Data Archive. There we issued a call for texts that discuss the experiences older persons with disabilities have of the service system and of getting old with disabilities in general. We did not define ‘getting old’ or ‘disability’ in any specific way in the call, to permit people’s self-identification. In addition, we did not specify whether the acquired services were older persons’ services or disability services but encouraged the participants to tell us about the services in the text.

The call was open from October 18 to December 31, 2021. The length of letters was restricted to 10,000 words. The call was distributed through different social media platforms. We received 24 written responses of which we excluded one text that was submitted twice, one that did not concern Finland, one that was written entirely by a relative, and two that did not contain any text about respondents’ experiences, only answers to questions on the background of the participants. Hence, in the end, we had 19 texts from older persons with disabilities to analyse. Background information on the participants is presented in Table 3.1.

Our data collection is not without limitations. Since the call was distributed through social media platforms and emailing lists, it was restricted to persons who actively use the internet. We distributed the call with the help of disability organisations, but also through more general platforms (e.g., Facebook group for people born in the 1950s) in order to find persons who are not active in disability organisations. Writing about

Table 3.1 Background information of the participants

<i>Age, gender and service use</i>	<i>Number of participants</i>
Age	
55–59	1
60–64	4
65–69	1
70–74	8
75–79	3
80–84	1
85–89	1
Gender	
men	4
women	15
Use of municipal services	
yes	10
no	7
N/A	2

one's own life with its ups and downs may be strenuous both in terms of time and energy, and therefore, only persons who possessed these two responded. In addition, reflection on one's own life and its difficulties is cognitively demanding, and hence, this most likely influenced the data. The call was made accessible also in a PDF (Portable Document Format) form that was compatible with screen readers, and the assistance of another person with the task was allowed. However, the call was not available in other languages than Finnish, and therefore, potential participants from other language groups were omitted.

Men are underrepresented in the data: only 4 of the 20 participants were men, whereas the disability prevalence difference between genders in the EU is much narrower. In the EU, 26.8 per cent of women and 22.1 per cent of men report disabilities (Grammenos 2021, 15). However, the difference may be greater in old age, since women have a longer life expectancy and disability prevalence increases with age (*ibid.*). Still, our data have an overrepresentation of women compared to men.

We analysed the data using reflexive thematic analysis, developed by Braun and Clarke (2019), focusing on reflections around dependency related to impairments and old age. Reflexive thematic analysis is a revised or renewed version of the thematic analysis that Braun and Clarke proposed years before (2006), and their later reflections on the method have clarified their stance on thematic analysis (Braun and Clarke 2019; Clarke and Braun 2018). In their formulation of thematic analysis, the role of the analyst is recognised and kept in mind while doing the analysis (Braun and Clarke 2006, 2019; Clarke and Braun 2018). According to this method, themes in the data are not 'discovered', and they do not 'emerge' from the data, but themes are rather created and constructed during the process, with the analyst (with their abilities, knowledge, previous experiences, etc.) being an active actor in the creation. Hence, reflexive thematic analysis is a deliberate process, where the choices of the researchers and their effects are acknowledged. Even though the core of Braun and Clarke's thematic analysis has not changed throughout these years, we followed the latest formulation, which they call reflexive thematic analysis. Reflexive thematic analysis highlights the 'open, exploratory, flexible and iterative nature of the approach' (Braun and Clarke 2019, 593).

We took in/dependence as a starting point for our analysis, since dependency and independence are discussed widely in the ageing and disability fields, but just as disability in old age, they often mean different things in the two spheres. First, the accounts were read multiple times whilst taking notes. After that, the initial coding was performed, noting any relevant content in the data. Issues regarding in/dependence as well as conceptual differences within the disability and ageing spheres were familiar to us, and we chose to analyse the texts from the viewpoint of in/dependence, as it seemed to be relevant to the data as well. After a few rounds of reviewing and recreating, we presented the results in three themes. We focused rather on the

conceptualisations than the individuals, so each letter can contain multiple depictions of the conceptualisations. The analysis was performed by the first author but reviewed by both authors.

Findings: Navigating in/dependence

In general, the accounts included descriptions of how the participants' impairments had started, when, and what kind of medical encounters the participants had had in the past. The texts focused on the impairments, services, and the help the participants had received due to their impairments, and what they thought about the future. We did not separate those *ageing with disability* and *ageing into disability* as we wanted to categorise people as little as possible.

In our analysis, we focused on navigating between dependency and independence, and what kind of meanings they appear to convey. We noted that (1) fear of dependency was visible in the accounts; there were stories of how limiting it was to ask for help, and how scary it feels to become more dependent in the future. The second theme discusses (2) asking for help and justifying it: sometimes one has to be active and even make a demand in order to be helped. Some participants seemed to justify getting help as there were accounts emphasising reciprocity that allows one to be dependent: a long working career or caring for grandchildren can enforce a feeling of 'doing one's part in the world' and therefore deserving help in return. By contrast, the third section discusses (3) the independence that getting help brings: relationality in independence. The accounts indicate that independence can be achieved relationally, with the assistance of others. Here, however, problems with services through which independence could be achieved were raised.

In the following, we will discuss the different meanings of in/dependence reflected in the accounts. Some seemed to be related more to interconnected and relational independence, while others appeared to view dependency as an unwanted quality (although inevitable in old age), and therefore adhering more to the general perception of the ideal of self-sufficiency and self-reliance.

Fear of dependency

A great deal of fear was expressed in the accounts: participants feared getting old and dependent. For many, progressing impairments were inevitable, and even though the situation was good for now, the future was unknown and worrisome, as more needs could be expected to emerge. The next quote expresses the worry about the future:

As I age, I often wonder how I will survive as my physical strength begins to wane and my illnesses progress [...] it remains to be seen where I will find myself if my own strength fades so I can't cope alone.

(Woman, 70–74 years, uses services)

Dependency seems scary and not wanted. Being dependent, as Fine and Glendinning (2005, 605) noted, is regarded negatively: ‘dependency is cold and its connotations are almost entirely negative. Those identified as dependent are assumed actively to seek to reverse this status’. There were also accounts where participants did not currently describe impairments as difficult but expressed worry about the future with progressing impairments. The next quote expresses the feelings of loss when a person realises that something is no longer possible (without help):

It feels weird to write about limitations because I’m so used to ignoring them. I don’t think much about these things in my daily life. I run into a wall in situations where it happens – but it’s annoying just then, or even crushing – that’s no longer possible. That feeling of loss cuts deeply and reminds me of reality and the future.

(Woman, 60–64, no services)

Although not explicitly expressed, this quote can be interpreted to include worry and sadness about the future, and the feelings of loss of things that were previously possible: it ‘cuts deeply’ and is even ‘crushing’. The same participant continued:

All in all, ageing with this impairment is very challenging, even scary and degrading. At least I myself don’t know if I can get any help from my municipality or public health care. Now I can still be an independent disabled person living in my own home. Even though I can no longer take care of my home alone, I need the support of my spouse more and more.

(Woman, 60–64, no services)

The above participant described ageing with her impairment as ‘very challenging, even scary and degrading’, and continued by noting her unawareness of municipal services. She lives in her own home with the support of her spouse, who could be considered an informal carer – most likely unofficially, as she does not have knowledge of municipal services. This is common to many Finns: in the year 2020, there were over 50,000 ‘official’ informal carers who get receive support from the municipality (Sihto, Leinonen and Kröger 2022), but it is estimated that over 1.2 million Finnish people provide help to their close ones, many of whom are older persons with disabilities (Vilkko et al. 2014).

Asking for help can be difficult when dependency is seen in a negative light. One participant wrote that her children most likely would help if they had the time, but she thinks it is wrong to ask:

My children might help if they had time in their hurried lives. I think asking is wrong. I have had to cope on my own all my life, even in difficult

situations; I now realize that I will be asking for help at the last minute. That time will soon be around the corner.

(Woman, 70–74, no services)

The participant continued by writing that she has had to cope alone even in difficult situations: it is expressed in a negative way, as she *has had to* cope alone. This seems to indicate that she has not wanted to do it alone, and even now she does not want to ask for help since she thinks it is wrong.

The above quotes describe the fear of dependency and of having to rely on someone else to perform certain tasks. This relates to the larger picture depicted, especially in the context of ageing: the responsibility of staying active and healthy is shifted to the individual, hence enforcing the idea of dependency as the failure of an individual. Likewise, Timonen (2016, 45) has argued that, at the EU level, active ageing policies are ‘intended to maximize self-care and autonomy and push the “heavy lifting” of care from the public/policy sphere to the private sphere’. One downside of active ageing ideology can be the fear of admitting dependency and therefore delaying seeking help.

Seeking and justifying help

The participants also described difficulties related to seeking, asking for, and getting help. The accounts included descriptions of having to behave in a certain way in order to get help: one needs to be active, or one has to be brave enough to hold one’s ground, or one has to have a good sense of humour in order to navigate the services and society more generally. Perhaps because asking and getting help in a culture that emphasises independence as self-sufficiency is difficult, there were accounts that seemed to emphasise justifications for asking and getting help, for example, by describing help the participants themselves were providing for others, but also by underlining long careers before acquiring impairments. First, we will view the ‘requirements’ for getting help, and following that, we will move on to the ‘justifications’ for help.

First, there needs to be knowledge of the services one requires. As in the previous section, here too, the lack of knowledge and difficult bureaucracy, especially in a possible transition phase, were mentioned:

[...] access to information and communication with the disability service and the future care home unit has been cumbersome and bureaucratic. [W]hen, without knowledge, you cannot understand which services need to be applied from where, not to mention that the forms are difficult or impossible to fill out and send by computer in a way that would in any way fit their purpose.

(Man, 60–64, uses services)

As mentioned previously, getting help can be difficult due to many factors. Not only is it hard on its own because of the ideals of independence as

self-sufficiency, but surrounding barriers add to the obstacles. The task of seeking help becomes more strenuous as more challenges arise, and the requirements for the individual seem to increase:

In our welfare society you must be able and dare to open your mouth and hold your own, otherwise you are classified as ‘toxic waste’ and ignored in silence in the care service queue.

(Woman, 70–74, no services)

The above quote depicts a cold reality, where one needs to be active and daring to get help and not be regarded as ‘toxic waste’ in the society. This emphasis on a person’s own activeness is visible throughout the data. Another participant briefly noted that ‘who applies and wants, gets help, a lot of things depend on your own activeness’ (Woman, 75–79, service user). The responsibility lies with the individual, who needs to find help and sometimes even demand it. As one participant noted earlier about her unawareness of available services, first there needs to be knowledge of the help and only after that, can one apply, sometimes assertively.

Asking for help can be difficult, and there were accounts that seemed to justify the services or the help the participants get from family and friends. The next quote indicates how dependency is negotiated through reciprocity:

I live alone; my children help as needed, and I have cared for six of my grandchildren myself since they were babies. Now two of them are in primary school.

(Woman, 70–74, N/A)

The participant described how her children help her when needed and immediately continued by describing her contribution to her grandchildren’s care. It seems that she accepts dependency through reciprocity: one deserves help after helping others. In addition to reciprocity related to family and friends, working lives were described and seemed to be offered as a justification for getting (or deserving) help now – being a productive worker is important in the self-sufficient ideal. One participant explained how he had had a long career, and after getting injured tried to get back to work, and finally left working life:

I worked as a [title] in [working place]. After an accident at work in [around 20 years ago] ... [description of the incident], I returned to work after two months’ sick leave and again [another similar incident]. Again, I had an endoscopic surgery like the first time. Now I was on sick leave for three months and returned to work, but my knee lasted no more than six hours. I told management that the leg could not last, so I would retire.

(Man, 75–79, N/A)

The participant described his injuries in detail, with specifics of the accident. He had tried multiple times to continue working, but due to his injuries, he had to retire. It seemed that this was not what he wished for; he would have wanted to continue working, but he had no choice. There seems to be a need to justify retiring and not working, that is, being a productive, self-sufficient human being.

The quotes above paint a picture of the difficulties of asking for and getting help. Dependency seems to be justified through reciprocity, but also through earlier productivity during a person's working life.

Being independently dependent

Whereas the first theme saw dependence as something highly negative and something to be feared and the second theme described the challenges of and strategies for acquiring help, the third theme focuses on notions of help as an enabler. This latter aspect of the in/dependence nexus seems to be closer to the principles and theoretical assumptions of the disability movement and care ethics: independence is achievable through help, as no one is truly and fully independent.

In many accounts, being independently dependent manifested in focusing the gaze on surroundings and services instead of individual impairments. For example, the following participant focused on the difficulties related to the assistance he was utilising:

However, getting around is always difficult and getting a taxi is uncertain, and the use of the taxi is inflexible, so that you may be late for a meeting or you may have to leave early due to the driver's schedules.

(Man, 60–64, uses services)

The participant described how he needs help moving outside the house, but that there are some issues with the assistance. The writer did not specify the difficulties with his mobility outside but instead focused on the problems related to the taxi service. It can be interpreted as meaning that the participant could be more independent if the taxi service worked more on his terms rather than according to the driver's schedules – the participant did not explicitly raise the dependencies caused by his impairments but instead raised the deficiencies in the assistance provided. This can be seen to reflect the social model of disability, as the *disabling* issue here is the problems related to the service and not to the impairment of the person.

Especially transportation services are used by older persons: 61 per cent of transportation service users in 2021 were 65+ years old (THL, 2022). There has been no age-related limit in transportation services, and a survey by THL, the National Institute of Welfare and Health, noted that many see a need for restricting the service, as it has been used widely among the older population and not only persons with disabilities (Sirola and Nurmi-Koikkalainen

2014). The age-related restriction in disability services has been the topic of a long-running debate (see, for example, Era 2021). However, transportation service is the most used disability service and does not currently have any age-related restriction, and the pressure to cut its costs can result in services of lower quality.

The above quotes describe the independence and autonomy that help brings. However, there was also fear of losing the services – and thus fear of losing independence:

Yet I am greatly grateful even for this support I have received from the city. Still, there is always the fear that these benefits can be taken away or made more difficult, for example, if the right to use your own taxi is lost. That fear is present also concretely, because the cuts always hit those of us that are the weakest, and these benefits can be taken away or otherwise limit our lives.

(Woman, 60–64, uses services)

The above participant was not the only one to be worried about losing services. Especially in relation to getting old, the transition to older persons' services seemed to represent a change for the worse:

The increase in functional limitations raises concerns, as I end up from being a client in Kela's rehabilitation services, to presumably a client of older persons' services, which do not sufficiently take into account the significance of disability in ageing.

(Man, 60–64, uses services)

Kela, the Social Insurance Institution of Finland, provides rehabilitation services for persons with disabilities, but most only until 65–67 years of age (*Kansaneläkelaitos* 2022). Municipal disability services do not have an age limit, but our participants seemed to be familiar with the discussion around this issue: after specifying her impairments, one participant wanted to add 'but nothing is age-related' (Woman, 70–74, service user).

It seems that many of the quotes on this theme were written by disability service users, as they described kinds of support that are only available through disability services. As noted before, the social model-guided disability services are based on a relational perspective on independence – an interdependent perspective, as Reindal (1999) noted – and perhaps these quotes demonstrate this. However, problems with disability services and worries about losing them with ageing were expressed.

Concluding remarks

In this chapter, we discussed the understandings of in/dependence through the experiences of older persons with disabilities in Finland. The participants

described their impairments, their lives, and the help they get in their day-to-day activities. Some wrote about disability services, and some noted older persons' services as well as the help they get from their children, spouses, and friends. In addition, peer support and activities provided by disability organisations were mentioned as important sources of different kinds of support. Financial resources can play a significant part in the availability of services, but in these data, there were almost no mentions of finances. However, some participants expressed fear of welfare cuts that may affect them, as it seems that the cuts 'always hit those of us that are the weakest'. When cuts are made from social services, public benefits are lost.

Even though the accounts present only a limited view, we can draw some preconditions to getting sufficient help, to be independently dependent: having knowledge of available services, and being willing to receive help, being active enough to apply for help, and sometimes being prepared to demand help. Of course, sufficient and suitable help has to exist first, and some problems with services were expressed as well. Discussions around in/dependence relate closely to getting help, be it assistance, care, or some other kind of support.

Especially the second precondition – being willing to receive help and being active enough to ask or demand help – seems relevant to discussions on in/dependence. We found that in/dependence presents itself in different ways in our data. First, fear was expressed about getting old and dependent, which was seen in a very negative light. Second, asking for help appeared to be difficult and negotiable in different ways: there was hesitation about asking for help from relatives, even though this could be negotiated through reciprocity. Justifying deservingness, most of the accounts described earlier participation in working life, only after which the respondents had started to need help. Also, a person's own activeness was raised: one needs to be active and assertive to get help. Third, help was presented as a vehicle for independence: the help, be it informal or formal, enabled being independent.

Conceptual difficulties have been recognised as one issue in bridging the two research and policy fields of disability and ageing (Leahy 2018). In this chapter, we discussed the conceptual confusion surrounding the conceptualisation of in/dependence. Our data indicate that in/dependence presents itself in varied and interconnected ways, where it is difficult to pinpoint where independence ends and dependence starts, or vice versa. In our data, there were relational manifestations of independence, but also notions of asking for help or being dependent as something very negative and undesired. The relational views of independence come close to the meanings of independence promoted by the disability movement and care ethics, whereas the negative approaches to dependence resonate with the ideal of self-sufficiency.

As seen in the accounts, having to ask for help is a difficult task: it requires admitting dependency. However, even after that step – as was noted in the accounts – receiving help requires activeness and sometimes help may not be available. In a sense, one needs to be self-sufficiently independent in claiming

dependence. In getting sufficient help, the ideal of independence as self-sufficiency seems to do harm.

Besides, or instead of, independence or dependency, several writers in disability studies as well as ageing and care research wish to refer to ‘interdependence’ (e.g., Shakespeare 2000). Interdependence recognises that all human beings are interdependent and vulnerable, as we all are connected and dependent on each other on some level. However, the conceptualisation of independence as used by disability researchers and the concept of interdependence are not poles apart: both support self-determination over self-sufficiency and recognise the connectedness of all humans (Kröger 2009). Nevertheless, in consistency with Kittay (2011), Fine and Glendinning (2005) have argued for the continuing use of ‘dependency’ in addition to ‘interdependence’ for its relevancy in, for example, recognising oppressive activities related to care.

In relation to disability, Reindal (1999) has argued that in/dependence as a dichotomy ascribes to the individual models of disability, where disability is seen as an individual (medical) issue and not as something created by the environment. Independence as interdependence, on the other hand, is more connected to the social models of disability, where disability is intertwined with the social and built environment, and issues related to disability are not individual but relational (*ibid.*). Many authors in the nexus of disability and old age have concluded that ageing research and policies reflect more the individual and medical models of disability, whereas disability studies and policies prefer the social models of disability (e.g., Era, Katsui and Kröger, forthcoming; Leahy 2021; Priestley 2006). Equally, many have argued for a ‘social model of ageing’ (Elder-Woodward 2013; Naue and Kroll 2010), a ‘social model of dementia’ (Thomas and Milligan 2018), or other socially oriented models to be applied to ageing as well.

Due to the demographic change among persons with disabilities, the need for research in the disability – old age nexus will only increase in the future. At the moment, there are still conceptual and theoretical divisions between ageing research and disability studies that need to be addressed in order to strengthen the research fields at their intersection. In our view, interdependence could be one concept that can be used to build bridges between ageing and disability. A unified framework for older persons with disabilities would be helpful to prevent anyone from falling through the service system’s safety net. Even in Finland, the happiest country in the world, there are many barriers for ageing people with disabilities to ask for and receive help. Adopting interdependence as a framework or underlying principle in disability and old age policies could help remove some of these barriers and lower the threshold to seeking and receiving necessary assistance.

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4 One step backward?

Exploring the outcomes of the COVID-19 pandemic for persons with intellectual disabilities in supported and service housing

Sonja Miettinen

Introduction

On 11 March 2020, the World Health Organization (WHO) declared a pandemic due to a novel virus that was spreading around the world and causing acute and severe respiratory illness. The virus was identified as a type of coronavirus, and the illness it caused was named COVID-19. Countries worldwide took measures to protect their citizens from COVID-19 and control the pandemic, including closure of public places, social distancing measures, assembly restrictions, face mask regulations, and quarantine mandates in case of infection. However, these protective measures can in themselves have negative effects on the psychosocial well-being of citizens. Furthermore, they can affect citizens who hold different positions in society in different ways (Shakespeare, Ndageri, and Seketi, 2021).

Before the outbreak of the COVID-19 pandemic, people with disabilities in Finland were already experiencing various types of deprivation, such as financial difficulties, unemployment, and loneliness, to a greater extent than the general population (Teittinen and Vesala, 2021). Population surveys conducted by the Finnish Institute of Health and Welfare show that the psychosocial well-being of people with disabilities further deteriorated during the pandemic and that the pandemic has had more negative consequences for people with disabilities than people without any disability (Sainio et al., 2021; Holm et al., 2021). The data also show, however, that people with disabilities are not a homogeneous group. Their experiences of the crisis vary widely (Holm et al., 2021).

This chapter explores the experiences that people with intellectual disabilities (ID) have had during the COVID-19 pandemic in Finland. This is a group that is difficult to reach through conventional surveys, which is why it is important to complement information about the impact of COVID-19 on different members of the society with studies using other, more inclusive research methods. This chapter utilises as its research material in-depth interviews with adults with ID who use housing services,

their family members, and support workers. The aim is to find out what the interviewees say about how the everyday life of residents with ID changed during the COVID-19 pandemic and how these changes affected their capabilities.

Capabilities are defined in this study following Martha Nussbaum's (2006) approach, in which they are described as opportunities to achieve valuable activities and states of being. According to this approach, there are ten central human capabilities: life; bodily health; bodily integrity; senses, imagination, and thought; emotions; practical reason; affiliation; other species; play; and control over one's environment (regarding the contents of these capabilities, see pp. 76–77). These capabilities can also be seen as basic rights of every member of society, regardless of their gender, ethnic origin, abilities, or other individual characteristics. Central human capabilities are promoted for the members of society through a two-pronged programme that involves enabling individuals to develop their personal abilities and skills on the one hand and by constructing legal frameworks, services, and supports that promote human dignity on the other.

The chapter starts by describing how Finland has tried to curb the COVID-19 pandemic and what we currently know about how these measures have affected the support provided to people with disabilities. The next section will present and analyse the interview data. After that, findings from the interviews will be described in detail. The chapter ends by summarising the results of the analysis and discussing them in terms of how Finland has succeeded in protecting the capabilities of people with ID amid a public health crisis.

Finland's strategy of managing the COVID-19 pandemic

In Finland, the first COVID-19 case was detected in January 2020 (Yleisradio, 2020). On 16 March 2020, the Finnish government, jointly with the President of Finland, declared a state of emergency due to COVID-19 (Finnish Government, 2020a). This enabled the government to adopt the powers laid down in the Emergency Powers Act and to initiate a full lockdown, including the closure of schools and most government-run public facilities, limitations on public meetings, and prohibiting outsiders from entering health care facilities and hospitals.

Due to these measures, the spread of the virus decreased, making it possible to lift the lockdown on 16 June 2020 (Finnish Government, 2020b). Since then, Finland has followed a so-called hybrid strategy to manage the corona crisis (Finnish Government, 2021). The aim of this strategy has been to curb the pandemic effectively while minimising detrimental impacts on people, businesses, society, and the exercise of fundamental rights. However, as the pandemic has ebbed and flowed, various lockdown measures have been implemented locally and regionally, in the manner outlined in the Finnish Ministry of Social Affairs and Health's (2021) Action Plan.

How has Finland taken the rights of people with disabilities into account in this strategy? There are some national guidelines that focus specifically on the needs of people with disabilities. According to one, measures to curb the COVID-19 pandemic do not override the right to receive disability services (Finnish Ministry of Social Affairs and Health, 2020a). This means that instead of terminating services, they should be reorganised so that they are safe to use. However, there are reports showing that some disability programmes, such as day and work activity and personal assistance services, disintegrated in some areas of the country at the onset of the corona crisis due to the lack of adequate plans and preparations for such situations (Nurmi-Koikkalainen et al., 2021; Hakola et al., 2021). In other words, due to the pandemic, many individuals with disabilities were left without the services and support they were entitled to.

Furthermore, other types of problems have been acknowledged. In their monthly COVID-19 briefings for the government, Finnish intellectual disability organisations raised concerns that some housing units had introduced extreme restrictions on the freedom of movement of the residents (Finnish Association on Intellectual and Developmental Disabilities [FAIDD], 2020). According to these organisations, residents had been prohibited from leaving the housing unit or receiving any visitors in it, including personal assistants and physiotherapists. The Finnish Ministry of Social Affairs and Health reminded service providers in guidance on 1 April 2020 that freedom of movement is a basic human right, and Finnish legislation allows segregation of individuals on account of life-threatening communicable diseases such as COVID-19 only if the person has been exposed to this disease and only by the order of the municipality's responsible physician (Finnish Ministry of Social Affairs and Health, 2020b). However, intellectual disability organisations continued to report cases of categorical restrictions even several months after the guidance was issued (FAIDD, 2020).

In summary, even though government policies have emphasised the protection of fundamental rights of people with disabilities in the management of the COVID-19 pandemic, there are indications that there has been a variance in the ways in which disability services have responded to the crisis on the local level. Furthermore, some of these responses may have jeopardised the ability of people with disabilities to exercise their rights. The next section explores in greater detail what kinds of experiences people with ID have had during the corona crisis.

Collecting and analysing pandemic experiences

The data utilised in this study were produced by a project “The survival and coping of persons with disabilities and persons of migrant origin in times of crisis and emergencies—Creating a new future using experiences from the COVID-19 pandemic (2021–2023),” which was funded by European Social Fund. The project involved parallel studies on the COVID-19-related

experiences of persons with disabilities and persons with migrant origin. Both quantitative and qualitative methods were utilised in studies focusing on people with disabilities. The results of studies employing quantitative methods have been reported elsewhere (Holm et al., 2021; Sainio et al., 2021). This chapter reports findings from research material that was collected through qualitative interviews. Qualitative interviews enable the interviewees to describe their experiences in their own words and to participate in determining the topics discussed in the interviews. However, qualitative interviews allow participation only for those individuals who can describe their experiences verbally, thus excluding many individuals in the category of “severe” or “profound” intellectual disability. While previous studies have used other methods, such as participant observation, to shed light on their lives (see e.g. Mietola, Miettinen, and Vehmas, 2017), it was not possible to use this method in this project, which was very time-limited and also had to operate under the conditions of COVID-19 pandemic. In practice, the only way to include the experiences of those residents with ID who were not able to describe them in their own words was to interview people who know them well—in this case, their family members and support workers.

Consequently, interviews were conducted with these three groups: persons with ID, family members, and support workers. In recruiting the interviewees, we were able to utilise the nationwide, well-established networks of the Finnish Association on Intellectual and Developmental Disabilities (FAIDD) and to contact individuals and organisations who were or had previously been cooperating with this NGO. Altogether, 25 people participated in the interviews, of which 13 were persons with ID, 8 were support workers, and 3 were parents. They were interviewed either individually or in groups. There were seven individual interviews (four with residents and three with family members) and four focus group interviews (two with residents and two with employees). In addition, there was one couple interview with a couple with ID who lived together in supported housing. The interviews were conducted by project worker Niina Sillanpää and researcher Sonja Miettinen, took place during the latter half of 2021, and lasted from 40 to 60 minutes of talking.

The residents with ID who participated in the interviews in person or through their representatives were adults whose ages ranged between 20 and 70 years. Male and female residents participated in roughly equal numbers. Those who participated in person lived either in group homes (i.e. in service housing) or semi-independently (i.e. in supported housing). All of those who participated through their representatives lived in group homes, as living in supported housing is still rather uncommon for people with severe or profound ID in Finland. The housing units of the residents were situated in four different Finnish regions (Pirkanmaa, North Karelia, Uusimaa, and Southwest Finland).

Informed consent was obtained from all participants. For participants with ID, information about the interviews and their purpose as well as data

management was provided in documents written in easy language. These were provided in advance and participants' support workers were asked to help them review the documents. At the beginning of each interview, the interviewer ensured that the participants had read and understood the documents and were willing to participate. Anonymity and confidentiality were guaranteed for all participants.

The interviews were based on a loose thematic structure. Themes included COVID-19-related changes in living conditions and how these were experienced by the residents; what kind of support they had received; whether that support had been adequate; and how they had obtained health information during the pandemic. The interviewees were encouraged to discuss these themes based on their personal experiences and in their own words.

The interviews were analysed using data-driven content analysis. The analysis started by examining singular expressions and the similarities and differences between them. These were then grouped into six main themes: (1) restrictions on movement and social contact; (2) rollback of support services; (3) narrowing everyday life; (4) psychological strain and malaise; (5) continuation of meaningful activities; and (6) continuation of meaningful social relations. The first three themes describe changes in the living conditions of residents with ID brought on by the COVID-19 pandemic. Themes 3 and 4 describe the effects of these changes on the capabilities of the residents. Themes 5 and 6 describe ways in which the capabilities of the residents were supported in the changed situation. The following sections illustrate these themes in detail.

Changes

The main changes in the living conditions of residents with ID described in the interviews fell into the category of the first two themes: restrictions on movement and social contact and rollback of support services. Both themes appeared in some form in all of the interviews. Starting from the former theme, restrictions on movement and social contact were described by the participants as rigid and expansive, as Excerpt 1 demonstrates.

Excerpt 1 (individual interviews / residents / interview no. 1)

P: I didn't go anywhere, I just stayed at home. We weren't allowed to go shopping, we weren't allowed to go anywhere but outdoors. If you wanted to go somewhere, you weren't allowed to come back to your own home for a week. Such a strict rule. For example, you had to stay one week at your parents' before you could come back to your own home. And then we had a strict ban on visitors. The parents of the residents and everyone else stopped visiting. It was quite hard, not being able to see anyone and not being able to go to work, just staying at home.

In addition to restrictions on movements outside group homes, interviewees indicated that movements inside group homes were also restricted. For example, in housing units that contained several homes within one building, the residents were not allowed to go to other parts of the building and were thus unable to “see other friends in the housing unit,” as one group home resident put it in the interview (individual interviews/residents/interview no. 4). In addition, the kitchen was among the no-go areas. This was experienced as frustrating by the interviewees because it meant they were unable to do their usual cooking (individual interviews/residents/interviews nos. 1 and 3).

In addition, all outsiders were disallowed from entering the housing units, including family members, personal assistants, and physiotherapists, which further limited the activities and social contacts of the residents. This is illustrated in Excerpt 2.

Excerpt 2 (group interviews / employees / interview no. 1)

P2: It was like, suddenly we were trapped inside with the residents. All the outsiders who had been visiting us before stopped coming in. Even the cuddle dogs, dances, everything stopped.

According to the interviews, all residents were subjected to the restrictions on movement and social contact, not just those who were quarantined due to exposure to the virus. The restrictions continued usually for about four months, but in some places even longer.

However, restrictions were not always imposed on the residents from outside. Sometimes the residents themselves choose to restrict their movements in order to avoid becoming infected or infecting others. This was the case with some of the residents living in supported housing who were themselves or whose family members were in risk groups for severe disease caused by COVID-19. By virtue of living in and having control over their own individual flats, the participants who lived in supported housing seemed to have more room for exercising discretion about protective measures than those living in group homes. This can be seen in Excerpt 3, which is from the interview with the couple living together in supported housing.

Excerpt 3 (couple interview / residents)

P1: The support worker thought that it [i.e., having visitors] was not allowed, but we thought that we’ll take in one person anyway, that we’ll take the risk. We know we were in a grey zone, but we thought that okay, you can come in.

Some of the participants criticised the restrictions in a more outspoken manner than others. One group home resident likened them to rules in

old-fashioned institutions and contended that they stemmed from an overwhelming fear of the virus (individual interviews/residents/interview no. 3). Even support workers were sceptical about whether all the restrictions were in fact necessary or well-founded. In one of the focus group interviews with the support workers (group interviews/support workers/interview no. 1), participants said that they viewed the protective measures adopted in the housing unit at the beginning of the pandemic as “nit-picking.” They also disclosed resentment over “having to act like police,” as this kind of role sharply contradicted what they thought their role should be in relation to the residents.

Another COVID-19-related change in the living conditions of the residents with ID mentioned in all interviews was the rollback of support services. This theme involves experiences of reductions or suspension of support services that the residents with ID had been using prior to the pandemic and were still formally entitled to. This change is interlinked with restrictions on social contact and movement, as the services were rolled back to limit contact that would allow the virus to spread. The participants reported simultaneous withdrawal of several different support services, such as work and day activities, personal assistance, and physiotherapy.

For some of the residents, work and day activities continued remotely, but this was not the case for everybody. In particular, those living in supported housing were at risk of losing their normal activities. The interviewed couple with ID said they had both been laid off when the pandemic started and had continued to be unemployed for half a year without any organised activities. They also disclosed that they had not done any video calls during the lockdown and appeared to be altogether unfamiliar with the technology. A third participant living in supported housing reported that he had been offered remote day and work activities but was unable to participate due to problems using the required software (group interviews/residents/interview no. 1). A fourth participant living in supported housing said that he had been able to participate in remote day and work activities thanks to help from his father, who had acquired the proper online connections for him and showed him how to use the video call software (individual interviews/residents/interview no. 2).

Participants in supported housing also talked about diminishing in-home support due to the pandemic. For example, one participant said that he had met his support workers only in the yard (individual interviews/residents/interview no. 2), and another said that their support workers had been checking only once a week on how they were doing (group interviews/residents/interview no. 2). Overall, the residents in supported housing emphasised that there had been very little contact with support workers. There was one participant for whom diminishing in-home support had resulted in having to move out of supported housing and back to her parents (see Excerpt 4).

Excerpt 4 (group interviews / residents / interview no. 1)

- P2: I lived from last year to this year at my parents', 'cause I didn't get proper help (...)
- I: Why didn't you get help from the housing unit?
- P2: They refused it. They said to me that no one gets help from us, that if you live in supported housing, you must help yourself (...)
- I: Did you have corona?
- P2: No, I didn't have corona, but they had instructions or orders, that is what they said to me, that they had to do it that way. But I think it was stupid that they refused to help me, that they wouldn't go shopping or do anything else with me. In my opinion it was quite wrong.

The situation in group homes was different in the sense that staff continued to work at these facilities and were thus continuously present in the daily lives of the residents. This allowed the staff to provide various kinds of support for the residents. For example, one resident reported that the support workers in his group home had cheered up the residents during the lockdown and that the support workers had been willing to talk with them and explain to them what was happening—when they had heard something on the news, for instance when someone had heard something on the news (individual interviews/residents/interview no. 4). In addition, the support workers in group homes often organised activities for the residents, such as baking, crafting, going outdoors, concerts, and holiday celebrations.

In these ways, the interviews showed that the COVID-19 pandemic brought on drastic changes in the living conditions of residents with ID. Many of the participants reported that over time, the restrictions on social contact and movement were loosened and support services restored. However, in one of the housing units, the lockdown was still in effect at the time of the interview—one and a half years after the onset of the corona crisis in Finland. Support workers at this residence reported that activities outside the group home were still on hold and that there was no plan to return to normal (group interviews/support workers/interview no 2). The prolonged lockdown was also mentioned by a parent whose adult daughter lives in the group home in question (individual interviews/family members/interview no. 1). This raises the concern that the COVID-19 pandemic may have caused long-term deterioration of living conditions for some individuals with ID, depending on their place of residence.

Consequences

The changes in the living conditions described above affected the capabilities of persons with ID in tangible ways. To start with, the interviewees talked about having a narrowed life. This theme was present in all interviews. First, narrowed life involved a lack of meaningful activities, which made everyday life dreary.

Second, narrowed life often also involved a lack of meaningful social contacts. The residents were often separated from their loved ones for long periods of time, which was experienced as painful by many, as Excerpt 5 demonstrates.

Excerpt 5 (individual interviews / residents / interview no. 2)

It was quite hard for me and my mum, because we are used to spending a lot of time together. This was on the top of not being able to work, not able to see my mum. It is such an important part of my life, after all.

In one of the group interviews of support workers, the participants weighed the consequences of the COVID-19 pandemic for residents with ID by comparing them with the effects on the general population. They emphasised that the narrowing of life has gone further with the former group, as exemplified in Excerpt 6.

Excerpt 6 (group interviews / employees / interview no. 1)

P3: Social contacts went to the bare minimum. This happened to some extent to everyone, of course, but in here they were totally minimised. We were able to go shopping on their behalf and such, but they didn't even have that, as running of errands and all visits of family members and friends stopped for them.

For those individuals who need support in communicating, COVID-19-related restrictions also often led to the withdrawal of their means of communication. This consequence was brought up by one family member (individual interviews/family members/interview no. 2). She reported that she had had an interpreter for her disabled daughter who was unable to speak, and the interpreter had succeeded in forming a connection with her and enabling her to express herself. But the interpreter was denied access to the housing unit for several months due to the lockdown. The mother emphasised that this resulted in her daughter being unable to describe her experiences, ask questions, and get answers during that part of the crisis.

Narrowing of everyday life also involved the sense of a loss of freedom. Several participants compared the life of the residents with ID during the pandemic to incarceration. In other words, the measures to curb the pandemic were often experienced by these residents as rules imposed on them that limited their ability to exercise control over their lives. In Excerpt 7, one resident with ID reflected elaborately on this experience.

Excerpt 7 (individual interview / residents / interview no. 2)

P: It felt really difficult, when you had been used to being allowed to do things and having freedom. Then the freedom is suddenly taken away,

and you are being told what you are allowed to do and what you are not allowed to do from the outside. I wasn't used to that. It made me anxious.

The second main effect on capabilities described in the interviews was psychological strain and malaise. This theme was present in 9 of the 12 interviews. These include seven resident interviews, one support worker interview, and one family member interview. It is thus less pervasive than the other themes described in this chapter, which indicates that there are differences among residents in regard to this type of experience. These differences will be discussed in the next section.

The theme of psychological strain and malaise involves expressions of negative emotions, such as having a hard time, being bored, or missing friends and family members. The narrated intensity of these emotions varied. At worst, they took the form of paralysing anxiety and depression. For example, the resident cited in Excerpt 7 became so anxious during lockdown that at times he was not able to do anything but lay in bed.

Sometimes the emotions that were expressed under the theme of psychological strain and malaise were described as reactions to the pandemic itself, which, after all, involves the spread of a life-threatening virus. Some residents said they were very worried that they or their loved ones would become infected. However, it was even more common to describe these experiences in the context of narrowed life. In this way, this consequence was also linked to measures used to curb the pandemic.

For residents who were unable to communicate verbally, their psychological strain and malaise were described in the interviews as recognisable changes in their behaviour and appearance. For example, one of the parents noticed that her daughter had lost her appetite and become apathetic during lockdown. Since no physiological cause had been found, the mother presumed that the lapse was psychological in origin. She viewed it as her daughter's reaction to the loss of her previously active and social lifestyle, which had at the onset of the corona crisis been replaced by "life in institution," an expression the mother used to refer to a life that is overtaken by monotonous routines (see Excerpt 8).

Excerpt 8 (individual interviews /family members/ interview no. 2)

P: It is kind of a life where you get up from bed, then eat breakfast, then wait for lunch, then wait for afternoon coffee, you don't always get it, then you wait for dinner. You won't go out because it rains or it's too cold.

The mother also described a lack of mutually rewarding and respectful interaction between the staff and the residents in the group home. According to her, such living conditions had already existed in the group home before the onset of the COVID-19 pandemic. In her view, the crisis had opened up

opportunities for improving work practices, but these opportunities were not seized in this group home, as shown in Excerpt 9.

Excerpt 9 (individual interviews / family members/ interview no. 2)

I thought then that this is a wonderful opportunity for the support workers to learn about communication and be really present in the lives of these people [i.e., the residents with limited verbal communication]. They always say that they don't have time. Well, now they had time, but it was not utilised in this way.

This observation is in line with how the support workers themselves described the situation in this particular housing unit (group interviews/support workers/interview no. 2). In addition to wishing for clearer instructions on how to act in exceptional situations, the support workers pointed out that it was important to "stop to reflect about the effects of changing situations on the residents and if there should be resources and plans that enable meaningful life inside these closed walls." This implies that such resources and plans did not exist at the time of the interview. In these ways, participants also conveyed the lack of managerial guidance and backing for the support workers in the group home.

Interestingly, the descriptions provided by support workers and family members diverge, depending on which group home the residents they represented lived in. As the next section demonstrates, support workers and family members representing residents living in a different group home from the example above expressed much more positive views about the well-being of the residents and the capacity of the staff to support the residents during the COVID-19 crisis. One way to explain these differences is to see them as ramifications of differing "group home cultures" (Humphreys, Bigby, and Iacono, 2020), which may play a role in how housing units succeed in supporting the capabilities of their residents in times of crisis.

Persistence

Not all residents experienced the corona crisis as equally distressing. For example, the couple who lived together in supported housing indicated that living through the half-year lockdown had not been overly difficult, stating that, "time went surprisingly fast." They also reflected on the factors that had enabled them to cope during the lockdown (see Excerpt 10).

Excerpt 10 (couple interview / residents)

P2: Let's say that without the dog it would have been really dull, just being at home. Getting out helped and we went for walks with it more often.

- P1: We went on one- or two-hour walks with it. That's how we had something to do.
P2: Without him it would have been really dull.

Later in the interview, the couple added that they had helped each other, pointing out that, "if we lived alone and didn't have a dog, it would have been much more awful." In other words, in their view, both their pet and their couple relationship had functioned as supportive factors during the crisis. Having some way to continue meaningful social relations and activities was a common feature in the descriptions of situations of those residents with ID who found it easier to adapt to the changes in their living conditions during the pandemic.

The relations and activities mentioned as most important in this respect varied among participants. Residents described various solitary activities they had engaged in during the lockdown that had given stimulus and structure to their days, including doing homework, listening to music, reading or listening to books, watching movies, and playing video games. Some had continued their normal day and work activities remotely. As has already been pointed out, the ability to utilise digital connections usually required residents to have support for acquiring the appropriate devices and learning how to use them—support that was not necessarily in place for everyone.

In addition, as Excerpt 11 indicates, digital connections were not always experienced as an appropriate way to maintain social contacts, even if support for using them was available.

Excerpt 11 (individual interviews / family members / interview no. 1)

P: I got a video call from the group home. There was me, the support worker, and my daughter on the call. Well, me and my daughter, we stared each other on the screen looking stupid. You know, I hold the phone in my hand and she looks at me at the other end and recognises that there is her mum. We didn't know what to do. I couldn't start signing to her through that small screen. I just tried to ask, "How are you?" She looked at me and seemed baffled [...] we never learned to use it. I said that this doesn't really work for us, I want to see her face to face.

Social relations with people living outside the housing unit were also maintained in more traditional ways. Some talked with their loved ones on the phone. In addition, face-to-face meetings were sometimes arranged in spaces where it was possible to keep distance from others, such as private flats or rooms, or outdoor spaces.

Sometimes the relations that were seen to buoy residents' spirits existed inside the group home itself. In contrast with the parent quoted in Excerpts 8 and 9, the two other interviewed parents (individual interviews/family members/interviews nos. 1 and 3) did not recognise any worrisome changes in behaviour or appearance of their adult children living in the same group

home, even though they had kept an eye out for them. Parents of both residents were confident that their adult children had thrived in the group home, having good relations with the personnel and the other residents. These parents assumed that the fact that these supportive relations remained intact during the pandemic had enabled their adult children to cope well under lockdown conditions.

The support workers at the group home in question said that they viewed the pandemic as an opportunity to nurture their relationships with the residents (group interviews/support workers/interview no. 1). The slowing down of everyday life finally gave them a chance “to do a bit more with the residents than just the routine tasks,” as one support worker put it. The support workers posited that such efforts had mitigated the impact of the lockdown on the residents. Spending more time with the residents was also experienced as rewarding for the support workers themselves.

Conclusion

According to Nussbaum’s (2006) capabilities approach, health is one of the central human capabilities that societies should promote for all their members equally. Finland has undoubtedly been relatively successful in reducing the loss of human lives and preventing the collapse of the health care system during the COVID-19 pandemic. However, from the perspective of the capabilities approach, health or any other central human capability is not more important than the other capabilities. They are all seen as equally important, which is why promoting health at the expense of other capabilities is not justifiable according to this theory. Furthermore, all capabilities, including health, should be promoted in such a way that people impacted are involved in decision-making and can make choices regarding the ways in which they develop and exercise their capabilities.

Against this background, the interviews of persons with ID and their family members and support workers that were analysed in this chapter reveal several shortcomings in the way in which the corona crisis has been managed in Finland. While governmental policies have emphasised the protection of basic human rights in times of crisis, in practice, the service system has not always succeeded in enabling persons with ID to maintain the full set of central human capabilities in this situation. Instead, many persons with ID have experienced a long-term lockdown that has significantly reduced their capabilities for social contact, rewarding activities, and self-determination. As a further consequence, some residents have also experienced deterioration in their emotional well-being, thus losing part of another important capability.

Yet the outcomes persons with ID have experienced were by no means invariable. In this study, these experiences were shaped by, among other things, the place of residence. Those participants who lived in supported housing described somewhat looser control during the lockdown than those who lived in, or represented individuals living in, group homes. Thus, the

residents in supported housing appear to have had somewhat better opportunities for making decisions about how to go about their daily lives amid a public health crisis. On the other side of the coin, they were required to survive largely on their own. In some cases, this resulted in increased dependence on their family members and even loss of the ability to live independently.

However, varying experiences of group home residents indicate that there have been differences in the organisational responses to the corona crisis not only between the types of housing services but also within them. While, in principle, the uninterrupted presence of staff allows group homes to provide continuous support for residents to survive and cope with the crisis, the analysis presented in this chapter suggests that some group homes have nevertheless been unsuccessful in reorganising their staff activities and resources for this purpose.

To conclude, the occasions of controlling, isolating, and abandoning persons with ID during the corona crisis can be seen to reflect their fragile citizenship status in Finland. To avoid taking steps backward in the development of their rights, it is important to ensure that the supports and freedoms they have lost due to the pandemic are restored as soon as possible. At the same time, more efforts should be made towards taking the varying requirements of different groups of people into account in the public planning for future crises, so that all members of society will have equal opportunities for survival and coping when the next crisis hits.

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5 The state of inclusion in the state of inclusion?

Inclusion as principled practice in Finnish basic education

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Introduction

Inclusion in education is a globally shared principle with the aim of guaranteeing, securing, and promoting the equality and equity of people by removing barriers to learning and social participation. The Council of the European Union (2018) asserted that

[e]nsuring effective equal access to quality inclusive education for all learners, including those of migrant origins, those from disadvantaged socioeconomic backgrounds, those with special needs and those with disabilities – in line with the Convention on the Rights of Persons with Disabilities (CRPD) – is indispensable for achieving more cohesive societies.

(Clause 16: 3)

Finland has secured both financial and physical access to education for all learners regardless of their backgrounds. In a practical sense, *all students* attend a school providing public compulsory education at no cost to the families – a principle that covers education from preschool and first grade to higher education. At the policy level, Finland is committed to international declarations, programmes, and agreements with the aim of guaranteeing everyone’s right to free education in their neighbourhood school as called for in the Salamanca declaration (UNESCO, 1994) and the Convention on the Rights of Persons with Disabilities (CRPD) (UN General Assembly, 2007), which was ratified in Finland in 2016.

Furthermore, as argued by Simola and colleagues (2017), the quality of Finnish basic education is an internationally well-known success story written in the recent history of Finland. This story arose after the high ranking in the Programme for International Student Assessment (PISA) over two decades ago. Regardless of a substantial decline in the results on various fronts – the most concerning being the increasing performance gap

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related to gender and socioeconomic backgrounds – Finland keeps ranking among the topcountries within The Organization for Economic Cooperation and Development (OECD) (see, e.g., Ahonen, 2021a). The quality is often attributed to university-level teacher qualifications in early childhood and basic education, firm beliefs in education and the teaching profession, the pedagogical freedom experienced by teachers, and the absence of external inspections and testing (e.g., Sahlberg, 2011; Simola et al., 2017). Also, the success story is attributed to a well-developed part-time special education system (e.g., Kivirauma and Ruoho, 2007) and other factors, such as Finland being a Nordic welfare society (e.g., Simola et al., 2017).

However, providing equal access to education with the abovementioned attributes does not denote inclusion in education outright. According to the Finnish Disability Forum survey on how people with disabilities perceive their rights being met in Finnish society as per stipulated in the CRPD (Vesala and Vartio, 2019), students with disabilities¹ experience discrimination related to pedagogical accommodation, physical accessibility, accessibility for information, and language and communication throughout their schooling (Teittinen and Vesala, 2022). In addition, experiences of being bullied and excluded seem to shadow the school experiences of people with disabilities from generation to generation (Kivirauma, 2015; Laitinen and Pietilä, 2022). Discrimination, bullying, and exclusion are examples that reflect the non-inclusive state of the school system in terms of physical, pedagogical (e.g., information, communication), and socio-emotional (e.g., safety, belonging) accessibility of education, as they are system-level phenomena that cannot be reduced to representing individual level experiences. Instead, whether access to quality education is inclusive depends on how inclusion is conceptualised as a principle and as a practice.

We understand inclusion in education as being an ongoing principled *process* – not an *outcome* – that requires commitment and dedication to be carried out through alignment between inclusive policies, culture, and practices (e.g., Danforth and Naraian, 2015). This means that the values and aims of the philosophy of inclusion in education should be the guiding principles of the letter and the spirit of education policy. These include respecting and celebrating human diversity by denaturalising normality, rejecting medical and psychological explanations of educational difficulties, and the ensuing categorisations of difference, as well as promoting equality, equity, social participation, and a sense of belonging (see Armstrong et al., 2011; Graham and Slee, 2008; Thomas and Loxley, 2007; Schuelka et al., 2019).

In this chapter, we critically discuss the state of inclusion as a principled education practice in Finland. For this purpose, we present a literature synthesis (Jaakkola, 2020) to discuss and argue the multifaceted nature of inclusion in education in Finland. By synthesising the relevant yet distinct literature from the fields of education policy, disability studies, special education, and inclusive education, as well as relevant Finnish policy documents,

we establish that inclusion in education in Finland is not as straightforward and successful as it is often presented internationally.

The focus is on comprehensive schooling, also often referred to as basic education (grades 1–9, ages 7–16). In Finland, compulsory schooling ended after basic education until 2021. Since August 2022 compulsory schooling was extended to cover the last three years of post-basic education as well, called secondary education in the Finnish taxonomy (grades 10–12, ages 16–18). Our focus is on basic education because this is the period within compulsory schooling in Finland when equality and equity are the guiding principles in providing access to the same education for all. By contrast, secondary education, which is divided into vocational or upper secondary school education (or apprenticeship training), is selective in terms of study performance and not designed to be equally accessible – it is ableist by default. For instance, students’ right to receive special education services in upper secondary school was not secured by law until 2018 nor enacted until 2021 (Act on General Upper Secondary Education 714/2018) and exclusionary vocational or apprenticeship training institutions for students with disabilities have long existed in Finland.

We will first provide an overview of the policy-level progress towards inclusion in education from the early years of Finnish independence to date, mainly focusing on 21st-century reforms and national-level initiatives relevant to understanding the state of current policy development. We will then move on to provide a critical overview of the ambiguous nature of inclusion in education at the national level, focusing on how inclusion as a principle of education practice is formed in education policy and governed to be implemented in practice. We will conclude by discussing competing ideologies that have an impact on education and challenge inclusion, followed by outlining some nationwide programmes and initiatives that illustrate the commitment in Finland to improve the basic education system on various fronts to respond better to some of the pressing barriers to inclusion in education. After all, Finnish education policy is strongly committed to reducing inequalities and meeting diversities in basic education and finding ways to change both the system and practice accordingly.

Inclusion as the agenda for special education – Progress towards inclusion in education in Finnish Education Policy

From the first basic education act to special education reform

UNESCO (2020: 25) defines inclusion as “a process that helps overcome barriers limiting the presence, participation and achievement of learners”, and equity as being “about ensuring fairness, where the education of all learners is seen as having equal importance”. It is noteworthy that whereas the civil and human rights ideal of inclusion arose from disability activism, *inclusive education* emerged from the field of special education with long historical

roots in identifying, naming, and segregating differences and disabilities, and treating, rehabilitating, or accommodating it accordingly (Richardson and Powell, 2011). It is not surprising then that in Finland, the process of inclusion and equity is the history of special education tied to reforms relating to physical and social segregation and integration.

Finland has been committed to providing education for all since the first Basic Education Act in 1921 which declared a minimum of six years of compulsory elementary schooling. However, the Act exempted some students based on their geographical location or so-called feeble-mindedness (Ahonen, 2021b; Jahnukainen, 2021). The first milestone on the path to equal access to schooling took place in the 1970s along with the Act on Basic Education Reform in 1968 (Act 467/1968). The reform secured a unified nine-year-long basic education system for all students, including students with disabilities (Jahnukainen, 2021; Kivirauma and Ruoho, 2007). Education for all was not fulfilled until the integration of students with mild and moderate intellectual disabilities from social welfare services into the comprehensive education system in 1985 followed by the integration of students with severe and profound intellectual disabilities in 1997 (Ahtiainen, Pulkkinen and Jahnukainen, 2021; Jahnukainen, 2021). Regardless of having achieved the goal of providing education for all at the system level, students with severe and profound intellectual disabilities were integrated into the system mostly by providing education in separate special schools or facilities with separate curricula (Jahnukainen and Korhonen, 2003).

Finland took significant milestones relating to inclusion in education at the end of the 1990s and early 2000s by enabling the organisation of full-time special education for students with disabilities in mainstream classes along with the current Basic Education Act launched in 1998 (628/1998). The next milestone occurred in 2007 when a committee appointed by the Ministry of Education published the Special Education Strategy (Ministry of Education, 2007). Triggered by rapidly increased numbers of students in special education in the early 2000s, the Special Education Strategy laid the ground for two significant education policy reforms in the 2010s, one concerned the special education support system and the other the funding of the special education system.

Special education reform

The Special Education Strategy (Ministry of Education, 2007) stressed the importance of developing preventative strategies and early interventions. The special education reform (Act 628/ 1998, amendment 642/2010) activated in 2011 introduced the presently existing support model in comprehensive schooling. Until 2011, support provisions were based on a two-tiered system: general and special education. Support in general education consisted of a wide range of practices applied to short-term support for every student, whereas students were entitled to special education owing to challenges

in schooling caused by disability, illness, functional deficit, or the need for mental health or social support (Thuneberg et al., 2013). The transfer to special education required an administrative decision and an Individual Education Plan (IEP), and special education could be provided in a general education classroom or in a segregated special educational setting. Part-time special education was provided in both general and special education.

As was suggested in the Special Education Strategy in 2007 (Ministry of Education, 2007), an additional middle-tier called intensified support was added in the current support model. From 2011 onwards, the three-tiered model, officially called *Learning and Schooling Support*, was implemented (Act 642/2010, Ministry of Education 2007, 27, 58). *General support* (Tier 1) consists of every action made by the classroom or subject teacher in terms of differentiation, co-teaching, as well as school-wide efforts to meet students' diverse needs for support; *intensified support* (Tier 2) consists of remedial support by the class or subject teacher via co-teaching with the special educator and/or temporal individual or small group learning in part-time special education; and *special support* (Tier 3), which requires an administrative decision, consists of specialised means of support as formulated in the IEP provided either in mainstream classes, part-time or full-time small group, or special schools (Jahnukainen and Itkonen, 2016).

The aim of this reform was to improve the provision of a continuum of services at schools by intensifying the means of support when moving from one tier to another. The reform emphasised the preventative role of the first two tiers, whereas the third tier should be considered only after the two preceding steps to support schooling were shown to be insufficient, in which case an official IEP needed to be formulated. However, there are no normative descriptions regarding what means of support should be provided in each of the tiers nor when students should move from one tier to another. Municipalities and schools possess autonomy regarding how to interpret, apply, and realise tiered support as it is a matter of municipal policy to structure and implement education at the local level (see e.g., Pesonen et al., 2015).

It is also noteworthy that since the beginning of the 2000s, diagnoses have played no official role in the Finnish support system. In addition to structural change, the Special Education Strategy also addressed the need for a conceptual change regarding students' needs for support (Ministry of Education, 2007). Identification of the need for more support as well as planning and implementation of support should be grounded on pedagogical evaluation and only supplemented with psychological or medical statements if necessary. The idea of the reform was to place the child who needs various means of support at the centre of the pedagogical environment and focus on modifying the context accordingly. Through these emphases, the responsibility for educating the heterogeneous student population shifted from the professional realm of special education to general education. A new needs-based pedagogical language was also implemented. The earlier pedagogical

discourse construed the somewhat overtly stigmatising idea of *special pupils*, putting emphasis on child characteristics that deviate from “normalcy”. The contemporary discourse communicates about *special needs*, allegedly placing the focus more on pedagogical contexts from which individual *special educational needs* (SEN) emerge. Thus, the discourse and rhetoric about *students with SEN* gained ground.

Reform of funding the special education system

The 21st-century policy reforms also had obvious ties to financial factors (see Ahtiainen et al., 2021). The government financial aid system was changed at the same time as the special education support system. In Finland, the government allocates funding for education to municipalities, but the municipalities have autonomy in how they fund education and other public expenditures. The funding of the special education system was reformed in 2010 as part of a larger reform aimed at simplifying the government transfer system for basic services (Ahtiainen et al., 2021).

Prior to the reform, special education funding was weighted, meaning that a municipality received funding from the government based on the number of students receiving full-time special education. Weighted funding was 1.5 times more than the basic funding provided per student in most of the cases, but 2.5 or 4 times more than basic funding in case of students with severe disabilities or serious illness, owing to which the duration of their compulsory education was extended. After the reform, the education providers continued receiving weighted funding only for students for whom the duration of compulsory education was extended. The proportion of these pupils has been marginal over the years. In autumn 2022, 9,7 per cent of all students received some degree of special support (Tier 3), and of these, 22 per cent had the duration of their compulsory education extended (Statistics Finland, 2023).

Before the reform, the weighted system had functioned as an incentive to identify students for full-time special education. Despite allocating funding according to special education provisions, municipalities had the freedom to allocate the funds independently for other purposes. As research points out, the weak financial situation of the municipality increased the number of students receiving special education services between 2001 and 2010 (Kirjavainen, Pulkkinen and Jahnukainen, 2014). The purpose of the funding reform was to curtail the increase in the share of students in special education as well as the growth of costs of special education service provision. In this sense, it seems to have the sought-after effect at least in the early 2010s. Research shows that between 2008 and 2014, the reform incentivised municipalities to decrease the identification rate of students receiving full-time special education; however, full-time special education and special class placements were more common in large municipalities whereas part-time special education was more common in small municipalities (Pulkkinen et al., 2020).

The socioeconomic characteristics of the municipality seem to have some influence on special education provision in Finland, as segregated placement is more common in urban, densely populated areas which are in a better financial situation (Kirjavainen et al., 2014; Pulkkinen et al., 2020). The demographic reality may also be that urban areas entail more students with disabilities and more supply and demand for segregated schooling provisions, whereas in rural areas, this might not be the case. However, the result calculations made by the National Audit Office of Finland of special education within basic education after the reform pointed out that the socioeconomic background of students receiving special education support is lower than those in general education, suggesting that municipalities with a lower socioeconomic status have more students that could benefit from special education than other municipalities but no resources to do so. The report critically concludes that the economic perspective is strongly present in the reform, which seemingly gives the state some surplus but causes the municipalities to arrange even more multifaceted education with even more dwindling resources (Valtiontalouden tarkastusvirasto, 2013).

The development plan for education and research 2011–2016 formed by the Ministry of Education and Culture emphasised the economic point of view when bringing up the demand of cost-effectiveness in education (see Ketovuori and Pihlaja, 2016). This economic perspective follows the idea of neo-liberal policy focusing on efficiency and calculation (see Rizvi and Lingard, 2010). It seems as though the reform can also be interpreted through the words of Loxley and Thomas (2001) as being antithetical to inclusion as per promoting equality and equity in education. As argued by Pulkkinen and colleagues (2020), for the education reforms to improve the support services for students and to reduce regional differences in special education services, government funding should ensure that it is possible to arrange sufficient support services within all municipalities. Thus, funding reforms should align with the aims of education reforms.

Conceptualisation of “demanding special support”

Since the enactment of the three-tiered *Learning and Schooling Support* in Finland in 2011, concerns about the inclusive education arrangements for students who often require frequent interprofessional support in their schooling arose among special education scholars. This concern was explicitly directed at schooling arrangements of students with severe mental health issues, multiple, severe, or intellectual disabilities, or Autism Spectrum Condition. Singling out this diagnostic disability grouping of students was warranted by the observation that these groups of students had so far received little attention in previous research and development projects. Thus, a research and development project called VETURI, which was funded by the Ministry of Education and Culture and undertaken in 2012–2015, introduced the concept *vaativa erityinen tuki* (verbatim translation: *demanding special*

support) (see Kontu et al., 2017; Pesonen, 2016). The idea was to conceptualise child-centred praxis provided in interprofessional collaboration (Äikäs and Pesonen, 2022; Äikäs, Syrjämäki and Pesonen, 2022).

To some extent, the conceptualisation of demanding special support is contradictory to the idea of providing pedagogical support without diagnostic premises. In this regard, it seems as if it was developed as a reaction to maintain the Finnish interpretation of inclusion that existed prior to the special education reform or to a concern about the Finnish school system being inadequately prepared for the changes the special education reform called for and brought forth. Regardless of the misleading name that paints the picture of the fourth support tier, the initial idea of the conceptualisation was not restricted to the context of special education nor tied to any tier of support, but rather it was to complement the existing tiered support by emphasising the diversity of needs for means of support that cannot be met within the pedagogical actions in the three-tiered support frame alone (Äikäs and Pesonen, 2022). For example, pupils who require interprofessional support, such as temporary hospital schooling due to a sudden traumatic event, fall under this conceptualisation.

Although the concept is neither administrative nor has a role in normative governance, it has consolidated its position in the contemporary education policy documents and practice. In 2018 the Ministry of Education and Culture and the Finnish National Agency for Education established a nationwide network called *vaativan erityisen tuen verkosto* (verbatim translation: the *demanding special support network*) or *VIP network*, which currently includes most of the municipalities in Finland. According to the network's website, the name VIP (an abbreviation of *very important person*) stands for students *in need of demanding special support* and cultivates the child-centred focus of support provisions (VIP Network, 2022). The VIP network is coordinated by the National Centre for Learning and Consulting (Valteri), which operates all six government-owned special schools – so-called Valteri schools – under the Finnish National Agency for Education. The overall aim of the network is to establish best practices to support the principle of providing schooling for every student in their neighbourhood schools by developing *demanding special support* practices as well as preventative and early support in early childhood and comprehensive education (VIP Network, 2022).

Ambivalence of inclusion as principled education practice

Ambiguous education policy guidance about inclusion in education

Policymaking is a fundamentally political process. It involves major trade-offs between values. Public policies in education simultaneously deal with a range of values, such as equality, excellence, autonomy, accountability, and efficiency. This means policymakers must assemble, organise, and order

them, configuring them in such a way as to render them somewhat consistent. This requires privileging some values ahead of others and re-articulating their meanings (Rizvi and Lingard, 2010, 72). Policy is constructed and presented discursively in public documents, like legislation or core curriculum (see Ozga, 2000).

The guiding norms of education include laws, decrees, and the National Core Curriculum (NCC). Inclusion has occurred in the Finnish education system through a commitment to the international human rights frameworks such as the Salamanca Declaration (UNESCO, 1994). The Salamanca Declaration described inclusion as the new norm in education and demanded the principle that all students attend their neighbourhood schools. The values of the Salamanca Declaration are manifest in the Finnish Basic Education Act, perhaps the clearest in section 6 (Act 628/1998, 6 §), which emphasises the principle of allocating students to their own teaching group and neighbourhood school by means of various flexible arrangements – unless their best interests necessitate transfer to another teaching group or school in order to provide support – and in section 2 (Act 628/1998, 2 §), in which the promotion of equality and equity are declared to be the aims of basic education.

However, the term “inclusion” is not mentioned in the Basic Education Act at all (see Jahnukainen, 2011; Vitikka et al., 2021). A task force was established by the Finnish Ministry of Education and Culture to develop a programme to promote equal learning opportunities in early childhood, preschool, and basic education (Oikeus oppia [in English: Right to Learn] development programme). In their interim report, they stated that despite the lack of inclusion being mentioned in the Basic Education Act the views of inclusion are conveyed through sections 3 and 17 (Vitikka et al., 2021, 34). These sections state that the education should be based on the child’s age and prerequisites for learning in a way that promotes the child’s healthy growth and development (Basic Education Act 628/1998, 3 §) and that special needs education is to be organised in line with the student’s interests and the prerequisites for the local education provision either within a general educational setting, a part-time or full-time special educational setting, or in some other suitable setting (Basic Education Act 628/1998, 17 §). The idea that these sections convey the views of inclusion is contestable. As Tervasmäki (2022) argues, section 3 outlines the principles for sensitive, child-centred education provision without taking a stand on how to implement this based on the principles of inclusion, whereas section 17 is merely about the special education placement ranging between integration and segregation.

Thus, Finnish education legislation does not explicitly provide a guide about inclusion in education. At a normative level, the term inclusion is mentioned only once in the NCC determined by the Finnish National Agency for Education. NCC is a significant educational policy document that defines the guiding operating principles of compulsory education, including values,

objectives, and general principles and subject syllabi of basic education that every teacher and education provider must implement. It creates the foundation for local curriculum work within the municipality and individual school levels. Despite the common framework, municipalities and individual schools have considerable freedom to interpret the curriculum in their own fashion (Lähdemäki, 2019).

The only reference to inclusion in the NCC is located under the section “Mission of basic education”. To paraphrase the core message of this lone passage,

schools comply with principles of inclusion in order to support every pupil’s learning, development and wellbeing, and to build positive identity as a human being, learner and community member in a society built upon the values of democracy and human rights.

(Honkasilta et al., 2019, 487)

In principle, the rhetoric in the NCC seems to live up to the inclusive ideology: equality and participation are the most cited values in the NCC which contains crucial content for building inclusive *modus operandi* at schools (Pihlaja and Silvennoinen, 2020; Tervasmäki, 2022; Vanhanen, Vainikainen and Mäkihönko, 2022).

However, guidance about inclusion in education in the NCC is ambiguous. First, inclusion is not conceptualised in the NCC (Honkasilta et al., 2019; Pihlaja and Silvennoinen, 2020; Tervasmäki, 2022) nor is any of the content including principles and practices explicitly linked to inclusion (Tervasmäki, 2022). In his in-depth discourse analysis on NCC, Tervasmäki (2022) points out how this translates into a contradictory portrayal of the ideology of inclusion. On the one hand, the values of social inclusion are present in the emphasis on accessibility of teaching and learning, individualised supports, as well as school cultures built on values of equity and equality, anti-discrimination, participation, interdependency, and reciprocity. On the other hand, this view of inclusion as social participation is weakened by simultaneously equating principles of inclusion with integration and segregation, paradoxically portraying inequality, exclusion, and marginalisation as both a threat to inclusion in education and a potential means of implementing it (Tervasmäki, 2022).

Second, the NCC is strongly written on ableist premises. As pointed out by Pihlaja and Silvennoinen (2020) and Tervasmäki (2022), the valued participation in the NCC is based on the idea of an active, self-regulated, and autonomous pupil while the message regarding the role of the community in which this valued participation ideally takes place remains weak. The scarcity of instructions on how to differentiate teaching for students with disabilities is another example of ableism in the NCC, sustaining the dichotomy between general and special education as pedagogical provisions and as professions (Tervasmäki, 2022). However, the most explicit form of ableism is the silence

on disability, as diversity is linked to language and cultural diversity (Pihlaja and Silvennoinen, 2020; see also Tervasmäki, 2022).

Current education policy in Finland seems to present a discrepancy between ideologies of inclusion and education excellence (Pihlaja and Silvennoinen, 2020, see also Lempinen, 2018; Silvennoinen and Pihlaja, 2012). Paradoxically, while inclusion as a concept and as a guiding ideology in education has established its central position in Finnish education policy (Hakala and Leivo, 2015), the status of learners with disabilities has increasingly been marginalised in normative policy documents. Researchers have pointed out the trend of reducing or omitting content and guidance related to learner diversity and diverse ways, pace, and the development of learning throughout the development processes of education policy documents (Ketovuori and Pihlaja, 2016; Tervasmäki, 2022). This reflects a change towards harder values in education policy as per neoliberal ideology, which emphasises competence, efficiency, and good learning outcomes and cultivates the idea of an economically independent citizen as being an ideal subject. Students with diverse cultural and language backgrounds seem to be worthy of paying attention to in the current neo-liberal education policy governance pegging the question, where do students with disabilities fit into this picture of inclusion in education?

Ambivalence of inclusion as principled practice

Education for all *preferably* provided in neighbourhood schools forms the liturgy of inclusive education in Finland, and municipalities are responsible for organising basic education accordingly. In this regard, student placement is one example reflecting the state of inclusion in education at the system level. As previously mentioned, the general trend of serving students who need more individualised support at schooling since the late 1990s has been towards full-time or part-time placement in general education, and the number of special schools² has decreased steadily (Jahnukainen 2011; 2021; Statistics Finland, 2023). However, no information is available on whether some special schools are closed instead of them being merely administratively merged with a general education school into one school unit while in practice still physically existing as its own service provider. According to the Register of Educational Institutions, some schools that have been merged are listed as mainstream schools (Statistics Finland, 2022a), yet they provide education full-time in separate small groups or classes based on the disability grouping of students (e.g., autism) or other rationale.

According to Statistics Finland (2023), in autumn 2022 9,7 per cent of all students received special support (Tier 3). Among them, 34 per cent received education full-time in a segregated setting in grades 1-6 and 29 per cent in grades 7-9, either in special schools (5,7 per cent) or in separate small groups or classes in schools listed as mainstream schools. In addition, another 32 per cent of students in the third support tier in mainstream schools received

education in an exclusionary setting part-time. Statistics Finland (2023) defines inclusion on the basis of placement, depicting that inclusion means that the student receives education 80–100 per cent of the time in a general education group. Although this statistical approach does not distinguish inclusion from physical integration (i.e., placement into a general education group without adequate support), and there is a huge difference between students spending closer to 20 per cent or closer to 100 per cent of their time in small classes or groups outside general education, it is illustrative of the use of separate small groups and exclusionary classrooms in Finland, which is among the highest in Europe (Saloviita, 2020a).

It is reasonable to argue that aspects of the Finnish basic education system are inclusive, in that students have relatively easy access to additional support without formal evaluation and diagnostic labelling of any sort, and the additional support for students with specific learning difficulties (i.e., reading, writing, and mathematics) has almost from the beginning been organised as part of general education and focused on early intervention (Itkonen and Jahnukainen, 2010). However, the extent and the way of using separate schools, classes, and a small-group pull-out model calls into question whether the Finnish interpretation of inclusive education contrasts with the notion of inclusive education. Of course, this depends on the view on inclusive education.

On the one hand, the Finnish approach is in line with the Salamanca Declaration's idea of education for all adapted to diverse individual circumstances (UNESCO, 1994). On the other hand, CRPD article 24 states that people with disabilities are not to be excluded from the general education system based on disability (UN General Assembly, 2007). In Finland, students with severe disabilities tend to be taught separately from the mainstream education (see Pirttimaa et al., 2015; Niemi, Mietola and Helakorpi, 2010). Also, parents seem settled and satisfied with the segregated schooling arrangement; the more support the children need and receive, the less important neighbourhood school allocation is (Lempinen, 2018). This is a revealing example of the paradox of inclusion in education. The child-centred approach provides education and a sense of belonging among peers deemed “special” while the system simultaneously excludes from social participation among peers deemed “normal” (see, e.g., Niemi et al., 2010).

The education policy provides an abstract, vague, and ambivalent notion of inclusion let alone weak guidance about implementing inclusion in education, leaving the idea of inclusion as principled education practice open to interpretation. Not surprisingly, municipalities and schools practice inclusion in education at the local level in several ways; some implement inclusive education by re-organising and resourcing practices accordingly, some practice physical integration by placing students in a mainstream education setting while cutting resources from special needs education provisions, and some maintain the already established segregating special education

practices (Lempinen, 2018; Lintuvuori & Rämö, 2022; Lintuvuori, 2019; Jahnukainen 2015). This ambivalence in practices also becomes reflected in teachers' accounts in Finland (Honkasilta et al., 2019) and those of the news media (Pitkänen et al., 2021). Inclusion is deemed unsuccessful based on attempts to provide cost-effective equal access to education by closing special schools or groups followed by integrating students formerly taught in these settings into mainstream classrooms without adequate means of support. Simultaneously, inclusion is portrayed as being feasible through resourcing, planning, and implementation of education provision (Honkasilta et al., 2019; Pitkänen et al., 2021).

The wide variation among municipalities originates from contextual causes, such as local political traditions, special education policies, and existing services (Lintuvuori, 2019). This is illustrated in the study by Laakso and colleagues (2022) on how the heads of local education departments perceive inclusion and inclusive leadership in basic education. The researchers found that the leaders generally have a positive attitude about inclusion, but they conceptualise inclusion in varying ways. Most respondents viewed special schools and classes as part of inclusive education; the discrepancy in views concerned the suitability of these education settings for students with learning difficulties, intellectual disabilities, or problems with the social and emotional spheres of schooling or life (Laakso et al., 2022). This view is shared by Finnish teachers and teacher students (Takala, Pihlaja and Viljamaa, 2022). Several studies have reported that teachers are critical of the idea that a non-segregated approach to inclusive education benefits all students, particularly students with intellectual disabilities (Moberg et al., 2020) or manifesting emotional or behavioural problems (Moberg et al., 2020; Yada and Savolainen, 2019; Saloviita, 2020a). The latter grouping of students also tends to be excluded from participatory practices more easily than other peers (Butler and Naukkarinen, 2017).

Furthermore, local education leaders regarded their job as mainly being about management, passing the leadership on implementing inclusion from municipalities to individual schools (Laakso et al., 2022). With schools possessing strong autonomy in interpreting and implementing inclusion as principled practice, it seems obvious that if the head teachers and teachers are not committed to inclusive education, the chances of success are greatly reduced. In her dissertation on school strategy and management, Kristiina Engblom-Pelkkala (2018) concludes that although head teachers are a central figure in school management, they face challenges doing so because of multiform oversight by the government, the way the school is treated as a unit of the economy, and the difficult-to-change practices of the school. In practice then, “our school systems do not become inclusive before the key players, namely teachers, have acquired the needed positive attitudes as well as the necessary skills and beliefs in their abilities to implement [inclusive education] successfully” (Moberg et al., 2020, 112).

Polarised teachers implementing inclusion in education

Teachers' attitudes to inclusion in Finland are ambivalent, polarised, and predominantly negative (Saloviita, 2020a, 2020b), and so is the media representation (Pitkänen et al., 2021). In turn, this translates into pre-service teachers' ambivalent and negative attitudes about inclusion (Takala et al., 2022). This ambivalence is well illustrated in a large sample size study on teachers' attitudes about inclusion, which found that despite the vastly negative attitude about inclusion – 20 per cent even strongly opposing inclusion – a small majority of teachers accepted the basic idea that students who need individualised means of support at school can be effectively instructed in regular classrooms (Saloviita, 2020a). Thus, it seems as if teachers simply do not want to get rid of segregated education arrangements even when acknowledging it as being pedagogically possible. In this regard, research on teachers' accounts (Honkasilta et al., 2019) and media representation (Pitkänen et al., 2021) reveal how inclusive education is both supported and opposed by referring to pedagogical and resource factors. Additionally, inclusive education is supported by arguing for students' right to equality and equity and opposed with arguments regarding teachers' strain, workload and lack of adequate expertise, and contemporary inclusive practices at local schools violating all students' rights to quality education (Honkasilta et al., 2019; see also Pitkänen et al., 2021; Saloviita 2020a, 2020b; Takala et al., 2012).

Pre- and in-service teachers feel unprepared for implementing inclusion in education when it comes to teaching students with intellectual disabilities or manifesting emotional or behavioural problems (Moberg et al., 2020; Yada and Savolainen, 2019; Saloviita, 2020a; Savolainen et al., 2012; Takala et al., 2012; Paju, 2021; Saha and Pesonen, 2022). Although teachers' experiences of unpreparedness cannot solely be addressed in teacher training, these issues are currently scantily addressed in teacher education programme curricula (Kärnä et al., 2022; Gagnon, Honkasilta and Jahnukainen, 2023; Närhi et al., 2022). Pre-service class and subject teachers study approximately five credits (i.e., one course) worth of special needs education contents as part of their mandatory course work (300 credits), at best providing them with an introduction to evidence-based instruction and differentiation. This hardly addresses the competence needs in schools.

Teachers' negative stance about inclusion in education let alone its predominance seems rather absurd when inclusion is viewed as actions taken in response to concerns over equality, equity, and desegregation rooted in social justice. Teachers, education administrators, and policymakers are undoubtedly not against these values, principles, and human rights when opposing or being negative about inclusion in education. Although teachers do regard aspiration to create inclusive schools and pedagogies as prerequisites for inclusion in education (Honkasilta et al., 2019) – suggesting that not all colleagues are that willing – the apparent negative stance and

polarised views on inclusion are not solely based on attitudes but on teachers' experiences regarding access to adequate resources. Coming from teachers, these resources include

smaller class/group sizes, universal design, adaptable learning environments, pedagogical materials, teaching staff resources (e.g., special education teachers, co-teachers, supply teachers, school attendance and personal assistants), student welfare staff resources and services, updating career training and work supervision for teachers, and paid time for planning of teaching or co-teaching in an inclusive learning environment.

(Honkasilta et al., 2019: 489)

Teachers' positive attitude about inclusion has been associated with their use of various instructional strategies and differentiation methods, a higher sense of teacher efficacy, co-teaching, and viewing special classes as inappropriate places for students who need individualised means of support (Kokko, Takala and Pihlaja, 2021; Saloviita, 2019; Savolainen, Malinen and Schwab, 2020; Saloviita, 2018). Adequate pre- and in-service training, reliance on one's own competence and involvement in the assessment and planning processes of individualised support (i.e., experience in teaching students with disabilities), confidence in support networks, and access to educational resources (e.g., co-teaching; in-classroom teaching assistant) are all associated with having a positive attitude about inclusion (Lakkala and Thuneberg, 2018; Saloviita, 2019, 2020b; Savolainen, Malinen and Schwab, 2020; Paju, 2021). In addition, age, gender, and teacher category are associated with positive attitudes in that younger, female, and special education teachers are reported to be more positive than older, male, and subject and classroom teachers (Lakkala and Thuneberg, 2018; Saloviita, 2019, 2020b). Thus, demographic (cultural) factors aside, teachers' stance reflects system-level factors deriving from how municipalities or schools interpret and implement inclusion in education.

Existing barriers to inclusion in education

The reduction of inclusion into the SEN discourse

It is argued within inclusive education and disability studies scholarships that to emphasise inclusion as a policy discourse advocating social justice, democracy, and equity, inclusion in education should be disentangled from market-based neoliberal values of governance and disassociated from the SEN discourse (Graham and Harwood, 2011; Danforth and Naraian, 2015; Glazzard, 2016; Schuelka et al., 2019). The well-meaning child-centred discourse focuses on the disability within the child instead of the disabling social, political, institutional and material factors.

The discourse on inclusion in education in Finland is the discourse on SEN, not so much a discourse on rights beyond that of access to education and

learning or being a valued profitable member of a society. In this discourse, whether cultivated by education policy documents (e.g., Tervasmäki, 2022), local education leaders (Laakso et al., 2022), school principals (Jahnukainen, 2015), teachers (Honkasilta et al., 2019) or news media (Pitkänen et al., 2021), the rhetoric of physical integration, and assimilation is equated with inclusion. The ethical and philosophical foundation of promoting social participation characterised by equality and equity among peers is muffled by pragmatic concerns regarding how to organise teaching for a group of students characterised by their so-called special needs in an education system originally not designed for including *them* in their peers deemed “normal”.

As pointed out by Pitkänen and colleagues (2021) in their analysis of news media discourse on inclusive education, this arbitrary group of students with SEN is portrayed as a homogenous group of students with either behavioural problems or an immigrant background. As in the education policy discourse (Pihlaja and Silvennoinen, 2020), disability remains marginal in what is generally communicated to people about inclusion in education via news media (Pitkänen et al., 2021). In other words, inclusion is reduced to SEN, yet disability inclusion is excluded from the picture.

The contemporary rhetoric on *demanding special support* has to some extent further strengthened this trend. The well-meaning yet confusing conceptualisation of the child-centred interprofessional collaborative praxis distinguishes students categorised under certain pathological diagnoses from the already vague concept of SEN by creating a distinction between SEN and demanding SEN. This is already seen in practice. Äikäs and Pesonen (2022) report how the concept of demanding special support is regarded as a fourth tier of support by some teachers and students in teacher education. This can potentially strengthen the professional boundaries, related responsibilities, and segregated practices between different agents in support of provisions of schooling. Thus, to clarify the concept and its role in relation to the existing three-tiered support system, scholars have later suggested describing the concept in the literature as *vaativa monialainen tuki* (verbatim translation: demanding interprofessional support) or *vaativa tuki* (verbatim translation: demanding support) (Äikäs and Pesonen, 2022; Äikäs, Syrjämäki and Pesonen, 2022) and use the concept *significant support* in English (Äikäs et al., 2022).

As per suggested by scholars, the concept will change in the near future within the compulsory schooling as a result of the development programme called *Oikeus oppia* (in English: Right to learn) initiated by the Ministry of Education and Culture. The concept *demanding interprofessional support* will be adopted in both early childhood education and basic education (Alila et al., 2022) whereas in vocational education *demanding special support* is already a legal requirement for students with severe learning difficulties, disabilities or illness (Opetus- ja kulttuuriministeriö [OKM], 2019), and six institutions alone are permitted to organise demanding special support in a segregated setting (Opetushallitus [OPH], 2021). Thus, in vocational

schooling, the concept is strongly segregative whereas it is not yet known in early childhood and basic education wherein the concept will settle between the boundaries of segregation, integration and inclusion, and with what outcomes.

While changes in nomenclature may communicate better about or clarify the core idea of praxis under conceptualisation, they do not address the issue of whose voice is being represented. The language of “demanding (special) support” or “special needs” is not supported in the language of the CRPD. This is simply because they gain meanings vis-à-vis ableism and established typical practices (e.g., Vehmas, 2010). In other words, so-called needs – that is means of support that likely represent the viewpoint of professionals authorised to name what the subject’s support needs are (see, Honkasilta, 2017) – are described as *special* because they deviate from the business-as-usual practices and established norms and normative expectations for being, functioning, and performing. Also, this bureaucratic nomenclature tends to be used as identity categories and as such comes with stigmatising effects (e.g., Honkasilta 2019; Niemi, 2022). In this regard, as the rhetoric of *children with SEN* emerged along with the special education reform, so has the rhetoric of *children with demanding SEN* emerged in vernacular in recent years in the field of education (see, Äikäs and Pesonen, 2022). Instead, the CRPD uses the term *reasonable accommodation* with the following definition:

[N]ecessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

(CRPD, Article 2)

The language of CRPD is relevant when discussing the support provisions within the framework of inclusive values in education. It is particularly relevant in the context of conceptualising *demanding (special or interprofessional) support*, since apart from the notion of reacting to sudden needs for support, these concepts are based on singling out certain disability groups as per the medical model of disability. In their definition of reasonable accommodation, the disability advocacy movement built on disability activism refrains from imposing a burden on service providers while seeing the varying needs for support being met. This begs the question about what the provision of reasonable accommodation determined as special, demanding, or significant is based on: is it available resources, institutional operating cultures, attitudes, the number of services or service providers, or what?

Both the contemporary concept demanding special support and the forthcoming demanding interprofessional support encapsulate the viewpoints of service providers, education policymakers, administrators, and teachers, not the viewpoint of individuals who rely on reasonable accommodation to function in schooling and/or participate in it as a valued member. At best, the

contemporary conceptualisation and its proposed alternatives communicate that administering a support network is demanding owing to existing system-level structures. When child-centredness is promoted or advocated through disability labels (SEN, demanding special support) and diagnoses (intellectual disability, autism), and coordinated by institutions operating special schools, the question remains about the extent to which the child-centred focus – the flagship of Finnish education – enables segregation and exclusion to be maintained under the banner of promoting inclusion in education.

The vicious circle of the ambiguity of inclusion in education governance

Inclusive ideology portrays a risk for the status quo prevailing in school cultures and professional practices in Finland (Paju, 2021; Mäkinen, 2018; Pitkänen et al., 2021). Successful inclusion in education requires strong simultaneous top-down support (e.g., policy) and bottom-up support (e.g., teachers) (e.g., Pesonen et al., 2015). Presently, resistance of both the status quo and inclusion in education emerges from both the top and the bottom.

One conclusion of Birgit Paju's (2021) dissertation on factors influencing the collaboration of teaching staff to develop so-called inclusive teaching practices (i.e., pedagogies that enable social participation and learning) was that the development of inclusive practices is demanding due to the existing historically evolved contradictions between the boundaries of general and special education. Similarly, Hakala and Leivo (2015) concluded their investigation on the contradictions between an inclusive education ideology and the national education policy in Finland that the implementation of inclusion has been slow due to the national policy having been cautious and burdened by this dual system. This cautiousness creates a vicious circle, as Saloviita (2020a) concludes:

the negative climate towards inclusion prevents the legislation that would guarantee adequate resources for mainstream teachers who have students with support needs in their classrooms. The lack of legal guarantees, in turn, prevents negative teacher attitudes towards inclusive education from changing.

(Saloviita, 2020a: 64)

Not only do varying practices at the municipality level reflect the lack of clear education policy governance but also the lack of willingness to lead towards inclusion in education from the top-down.

Inclusion in education could be promoted by pre- and in-service teacher training with particular emphasis on special educational knowhow and adequate resourcing to support teachers, students, and their families, as well as restructuring collaborative pedagogical practices and interprofessional support networks (e.g., Paju, 2021; Äikäs and Pesonen, 2022; Gagnon, Honkasilta and Jahnukainen, 2023). This requires a more explicit commitment to leadership towards inclusion in education in policy, local

practices, and in teacher training programmes at universities. The Finnish education system is not governed for implementing inclusion in education through interprofessional collaboration that could provide support for all students in their neighbourhood schools in ways that would ensure social participation and a sense of belonging in that very school.

Towards clearer principles for promoting inclusion in education

A recent report by UNESCO (2020) on how inclusive education has been globally implemented and promoted 25 years after the Salamanca Declaration outlines the following six recommendations to inform actions that should be taken to promote inclusion and equity within education systems: (1) establish clear definitions of what is meant by inclusion and equity in education; (2) use evidence to identify contextual barriers to the participation and progress of learners; (3) ensure that teachers are supported in promoting inclusion and equity; (4) design the curriculum and assessment procedures with all learners in mind; (5) structure and manage education systems in ways that will engage all learners; and (6) involve communities in the development and implementation of policies that promote inclusion and equity in education.

The threat of inclusion being a watered-down cost-saving agenda has been acknowledged by policymakers, and actions to promote inclusion better are on the horizon. The Ministry of Education and Culture launched a two-year development programme in 2020 called *Oikeus oppia* (in English: The right to learn) to improve the quality and equality in basic education. The aims of the programme targeted at strengthening (1) equality in education and learning outcomes (e.g., socioeconomic, regional, and gender factors in learning outcomes); (2) the existing Learning and Schooling support provision system and pupils' well-being (e.g., best practices to promote inclusion and three-tiered support); and (3) the quality of teaching (e.g., pre- and in-service teacher training) (Ministry of Education and Culture, 2022a). These measures would assist in striving to establish effective operation models for consideration in the preparatory work of new reforms aimed at securing the neighbourhood school principle, positive discrimination funding, and free basic education (Ministry of Education and Culture, 2022a).

Based on the final report of the programme (Alila et al., 2022), it appears that inclusion as a principled practice will be strengthened in education policy in a range of ways (also, Poikola, 2022; Pihlaja, 2022). The need for defining inclusion in the basic education act as the premise and value system in preschool and basic education is recognised, and practices supporting these premises are planned to be clarified in the next NCC. Also, the final report shows that the tiered Learning and Schooling support system will be strengthened in the Basic Education Act and the NCC by providing clear definitions and guidance for their implementation (Alila et al., 2022). Thus, forthcoming changes are likely to address the ambivalence and ambiguity

caused by the current lack of normative descriptions regarding the implementation of the tiered support system.

As for ambivalence practices, the Ministry of Education and Culture has also supported many projects aimed at developing inclusion in education at all stages of the education system, and action plans to improve the inclusive mode of operation in local schools (e.g., co-teaching, multi-sectoral, and interprofessional collaboration and consultation) and in teacher training programmes. One example is the HOHTO project (2021–2022), the aim of which is to strengthen the special educational skills, as well as the technological and pedagogical skills of teacher educators to support their well-being and learning in the profession (see Ministry of education and culture, 2022b). In addition, regardless of the conceptual critique of the demanding special support presented in this chapter, the concept has helped to summon the will to develop school systems through the national VIP network, which plays a significant role in these future steps towards improving inclusion in education (Ministry of Education and Culture, 2022a). The idea of establishing a national network that provides consultation and support for schooling and learning in collaboration with local schools is promising if ambitiously governed according to the letter and spirit of inclusion.

Concluding remarks

The aim of inclusion in education should go beyond ideas, structures, and practices currently conceptualised through the rhetoric of “inclusive education”, “special education”, “special needs”, or “integration” (Schuelka et al., 2019). Such conceptual rhetoric reflects and strengthens the distinction between mainstream, special, and inclusive and maintains the idea of inclusion being about providing education for marginalised and/or disadvantaged groups either into mainstream education (i.e., inclusive education setting) or as part of segregated education (i.e., special education setting). As depicted by Schuelka et al. (2019: xxxiii) in their introduction to “The handbook of inclusion and diversity in education”, “inclusive education is meaningful only when embedded in understandings about community and communality; only when seen as both reflective of, and as creating, inclusion in society”. A positive sense of belonging and identities, health, safety, acceptance, learning, recognition, and friendships, as well as meaningful societal participation and contribution, including employment opportunities, are all part of inclusion in society and thus are aims for quality education. In turn, class, gender, race, and disability, racialisation, ableism, disablism, and hetero- and cis-normativity, as well as geographic location, poverty, and resource allocation are examples of intersecting issues that pose barriers to inclusion in education (Schuelka et al., 2019).

This chapter has highlighted how varied the inclusive educational arrangements can be due to the interpretation of policy by municipalities, principals, and teachers. These different actors are bringing their experiences,

values, and professional norms into their interpretation of policies and pedagogical practices which impacts the state of inclusion in diverse ways. So far, regardless of the political liturgy of strong commitment to inclusion in Finland, the vagueness of the conceptualisation, the reducing of inclusion to a special education agenda cultivated through (demanding) a special needs discourse, and the lack of centralised governance of the fundamental ideals of inclusion in education pose a threat of watering down the agenda of inclusion.

In line with Armstrong and colleagues' (2016) notion that when the term inclusion is used in diverse ways with varying meanings it becomes meaningless, we are concerned whether inclusion or inclusive education are (on the verge of becoming) politically correct empty signifiers in Finnish education policy. It appears that changes to improve inclusion in education are gradually taking place in Finland at the policy level. It remains to be seen how the notion of inclusion in education will be formulated in policy documents and how will the principles of inclusion be interpreted, governed, and implemented in practice.

Notes

- 1 The survey did not use a predetermined disability classification. Respondents reported disabilities related to sensory, physical, and cognitive impairments, sign language, neuropsychiatric disorders, intellectual disabilities, or other factors (progressive neurological conditions, sensory defensiveness, epilepsy, brain damage, or mental health problems) (Vesala and Vartio, 2019).
- 2 A total of 60 special schools existed in 2021 with 3500 students (Statistics Finland, 2022b).

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6 Media Representations of Disability¹

Marjaana Hakala and Hisayo Katsui

Introduction

In Finland, the legal basis of the rights of persons with disabilities lies in the United Nations' Convention on the Rights of Persons with Disabilities (United Nations' Convention on the Rights of Persons with Disabilities [UNCRPD], 2006) which was ratified in 2016, the Constitution of Finland (731/1999), the Non-Discrimination Act (1325/2014), the Act on Special Care for People with Intellectual Disabilities (519/1977), the Disability Benefits Act (570/2007), the Act on Disability Services and Assistance (380/1987), and the Occupational Safety and Health Act (738/2002). The legal foundation is indeed comprehensive. Currently a significant disability legislation reform is also underway, which aims to strengthen the participation, equality, and self-determination of persons with disabilities and to secure adequate, high-quality services based on individual needs (Ministry of Social Affairs and Health, 2022). On the policy level, the legislation on the rights of persons with disabilities is already officially quite good in Finland, but the problem is the realization of these rights in everyday life (see Vesala and Vartio, 2018). Disability is one of the most common grounds for discrimination reported to the Non-Discrimination Ombudsman (Non-Discrimination Ombudsman, 2018). Many persons with disabilities experience discrimination due to a lack of knowledge and negative attitudes. For example, the employment rate of persons with disabilities is low in comparison to their level of education. About 80 per cent of persons with disabilities are currently unemployed, even though 60 per cent have completed secondary education or have a higher education degree (Non-Discrimination Ombudsman, 2018: 6, 9). Obstacles to employment can be caused by employers' lack of information on available support, and by prejudices and negative attitudes (Non-Discrimination Ombudsman, 2018: 9; Kyröläinen, 2020: 40). Persons with disabilities also experience discrimination at all levels of education, starting from preschool (Teittinen and Vesala, 2022). The attitudinal climate affects their feeling of safety and many encounter harassment and hate speech (Ministry of Social Affairs and Health, 2018: 28). For equal participation of persons with disabilities, a change in attitudes is needed in Finnish society.

This requires awareness raising, education, and active use of legal remedies (Non-Discrimination Ombudsman, 2016: 100).

Attitudes towards persons with disabilities are influenced by the socio-cultural environment, childhood experiences, socio-economic status, interaction with persons with disabilities, feelings related to physical differences, and the stereotypes associated with disability (Livneh, 2018: 15–28; Braathen et al., 2021: 34; Nario-Redmond, 2010). The media are significant influencers of attitudes. The presence of the media in people's daily lives has increased, and as a result, people's attitudes, opinions, and values are increasingly influenced by them (Nieminen and Pantti, 2009: 14–17, 101, 118–121; Seppänen and Välvirronen, 2012: 41, 90–97). The UNCRPD (2006: Article 8) urges State Parties to raise awareness of disability and to combat stereotypes and prejudices by encouraging the media to portray persons with disabilities in a manner that respects and promotes their right to self-determination, participation, and equality. The importance of media representations in changing attitudes towards persons with disabilities was also mentioned in a publication of the Ministry of Economic Affairs and Employment on the structural barriers to employment of persons with disabilities (Kyröläinen, 2020: 11, 15, 43). Thus, the media affect our ideas of humanity, normality, and good life in general, and through this they influence how disability is understood and how persons with disabilities are treated.

According to a survey conducted by IRO Research in 2022, Finns consider reliability and expertise to be the most important characteristics of news media and current affairs media and believe that newspapers play a significant role in promoting democracy and social issues (Aaltonen, 2022). A survey conducted in 2021 as part of the RARE X Diversity research project (RARE Media, 2022) examined what Finns think of diversity in the journalistic media. Of the respondents, 59.1 per cent claimed that the journalistic media do not describe Finnish society well enough, and 96.1 per cent believed that they should promote diversity. These findings not only imply the importance of these media in the formation of people's perceptions and truths but also set a demand for them to provide even more reliable and realistic information in the future. Journalists also have an ethical obligation to strive for truthful reporting and to respect everyone's human dignity (Council for Mass Media, n.d.). For these reasons, the focus of this study was on the journalistic media. Previous studies of the representations of disability in these media have mostly focused on analysing different kinds of media representations (e.g., Pesonen et al., 2020; Swanljung, 2019; Eriksson et al., 2016; Kastikainen and Lehtonen, 2015; Randelin, 2014; Mattsson, 2010). For example, according to the findings of Mattsson (2010), persons with intellectual disabilities are often presented as passive objects of action. Eriksson's et al. (2016) study findings concerning portrayals of athletes with disabilities imply that disability is not approached as a social phenomenon

but as stories of the individual. According to Kastikainen and Lehtonen's (2015) findings, disability can be represented in the media as 'an otherness', 'a compensable feature', 'a challenger of social norms', 'a positive way of being', or 'a life change'. The perceptions of persons with disabilities themselves regarding this media representation have been studied less.

The objective of this study was to examine (1) Finnish disability organizations' opinion of the representations of disability in the Finnish news; magazine media, and current affairs programmes; (2) what kind of representations the organizations would prefer to see in these media; and (3) how the organizations think media representations could be influenced. The content of this chapter is based on the research data from 9 semi-structured interviews of 11 representatives of Finnish disability organizations who are also members of the Finnish Disability Forum, which is the umbrella organization of the Finnish national organizations of persons with disabilities. Seven interviews were conducted with one interviewee, while two were with two interviewees who represented the same organizations. The data were examined using theory-driven content analysis. The following section introduces the theoretical framework, which takes a social constructionist approach to disability and presents different paradigms of disability, previous research findings, and the concepts of self-determination, participation, and equality. The third section presents the methodological choices, data, and ethical considerations. The fourth section presents the results. Before the conclusions, we discuss how media representations could promote diversity and the social status of persons with disabilities in society through participation.

Theoretical framework

Disability as a social and cultural construction

The social constructionism theory emphasizes the meaning of language, ideas, and values as the basis of material conditions—language not only describes reality but also creates it (see Vehmas, 2005; Hughes and Paterson, 1997; Rembis, 2019; Oliver, 1996). According to the social constructionist approach, the definition of disability and how persons with disabilities are treated fluctuate over time, depending on historical and cultural contexts. The social status of persons with disabilities reflects society's perception of humanity, normality, and a good life and depends on whether the attitudinal, environmental, and political structures that maintain inequality are questioned or renewed in society (Vehmas, 2005, 2012). This chapter, and the study on which it is based, approaches disability as a social and cultural construction. However, it also considers the postmodern criticism of how all dimensions of disability cannot be explained by only social factors (Vehmas, 2005) and understands disability as a multifaceted, complex phenomenon.

Paradigms of disability

The UNCRPD (2006, preamble) defines disability as

an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

However, the concept of disability is problematic. The definition varies depending on the context, and even experts, researchers, disability organizations, and persons with disabilities have different opinions. Several approaches to disability emphasize either an individual, social, or legal perspective (see Katsui, 2020). This section summarizes different approaches to disability. However, it must be acknowledged that the following are theoretical distinctions only; reality is often mixture of many co-existing approaches.

The moral model, the charity-based approach, and the medical model of disability are very individual-oriented perspectives. According to the moral model, disabilities and illnesses result from individuals' immoral actions (Vehmas, 2012). The charity-based approach understands persons with disabilities as passive objects requiring help and pity and as victims of their defective bodies (Vehmas, 2005; Katsui, 2020). The medical model defines disability as a result of physical and psychological impairments and a restricted ability to perform an activity within the range considered normal for a human being. This definition leads to medical and administrative solutions which emphasize medical treatments and rehabilitation (Oliver, 1996; Katsui, 2020).

The social model of disability understands disability as a collective experience in society that results from discriminating structures, such as attitudinal and environmental barriers. However, the social model has been criticized for not considering the diversity of disability (Oliver, 1996; Katsui, 2020). The biopsychosocial model has a more holistic perspective and combines elements of the medical and social models of disability. In addition to the health status of the individual, this model also emphasizes other individual and environmental factors, such as having a family, access to work, available services, and assistive devices. WHO's International Classification of Functioning, Disability and Health (ICF), for example, represents this model (Katsui, 2020: 11; Mitra and Shakespeare, 2019; Finnish Institute for Health and Welfare, 2021; World Health Organization, n.d.). However, the model has been criticized for its health-centred approach and not sufficiently considering personal and environmental factors; its narrow understanding of well-being; and its sparse attention to agency (Mitra and Shakespeare, 2019). The capability approach of Sen (1993, 1999, 2009) and Nussbaum (2000), which should be understood in terms of people's capabilities, functioning,

opportunities, freedoms, and rights, in turn offers a broader idea of well-being and participation (Katsui, 2020: 11; Mitra and Shakespeare, 2019).

The human-rights-based approach is a continuum of the social model and focuses on the implementation and realization of the human rights of persons with disabilities (Katsui, 2020). The political model of disability is an extension of the social model and the human rights model. It understands disability as a lack of rights and persons with disabilities as citizens whose personal problems stem from surrounding structures of society that disregard the rights of people with disabilities (Katsui, 2005).

In addition to these approaches, disability can also be seen as an identity issue and a minority group issue. The affirmative model does not consider physical impairments and disabilities a tragedy but sees them as an opportunity to build a positive identity as an individual and as part of a community formed by persons with disabilities. The ideal is an accessible society in which persons with disabilities have equal rights and opportunities but which also values diversity (Swain and French, 2000). Disability can also be understood as cultural pluralism. For example, many deaf people do not consider deafness a disability but believe they form a minority culture with its own language, history, and institutions (Savtschenko et al., 2010). The minority group model focuses on civil rights. This approach sees the poor social status of persons with disabilities as a result of social discrimination, for which one solution is a legislative reform (Vehmas, 2005: 110).

When it comes to Finland, that is part of the Nordic Welfare States, a relational model of disability is also important to acknowledge. This model conceptualizes disability in the mismatched relationship between the person and the environment (Tossebro, 2004). Disability is relational, relative, and contextual based on the principles of citizenship and equality that are exemplified in the Normalization ideology of 1960s (Traustadóttir, 2009). This led to the disability policy and services in the 1970s including deinstitutionalization without separating impairment from disability, as was the case in the UK disability models.

Media representations of disability

Disability is a very broad concept, shaped and contextualized by time and environment. The media for their part can influence how disability is understood by either reproducing or questioning stereotypes and approaches to disability. Shakespeare (1994: 287) has stated that cultural representations of disability portray persons with disabilities as objects rather than subjects. Building on Clogston's (1990) work, Haller (1995) has listed eight typical models of the representations of disability in the media in the context of the US media. Five of these models (numbers 1–3, 5, and 6) are created by Clogston (1990), which Haller (1995) has expanded by creating three additional models (numbers 4, 7, and 8). The models are divided into traditional models, which can be considered negative representations that emphasize

individual and medical approaches to disability, and progressive models, which present disability in a more positive light and emphasize the social and legal perspectives. Haller (1995: 29–30) summarizes the theoretical models as follows:

Traditional Models

- 1 *Medical Model*: Disability is presented as an illness or malfunction. Persons with disabilities are considered passive and dependent on health professionals and treatment.
- 2 *Social Pathology Model*: Care and support are considered a gift, not a right. Persons with disabilities are presented as disadvantaged.
- 3 *Supercrip Model*: Persons with disabilities are presented as superhumans because they can live an ordinary life despite their disability.
- 4 *Business Model*: Persons with disabilities and their issues are considered costly to society and businesses. Making society accessible is not worth the cost.

Progressive Models

- 5 *Minority/Civil Rights Model*: Persons with disabilities are seen as members of the disability community, which has legitimate political grievances. Accessibility to society is a civil right.
- 6 *Cultural Pluralism Model*: Persons with disabilities are seen as multifaceted. They are portrayed as persons without disabilities and their disabilities do not receive undue attention.
- 7 *Legal Model*: Discrimination against persons with disabilities is wrong, and these people have legal rights that should be addressed.
- 8 *Consumer Model*: Persons with disabilities are presented as consumers and a market area. Making society accessible is profitable because it reduces the need for assistance and increases consumption if persons with disabilities have better access to work.

Although Shakespeare's statement and Clogston's and Haller's classification are relatively old, they are still relevant. For example, according to Barnes and Mercer (2010: 193), traditional models appear in media representations more often than progressive models in the UK context. Many studies have also shown that the mainstream media and movies still emphasize the medical approach, as they often present persons with disabilities as objects of care, pity, and charity; as victims or as abnormal (Soffer et al., 2010; Chen et al., 2012; Conn and Bhugra, 2012; Haller et al., 2012; Eriksson et al., 2016; Diffrient, 2017) or, in contrast, as heroes (Soffer et al., 2010; Haller et al., 2012; Eriksson et al., 2016; Diffrient, 2017). These approaches can also be seen in the media representations produced by persons with disabilities or their families in social media (Stamou, Alevriadou, and Soufla, 2016;

Kannisto, 2019), although some of them use media to question and criticize the medical model (Cocq and Ljuslinder, 2020; Thoreau, 2006), and the heroic approach arouses conflicting feelings among them (Kannisto, 2019; Zhang and Haller, 2013). However, besides these there are several other approaches to disability that emerge in the media content produced by them, such as the biopsychosocial model (Thoreau, 2006), the social model, the minority group model, the cultural pluralism model (Cocq and Ljuslinder, 2020), and the affirmative model (Stamou, Alevriadou, and Soufla, 2016). These more progressive approaches to disability have also started to appear in representations produced by media professionals, such as the cultural diversity (Pesonen et al., 2020), minority group (Chen et al., 2012), and human-rights-based approaches (Haller et al., 2012: 59). Persons with disabilities are also given more humane and realistic roles (EnglandKennedy, 2008), and the language used in their representations increasingly respects their personality and agency (Haller, Dorries, and Rahn, 2006; Wilkinson and McGill, 2009). The studies mentioned above were conducted in Finland (Pesonen et al., 2020; Kannisto, 2019; Eriksson et al., 2016), Sweden (Cocq and Ljuslinder, 2020), the USA (Haller, Dorries, and Rahn, 2006; EnglandKennedy, 2008; Conn and Bhugra, 2012), the UK (Wilkinson and McGill, 2009; Thoreau, 2006), Canada (Haller et al., 2012), Israel (Soffer et al., 2010), Taiwan (Chen et al., 2012), and South Korea (Diffrient, 2017). People from 18 different countries participated in Zhang and Haller's (2013) study. Stamou, Alevriadou, and Soufla's (2016) research data were collected from Facebook groups using Greek, English, and French languages. Findings show that persons with disabilities are not a homogeneous group, and that disability is explained and presented in many different ways.

Methodology and ethical consideration

This is a qualitative study based on the primary interview data. The content of this chapter is based on 9 semi-structured interviews of 11 individuals from Finnish disability organizations who are also members of the Finnish Disability Forum. Disability organizations and their representatives have good knowledge of their members and their diverse voices and thus were selected to be interviewed, so that the diverse views including critical and/or analytical views could be heard in this study. Their citations are marked by the codes SP1–11, meaning Study Participant 1–11. Neither the organizations nor the interviewees are described in any detail because it was agreed with the participants that any information that could possibly identify them or the organizations they represent would not be revealed. All the interviews were conducted by the first author. The organizations themselves selected one or more participants from their staff to represent them in the interview. The participants received the main questions of the interviews in advance, so that they were able to reflect on their opinions and discuss the questions with other employees of the organization beforehand. The questions concerned

the organization's attempts to influence the media representations of disability; organization's opinions about current media representations of disability produced by journalistic media; and organization's opinions about which kind of media representations would increase awareness and promote the realization of rights of the persons with disabilities and their inclusion in society. The questions also included a table that briefly introduced different approaches to disability (Figure 6.1). Based on this figure, it was discussed with the interviewees which kind of approaches to disability are seen or are not seen in the media from their opinion; which approaches they consider preferable or to be avoided; and whether there are contradictions in the use of some approaches. We collected the data during the summer of 2021 via video conference (Zoom) due to restrictions related to the COVID-19 pandemic. The interviews lasted between 73 and 106 minutes, on average 93 minutes. They were recorded, after which they were transcribed and analysed using ATLAS.ti software. We removed any identifiable information from the texts during the transcription process, after which we destroyed the recorded data.

The Finnish Institute for Health and Welfare (2022a) has more than 60 Finnish disability organizations listed on its website, and so our data could not fully cover the experiences and opinions of them all. Moreover, we cannot rule out that the answers could have been guided by the organizations' desire to highlight definitions and presentation methods of disability that promote the interests of their own group. However, different interviewees repeated certain themes and issues in the data, so they still offered important information on and perspectives to the contents of the media representations of disability, and how they could be developed.

The data used in the study were analysed using theory-driven content analysis (Eskola, 2018: 182; Vuori, 2021). The social constructionist approach to disability, the different paradigms of disability, previous research findings on the media representations of disability, and the key concept of self-determination formed the theoretical framework that guided the analysis phase. The right to self-determination means the right to life, personal liberty, autonomy, equality, integrity, and security (Finnish Institute for Health and Welfare, 2022b; UNCRPD, 2006; Constitution of Finland 731/1999). Topo (2013: 5–7) presents several dimensions of self-determination: (1) access to information, (2) decision-making, (3) opportunity to implement decisions, (4) sense of capability and use of capabilities, and (5) privacy. Based on the principle of the self-determination, this study made a methodological choice to focus on the voices and experiences of persons with disabilities and their representative organizations regarding media representation of disability.

Table 6.1 presents how these theoretical concepts were operationalized in this study that is based on the interviews to representatives of Finnish organizations of persons with disabilities.

The common ethical values of science are the production of new information, independence, objectivity, accuracy, adherence to scientific research methods, respect for human dignity and self-determination, informed

INDIVIDUAL APPROACH	SOCIAL APPROACH	RIGHTS-BASED APPROACH
<p>Moral Model</p> <ul style="list-style-type: none"> Disability as a result of immoral or bad behavior 	<p>Social Model</p> <ul style="list-style-type: none"> Distinction between impairment and disability Environmental barriers Attitudinal barriers 	<p>Human Rights-based Approach</p> <ul style="list-style-type: none"> Human rights: obligations and fulfillment Persons with disabilities as rights-holders
<p>Charity-based Approach</p> <ul style="list-style-type: none"> Need for help Persons with disabilities as objects of charity and pity 	<p>Political Model</p> <ul style="list-style-type: none"> Disability as a lack of rights Persons with disabilities as citizens whose problems stem from surrounding structures of society that disregard their rights 	
<p>Medical Model</p> <ul style="list-style-type: none"> Impairments, diagnoses, diseases Treatment, rehabilitation Professionals' opinions 	<p>Minority / Civil Rights Model</p> <ul style="list-style-type: none"> Accessibility to society is a civil right Persons with disabilities as members of the disability community, which has legitimate political grievances 	
<p>Biopsychosocial Model</p> <ul style="list-style-type: none"> Health conditions, personal factors, environmental factors Bodily functions, participation 		
<p>The Capability Approach</p> <ul style="list-style-type: none"> Quality of life and wellbeing Freedom and right to different capabilities, functioning and opportunities Personal factors, resources, structural factors 		
<p>Supercrip Model</p> <ul style="list-style-type: none"> Survival stories Persons with disabilities as superheroes or as special 	<p>Cultural Pluralism Model</p> <ul style="list-style-type: none"> Diversity Persons with disabilities are portrayed as persons without disabilities Disabilities do not receive undue attention 	
<p>Social Pathology Model</p> <ul style="list-style-type: none"> Need for support, which is considered a gift, not a right Persons with disabilities as disadvantaged 	<p>Consumer Model</p> <ul style="list-style-type: none"> Accessibility is profitable if persons with disabilities have access to work and society, they can consume more and they need less assistance 	
<p>Business Model</p> <ul style="list-style-type: none"> Accessibility is not worth the cost Persons with disabilities and their issues are costly to society and businesses 		
<p>Affirmative Model</p> <ul style="list-style-type: none"> Disability as a feature that can be celebrated and can enrich life Positive social identities, both individual and collective The ideal is an accessible society in which persons with disabilities have equal rights and opportunities, but which also values diversity 		
<p>Nordic Relational Approach</p> <ul style="list-style-type: none"> Disability is relational, relative, and contextual based on the principles of citizenship and equality 		

Figure 6.1 The key elements of and main differences between the models and approaches to disability.

Sources: Clogston (1990); Haller (1995); Katsui (2020); Mitra (2006); Mitra and Shakespeare (2019); Nussbaum (2000), Savtschenko et al. (2010); Sen (1993, 1999, 2009); Swain and French (2000); Finnish Institute for Health and Welfare (2021); Vehmas (2005); World Health Organization (n.d.); Traustadóttir (2009).

Table 6.1 Operationalization of theoretical framework

<i>Theory/concept</i>	<i>Questions for the data</i>	<i>Categories of analysis formed on the basis of coding</i>
Social constructionism	<p>What kind of language is used in media representations of disability according to the interviewees?</p> <p>What kind of language should be used according to the interviewees and why?</p>	Language
Paradigms and models of disability	<p>What kind of approaches to disability appear in media representations and what effects do they have according to the interviewees?</p> <p>Should some approaches be favoured or avoided in representations according to the interviewees? Are any contradictions associated with some of the approaches?</p>	Approaches to disability
Roles and agency	<p>In what kinds of roles do media representations portray persons with disabilities according to the interviewees?</p> <p>In what kind of roles should they be portrayed according to the interviewees and why?</p>	Roles and agency of persons with disabilities
Self-determination	<p>What kind of media representations would not reproduce the negative stereotypes of disability according to the interviewees?</p> <p>What kind of representations would increase awareness and respect and strengthen the self-determination, participation, and equality of persons with disabilities according to the interviewees?</p> <p>Who appears in the media representations of disability and who does not according to the interviewees?</p> <p>What things affect media representations of disability according to the interviewees and what means are there to influence?</p>	Presentations and themes Language Roles and agency of persons with disabilities Approaches to disability Persons with disabilities and other groups Influencing factors and means

consent, confidentiality, privacy, assessment of the consequences of research, and the avoidance of harm (Kuula, 2015: 18–19; Hirsjärvi and Hurme, 2008: 20, 41). We followed all these principles in this study. Participation in the interviews was voluntary for everyone. Before conducting the interviews, a cover letter and a consent form were sent to the representatives of disability organizations. These documents described the topic, objectives, practical issues, and data management of the study. At the beginning of the interviews, these were repeated orally, and consent was confirmed.

The main objective of the study was to produce information to clarify and strengthen the social status of persons with disabilities. This was greatly influenced by the fact that the first author is the parent of a child with a disability. A genuine, shared interest in a common cause contributes to an open and authentic atmosphere, although being an insider may also make either the interviewer or the interviewee assume that the other person understands things in the same way, which may lead to misunderstandings (Juvonen, 2017: 346–347, 354). For these reasons, the first author's personal connection to the subject was stated in the interview request sent to disability organizations.

Results

Perceptions about the current media representations of disability in the Finnish media

This part presents and analyses how the interviewed representatives of disability organizations perceive media representation of disability. According to the interviewees, although diversity and versatility have increased in the Finnish news media, magazine media, and current affairs programmes, they still tend to be part of the social structures that perpetuate negative stereotypes and discriminate against persons with disabilities. All the approaches presented in Figure 6.1 were seen in the media representations of disability to some extent, but usually, several approaches occurred side by side in the same story. According to the interviewed disability organizations, the medical model, the social pathology model, the charity-based approach, the supercrip model, and the social model of disability are all emphasized in the media. In other words, the interviewees expressed that traditional approaches are still more prominent than progressive approaches. The moral model is rarely directly observed, but the interviewees associated this model with times when parents of children with disabilities are asked whether they knew about the child's disability during pregnancy, or in discussions on matters related to fetal alcohol spectrum disorders (FASDs), noise injuries, or the parenting of persons with an intellectual disability.

SP6: The social pathology emerges, also heroism and medicine. These are things that come up strongly in the media.

SP7: Typically, in the media, concrete things appear more and abstract things less. Due to this (...) environmental obstacles are an easy topic. And then individual stories, hero stories, how someone survives despite their disability. Then charity (...) pity related to “inspirational porn” may also occur. Sometimes also diversity (...) persons with disabilities are represented as persons without disability and that’s a good thing.

According to the interviews, persons with disabilities are often portrayed in either strong admirable roles as heroes, fighters, and survivors; as passive objects of charity, care, and pity; or as sufferers, victims, and cause of expense. Disabilities often receive undue attention, but persons with disabilities are also increasingly portrayed as ordinary people, especially as *experts by experience* (*kokemusasiantuntija* in Finnish). Based on the data, persons with disabilities who are active or public figures, or have a good socio-economic status, usually appear more in the media than those who are in a socially weaker position or are members of some other minority group. Those who express themselves verbally are also more often interviewed than those who communicate in sign language or via alternative communication means, such as persons who are deaf, persons with profound intellectual and multiple disabilities, or persons with complex communication needs. The interviewees assumed this is because journalists find it challenging to deal with the lack of a common language or using an interpreter. They felt that the media’s interests vary according to whose issues are currently topical in society.

According to the interviewees, more appropriate and politically correct language and terms have been increasingly used in recent years, and old-fashioned terms are used less. Nevertheless, terms and concepts may be used incorrectly or inappropriate terms such as *cripple*, *deaf mute*, and *invalid* and medicalized or passivating language such as *suffers from disability*, *despite disability*, or *wheelchair-bound* can still be heard. Words or diagnoses that describe disabilities are often used as nouns instead of adjectives; for example, *the blind* instead of *persons who are blind*, in which case the disability acts as a determining factor instead of being one characteristic among others.

SP3: (...) a person with intellectual disability is used [nowadays]. Or in general, such concepts that show that now we are talking about people whose one characteristic among others is an intellectual disability. (...) [because] essentializing and (...) categorical language is (...) alienating and othering.

According to the data, media representations may sometimes involve unnecessary confrontations between persons with disabilities. Confrontations may also occur between persons with disabilities and persons without disabilities. The interviewees speculated that this may be partly due to the media’s

tendency to use confrontation as a rhetorical device but also due to competition for services or hierarchical attitudes towards different impairments.

SP3: When a person with a physical impairment tells their story, and it's a tragic and touching survival story, and its closing words are 'Luckily, I can still think—I haven't disappeared anywhere as a person.' There's something tricky about that. What if the impairment is really in that area? What's the value of that person then?

The data revealed that media representations of disability are also often one-dimensional, unrealistic, sensational, and lack contextualization, intersectionality, and depth, although there are exceptions. The interviewees believed that the reasons for simplistic or inappropriate representations were lack of knowledge, prejudice, attitudes, time pressure, insecurity, limited story length, and competition for audience. Table 6.2 presents how disabilities and persons with disabilities are currently most commonly represented in the Finnish media according to our study findings.

Preferred media representations of disability

Our interviewees wished that the cultural pluralism and human-rights-based approach in particular could be seen more in the media representations of disability. They argued that the media should try to normalize diversity by presenting persons with disabilities in different life situations and contexts in which the subject is not disability. They continued that disability should be presented as one characteristic among others and not be unduly emphasized.

SP7: A neutral approach to disability would be best. That it's a normal difference that appears in society.

SP9: We have to understand that persons with disabilities are everywhere. We have to understand that they are not just receiving services but are also employees. They are students. They have families.

Regarding the human-rights-based approach, the interviewees felt political and structural perspectives should be analysed more and the reasons why some human rights are not being realized in the lives of persons with disabilities should be investigated.

SP7: (...) [we] should look at broader trends and structures and not just concentrate on failures, because usually failures are the tip of the iceberg of some wider problem.

Other recommendable approaches to disability in the data were the social model, the consumer model, and a future-oriented approach. As regards the

Table 6.2 Current media representations of disability according to the data

<i>Approaches</i>	<i>Language</i>	<i>Roles</i>	<i>Groups</i>	<i>Presentations</i>
THE MOST COMMON APPROACHES: <u>Traditional</u>	MORE APPROPRIATE LANGUAGE AND MODERN TERMS IN RECENT YEARS	THE MOST COMMON ROLES: <u>Strong and admirable</u>	PERSONS WITH DISABILITIES: <u>Seen more</u>	MORE DIVERSE AND VERSATILE REPRESENTATIONS IN RECENT YEARS
Medical model	BUT ALSO:	Hero	Active, strong, good socio-economic status	BUT ALSO:
Social pathology model	Incorrectly used or inappropriate terms	Fighter	Public figures	Unnecessary confrontation
Charity-based approach	Medicalized or passivating language	<u>Passive objects</u>	Express themselves verbally	One-dimensionality
Supercrip model	Impairments/ disabilities as nouns instead of adjectives	Sufferer	<u>Seen less</u>	Unrealism
<u>Progressive</u>		Victim	Socially weaker	Lack of contextualization
Social model		Object of charity, care, and pity	Members of some other minority group	Lack of intersectionality
		<u>Cause of expenses</u>	Communicate in sign language or with alternative communication means	Lack of depth
		<u>Expert by experience</u>		Sensationalism
		<u>Ordinary person</u>		

social model, the organizations wished that the media would focus more on the attitudinal barriers of society. In relation to the consumer model, persons with disabilities should be presented as active, productive members of society. A future-oriented approach was mentioned in one interview, referring to the need for public discussion on what kind of society persons with disabilities would like to live in and how to achieve this.

The social pathological and the moral models of disability were seen as approaches to avoid according to the interviewees. For example, in relation to FASD, the interviewees felt that instead of moralizing about a mothers' substance use, the focus should be on structural issues such as the availability of treatment.

SP10: The moral aspect is scary because it makes us think that some people are good and others are bad. Or that some are entitled to rights and benefits, and others are not.

The rest of the approaches were considered controversial. The medical model should not be dominant, but it is still seen as necessary to discuss and for raising awareness of identifying diagnoses, prevention, rehabilitation, treatments, assistive devices, and services. However, these issues have to be addressed from many perspectives, because 'how people with disabilities experience it can be completely different from how the rehabilitation sector sees it, and it is important to discuss this contradiction, that doctors do not understand them and their needs (SP6)'. The biopsychosocial model was seen as too health-centred, but on the other hand, issues related to the functional ability and participation of persons with disabilities, such as individual needs and the importance of environmental factors and support should be covered in the media. Thus, the capability approach seemed to be preferable to the biopsychosocial model.

Regarding the charity-based approach, it was emphasized that pity is not a good thing but that compassion and desire to help are acceptable, and the need for help may be a reality for some persons with disabilities. In one interview, the participants said that the media could highlight the activities of disability organizations more, as well as the fact that 'many persons with disabilities themselves work as volunteers and that charity and participation is not only for celebrities and rich people (SP10)'. The traditional business model was not considered acceptable, but the economy and costs could be discussed in the media if the focus was on the long-term effects and benefits of accessibility instead of on short-term costs.

The minority group model was seen as contradictory because of the heterogeneity of persons with disabilities. The organizations pointed out that all persons with disabilities did not form a unified group or subculture, and that smaller groups may feel they form their own minority culture. Using the affirmative model as an approach could have a positive effect on the understanding and appreciation of diversity in society. However, the

organizations also highlighted how, although some people perceive their disability as a positive characteristic, others might have impairments that cause pain or restrict their ability to function. In this sense, a relational approach to disability is relevant. Moreover, emphasizing positive aspects, for example, describing special features related to the autism spectrum, may strengthen existing stereotypes. Along the same vein, the organizations regarded the heroic approach as highly contradictory—as creating one-sided, unrealistic perceptions of disability and rehabilitation. However, they did also recognize the importance of role models and examples.

SP7: (...) I think that people in our society, including people with disabilities, depend on examples (...). [They] really affect what we consider possible career choices or what we don't consider possible. [They] really affect our perspectives and how we think about our place in society and our opportunities. (...) that if this power of example could be strengthened in such a way that people with disabilities would be presented as different actors.

In one interview, the global approach to disability was mentioned in a wish that the media would discuss the situation and the rights of persons with disabilities in other countries. However, there was also concern that the superiority of Finland would be emphasized in relation to other countries, which could lead to questioning current benefits and possibly result in accessibility and services no longer being demanded.

According to the organizations, the media representations of disability and the language used in them should be neutral or positive. They argued that on a general level modern, official terms approved by disability organizations should be used. However, it is also important to ask persons with disabilities for their opinions on the language because they have different preferences regarding how their disability is referred to. Based on the data, persons with disabilities should be portrayed as active, ordinary people, such as citizens, consumers, parents, and employees. Although the organizations considered the role of expert by experience meaningful, they wished that persons with disabilities would more often also be seen as experts of subjects other than disability.

SP3: We don't want to produce an image of persons with a disability as victims who need a savior. We want to highlight their ability, agency, citizenship, and equality, and not cling to a diagnosis.

The interviewees emphasized that persons with disabilities are a heterogeneous group and that issues related to disability are often complex. Therefore, contextualizing, sensitivity, and use of multidimensional approaches, including the relational approach to disability, were considered important in the media representations of disability. Both experiential and expert knowledge are

important to create comprehensive, realistic representations, although some issues might not be easy for persons with disabilities to speak about in public. In this case, journalists could consider whether having an experience expert was really necessary, or whether it would suffice to interview a representative of disability organizations. The organizations also argued that it is important to ensure that persons with disabilities are not undermined, silenced, or censored by others, for example, family members, personal assistants, staff of housing services, or experts.

Table 6.3 summarizes the recommendations for media representations of disability based on the findings. All the interviewed organizations were interested in influencing the media on disability representation issues, even though none of them currently had media guidelines and only one establish them after this study in 2022. The data revealed many other possible means by which the media could be directed in the desired way. For example, organizations could give interviews and find interviewees; send press releases; provide information and feedback; write responses; show an example through their own media content; educate, monitor, and analyse the media; and have a media strategy. One interviewee told us how they had made a complaint to the Council for Mass Media, to no avail. Indeed, filing complaints was not considered the most constructive way of influencing. Media professionals for their part could discuss the contents and preferences in advance with their interviewees, ask for and receive feedback, reflect on their prejudices and working methods, and increase their awareness of disability using a multi-dimensional and investigative approach, identifying disability groups that are missing from the representations, and hiring persons with disabilities to work in the media production teams. According to the interviewees, persons with disabilities could also boldly give feedback on the interview processes or representations and demand that programmes concerning them not be produced without their input.

Discussions

The findings of this study based on the interviews to nine disability organizations show that traditional approaches emphasizing an individual perspective to disability are more prominent than progressive approaches that emphasize social and legal perspectives. This is congruent with Barnes and Mercer's (2010: 193) statement about media representations of disability in England. Nevertheless, media representations are increasingly approaching disability in more versatile ways, especially from the perspective of the social model and environmental barriers. This finding conforms to those of previous studies presented in the theoretical framework, according to which more progressive approaches have started to appear in media representations in different countries (Chen et al., 2012; Haller et al., 2012; England Kennedy, 2008; Haller, Dorries, and Rahn, 2006; Wilkinson and McGill, 2009).

Table 6.3 Recommendations for media representations of disability according to the data

<i>Approaches</i>	<i>Language</i>	<i>Roles</i>	<i>Groups</i>	<i>Presentations</i>
RECOMMENDABLE:	RECOMMENDABLE:	RECOMMENDABLE:	RECOMMENDABLE:	RECOMMENDABLE:
Cultural pluralism	Neutral or positive language	Active member of society	Persons with disabilities with different kind of impairments in different life situations who are missing from the current representations	Normalizing diversity
Human-rights-based approach	Disability as an adjective	Ordinary person		Multidimensional and intersectional approaches
Political and structural approach	Modern official terms approved by disability organizations	Rights-holder		Investigative journalism
Social model		Citizen		
Capability approach	Asking about language preferences of persons with disabilities	Role model		Realism
Consumer model		Expert by experience		Contextualizing
Future-oriented approach		Expert of other fields		Sensitivity
Nordic relational approach		Member of media production team		
CONTROVERSIAL:				
Medical model				
Biopsychosocial model				
Charity-based approach				
Business model				

Minority group model	AVOIDABLE:		AVOIDABLE:	AVOIDABLE:
Affirmative model	Old-fashioned terms		Persons with disabilities are undermined, silenced, or censored by others	Unnecessary confrontation
Supercrip model	Disability as a noun	Passive object		One-dimensionality
Global approach	Medicalized or passivating language	Cause of expenses		Unrealism
AVOIDABLE:		Superhero		Sensationalism
Social pathological model	Language emphasizing suffering			
Moral model	Degrading language			

These results are consistent with those of previous Finnish studies. For example, according to Pesonen et al. (2020), Finnish newspapers mainly present autism spectrum disorder (ASD) from an informational or clinical point of view, to educate the public. They also found four other themes of medical and societal ASD reporting: (1) MMR vaccination controversy as a foreign problem, with the message that Finns can trust their health care providers, (2) employment obstacles, (3) criminal behaviour, and (4) ASD as a cultural and neurodiversity. Eriksson et al. (2016) examined newspaper texts covering athletes with disabilities which mostly understood disability through the body and its capacity, or survival narratives. Some stories also contained power relations and social hierarchies that were based on distinctions between normal and deviant. However, other representations focused only on the sports performance itself or tried to convey the ideology of equality between parasports and other sports. Thus, these two studies also found that both traditional and progressive models appear in the Finnish media. They also confirm the tendency to confrontations and hierarchies in the media representations of disability. As part of the RARE X Diversity research project, media professionals and researchers were interviewed about the diversity and inclusiveness of Finnish journalistic media. The interviews showed that although the discussion on diversity is now being addressed, prevailing power structures are still easily reproduced, and that those who have power and higher income or social class are highlighted (RARE Media, 2022). Our findings thus also revealed these power structures in the media representations of disability.

When comparing our research findings to Clogston's (1990) and Haller's (1995) listing of traditional and progressive models of representations of disability in the media, some differences arise. According to Clogston and Haller, traditional models are usually negative in their effects, and progressive models are positive. However, in our study, only the social pathology model was seen as purely negative and avoidable, whereas the cultural pluralism, legal, and consumer models were seen as positive and recommendable. The rest of the models were considered contradictory. In addition, previous studies have used theoretical frameworks in which the data have been based on media representations produced by persons with disabilities (Thoreau, 2006; Cocq and Ljuslinder, 2020) or their families (Stamou, Alevriadou, and Soufla, 2016) and have emphasized several different approaches to disability. In Finland, Kannisto (2019) has researched Facebook profile pictures of para-athletes and their possible influence on the prevailing stereotypes of disability by conducting image analyses and interviewing the athletes. The athletes were portrayed in versatile ways in their pictures, but their common goal was to break stereotypes through social media. Pictures showing an impairment evoked conflicting feelings, because the athletes did not want to hide them but neither did they want to emphasize them. According to the study, showing an impairment can challenge the stereotype of incapacity and the discourse of pity, but it can also reinforce the supercrip stereotype

(ibid.: 2, 80). These research findings also reinforce the fact that defining approaches to disability as only good or bad is not reasonable, and that more detailed, multidimensional, and nuanced approaches based on the diverse reality are needed.

As a result of the RARE X Diversity research project, RARE Media (2022) created a guide to more diverse and inclusive journalism. According to the guide, increasing diversity and inclusiveness within editorial and production teams and management is one step towards more equal and versatile media. It is also important to change work communities' cultures in such way that equal participation is possible for everyone, and that there is enough resources and time to produce high-quality journalism. The guide highlights the need for education and the need to identify prejudices, renew working methods and media contents, oppose the current media logic, and to promote journalistic values such as justice and equality, on a practical level (RARE Media, 2022). Many of these means were cited by the disability organizations interviewed for this study, and all are relevant in terms of promoting the equality of persons with disabilities. However, the roles of persons with disabilities and the approaches to disability in media representations could also be further analysed from the perspective of self-determination.

Our results show that the media can normalize diversity, increase appreciation, and eradicate attitudinal discrimination by approaching disability as cultural pluralism and by portraying persons with disabilities as active and ordinary people in society. Respecting and promoting the right to participation and autonomy means prioritizing the experiences and opinions of persons with disabilities over experts' views of what is best for them (Shakespeare, 2017). This can be done by presenting persons with disabilities in the role of experts of experience. Directing attention towards the legal obligations of the state and the surrounding structures and attitudes gives persons with disabilities roles of citizens and rights-holders, and this strengthens their position as full members of society and promotes their rights, equal recognition before the law, and equal opportunities. The role of the citizen advocates the right to influence the development of society and the environment. Media representations of persons with disabilities imagining alternative futures from the viewpoint of participation can involve them in decision-making. Well-being and participation at all levels can also be strengthened by highlighting the importance of accessibility, reasonable adjustments, assistive devices, services, and positive action in the light of capabilities, opportunities, rights, and profitability. Even though the role of hero is contradictory, a role model position could strengthen the sense of capability and faith in possibilities and the future of the persons with disabilities in the audience.

Conclusions

As many persons with disabilities in Finland experience discrimination due to the lack of knowledge and negative attitudes of persons

without a disability, a large-scale change in attitudes is needed to achieve equal opportunities for participation and the realization of rights (Non-Discrimination Ombudsman, 2016). These research findings indicate that current media representations have been contributing to maintaining these negative attitudes, although awareness of diversity and versatility has increased. Dismantling discrimination and changing attitudes require media representations that (1) break down prejudices and increase understanding by challenging prevailing stereotypes and producing more realistic, informative representations; (2) acknowledge and explore the complexity of the disability experience; and (3) facilitate the meaningful integration of all persons with disabilities into society by promoting and respecting the right to self-determination, participation, and equality (EnglandKennedy, 2008; Barnes, 1992; UNCRPD, 2006).

The collected interviews and their analysis indicate that the media need to consider their language, images, and contents in their representations and to integrate persons with disabilities into all media levels. As a multifaceted phenomenon, disability should also be approached from many different perspectives. To make this possible, the work culture of the media industry must develop in a direction that values diversity and high-quality journalism, that renews the current media logic and working methods, pursues a dialogue with disability organizations and persons with disabilities on this issue, is aware of human rights, and aims to respects and promote these issues.

Two major reforms of health and social services and disability legislation are currently underway in Finland. The aim of the health and social service reform is to ensure efficient, good-quality services for all and to reduce inequalities in health and well-being. The other legal reform will merge two separate laws on disability into one new law and aims to strengthen the participation, equality, and self-determination of persons with disabilities and secure adequate services according to individual needs. The new legislation should enter into force in October 2023 when the responsibility for organizing health and social services is transferred from municipalities to well-being service counties in January 2023 (Ministry of Social Affairs and Health, n.d.). According to the interviewees, the media have a great deal of power over what kind of public opinion and pressure is generated in relation to implementing these reforms. For example, it could promote the rights of persons with disabilities by emphasizing the multidimensionality of disability and the different perspectives and concerns related to the reforms. This will require identifying those who have already been able to participate in the discussion through the media and those who have not. The media could also examine the reforms from different approaches to disability and raise a discussion on how the participation and democracy of persons with disabilities have been considered in the preparation processes and operation of the future well-being service counties.

In the future, the development of the media representations of disability could be influenced by creating media guidelines that recognize the

multidimensionality of disability, discuss the effects of different approaches, and provide concrete instructions on how to respect and promote the rights of persons with disabilities. In addition to these guidelines, a media participation indicator could be developed to evaluate the participation of persons with disabilities in the media (compare, e.g., the Experiences of Social Inclusion Scale, Finnish Institute for Health and Welfare, n.d.). In addition to these, there is a demand for more awareness campaigns, education, and open dialogues between the stakeholders. Further research on media representations of disabilities is also required; for example, studies that directly examine the opinions of general persons with disabilities at the grassroots level. This could be done by interviewing them or analysing the motives, meanings, and impacts of the social media representations they produce. Representations of parents of children with disabilities would be essential for examining children's rights to privacy and self-determination. It would also be important to interview media professionals to achieve a broader understanding of these issues. If the journalistic media sector continues as it is now, this will definitely contribute to reinforcing the disabling social structure of which the media are too often a part. It is high time we question the media representations of disability so that Finland can genuinely deserve the title of the happiest country in the world, also from the disability perspective.

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7 Reforming disability services to balance rights and needs

Stina Sjöblom and Päivi Nurmi-Koikkalainen

Introduction

The reformation of legislation on disability services based on individual needs has been ongoing for a decade. Parallel processes for inclusion and implementing the rights of persons with disabilities in all policies and services have taken place. This chapter is a discussion among experts in disability policies on the ways in which various policy documents related to disability services have incorporated the language and aims of the UN Convention on the Rights of Persons with Disabilities (CRPD). The period in focus stretches from 2007 when Finland signed the CRPD up until the end of 2021. By examining key policy documents of this time, we explore how disability services are intended to enable inclusion and support independent living and participation in the community. The selected documents guide us concerning the development of trends and ideas within the policy context during this period.

This chapter focuses on disability services on a structural level as a means of the welfare state to support the rights and living conditions of persons with disabilities. We look at services for persons with disabilities based on special legislation; in short, disability services, in the context of welfare services and disability policy developments in Finland. Our exploration aims to reveal both the progress in and the hindrances to developing disability services in accordance with the requirements of the CRPD. We are tracing the ways in which disability services developed in Finland and how they have adopted the principles of the CRPD. The chapter starts with a background to disability services and what the concept entails in the context of disability policy in Finland. Then we highlight the theoretical and human rights concepts pivotal to this chapter. Following that, the aim and the research question of this study are presented together with a methodological discussion, followed by the main thematic areas that came up in the exploration. To do our analysis we draw on the concepts of the CRPD. The thematic areas, individual services and inclusion are discussed, formulating answers to the research question. The chapter ends with concluding remarks on the findings of this study.

Background

The effects of policies aiming at implementing rights are always an interplay between norms, recourses and practices (Klami 1990). Good practice is necessary to turn policies into desired practice and rightful outcome. There are aspects on different levels affecting the organization of social services in Finland. For the scope of this chapter, we make a general distinction between three levels of impact for practice. First is the level of policymaking, where legislation and guidelines are formulated. Second is the level of organizing services on a local and regional level (the wellbeing services counties), and third, the concrete level of practice where legislation is interpreted, and decisions are made. On the level of practice, decisions are based on the individual needs of a person and on social work discretion. All these levels affect the outcome, yet in this chapter we focus on the level of policymaking.

As our exploration stretches over more than a decade, it is important to note that the understanding of disability has progressed as well as the mainstreaming of disability policy in all sectors of society. With the guiding idea of ‘a society for all’, systematic measures have been taken to reduce obstacles and barriers to ensure accessibility and participation for all, in all areas of life (Ministry of Social Affairs and Health 2010; Sjöblom 2016). Mainstreaming disability rights in all sectors of society simultaneously diminishes the need for individual services to overcome obstacles and barriers. The Social Services Act was reformed in 2014 with the goal of strengthening the basis of universal services and including all, with special attention paid to persons and families regarded as vulnerable (Sjöblom 2016; Ministry of Social Affairs and Health 2017). Nevertheless, services and support based on special legislation still play a significant role, granting the right to living independently and enabling participation for all (e.g. Könkkölä 2016; Hästbacka, 2021).

When studying the development of disability services in the Finnish context, it is useful to acknowledge history in terms of legislation such as the Act on the Care of Invalids (Invaliidihuoltolaki 907/1946) and the Act on Special Care for Persons with Intellectual Disabilities [Special Care Act] (Laki kehitysvammaisten erityishuollosta 519/1977) [Special Care Act]. In 1987 the Act on the Care for Invalids was replaced by the Act on Services and Assistance for Persons with Disabilities [Disability Services Act] (Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista 380/1987). The Special Care Act remained, granting lifelong special care, often in institutional settings, while the 1987 Disability Services Act was progressive for the time and recognized the crucial aspects of independent living. Since then, in Finland, on the grounds of disability and individually assessed needs, municipalities have been obliged to arrange services for living independently and in the community. A person can be granted the right to accommodations in the home and to transportation services for education and work, plus

a minimum of eighteen single transports within the municipality of residence or to the neighboring municipality for leisure and free time purposes. Personal assistance was originally bound to appropriations as an option that could be considered on the grounds of individual needs and at the discretion of social workers. Appropriation here means the money that was set aside by the municipality for this specific use.

In 2007 legislation was amended, and all persons requiring disability services were to be assessed primarily regarding the Disability Services Act, and only, when necessary, considering the Special Care Act for persons with intellectual disabilities. At the same time the rights to interpretation and day activity services were strengthened to enhance the possibilities to live independently and participate in the community. Next, in 2009 personal assistance became a subjective right granted by law to a person with a disability needing assistance. Thus, in thirty years the Disability Services Act (380/1987) has developed and now guarantees assistance and services to reduce obstacles and barriers in the everyday lives of persons with disabilities. Yet, as the surrounding context has changed, problems with implementing the act have emerged and led to the need to amend the legislation.

By international comparison, Finland and the other Nordic countries have a high level of welfare services for all (Brennan et al. 2018; Nordic Welfare Centre 2021). Yet, the welfare states have experienced difficulties to meet the demands of equal access and the rights of persons with disabilities to participate and to live independently in the community. Brennan and Traustadóttir (2020) have problematized the self-image of Nordic welfare states as world leaders in support of persons with disabilities. They point out that research highlights a gap between the political objectives and the reality of persons with disabilities and their experiences. According to the authors, individual support is still characterized by paternalism and an imbalance in the relationship between the individual and professionals in the field of disability. The support needs to be more flexible and based on the individual's needs to guarantee the possibility for independent living for persons with disabilities (Brennan and Traustadóttir 2020). British disability activists and researchers have critically pointed out that 'case and care management dominated by financial accountability and the rationing of services' has come to replace social (case) work (Oliver, Sapey and Thomas 2012, 1; Kivistö and Hautala 2020).

In practice some groups seem to have been overlooked and their questions unsolved. Persons who due to hearing loss, deafness or deaf blindness need and are intitled to interpretation services for communication but do not use it (Havakka and Härkönen 2021). Children with disabilities have the right to live with a family but are institutionalized. Even if the number of adults with disability living in institutions have continued to decline, we face the fact that some 100 Finnish children with disabilities are living in an institution. We even see a slight increase in the number of minors living in institutions, with 127 individuals in 2022 (THL 2023). Persons who need support with

self-determination are in various positions depending on if they have a person who supports them and how well the supporting person manages with the support task. In 2016 Parliament required the Government to continue developing the regulation concerning the right of self-determination (Finnish Government 2019a). Children with disabilities and the legislation on self-determination are repeatedly discussed, yet the progress in policymaking is not proceeding. Following this, the persons (and families) affected are left with insufficient support and a poor legal status. General recommendations for the different kinds of support in practice are still missing leaving professionals without the qualifications and/or tools to work in ways that guarantee the rights of all persons with disabilities equally.

Key concepts and theoretical framework for analyzing policy documents

Disability services, as presented in the beginning of this chapter, is one of the key concepts of this study, and we define disability services as the services in the social welfare system that are eligible for persons with disability on the grounds of special legislation and based on individual need. As mentioned, in Finland people with disabilities have the right to all the same social services as the rest of the population, and universal services must be accessible and useable regardless of any functional limitation. In welfare policy this means that all people are included in and can benefit from the welfare and service system on equal terms. Furthermore, in the Finnish welfare system, people with disabilities also have the right to services to overcome barriers and to get the help and assistance that they need due to their disability. This is a form of positive discrimination for which there is special legislation. Organizing services and support for people with disabilities is about balancing the universal right to social services and the more specific right to disability services based on individual needs.

In this chapter we use the conceptualization of the CRPD to analyze how inclusion is discussed in Finnish policy documents and gray papers covering the reform of special legislation on disability services. Inclusion is a key concept, as it is one of the general principles of the CRPD outlined in Article 3c on full and effective participation and inclusion in society. ‘Inclusive equality’ as defined by the CRPD Committee is a new model of equality that seeks to ensure equal opportunities as well as equal results (UN Committee on the Rights of Persons with Disabilities 2018; Broderick and Ferri 2019). By using these concepts, we try to reveal both the progress in and the hindrances to developing disability services in accordance with the requirements of the CRPD.

Inclusion is commonly used to emphasize that all people, regardless of their differences, have the equal opportunity to be part of a certain context, and included in something or somewhere. Thus, in disability policy and research, the right to live and act in the community on equal terms with others is emphasized. In relation to social services, this means the right to

all the same services that any other citizen with the same need is entitled to (Teittinen 2006, 18–19; Romakkaniemi et al. 2019).

The idea of independent living is pivotal for the CRPD, and disability services are a means to enable that. Yet, living independently and being included in the community, as defined in Article 19 of the CRPD, is not achieved alone by special legislation on services. For everyone to live independently and be included in the community, it takes multiple measures of implementing and mainstreaming disability policy. For the focus of our study, it is of interest how mainstreaming policies and guiding the use of universal services and support intended ‘for all’ is presented in the policy documents.

Inclusion as a theoretical concept guided our analysis together with the human rights principles, namely non-discrimination and equality and accessibility. These concepts are derived from the following articles of the CRPD: Article 19, the right to live independently and be included in the community; Article 3c, full and effective participation and inclusion in society; and Article 12, equal recognition before the law (CRPD). Inclusion, equality and non-discrimination as outlined in the CRPD are pivotal as ideas, aims and efforts in Finnish disability policy, where beside that, fundamental rights, human rights, mainstreaming and non-discrimination are emphasized (Ministry of Social Affairs and Health 2010). All these rights are connected to independent living and the participation of persons with disabilities and are the guiding principles of what disability services aim to achieve. We draw on these concepts of the CRPD when doing our analysis of the documents selected for our narrative review.

Aim and research question of the study

We are tracing the steps of Finland’s way to ratifying the CRPD and starting to implement it in practice. We look at how the rights-based ideas are formulated, focusing on disability services as a means to enable social inclusion in the changing welfare state. Following this, our research question is as follows: In what ways have disability services changed in terms of emphasizing the right of persons with disabilities to live independently and be part of the community?

Methods and data

To answer the research question, this study discusses the result of a narrative review of data from a selection of policy documents produced by or for the Ministry of Social Affairs and Health (MSH) between 2007 and 2021 and that in some way discuss the development of social services for people with disabilities in Finland. For this study thirteen policy documents, programs and project reports were selected (see Table 7.1). These documents were selected because they cover governmental policy and documented efforts to develop disability services during this period. As selection criteria, we used

Table 7.1 Documents included in the study

<i>Author(s)</i>	<i>Year</i>	<i>Policy document</i>	<i>Key content for the development of services</i>
Ministry of Social Affairs and Health	2010	Finland's Disability Policy Programme VAMPO 2010–2015 “A strong basis for inclusion and equality” (2010 in Finnish, 2012 published in English).	Policy program outlining 122 measures for mainstreaming policies and amending legislation in line with the CRPD.
Government of Prime Minister Matti Vanhanen	2010	Finnish government resolution concerning implementing the program for arranging housing for persons with intellectual and developmental disabilities and related services (KEHAS) from 2010 to 2015. Ministry of Social Affairs and Health.	Government's resolution on ending institutional living for persons with intellectual disability and a program for how to arrange housing and related services in the community. Joint effort of MSH and the Ministry of the Environment.
Ministry of Social Affairs and Health	2015	VALAS-loppuraportti 2015. Ministry of Social Affairs and Health.	End report of the working group to reform the legislation on disability services. Including a draft government proposal.
Ministry of Social Affairs and Health	2016	Laitoksesta yksilölliseen asumiseen. Kehitysvammaisten asumisen ohjelman toimeenpanon arviointi ja tehostettavat toimet vuosille 2016–2020. Seurantaryhmän loppuraportti. (<i>KEHAS evaluation and end report of the monitoring group with recommendations for the period 2016–2020</i>).	Evaluation report on the housing program KEHAS that ended in 2015. The evaluation report came with recommendations of intensified measures for the period 2016–2020 to end institutionalization and organize individual housing.
Sjöblom, Stina	2016	Finland's Disability Policy Programme (VAMPO) 2010–2015: Final report. Ministry of Social Affairs and Health.	Final report of the policy program VAMPO 2010–2015 ending with Finland ratifying the UNCRPD in 2016. Most of the 122 program measures taken. Changes made in the Special Care Act, as the reform of Disability Services Act continued.

Table 7.1 (Continued)

<i>Author(s)</i>	<i>Year</i>	<i>Policy document</i>	<i>Key content for the development of services</i>
Könkkölä, Kalle	2016	<i>Alternatives for savings in disability services. Rapporteur report</i> (in Finnish). Ministry of Social Affairs and Health.	Rapporteur was tasked to find alternatives for cutbacks in disability services. The cutbacks were a precondition from the government to continue the reforming of disability services.
Ministry of Social Affairs and Health	2017	Guide for the application of the Social Welfare Act. Publications of the Ministry of Social Affairs and Health 2017:5.	A guide for the application of the new Social Welfare Act. The act answers all kinds of social welfare needs and is intended as a universal act for providing services and support for those in need.
Hakoma, Riitta and Niemelä, Markku	2018	<i>Special care districts will be abolished but their work and services will continue – rapporteur report on the status of special care districts in the health and social services.</i> Ministry of Social Affairs and Health.	Rapporteurs were tasked to plan and communicate the structural reform when special care districts are abolished. Their work and services continue but reorganized in the health and social services reform.
Ministry of Social Affairs and Health	2018	<i>Right to social inclusion and equality. The National Action Plan on the UN Convention on the Rights of Persons with Disabilities 2018–2019.</i>	Finland's first national action plan outlined measures for social inclusion and equality for the remaining governmental period of the Sipilä administration.
Lehti, Susanna	2019	<i>Procurement of disability services that take the client into account – perspectives on the application of procurement legislation.</i> National Institute for Health and Welfare (THL).	Guiding document for the procurement of disability services that take the client into account. National Institute for Health and Welfare (THL).

(Continued)

Table 7.1 (Continued)

<i>Author(s)</i>	<i>Year</i>	<i>Policy document</i>	<i>Key content for the development of services</i>
Sivula, Sirkka	2020	<i>Securing the inclusion of people with disabilities in disability services – report by the working group on promoting inclusion.</i> Reports and Memorandums of the Ministry of Social Affairs and Health 2020:37.	The working group report on promoting inclusion/participation. Including parts formulated as a draft government proposal.
Ministry of Social Affairs and Health	2021	<i>Right to social inclusion and equality: National Action Plan on the UN Convention on the Rights of Persons with Disabilities (2020–2023).</i>	A national action plan was outlined for the governmental period 2020–2023. Included (among others) indicators to monitor the progress of implementing articles 12, 14, 19 and 29 with relevance for development of services.
Nurmi-Koikkalainen et al.	2022	<i>Results of the experimental project on personal budgeting for persons with disabilities. A proposal for the Finnish model.</i> Finnish Institute for Health and Welfare (THL). Discussion Paper 3/2022.	Experiment on personal budgeting for persons with disabilities and a draft proposal for the Finnish model according to the government program. A collaborative project worked out a model and piloted practices.

the timeframe since Finland signed the CRPD in 2007 until the end of 2021, and the use of documents produced within the administrative branch of the MSH. The administrative branch involves the ministry and all the governmental agencies (Ministry of Social Affairs and Health n.d.). The thirteen selected policy documents consisted of programs, program evaluations, guiding documents, rapporteurs' reports and project reports. The documents show the intended aims and goals with policy and legal reforms as well as some of the concrete issues emphasized within the administrative branch of the MSH. Such documents, produced by governments, academic institutions, businesses and industries, have been defined as 'gray literature' involving pros and cons when used in literature reviews (Kiteley and Stogdon 2014).

The selected data illustrates the development of disability services in Finland during the last decade. Documents with relevance for mainstreaming disability policy and documents concerning the concrete development of disability

services are relevant for inclusion, as these developments are parallel and intertwined. The selected documents are the most crucial ones to answer our research question. In a nutshell and chronologically, the documents include government decisions to end institutional living and develop community-based solutions for living independently (2010) and self-evaluation of how it succeeded (2016); reports of working groups and rapporteurs' reporting on the process of developing legislation and models for organizing services in line with the requirements of the CRPD, which were adoptable regarding austerity measures and the changing structures for organizing wellbeing services in Finland. Examining the selected documents reveals the change in emphasis, and by analyzing the documented change, we point out enablers and barriers to the political commitment to organizing services for independent living and participation.

We used qualitative content analysis to review the intended development of disability services by examining how the ideas of inclusion and equality are emphasized in the policy context during this period. We analyzed the policy documents from the perspective of the principles of inclusion, equality and non-discrimination outlined in the CRPD. Our frame for analyzing the policy documents of developing disability services in Finland is through the concept of 'inclusive equality'. The CRPD Committee defines 'inclusive equality' as a 'new model of equality' that seeks to ensure equal opportunities for disabled people as well as equal results (Broderick and Ferri 2019). We find this model useful for our analysis focusing on whether disability services have changed and how, in terms of emphasizing the right to live independently and be a part of the community.

With the framework of 'inclusive equality', we analyzed the selected documents from two angles. First, we have looked at policy intentions, for if and how services are addressed in the documents as means to ensure equal opportunities. Second, we have looked at policy outcomes exploring what the result has been for persons who use disability services. In our frame of analysis, this includes mainstreaming disability in all areas of society and all aspects of everyday living, as the acknowledgment of disability as one aspect of human diversity needing recognition (to be included). We also considered if and how equality is supported and enhanced (according to the documents) with services and support on an individual level.

We proceeded with inductive reasoning, first reading, and then discussing what we had found, reflecting on the parts of texts discussing disability services in terms of the CRPD leading to primary themes and categories. For the second reading we shared the documents and agreed to focus on enabling and hindering factors for equality when it comes to living independently and being included. Again, we returned to discuss our findings and thematizing emerging 'subjects' in the texts. We reflected on the parts of text that discussed disability services as enabling living independently and being a part of the community, and in what ways these texts reflected the ideas of the CRPD and 'inclusive equality'. When reading the documents, we focused on

what occurred in the text, but our analysis included a joint critical reflection on what was missing from the texts, which we will return to in the discussion. We share the understanding of significant findings.

Positioning of the researchers

Before discussing the findings in these policy documents, we want to be open about issues concerning research ethics in this specific context. This chapter is a reflection by experts in disability policies of the ways in which policy documents related to disability services have incorporated the language and aims of the CRPD. Both authors of this chapter have in many ways contributed to the programs, projects and evaluations included as data for this chapter. Both authors are affiliated with the Finnish Institute for Health and Welfare (THL) and have contributed to the policy documents from that position. Sjöblom is also a doctoral researcher at the University of Helsinki with an interest in the rights-based development of disability services in Finland. We acknowledge the risk of bias but are still committed to a critical and thorough analysis of the developments over the years of interest here.

As national specialists of disability services and policy, both authors have been involved in monitoring disability policy developments and working in the projects and processes connected to the preparation of a new disability services act. The positive thing is that we are familiar with the documents, while a negative aspect is that our research integrity can be questioned. Throughout the period of interest in this chapter, Finland has followed the principle of participation (Article 4.3) in the various programs and processes documented. Hence, to a great extent, the processes have been dialogical and open to criticism and ongoing debate between the parties involved. We trust that engagement in these discussions has enhanced our reflectivity and critical perspective on the documents and developments studied in this chapter.

What the selected documents reveal

The result of our narrative review of the selected documents highlights the possibilities and challenges in policy developments in Finland. The selected documents show the trends and emphasis of policymaking during the last fifteen years. In our analysis we picture what the documents reveal about the development regarding inclusion and disability services during this time. First, we have categorized the data and show on a general level what is emphasized in the different documents. The presentation in Table 7.2 shows the trends in policy over a timeline and highlights the change in emphasis. Second, we summarize the findings and thematize them by using the theoretical concept of inclusion and the human rights principles of non-discrimination and equality. We have focused on how disability services are developed in the

Table 7.2 Categories and themes emerging in the analysis

<i>Inclusive equality</i>	<i>In the documents 2010–2016</i>	<i>In the documents 2016–2021</i>
Ensuring equal opportunities	Guiding ideas behind the policy development regarding disability services and need for special legislation: Mainstreaming Non-discrimination (and the need for positive discrimination)	Guiding ideas behind the policy development regarding disability services and the need for special legislation: Personalization Disability rights and needs-based services
Ensuring equal results	Societal/structural change drivers: Deinstitutionalization Preparing reform of special legislation	Societal/structural change drivers: Austerity measures, efficiency and welfare reform Participation in practices

light of disability policy emphasizing inclusion and equality. Our findings reveal the documented narrative on policy developments and disability services from the perspective of the MSH.

The major policy commitment during the first half of this period was to ratify the CRPD which, among other developments, led to significant change processes in developing disability services. As disability services are the focus of this chapter, it is important to point out that the services develop in the context of the surrounding society and policies. Following the signing of the CRPD in 2007, Finland drew up a program for disability policy, VAMPO 2010–2015. VAMPO (2010) was the documented pathway for Finnish disability policy to meet the requirements of the CRPD, including necessary legal and practical changes to policy before Finland was to ratify the convention. In that document we identify the key drivers that are still in place, and which are relevant to discuss in this context. Thus, two parallel processes run throughout the fifteen-year time span of our analysis: (1) Implementing the rights of persons with disabilities in all policies, and (2) reform of legislation on disability services based on individual needs. Focusing on the development of disability services, we next present the themes that emerged connected to service development.

Equality in access to social services and housing

Disability policy documents emphasize universal and structural solutions, such as accessibility and mainstreaming disability in all areas of society, thus promoting the inclusion of all people regardless of their functional capacity or disability.

The Social Welfare Act (Sosiaalihuoltolaki 1301/2014) was amended with the aim of achieving a comprehensive act covering everything from structural social work to the diversity of peoples' needs and including persons with support needs as well. As the new Social Welfare Act entered into force in 2015, it came with the promise of enhanced universal services for all. The MSH published a guide aiming at the proper application of the new act, meaning 'the promotion of social safety and well-being, as well as [...] other social welfare tasks and services provided by the municipality and their implementation' (Ministry of Social Affairs and Health 2017). The Social Welfare Act applies to all clients, from children to the elderly.

The Disability Policy Programme VAMPO (2010) outlined the goals and measures for mainstreaming disability policy in accordance with the CRPD. Concerning disability services, the emphasis was on creating community-based solutions and support for independent living, in addition to ensuring equal rights to participation in community and services and support to enable that, regardless of what kind of disability a person has. The government resolution concerning housing and related services for persons with intellectual and developmental disabilities (Finnish Government 2010) stated a commitment to end institutional living of this group and to implement alternative arrangements. The resolution led to the program for arranging housing and related services (KEHAS) from 2010 to 2015. The KEHAS evaluation and final report of the monitoring group (Ministry of Social Affairs and Health 2016) came with recommendations for the period 2016–2020. Thus, in practice the government's commitment to deinstitutionalization and implementation of arranging housing and related services stretched over the whole decade 2010–2020. Both programs (VAMPO and KEHAS) emphasized community-based living, related services and support for living independently and included concrete measures to promote these aspects.

Reforming special legislation to support community-based living

The Social Welfare Act does not offer individualized support and services to meet the diverse needs of all persons with disabilities. To meet individual needs is not always possible with so-called mainstream services. Thus, as we are exploring how services support people to live independently and participate in the community, disability services based on individual needs are meaningful as a means for inclusion. Hence, for many the services based on special legislation are necessary in everyday life, for social wellbeing and participation in the community. Deinstitutionalization and committing to societal inclusion have created new demands on how to develop a new act on disability services, to meet the diversity of individual needs.

Disability services are defined in the Disability Services Act (380/1987) as services and support for living independently and participating

in the community. In VAMPO and KEHAS, the emphasis was on non-discrimination and the equal right to live and act in the community. The need to amend the legislation was acknowledged, and a broad-based and participatory working group was set by the MSH in 2013, and it came with the first proposal for a new act on disability services in 2016 (Ministry of Social Affairs and Health 2015). The suggestions of the working group paved the way for a new act.

Following the program for deinstitutionalization, the discussion about how to best organize services for persons with intellectual disabilities (and some other groups of persons with disabilities whose needs had not been fully met) was intensified. First, the support for living in the community is primarily organized as mainstream social services and based on the Act on Disability Services. The later discussions (in the documents) revolve around how and what kinds of services are needed for living independently and participating in the community.

Disability services are supposed to function as means to enhance and support inclusion on an individual level. The services as such are not inclusion but tools to enable inclusion. In the policy documents, personal support systems, support with communication and supported decision-making come up. There is ongoing discussion about the role of disability services in enabling inclusion in education and working life (Ministry of Social Affairs and Health 2021; Nurmi-Koikkalainen et al. 2022).

With the expectation of an inclusive society with general accessibility and universal services suitable for all, special legislation on services based on individual needs are seen as positive discrimination and an enabling solution for persons with needs that cannot be met with general and universal solutions or with reasonable accommodations (Ministry of Social Affairs and Health 2021).

Needs-based services adjusting to a changing context

In a policy context, the development of services is affected by the changes in politics and surrounding policies. Throughout the period that this narrative review has covered, the reform of special legislation on disability services has been in the making. In 2016 it was necessary to find and present cutbacks to the suggested reform whether it was to be taken further. During the same government period, it was also necessary to discuss the new structures for organizing the services, as the special care districts were coming to an end. There was growing concern about the consequences of the ongoing structural developments. What was happening with the expertise and knowledge gathered in the institutions and what was happening with those who had moved to community-based housing services? The preparation for structural changes and the new legislation continued in reports and programs.

In his rapporteur's report, Kalle Könkkölä (2016) suggested alternative savings to get the new act into force without challenging the services and support the users get.

The aim should be to find ways to cut down in bureaucracy and not in services.

(Könkkölä 2016)

Riitta Hakoma and Markku Niemelä (2018) presented possible solutions for the future social and welfare areas, emphasizing the rights of persons with disabilities to use local accessible services, such as health and social services centers, in the way they choose and without restrictions. Supporting self-determination and enabling supported decision-making are mentioned as important matters for the next decade.

The solutions must be sensitive in recognizing an individual's needs and various life situations.

(Hakoma and Niemelä 2018)

Furthermore, the questions concerning disability services have changed to become more individual and more personalized. Following protests by disabled peoples' organizations against the procurement procedures leading to people having to move against their will, the MSH ordered guidelines and organized training to enhance good practice. A national training program on the organization and procurement of disability services presented the legislation related to the procurement of disability services and described different procurement procedures. The core message was that the rights of the client cannot be ignored under the provisions of the Act on Public Procurement and Concession Contracts (Lehti 2018).

Service users must be considered at all stages of service provision, the assessment of service needs, planning, decision-making on the services, and the implementation of services.

(Lehti 2018)

A so-called inclusion working group was appointed by the MSH to secure and further increase the inclusion of people with disabilities in the decision-making and organization of services concerning them (Sivula 2020). Parallel to the protests on procurements, there were ongoing discussion about personalization and the possibilities of personal budgeting leading to a commitment in the governmental program of Sanna Marin in 2019 (Finnish Government 2019b) to experiment on personal budgeting for persons with disabilities. The premise of the experimental project carried out between 2020 and 2021 was to strengthen the right to self-determination of persons with disabilities, and their participation and freedom of choice in the planning and

implementation of services. The collaborative project piloted personalized practices and drafted a proposal for the Finnish model on personal budgeting (Nurmi-Koikkalainen et al. 2022).

Discussing the findings

In our reading of the documents, we found a policy narrative discussing individual services and inclusion with a shift of focus that separates one period from the other. We have named that shift a turning point, to highlight the shift from one period to the other. We analyzed the turn with the guiding idea of ‘inclusive equality’ as a theoretical frame looking at the dimensions of equal opportunities as well as equal results found in the selected documents. On the dimension of equal opportunities, the documents outline that in the first phase, policies and legislation were geared toward inclusion by mainstreaming disability in society and granting persons with disability equal access by changing society and by arranging services to enable equal access for all. Disability policy in Finland has for more than a decade been committed to the idea of society for all. Nevertheless, we find a tension between implementing rights (mainstreaming disability) and addressing individual needs (disability services) to ensure equality. Policy documents and programs from the beginning of the 2010s focused on structural and policy changes for better inclusion of persons with disability in our society and an equal position legally. Mainstreaming was the way to ensure equality.

In the later phase, after the turning point in 2016, the vocabulary changed to emphasize the right to social inclusion and equality in practice. The turning point from mainstreaming to personalization occurred following the ratification of CRPD 2016 and was affected by the political turn that took place as part of the program of Prime Minister Juha Sipilä’s government in 2015. The program focused on balancing public expenditure and cutting bureaucracy, leading to austerity measures in existing services and potential cutbacks in ongoing reform projects.

What did the documents say about how the services change in terms of emphasizing the right of persons with disabilities to live independently and be part of the community? By analyzing documented policy of the last decade, it looks like the emphasis on disability rights as human rights, and on inclusion as the equal right to access and participation has had an impact on both universal services and the development of services based on individual needs, i.e. disability services. Our main finding was the turning point that occurred after the ratification of the CRPD in 2016. Until then, mainstreaming and deinstitutionalization were the outspoken common goals, and there was a joint public commitment to strive toward those goals. The ratification can be seen as an end point to a policy process that has since taken a new turn. The turn was accentuated by the political shift toward a more restrictive policy when it comes to funding, but also in efforts and generosity for cross-sectoral cooperation. What kind of a turn it has been so far, for the development of

disability services, can be seen in the policy documents produced since that turning point.

Nevertheless, we traced a development emphasizing inclusion and the rights of persons with disabilities, as well as change drivers and barriers in the processes of developing disability services. The legislation and guidelines for so-called universal services are developed to meet a broader variation of support needs to become accessible and usable for all, meaning eligibility for all based on need and not on categorization or diagnosis. However, at the same time the provision of services is challenged by structural changes and austerity measures.

The documents place a growing emphasis on participation and focus on individual needs and the personalization of services. Simultaneously, in our work on a structural level, we see a growing demand to classify and categorize needs to help systematize and generalize the models for service production and procurements.

The picture of policies guiding the implementation of both universal services and services based on special legislation becomes more diversified. This is due to participatory processes, diversified supports, individual needs and freedom of choice.

Conclusion

Despite the developments of disability policy until 2016, we argue that necessary resources and enabling practices are missing to make the policies a working everyday life and rights implemented in practice for all. Especially, persons who need support to make themselves heard (interpretation and support in communication, support in decision-making or guidance and support due to age, such as children or old persons with disabilities) seem to be down prioritized in policymaking.

Based on our narrative review of the selected policy documents, we conclude that progress has been made in terms of adopting the basic principles of equal opportunities and non-discrimination in policies and programs. In policy documents this manifests by emphasizing equal access to universal services and non-discrimination in all areas of life. We find legislative amendments to secure greater equality in eligibility to services based on individual needs, yet the commitments to guarantee resources to meet the needs are left open. Instead of emphasizing funding and sufficient staff for implementing rights, the reform of disability services legislation has been driven forward with requirements of cutbacks and adopting to the ongoing organizational reforms aiming at greater efficiency in the newly established wellbeing counties. On the crucial matter of self-determination, the legal reforms have been unprioritized. Many of the crucial questions concerning individual support remain open. Thus, further actions to re/address some of the barriers to societal inclusion are needed. To ensure equal results actions

are required on a policy level as well as when implementing the legislation on services on an individual level.

Besides the projects to reform legislation, the concrete measures taken have often been in development and piloting projects, developing practices in local and regional trials. There is a constant need to assess, validate and document the outcomes of the numerous projects and trials and to spread best practices to support, help and assist participation in various ways.

Implementing the CRPD requires maintaining and further developing policies informed by the practice and lived experiences of persons with disabilities. Collaboration is one way to raise awareness, and increasing awareness of disability in society is an emphasized and necessary next step to ensure inclusion in universal services and equal access to individual services and support.

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8 Employment, the Finnish disability pension system, and self-determination of people with intellectual and developmental disabilities

Lotta-Kaisa Mustonen and Hisayo Katsui

Introduction

This chapter touches upon one of the most important and yet debated aspects of disability in Finland: employment. Article 27 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) addresses work and employment. After the ratification of the UNCRPD in 2016, the first action plan (2018–2019) was established (Ministry of Social Affairs and Health, 2018) and evaluated in 2020 (Ministry of Social Affairs and Health, 2019). This plan highlighted that the right to work is the least realised right in the Finnish context (p. 52), particularly among persons with intellectual and developmental disabilities (Hoffren, 2018; Vesala, Klem and Ahlsten, 2015). This chapter focuses on one of the identified structural barriers to employment, the Finnish disability pension system (see Kyröläinen, 2020), and the decisions related to this, concerning persons with intellectual and developmental disabilities.

We first present the background information of the un/employment situation of persons with disabilities in Finland, which is followed by the selected theoretical framework. Then we present ethical considerations in the methodology, and then our research findings. This section is divided into three parts: the first part addresses the motivation to work, the second part discusses the opportunities for self-determination within the system, and the last part reflects on what is considered normal and how the system others people with intellectual and developmental disabilities. At its end, the chapter discusses the findings within the context of large-scale reforms in social and welfare services, as well as employment services.

The situation of un/employment of persons with disabilities in Finland

The existing data on disability and employment, for instance, the Eurostat database based on the EU Statistics on Income and Living Conditions

(EU-SILC), shows a clear discrepancy between the (un)employment rates of persons with and without disabilities in favour of those without disabilities (see Katsui and Valkama, 2022). Similarly, in a survey conducted by the Finnish National Advisory Board on the Rights of Persons with Disabilities, 75 per cent of the respondents with disabilities (N = 224) claimed that the right to employment was realised either poorly or rather poorly. According to the latest statistics collected on persons registered as having visual disabilities by the Finnish Federation of the Visually Impaired in 2021 (Tolkkinen, 2021: 57), 24 per cent of persons with visual disabilities between the ages of 15 and 64 are fully employed, 16 per cent are partially employed, 3 per cent are unemployed, 3 per cent are students, and 50 per cent are on a disability pension. The statistics for the whole population with and without disabilities are 72 per cent when the fully and partially employed are combined, and 7 per cent are unemployed. In the survey study conducted by the Finnish Disability Forum in 2018 (which was not a representative study), about half of the respondents (48.3 per cent) were on a full pension, 16.3 per cent were on a partial pension, but those who categorised themselves as unemployed made up 6.8 per cent. One of the problems of the existing data is the fact that it is unlikely that those on pensions are technically counted as unemployed but as pensioners. This means that the actual number of people with disabilities who are motivated to work but are on a pension is unknown. In an event of the Finnish Association of Physically Impaired in August 2022 on independent living, the current Minister of Economic Affairs and Employment, Tuula Haatainen, estimated that only 15 per cent of Finnish persons with disabilities are employed, which leaves 60,000 persons with disabilities and limited work capacity unemployed, despite being willing to work. This chapter focuses on this intersection of (un)employment and pension and attempts to reveal the hidden experiences of persons with intellectual and developmental disabilities. The focus is chosen because people with intellectual and developmental disabilities face structural barriers that only affect people with intellectual and developmental disabilities in entering labour markets and because they are considered to be the most marginalised in the labour market. For instance, only 600 persons with intellectual and developmental disabilities are employed out of 25,000 working age persons with intellectual and developmental disabilities (Hakola, 2021).

The latest Ministry of Economic Affairs and Employment report by Kyröläinen (2020) explicates the structural barriers to employment encountered by persons with disabilities in Finland today. One of these is the ‘pension trap’, which means that persons with disabilities cannot engage in the open labour employment due to the fear of losing their pension permanently and of receiving less money from a (most likely part-time) job than they would receive as a pension.

Theoretical frameworks

To understand the causes of this phenomenon in the employment and pension sectors, the theory of internalised ableism (Campbell, 2009) is useful. Katsui (2005) similarly explains that the prejudice of society limits the opportunities of people with disabilities, which in turn gives them low self-esteem as they reflect on their negative image, makes them passive and isolated, which reinforces the prejudice to make the vicious circle. In this way, ableism favouring abled bodies over disabled bodies is often internalised by the person with disability about own capabilities. Campbell (2009) links the internalised ableism to internalised oppression from Critical Race Theory. She notes that ‘ableism as a conceptual tool, goes beyond procedures, structure, institutions and values of civil society, situates itself clearly within the histories of *knowledge* and is embedded deeply and subliminally within culture’ (Campbell, 2009: 19, cursive original). The person who is not like the norm, in this case persons with disabilities, feels othered and tries to emulate what is perceived desirable, and blaming themselves for not fitting the mould. A person might have to conform to what is perceived to be the desirable, like a person without a disability, or to fit in what is considered acceptable for a person with disability in order to receive benefits (Campbell, 2009). Normalcy, as was described by Campbell (2009), is opposing life and qualities from the person with disabilities as it is the desirable life, which is unattainable for persons with disabilities with the current barriers and oppressive structures. In the same vein, Davis (1997: 6) explores the sense of normalcy and what is normal in a society in terms of critical disability studies. He argues that cultures are built on norms, and that the ‘majority of the population or should somehow be part of the norm’. He continues that how physical and personal traits outside of what are considered normal are ‘undesirable’ (ibid.: 9). These remarks of normalcy and disability make people with disabilities more passive and isolated, as a result of which the prejudice is reinforced (Katsui, 2005).

Wehmeyer (2020) explains self-determination in his work through Causal Agency theory, which in essence means that a person actively makes decisions and ‘makes or causes things to happen in their life’. Through acting by their own volition, the decision-making and actions following empower the person. According to Wehmeyer, self-determination is an integral part of quality of life, especially to people with intellectual and developmental disabilities.

One way out of this vicious circle is to exercise the right to self-determination as mentioned in the UNCRPD (see United Nations, 2006). Thus, in this chapter, we explore whether the self-determination of persons with intellectual and developmental disabilities was realised when the pension-employment decision was made in the lives of eight research participants with intellectual and developmental disabilities.

The Finnish disability allowance system

Nordic welfare model is supposed to provide state support for a person from cradle to grave, and healthcare, different types of social support systems and education are seen as fundamental parts of Western societies. In comparison to other Nordic countries, Finland does not have as extensive history with the Nordic welfare model (see, for example, Kettunen, 2019).

Finland has had very restrictive laws regarding persons with intellectual and developmental disabilities. From the 1950s to the late 1970s the primary care for people with disabilities was in closed institutions (Leppälä, 2014). People with intellectual and developmental disabilities were regarded unfit to work and their lives in institutions were thought to be the humane solution (Teittinen, 2012). While integrated workshops and day services were included in the first law to explicitly write about the care for people with intellectual and developmental disabilities, those activities were restricted to those with the mildest disabilities (Leppälä, 2014).

Throughout the 1900s the laws concerning the people with intellectual and developmental disabilities have changed multiple times. The current law about the care for the people with intellectual and developmental disabilities in Finland was originally drafted in the late 1970s, and it has been revised multiple times, especially before Finland ratified the UNCRPD.

People with intellectual and developmental disabilities can receive a disability pension. Some, usually based on a diagnosis, are given the right to the pension either when they turn 16 or when turning 20 years, depending on the case (Kela, 2023d). They can also apply for the pension later in life, such as at vocational training or in job coaching. In the current system, a person is allowed to earn an income of EUR 922 in addition to their disability pension (Kela, 2023a).

If EUR 922 per month is exceeded, there are two options. The first is to suspend the pension, which means that the person will only earn what they make excluding their pension for a shorter period of time (three months to two years). The second is to discontinue their pension altogether, which means giving up their right to disability pension. Once the entitlement for disability pension is lost, it cannot be returned. Even when the decision is made by the person themselves, many do not realise that it is permanent and think they are leaving the pension to 'rest'. Either option can profoundly impact the person's income (Kyröläinen, 2020).

Integrated workshops are a social service, with an incentive pay of 0–12 EUROS per day, with none of the rights of the labourer. If the person in integrated workshops takes time off from work, they do not receive the incentive pay from that time. Some people with intellectual and developmental disabilities have been in the same integrated workshop for years. This is considered to show a considerable commitment to their place of work (Vesala, Klem and Ahlsten, 2015).

Job coaching is also a social service, and it can be given to a person based on their disability. A person received support to apply for and retain employment. This might include meetings with the job coach several times per week, as they decide what kind of work environment, tasks, and workload is appropriate for the client. Unfortunately, this practice is not available in all municipalities, or it has not been developed the direction where it actually supports work-life activities, and many people with intellectual and developmental disabilities do not receive job coaching at all (Vesala, Klem and Ahlsten, 2015). Additionally, there simply are not enough funds to meet the various support needs that people with intellectual and developmental disabilities have when seeking and entering labour market or integrated workshops (Hakala, 2015). The issue with financing also came up in Kyröläinen (2020).

If the person with intellectual and developmental disabilities has either never received disability pension or has given up their right for the pension, they might have a right for another type of benefit, such as unemployment allowance. However, to apply and to receive the unemployment allowance, one has to be registered as unemployed job seeker at TE services (employment services) and has to apply to full-time jobs in order to receive benefits (Kela, 2023b, 2023c).

Methodology

This qualitative study focused on the perceptions of people with intellectual and developmental disabilities of their own experiences resulting from the decisions made on their involvement in work life and/or their pension. We chose an abductive research approach which would be able to link previous studies to the new findings of the current study. An abductive analysis also enables inductive ways of exploring meanings and using the language and the context that arises from the data (Bryman, 2012). The aim of this study was to examine the experiences of Finnish persons with intellectual and developmental disabilities of the Finnish disability pension system in terms of their self-determination. The key research question was as follows: *How do individuals with intellectual and developmental disabilities experience their disability pension decision in terms of their self-determination and motivation to work?*

We interviewed ten study participants: eight participants who were persons with intellectual and developmental disabilities themselves, and two substance experts without a disability in the field. The two substance experts worked as an advisor and as a researcher, respectively, for major disability organisations and were familiar with the institutional barriers to the entry of people with intellectual and developmental disabilities into the labour market. Six of the participants were part of 'Me itse', which is a self-help organisation of people with intellectual and developmental disabilities that advocates for their own rights. Two of the participants were unaffiliated

Table 8.1 Characteristics of study participants

<i>Participant</i>	<i>Organisation background</i>	<i>Contact</i>	<i>Personal experience of the system</i>
1	Yes	Disability organisation	Yes
2	Yes	Disability organisation	Yes
3	Yes	Disability organisation	Yes
4	Yes	Disability organisation	Yes
5	Yes	Job coaching	Yes
6	Yes	Job coaching	Yes
7	No	Job coaching	Yes
8	No	Call to interview	Yes
9	Yes	Direct	No, substance expert
10	Yes	Direct	No, substance expert

Source: Mustonen (2022).

with disability organisations. Four of the participants were recruited via Me itse, one was found through a call to interviews via Inclusion Finland KVTL (Kehitysvammaisten Tukiliitto), three were found through a job coaching organisation in Southern Finland, and the two substance experts were personally and directly invited to be interviewed.

The data was gathered between mid-February and late March as part of a Master's thesis (Mustonen, 2022). The call to interviews was done via contacting Me itse organisation, a job coaching organisation, and Inclusion Finland KVTL (Table 8.1). Me itse organisation sent out the call to interview to their members, and the job coaching organisation sent it to their clients. Inclusion Finland KVTL published the call to interview on their website. Participants contacted the first author. All participants were interviewed via the phone (4) or a computer video call application (6), due to the COVID-19 pandemic restrictions. Prior to the official interviews, a pilot interview was held with one person with intellectual disabilities at the beginning of February, to test the questions, obtain feedback, and finalise the interview questions. The questions used in the interviews were formulated using the principles of Easy Finnish, none of the questions needed reworking after the pilot interview.

The interviews began by confirming consent for the Interview and introducing the interviewer and the purpose of the study, although most details had already been shared while confirming the date for the interview with the participants. After the oral confirmation of consent, the interview continued with the participants' self-introduction to ease into the interview. The interviews were semi-structured, and the questions were open-ended to leave room for answers and further questions. They lasted for 15–50 minutes, generally about 30–40 minutes. The questions included if the participants received disability pension, what kind of work arrangements they had tried

out, and if they felt like they were listened to during those arrangements. They were also asked about if they perceive that they could be working within the labour markets and if they think they get to work the number of hours they think is right for them. The importance of the support from the organisation they are members in was also asked.

The phone interviews were recorded on a computer. Video calls were recorded both on the computer and using the application's own recording option. During the interviews, we took notes as a final backup. After the interviews, one of the authors transcribed the audio and video recordings and listened to them again once more to ensure accuracy. After the accuracy check of the transcription, the audio- and video-recorded materials were destroyed. As the native language of all the participants was Finnish, the interviews were conducted in Finnish. The transcriptions of the interviews have been translated by the authors. The age of the participants or the substance experts are not disclosed in this article in order to protect their privacy. This was a deliberate choice due to a genuine concern not to reveal the participants' identity. If we suspected that any personal details could possibly lead to their identification, we erased them from the interview transcriptions. Six participants were on disability pension and two were not. The two who were not had either given up their right to the pension or had never received it. One had given up their right to pension initially as they received a job offer within labour markets but later had lost the job due to layoffs. At the time of the interview, the participant received another financial aid from the state. The other, who had never received disability pension despite a diagnosis, had had short employment periods either full time or part time and lived on them. People with disabilities who cannot or have no motivation to work should also be heard in research, as it is as important to hear their thoughts as well (Katsui and Ngirabakunzi, 2009).

The analysis was conducted using a qualitative content analysis technique (Bryman, 2012) by first categorising the data into 12 thematic groups, such as participation in society and experiences related to normalcy, and then merging these and regrouping them into four thematic categories of motivation, normalcy, othering, and self-determination. The analysis phase was data oriented as the data on this topic was new. We utilised the key conceptual framework of self-determination (Wehmeyer, 2020) and theories of critical disability studies (Campbell, 2009; Katsui, 2005, 2020a, 2020b) to understand the experiences of disability in the context of work life and pension decisions.

Results

The study findings concerned four areas: (1) motivation to work, (2) self-determination realities, (3) experiences related to normalcy, and (4) experiences related to othering.

Motivation to work

Overall, the participants were highly motivated to work, all except the participant 6, who believed they were not able to work and did not want to. Katsui (2020b) emphasises that the motivation to work can be linked to societal expectations of normalcy, and our findings reflected these expectations well. Work experience varied considerably from one participant to another. Most of them had experience of integrated workshop activities, some had secured supported employment periods if they were not currently in supported employment, and some had experience of free labour markets. To protect the identities of the participants, we cannot describe their employment histories in detail, especially as one person had experience of several types of work activities.

The most common motivation to work was money (Table 8.2), which might be because many of the participants considered their pension small. Integrated workshops are one of the most common types of activities offered to persons with intellectual and developmental disabilities, which is not supported employment or sheltered work, but more of a rehabilitation service (Nevala et al., 2018). As mentioned before, integrated workshops pay no real salary, but ‘incentive pay’. Most often, incentive pay is from EUR 5 to 7 per day, and this may not even be enough for lunch during the day (Eriksson, 2008). One of the participants commented on incentive pay as follows:

The money we get, it’s not much and I’d rather earn much more than the incentive pay that we get. It’s so small we can’t get much of anything with it.
(Participant 4)

All the participants had a legal guardian, but having their own money was related to having more autonomy in their own daily decisions. In contrast to those in previous studies, our interviewees considered money central. In our study, one of the participants wished for more economic education for persons with intellectual and developmental disabilities. When she started working her salary was in the old Finnish currency, the Finnish mark, which

Table 8.2 Motives behind wanting to work

<i>Motivation</i>	<i>Direct mention</i>	<i>Indirect mention</i>
Money	6	0
Societal participation	5	0
Something to do	4	0
Mental health	2	3
No motivation to work	1	0
Does not know	1	0

changed to Euros, and she found it difficult to understand the current value of money.

Societal participation and having something to do were both mentioned in the context of normalcy when discussing motivations for work (Table 8.2). Having a rhythm to their days and contributing to the surrounding society was important to many of the participants. Mental health was also mentioned as a reason to work, which was linked to having a rhythm and routine to one's day.

I would probably get depressed, as I don't like sitting at home. [I like] to go and meet people and it would be terrible if...if I couldn't go to work at all, yes.

(Participant 3)

In relation to mental health, being needed and being part of a community is a human experience, which is why work activities, even in the form of integrated workshops, are considered meaningful (Garrels and Sigstad, 2019; Hakala, 2015). At the same time, work is considered a norm, an internalised ableistic norm, as the data shows. Therefore, when deviated from it and out of work or out of integrated workshops, they seem to be distressed.

One of the participants told us that he did not know what his motivation for work was, but he certainly seemed to be motivated. When asked what his dream job would be, he answered 'work is work', which indicates that he thought he ought to be working regardless of whether or not he found the actual work gratifying. However, three people wanted to work part time or reduced hours.

Previous research has also found high motivation to work among persons with intellectual and developmental disabilities (Eriksson, 2008; Garrels and Sigstad, 2019; Mustonen, 2022). Motivation and self-determination are closely linked, especially when one's willingness to work is met with resistance from one's family. Opposing a person's wishes to seek and retain a job on the labour market may be linked to internalised ableism (Campbell, 2009), as both structural barriers and internalised ableism are embedded so deeply within our society that they are often difficult to see. Self-determination opportunities, and the lack of those opportunities, within the pension system are explored in the next part.

Self-determination opportunities within the pension system

In the next part of this chapter, we examine whether the disability pension system and employment services offer persons with intellectual and developmental disabilities real opportunities for self-determination. According to the UNCRPD (United Nations, 2006), a person has the right to make decisions regarding their own lives. A person also has the right to receive enough

information to help them make decisions that suit them best. The convention also specifically mentions the right to work.

Most of the participants were on disability pension, apart from participants 2 and 6, who were not receiving a disability pension at the time of the interview. However, only one participant was actually able to directly have a say in whether or not to take disability pension. Participant 3 had willingly first applied for a disability pension and later also willingly given up the pension when starting a full-time job in the labour market. Regrettably, later on, the decision to give up the pension turned out to be a bad choice:

My income was so big that I had to decide to keep either my work or the pension. And the pension was so much smaller [than the pay, so it was worth giving it up]. Now I'm regretting my decision not to keep my pension. They didn't give me a choice to rest the pension.

(Participant 2)

As we also described in the previous part, a person cannot exceed the income level of EUR 922 per month if they receive a pension at the same time. It is hard for many people, especially those with intellectual and developmental disabilities, to comprehend the hugely complicated pension system, and this could have a long-term impact on their lives. Even in these interviews it became clear that they lacked genuine control over how they decide about their jobs and pensions as they did not receive necessary support and information of future consequences of their choices.

The other person who did not receive disability pension was participant 6, a client of a job coaching centre who had applied for a disability pension with their job coach, but KELA had rejected it. This experience was by far the person's most negative experience with the system.

I can't do full time work. [...] it's too difficult for me there, I don't understand anything [...]. They have to give me instructions many times, and sometimes I don't understand [...]. At times I totally freeze [...].

(Participant 6)

Participant 6 had requested the disability pension via the job coaching services, and their application for disability pension had been approved by a doctor. The job coach clarified the reason for KELA's rejection after the interview to one of the authors. While it had also been clarified to him, the subject was difficult to understand for the participant 6, since he was unhappy about KELA's decision. The normal procedure before the disability pension requires an application for sickness allowance. The job coach and the participant 6 had not applied for sickness allowance before applying for the disability pension. Participant 6 received other help from the city's disability services, which is another reason why they did not think to apply for sickness

allowance. This exemplifies how the organisations within the complex system do not communicate properly. It also shows the rigidity of the system (see Kyröläinen, 2020), which makes it difficult for the person seeking services to find the right ones. Moreover, the provided services may not be the best combination for the specific person. One of the substance experts claimed to have seen similar cases before:

I know of such cases in which employment has been difficult. A person can't fully support themselves by working, which leads to unemployment, and fixed-term employment periods, followed by unemployment. As an adult, the person realises that s/he/they might be better off with the [...] disability pension, but then it's a long process, with some kind of work history and places [to work]. Even if s/he/they can see that the same work history was not completely successful, with some periods of work and some periods of unemployment, especially if [the periods of work] were financially supported or otherwise supported internships, on the pension system side they interpret that the person is fit to work, because of all the records of work [and thus is not eligible to receive a pension].

(Substance expert 2)

When the person is refrained from receiving disability pension and has job history that the employment services deem as 'successful', the person does not have sufficient control over own life. The situations may be stressful, and the person with intellectual and developmental disabilities may not receive enough support at the workplace, or the employment services to seek and retain a job they themselves are content with. It is often not up to the self-determination of the person but up to the system to decide about the person. Most of the participants reported having received a disability pension but did not recall ever having discussed it, either when receiving it or later on in their lives.

Participant 7 reported that her mother knew more about her disability pension and her work history than she did. She was a longstanding client of job coaching and reported having control over the amount of work that she did and that she was very happy with her situation and the support she received. Still, society's low expectations of the capabilities of a person with disabilities were noticeable in her interview:

Well, if I was in paid employment, that would mean I'd have to do eight-hour workdays and those eight-hour days would be too tough for me. I've never even heard that anybody [with intellectual disabilities] does four-, five-, six-hour workdays and that it is paid employment. That I've never heard of.

(Participant 7)

Although job coaching may offer a person with disabilities more opportunities to negotiate their situation, their stance also depends on the internalised

Table 8.3 Pension experiences and decisions of study participants

<i>Participant</i>	<i>Pension</i>	<i>Decision discussed</i>	<i>Wanted pension</i>
1	Yes	No	Yes
2	No	Yes	Yes
3	Yes	No	Yes
4	Yes	No	Yes
5	Yes	No	Yes
6	No	No	Yes
7	Yes	Yes	Yes
8	Yes	No	Yes

expectations of their capabilities and how they see the distance between themselves and the norm (Campbell, 2009). To believe that no person with intellectual and developmental disabilities would be working even for part time, let alone full time, reflects the internalised perception that people with intellectual and developmental disabilities are outside of the norm. That is, ableism is internalised. Here, it is clear that although the participant is content with her situation, she is not aware of the possibility of part-time paid employment. Moreover, she evaluates herself according to her perceptions of normal for non-disabled people and normal for people with disabilities. Even in this more advantageous situation, the lack of information was evident and affected her views on her situation. This could be due to the wishes of her family, who sees life outside the labour market as more beneficial and safer for her, as has been observed also in previous studies, due to the vicious circle and existing prejudices about disability (see Hakala, 2015; Katsui, 2020b).

Lack of information and communication regarding the pension decision was common among many of the study participants, but only two out of eight discussed this (Table 8.3). The rest of the participants who had received their disability pension decision either did not recall any discussion on their pension at the time or later on, or did not remember when they had received a disability pension decision at all.

In those days we almost automatically went to the work and daytime activity centre, we didn't have a choice back then. It was the law of social services, so—school and daytime activities, much like school and work activities were in pretty much the same building.

(Participant 8)

So, in [the year] when I joined the work and daytime activity centre, we had no choice back then. There was no talk of [the labour market] work or integrated work.

(Participant 8)

Participant 1 similarly reported not having received enough advice or information about joining the labour market outside the work and daytime activity centre. This participant felt that the personnel who were assigned to help and find work for people in the daytime activity centre did not seriously listen to their wishes to join the labour market.

There were a few discussions, and of course I tried to inquire about it. We do have an advisor who should put us in integrated workshops. And we've discussed this a bit and I did try working at the retirement home, but I felt it wasn't my thing. So, I haven't been well informed about work life.

(Participant 1)

The work she did was in the framework of integrated workshop, and she was not instructed according to her own wishes. In addition to little support from the job coach, the participant 1 also lacked support from their own family members. Her wishes to join the labour force outside the work and daytime activity centre were not received well, and that the negative reaction from the family had been related to the prejudice against persons with intellectual and developmental disabilities according to her interview. In addition to the lack of self-determination opportunities she faced from both the municipality's job coach and her family, these experiences support the idea of a vicious cycle in the Finnish disability pension system and explain the intertwining relationship between society and the person with a disability (see Katsui, 2005, 2020a).

Participant 1 reported having discussed these issues with other people in the same work and daytime activity centre, whose experiences had been similar. A lack of information may be caused by a lack of funds, which has also been reported in earlier research (Hakala, Klem and Koskinen, 2019). Workplaces also seemed to lack information. Participant 3 had been in fixed-term employment for a longer period of time and had requested a permanent contract multiple times, but the request had been denied, showing a lack of self-determination opportunities although she had been working at the same school for long. She now worked with subsidised pay and was satisfied with the situation. She felt that her willingness to work had too often been undermined by the system, but that now she had been listened to and had autonomy over her workload.

This started off so that I was supposed to work at a school with a permanent contract, but I didn't get [the job] when the principal did not do anything to further the matter. I then started to talk to [her current employer] if it was possible that we would apply for subsidized pay for me. And we did that. [...] The principal had promised me so many times that we you will get [the permanent contract] next autumn and the autumn went. Then that you will get [the permanent contract] in the spring and spring went. And that's not okay. The principle just didn't fix my position there and

I really liked to work there and liked that place. I thought sometimes it could be my permanent workplace. Of course I was upset because I had gotten used to all the students and they had conversations with me, but no can do. [...] Now that what I do, the subsidized pay job, the working hours suit me. I wouldn't want to do more.

(Participant 1)

This overall finding of the lack of self-determination opportunities in work life and in terms of pension resonates with previous research findings. Hakala and her colleagues (2019) suggest that the flow of information between the services and employers has been limited, which has then limited the self-determination of persons with intellectual disabilities regarding their work life. Teittinen (2015) adds that not receiving enough information about one's work-life options can lead to feeling othered and is against Article 3 of the UNCRPD on 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.

What is 'normal'?

The participants emphasised two distinct themes and feelings that were closely related to having self-determination within the system. One of these themes was the sense of normalcy (Davis, 1997) that came from working and being part of society in a way they themselves deemed normal. Conversely, the other was the feeling of being left out and othering when out of work (see Simpson, 2012). Perceptions of normalcy are built on the non-disabled working population (Campbel, 2009; Vehmas, 2005). Internalised ableism plays into the perception that normalcy is something to be strived for, although perhaps unattainable, when a person has to play by society's rules to be accepted as a person with a disability (see Campbell, 2009).

The interviewees of this study often emphasised that going to work created a sense of belonging. A sense of normalcy seemed to strengthen the feeling of autonomy and control over their own lives, as has also been suggested in earlier research (Ekholm and Teittinen, 2014; Hakala, 2013, 2017; Hakala, Klem and Koskinen, 2019; Merrels et al., 2019).

Well, I think it's normal that in the mornings you go out and in the evening you come home. [...] Not like this COVID time and not like the last few weeks. Like, for example, a year ago when all the rehabilitating work activities were shut down for about two and half months. Staring at four walls, well. I'm glad I didn't lose it.

(Participant 8)

However, the sense of normalcy can also arise from integrated workshop activities that the person views as work, although integrated workshop

activities are technically not paid employment but are viewed as rehabilitating activities (Eriksson, 2008). Some people with intellectual and developmental disabilities view integrated workshop activities as work because their social contacts tell them so, according to one of the substance experts.

But this is something with which one must proceed carefully, because as I have discussed this with people, [a change in the system] for the parents is, on one hand, something they fear. [...] That there will be no integrated workshop activities, and from their point of view the main thing is that their offspring have meaningful things to do during the day. It is often the family members of the person with intellectual and developmental disabilities who uphold the idea of the person going to work, and so forth. They don't highlight the fact that [integrated work shop] is not real work and that you don't get paid for it.

(Substance expert 1)

A sense of normalcy is not, per se, a negative experience, and persons with intellectual and developmental disabilities are sometimes assured by the system and their parents that it is better for them to go to 'work' and are told they get income. Not telling the person about their actual situation reinforces the vicious cycle, especially regarding low expectations and limited opportunities (Katsui, 2005, 2020).

Conversely, in the study by Merrels, Buchanan, and Waters (2019), the interviewees felt a strong sense of othering and social exclusion from not being able to contribute to their surrounding society in a manner they themselves deemed 'normal'. In our study, participant 1 reported feeling left out multiple times during the interview (see Merrels et al., 2019). For example, the term 'outside' came up when they expressed their wish to join the labour market.

I think it would be nice to have a bit of money for myself and get a job so that I could get to work on the outside. I've been in the work and daytime activity centre for a long time, so it would mean a lot to me to get to do the kind of work I really want to do.

(Participant 1)

Referring to working 'outside' in this case implies a distance between the participant 1 and her perceptions of normalcy and the inequalities she encounters. The knowledge of their inequality was also apparent in the interview of participant 2.

I've been thinking about how people with intellectual and developmental disabilities could be equal with others, that we wouldn't be just a financial burden. We could also be thought of as tax payers if we were employed.

(Participant 2)

This part further indicates the complicated social fabrics that are tightly intertwined and manifested in the limited employment opportunities of the interviewees in the open labour market. In addition to the personnel of social and disability services and employment services, family members and society also explicitly and/or implicitly guide persons with intellectual and developmental disabilities to stay in the pension system, even against their will, and to stay away from the open labour market. Thus, the status quo is reinforced and normalised by multi-layered structures and social fabrics, but often also by the persons with intellectual disabilities themselves who have internalised their othering roles in society. That is, the ‘normalcy of persons with intellectual disabilities’ is heavily negotiated among different actors and has been often sophisticatedly and effectively differentiated from the ‘normalcy of people in general’, leaving the former behind.

Discussion and conclusion

When analysed through the key concept of internalised ableism, it is clear that although the current disability pension system is meant to be a safety net and indeed succeeds in providing safety, it fails to listen to the needs, motivations, and decisions of people with intellectual and developmental disabilities. Many of the participants did not know when their disability pension decision had been made. Moreover, and most importantly, multiple participants felt they were not listened to when discussing their own work-life future, could not access work life in the way they saw suitable for them, or were denied the pension altogether. Even if the closest person they work with, such as a job coach, does listen and tries to further the person’s self-determination, the system is too often so rigid that it compromises the person’s right to choose. This goes against the UNCRPD and a person’s right to self-determination (United Nations, 2006).

Within our society there seems to be belief that it is enough to hand out an opportunity to spend one’s day doing tasks, rather than working. For instance, Eriksson (2008) reported that earning an income did not come up in interviews as an important issue and concluded that professional identity and pride was more meaningful than money for persons with intellectual and developmental disabilities. However, this was a generalisation, as Eriksson (2008) only interviewed two people for her report on the self-determination of persons with intellectual and developmental disabilities. The study by Garrels and Sigstad (2019) also found that meaningful tasks and professional identity were important to persons with intellectual and developmental disabilities. They also found that money was a desired addition to daily life and future plans. The importance of income was also realised in this study, as it was the most mentioned reason behind work activities. Second to money was societal participation, which indicates the existence of internalised ableism. The participants realised they are outside the working society and want to be a part of it. The feeling of normalcy and internalised ableism is tied to all

of the motivations; it is considered normal to work and to participate in the society via work. The lack to self-determination opportunities seems to affect the feelings of normalcy.

To dismantle this huge problem faced by many persons with intellectual and developmental disabilities, Finland has adopted a similar employment channel system to the Swedish *Samhall* system, called *Työkanava Oy* (free translation: Work Channel Ltd). It is a company owned by the government and is intended to facilitate the employment of those with partial work capacity, including those with intellectual disabilities, in collaboration with existing local employment offices. The local employment office assigns a jobseeker to *Työkanava* when a suitable job has been found. *Työkanava* becomes the first employer (Ministry of Economic Affairs and Employment, 2022). The Act on *Työkanava* entered into force in July 2022 and started functioning in September 2022 (Ministry of Economic Affairs and Employment, 2022). It remains to be seen whether it will deliver the work opportunities promised. The *Samhall* system has received critique for teaching its workers that a person with a disability is not able to work, and for internalising being ‘not normal’ (Holmqvist, 2005). More recently, the *Samhall* system has been criticised for disregarding the needs of its workers and for prioritising the impact on the sectors in which it provides service and on its own profits (Torp, 2021). Therefore, it will be interesting to see how the newly adopted *Työkanava* will be implemented in the Finnish system, which already has several overlapping but poorly communicating organisations and institutions.

In addition to the structural changes that affect the lives of people with disabilities, Finland’s reform of healthcare, social welfare, and rescue services has been widely discussed among those who work with persons with disabilities and those who work with persons with intellectual and developmental disabilities in particular. The reform will especially affect people outside the capital city of Helsinki, as Helsinki is not joining the well-being service counties and will act separately, as before.

Regional inequality has already been established as a problem in terms of realising the rights of a person with disabilities (Kyröläinen, 2020; Valtioneuvoston kanslia, 2018). This is one of the reasons for the forthcoming reform. From the beginning of 2023, well-being service counties, instead of municipalities, will be responsible for disability services, including integrated workshop activities and job coaching. However, the reform has only been implemented for a couple of months as we are writing this chapter, and thus, we do not know exactly how future disability services will be carried out. It is possible that people outside the Helsinki area will face new structural barriers caused by a rigid system. This is a possibility if the reform does not take into account persons with disabilities and their rights to self-determination and work in their plans of action. Information on the new practices should be made accessible and should reach everyone before the reforms take place, and the new systems should be accessible and

transparent. A legislative reform on disability services has been planned to assess the current problems in the services (Valtioneuvosto 2022); however, at the time of writing this paper, the legislative reform only went through the Parliament in March 2023 and is yet to be implemented into practice from October 2023 onwards. Although the proposed legislative reform has the potential to provide services that persons with disabilities could find more flexible and enable them to exercise their freedom of choice, it will not change the established ways of implementations immediately, and this is something that must be closely monitored. A shift in practice may be harder to achieve, even when the reform and legal change have been carried out on paper and in the administrative structure. The chance to better the self-determination opportunities for people with disabilities would be now when the changes are being implemented.

Currently, the disability pension system, although it also provides income to those who do not wish or are unable to work, does not provide enough self-determination opportunities for them according to our study findings. The lack of choice and information are serious faults in the current system and marginalises many people with intellectual and developmental disabilities and other people with disabilities who receive disability pension. More good practices need to be accumulated and scaled up nationwide. As this chapter has revealed, significantly more self-determination opportunities are called for. Currently, people with disabilities are not viewed as equal in every aspect of life, a perception which is deeply embedded in our society. In conclusion, from the perspective of the employment and self-determination rights of persons with disabilities, it is hard to argue that Finland is the happiest country in the world.

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9 The happiness of having a hobby

Inclusion of persons with disabilities in leisure activities

*Eero Saukkonen, Jenni Valmari, and
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Introduction: Happy and hobby nation?

Typically, when the Finnish success story as the country of equal opportunities and well-being is discussed, this is approached from institutional perspectives emphasising the availability of social security (including social services) as well as equality of opportunities in education and employment. While these sectors obviously are highly relevant, this approach often hides from sight one very significant and vibrant field in Finnish society, namely cultural life and leisure activities. Leisure time plays a big role in producing that ‘social glue’ that contributes to social cohesion and trust measured by the World Happiness Report (Helliwell et al., 2022). In addition, leisure activities often provide opportunities for self-exploration, finding new interests and potential in oneself, which allows individuals to flourish. The importance of rich leisure time has also been acknowledged in article 30 of the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) enshrining the right of persons with disabilities to ‘participation in cultural life, recreation, leisure and sport’.

In recent decades the leisure activities of Finnish people have increased along with increasing leisure time (Zacheus, 2008). This has also impacted the appreciation of leisure time: according to the latest statistics, Finns find leisure time more important than time spent on work (Hanifi, 2021; Statistics Finland, 2019). Leisure is not only valued as time for ‘charging one’s batteries’—for relaxation and recovery from the pressure of everyday life and work—but also as time for strengthening social bonds and building one’s identity (Hanifi, 2021; Zacheus, 2008). It is a time when one is cut off from specific social roles and ‘can just be oneself’, with individuality, personal interests and freedom of choice characterising the approach taken by Finns to leisure (Orjala, 2021; Zacheus, 2008). As well as highly valuing leisure, Finns actively take part in a variety of leisure activities. The most common hobbies are reading and sports or physical exercise (*liikunta* in Finnish), which is also reflected in the high level of participation in services related to them (e.g. libraries and sports associations). Most Finns also participate in

different forms of cultural activities (e.g. attend the theatre, art exhibitions and concerts) at least occasionally (Statistics Finland, 2019; Zacheus, 2008). Some use leisure time to learn new skills, which is reflected in the active sector of popular education in Finland (see Finnish National Agency for Education and Vapaa Sivistystyö ry, 2021). Overall, during the latest survey on leisure by Statistics Finland, 70 per cent of Finns reported having at least one hobby outside their homes (Statistics Finland, 2019).

In this chapter, we examine the realities Finns with disabilities experience when taking part in organised or otherwise social leisure activities—in a word, hobbies. We first discuss leisure activities as a key policy focus—how leisure has been approached in the construction of a welfare state—and how persons with disabilities have been considered in this process. Then we move on to discuss our approach in this chapter to leisure and disability. We then discuss the participation of persons with disabilities in leisure time in three thematic sections. The first section discusses the organisation of leisure activities and how this affects the participation and inclusion of persons with disabilities. In the second section, we focus on the intersection of social services and leisure time, asking how the availability of specific types of support affects participation in leisure activities. Third, we discuss the meaning and value attached by individuals to having hobbies and vibrant leisure time. Our examination highlights the complexity of the question of equal opportunities for leisure activities: realisation of equality is not only a question concerning accessibility of the built environment or availability of necessary forms of services that support participation, but both are needed to make equal participation a reality.

Leisure activities as a policy focus and equality concern

The appreciation of leisure among the Finnish public is reflected by policy and societal investments made in leisure activities and leisure infrastructure. Pirnes (2021) argues that leisure had an important position in the building process of the Finnish welfare state and still is an essential part of Finnish welfare policy. From the policy point of view, availability of leisure activities is seen as enhancing active and participatory citizenship grounded on values of enlightenment and emancipation (*ibid.*). This value placed on leisure policy as part of wider welfare politics is mirrored by institutionalisation and the ossification of governance of leisure (*ibid.*). The leisure sector is largely publicly funded, with national funding flowing to actors in the sector either directly or through local (municipal) administration. While the public sector is typically in charge of the building and maintenance of infrastructure (e.g. swimming pools, concert halls) and funding of services, service provision is often implemented in collaboration with non-profit third-sector organisations (Tiihonen, 2021). According to common understanding, Finland is the promised land of associations (Julkunen, 2006; Ruuskanen et al., 2020), and this is reflected in hobbies, as almost any group of hobbyists

will invariably have their own officially registered local and possibly national clubs and associations.

While leisure, in particular in the form of culture and sports policies, has sustained its position as an important sector within the wider welfare policy, the policy strategies have been somewhat challenged by developments in the past decades. One key challenge is the persistence and even growth in differentiation of participation by different groups. While a key target of the sector has been to enhance equality—geographic, economic and social—by offering economically accessible leisure opportunities across the country, differences in participation levels have persisted and even increased, leading researchers to question whether the equal opportunities approach has failed to produce actual equality of participation (Tiihonen, 2021). There is clear differentiation by gender, age and socio-economic status both in levels of participation and in forms of leisure activities between and within different sectors (Hanifi, 2021). In particular, it seems that the dominant policy approach has failed to address differences in economic resources since the socio-economic status of a person or family continues to play a meaningful role in the quantity and quality of leisure activities (Zacheus, 2008). Researchers have thus argued that a more detailed examination of the factors and processes that uphold and even enhance differentiation is needed as a basis for updating welfare policy strategies. The legitimacy of the dominant policy strategy has also been challenged by calls for evidence of more direct societal benefits (e.g. to public health) to legitimise public investment in the leisure and culture sector (Tiihonen, 2021). These challenges not only question the long-standing policy strategy taken in Finland but also narrow the perspective taken on leisure as a policy sector. Focusing on measurable benefits marginalises or even hides those aspects of leisure that have been seen as keys to fostering a well-being society, such as community and identity building or strengthening agency (*ibid.*).

While the emphasis on equality in leisure policy would lead one to expect that disability would be a difference that is closely scrutinised, in fact there is a notable gap in the knowledge base related to leisure participation of Finns with disabilities. Most of the larger scale surveys have been collected in connection to national (policy) development work to enhance equality and/or accessibility in the sectors of culture (e.g. Ministry of Education, 2004; Ministry of Education and Culture, 2014), physical activity/sports (e.g. Hakanen, Myllyniemi and Salasuo, 2018) or popular education (e.g. Laitinen and Nurmi, 2013). In addition, Finnish disability organisations have had an important role in gathering and providing information about inequalities related to leisure activities. The existing body of knowledge suggests that there are major problems related to the participation of persons with disabilities and accessibility resulting in inequality in all key sectors of leisure (see e.g. Ministry of Education, 2014; Teittinen and Vesala, 2019). One finding that recurs across the different reports is that while awareness of accessibility has increased among leisure activity organisers such as cultural institutions,

sports associations or popular education institutions, there are still major shortcomings even in physical accessibility (e.g. Culture for All, 2012). This indicates that even the basic foundations for equality—people being able to physically get to their hobbies—are not in place: as Laitinen and Nurmi (2013: 44) state, in relation to accessibility the ‘built environment takes a primary position, it makes accessibility reality—or sabotages it’.

Data and aims

Our discussion below is based on our ethnographic research into intellectual disability services. Interaction with our research participants and actors and organisations working in the field has provided us a unique perspective from which to examine the opportunities for and barriers to participation in leisure activities for persons with intellectual disabilities. Second, to extend our perspective across different types of activities and fields of cultural life as well as a multitude of disability groups, we draw on previous research reporting on leisure activities and participation in cultural life among persons with disabilities.

The first author was one of two researchers in a project that used ethnographic methods to explore the opportunities young people with the most extensive support needs have for participation in physical activities. Over the course of three years (2020–2022), he visited over half a dozen young participants with severe or profound intellectual disabilities at their homes, schools and leisure sites in municipalities across Finland, observing their physical activities and talking to family members and professionals who worked with these young people.

The second author’s ongoing study focuses on how young people with mild intellectual disabilities create their social worlds. She collected the research data during six months of ethnographic fieldwork in 2022. During that period, she observed the young people by participating in their everyday life in a group home, their workplaces and leisure activities.

The third author did ethnographic fieldwork with adults with profound intellectual disabilities in 2015–2016 as part of a research project studying their everyday lives. During the fieldwork she and her colleague observed the research participants in all contexts of their everyday living, including leisure activities in or outside their group homes.

The emphases of these three studies in part explain the focuses taken in the next three sections. The first author’s research focus on sports activity has framed the examination of the organisation of leisure activities in the first section. We acknowledge that persons with intellectual disabilities form a specific group of people whose opportunities are strongly framed both by their individual support needs and by the Finnish system of intellectual disability services. Thus, some of the notions raised from our respective ethnographic studies are particularly pertinent to this disability group. However, as was noted above and is shown below, while barriers to equal participation

faced by persons with disabilities can vary according to specific accessibility needs, these barriers reflect the general condition of accessibility in the leisure sector and leisure's position in relation to disability services.

There are very few peer-reviewed studies on the leisure activities of persons with disabilities in Finland. Those that do exist almost exclusively focus on sports and physical activity. This state of affairs reflects both the fledgling state of disability studies in Finland and the long-standing priorities of the Finnish state in supporting physical activity and sports studies. Only in the better funded field of sports studies can we find a larger amount of research publications concerning the physical activity of persons with disabilities, and here the focus is often on competitive sports rather than physical activity as leisure.

For this reason, the observations of our own studies are supported here mainly with reference to two kinds of sources. The first is Finnish theses.¹ While the strength of evidence given by such sources is not equal to truly peer-reviewed studies, the volume of these smaller scale studies reflects the importance of the topic, in particular for local communities and institutions. Many of the theses have been written as part of different kinds of development projects focusing on the local or regional development of accessible leisure activities. The second type of source consists of reports and studies published by interested NGOs such as the Finnish Sports Association of Persons with Disabilities and Finnish Paralympic Committee; scientific societies such as the Finnish Society of Sport Sciences or the Finnish Youth Research Society; and public sector institutions such as the Finnish Institute for Health and Welfare.

Given the nature of the existing data, our purpose here is not to draw any irrefutable conclusions about the hobbies of persons with disabilities in Finland but rather to present some of our observations from the field—supported by the available materials—to provide a general overview and suggest lines for more thorough future research.

Organisation of leisure activities

In both public and academic discussions of leisure time in Finland, sports and physical exercise tend to be the main focus. Physical exercise, especially at a young age, has featured prominently in public policy for basically the whole century of Finnish independence, and regular national reports keep track of physical activity and the uptake of various sports in different age groups. Sports are indeed important to Finns: in a 2018 study, 93 per cent of Finns aged 7–17 reported participating regularly in at least one sport (Hakanen, Myllyniemi and Salasuo, 2018). Among similarly aged young persons with disabilities, this number was 78 per cent (Hakanen, Myllyniemi and Salasuo, 2019: 12). While this is something of a gap in itself, other studies have found that the physical exercise of persons with disabilities is also severely limited in variety, and most young persons with disabilities feel they do not have the

opportunity to participate in the sports they would like to do (Ainamo and Koponen, 2013; Eriksson, Armila and Rannikko 2018; Kantanen, 2015).

As in most other countries, hobbies in inclusive groups are rare in Finland. Persons with disabilities, especially persons with intellectual disabilities, mostly exercise alone or in segregated, disability-specific groups, contrary to the inclusive ethos of current Finnish policy (e.g. Eriksson, Armila and Rannikko, 2018; Korkiala, 2015; Taskinen, 2017). A solution has been sought in the dual model of adapted physical activity, where adapted physical activity and sports for persons with disabilities have been developed and organised simultaneously both separately and as part of a general sports culture (Korkiala, 2015; Rintala, Huovinen and Niemelä, 2012). The model could increase the choices of persons with intellectual disabilities concerning sports.

The Finnish Sports Association of Persons with Disabilities (VAU ry) has been a significant driver in the integration of sports for persons with disabilities into general sports culture, as well as a major commissioner of studies—theses and otherwise—into the state of the field (e.g. Ahonen and Pajulahti, 2017; Karppinen, 2018; Saari, 2015; Saari and Sipilä, 2018; Verkama, 2018). This activity as a driver of disability sports has continued after its fusion into the Finnish Paralympic Committee in 2020, as has its role in producing research in the field (e.g. Ahtee, 2021; Saari, 2021).

The latest surveys by the Paralympic Committee found that 66 per cent of surveyed sports associations in Finland reported offering adapted physical activity or disability sports or having members with ‘special needs’ (term used in the survey). This number has consistently risen in the previous decade. However, the reach of these surveys is unclear, and the true number of associations actually offering adapted physical activity or disability sports is estimated to be around 10–15 per cent of all associations offering physical activity (Saari 2021: 52).

The associations that were surveyed report that efforts to include persons with disabilities are hindered mainly by a lack of knowledgeable personnel or volunteers (reported by approx. 50 per cent both). Commonly reported obstacles include a lack of accessible spaces, difficulty in outreach to persons with disabilities and a lack of financial support for adapted physical activity (approx. 20 per cent each) (Saari, 2021: 67–69; see also Ahtee, 2021).

Sports associations in Finland largely rely on public facilities like swimming pools, ice rinks and sports centres to conduct their activity. Usually run by municipalities with spaces and time slots rented or freely given to associations, many of these facilities are decades old and remain physically inaccessible (Ahtee, 2021; Lammi and Tamminen, 2015; Saari, 2015; see also Rautiainen, 2021). Lack of accessibility is a problem, especially for those with mobility impairments, but various other issues such as reverberant spaces and poor lighting have also been reported. Lack of accessibility is also a problem for cultural hobbies, in which associations often rely on adult education and community centres which suffer from similar access issues (Ahonen, 2018).

The problem of outreach to potential members with disabilities has been discussed in relatively many publications. Sports associations often claim that persons with disabilities in their area rarely seem to know of any adapted physical activity or disability sport they might be offering (Saari, 2021). Persons with disabilities themselves often report a lack of suitable sporting opportunities in their area as a major factor limiting their leisure activities, especially in more sparsely populated areas (Ahonen and Pajulahti, 2017; Eriksson, 2018). While this perceived lack of opportunities is no doubt true to a large extent, some of this may also be attributed to a lack of information. Various studies lament the relative lack of communication and co-operation between activity-offering associations and the public services which persons with disabilities almost invariably use (Eriksson and Saukkonen, 2022; Saari, 2021; Verkama, 2018).

One notable attempt to tackle the combined problem of lack of information and sufficient assistance (discussed in the next section) has been the *Valtti* programme initiated by VAU ry and currently continued by the Paralympic Committee. Part of the EU's 'Sports Empowers Disabled Youth' projects (SEDY and SEDY2), *Valtti* connects volunteers with young persons with disabilities. The idea is that the *Valtti* volunteer instructor will assist the young people in seeking and trying out new sports and exercise possibilities. *Valtti* has reported positive results, with approximately half of all participants finding a new hobby (Ahonen and Pajulahti, 2017; Karppinen, 2018; Skantz, 2017), while many study programmes for adapted physical activity have incorporated working as a *Valtti* instructor into the curriculum.

It has been suggested that the tradition of segregated groups for persons with disabilities is still strong, and arrangements might not be made to include persons with disabilities in an association's activity unless they can form their own group (Saari and Sipilä, 2018; Verkama, 2018). This obviously has implications for inclusion and disproportionately harms persons with disabilities in sparsely populated areas, where there may simply not be enough persons with disabilities to form a group.

As sports and exercise instructors with the readiness to work with persons with disabilities are too few, the significance of individual teachers and coaches for the permanence of hobbies and groups for persons with disabilities is emphasised. During ethnographic fieldwork, the second author met a dance teacher who told a story about her dance group for persons with disabilities, which describes this situation well. She has taught the same dance group for over ten years, though she has changed locations and employers a few times. She has wanted to keep the group with her and together. The members of the dance group have remained almost exactly the same all this time. The dance teacher told the researcher that this group was magnificent, and she was very proud of every one of them. The dance group has competed several times, and they have succeeded well. These examples of dedication are worth mentioning, but reliance on exceptionally committed individuals

is not enough to guarantee equal opportunity and continuity in hobbies for persons with disabilities.

Even when suitable groups exist and information on them is available, many persons with disabilities may still be hesitant to join mainstream sports associations. This has been a central finding in many studies. Persons with disabilities fear discrimination and ridicule in non-segregated settings, often on the basis of their own previous experiences (Eriksson, 2018; Hakanen, Myllyniemi and Salasuo, 2019; Savolainen, 2019). Competitive sport is prioritised in many mainstream sports associations, and this can make both association organisers and persons with disabilities feel like the latter do not fit into the organisation's membership (Saari, 2021). The competitive focus of many Finnish sports federations has been the object of critical discussion and not merely from the point of view of persons with disabilities (Salasuo and Kangaspunta, 2011; Turtiainen, 2016).

In contrast to the field of sports and physical exercise, the cultural leisure activities of persons with disabilities in Finland are sorely understudied. At the grassroots there are plenty of activities, projects, case studies and participatory projects related to hobbies and leisure time like shadow theatres, dramas, visual arts and music (e.g. Eriksson, 2021; Javanainen and Tähtinen, 2018; Simola, 2013; Toivola, 2021; Väänänen, 2016). These have often been ignored in the academic discussion about the hobbies of persons with intellectual or other disabilities.

In our experience, cultural hobbies for persons with intellectual disabilities mostly take place within the organisational structures of adult education centres and support associations for persons with intellectual disabilities. One notable individual actor in the field of cultural hobbies is Music Centre Resonaari in Helsinki, a unique NGO-run music school for people with disabilities. The music school currently offers instrument and band tuition to over 300 pupils who attend a class every week. Their goal is to provide everyone with the opportunity to join music-making and to find ways to enable everyone to play. They have created the Figurenotes system, which makes it easier for everyone to learn to play, taking forward both the accessibility of music education and, more broadly, the equality of music education (Helsinki Missio 2023; Vakkala, 2012).

Where there's a will there's a way—But is there support?

The availability of suitable and accessible activities is an obvious key to achievement of equal opportunities. However, some individuals also need specific types of support to make participation a reality. While some of the major obstacles to participation that persons with disabilities face—like economic barriers, even poverty (see e.g. Teittinen and Vesala, 2015)—also affect the participation of persons without disabilities, many of the forms of support developed to counter these are specific to disability and based on disability legislation. This support is the focus of this section.

While it could be argued that leisure is often not the major focus of disability policy, current legislation concerning disability services acknowledges leisure as a vital part of an individual's life. This is reflected by specific forms of support that are granted not only with labour market participation in mind but to assure active citizenship and inclusion across different spheres of life (see also Ajasto and Arvio, 2012; Kivistö and Hautala, 2020; Odedeiy and Passi, 2019; Söderlund, 2014).

For many persons with a severe disability, participation in leisure activities outside one's home requires assistance. While organisations and cultural institutions organising activities might themselves have some assistive staff or service available (Ministry of Education and Culture, 2014), for many this type of support is provided by a personal assistant (PA) accompanying them to their hobbies. Personal assistance for leisure time is a subjective right for those who meet the requirements for a PA set by legislation. The minimum allocation of this service for service user is 30 hours per month. One particular benefit of this form of service is that even persons living in housing services (with its own staff) can get a PA for activities outside their home. Since assistance in group homes is typically shared by multiple service users, it is often difficult to stretch the staff resources to meet the needs of individuals, especially for leisure activities outside the unit that take place regularly (e.g. once a week). Thus, having a PA provides opportunities for service users to plan and spend their leisure time according to individual preferences.

While a PA for leisure time should be available for everyone who needs it, the current legislation has restricted the right to a PA to persons who are considered as having the capacity to express their needs and preferences concerning how this support is provided and for which activities (Finnish Act concerning services and support based on disability, §8c). In practice this means that people who struggle to specify and/or express preferences are left outside of this service. For such individuals there is an opportunity to apply for a support person. However, since a support person is not coordinated by a service provider in a similar manner as a PA and the terms of the work are closer to voluntary work than paid employment, finding, coordinating and keeping a support person is often time- and energy-consuming.

The capacity requirement of the act concerning PA and municipal disability services' interpretations of this have been criticised for treating people unequally (see also Nieminen and Rautiainen, 2021). In addition, the negative effects of the capacity requirement arguably impact exactly those people for whom support in leisure activities is key for living an active, flourishing life. In the third author's ethnographic study on the everyday lives of six adults with profound intellectual disabilities, only one of the participants—Ella (pseudonym)—had a PA for leisure. Ella also was the only one who had some regular hobbies (dance lesson, gym group) outside the intellectual disability service system, meaning housing unit and day activity services.

In practice, the PA travelled with Ella to these hobbies by taxi or bus and assisted Ella during class if needed. Not all of the hours assigned for the PA were spent on these regular hobbies, but the assigned hours made it possible for Ella and PA to spend time together in the local neighbourhood or in the city. One regular activity was to visit the local library to get CDs for Ella who enjoyed listening to music. Having a PA also allowed Ella to explore new things, for example going out to eat sushi or going to music events. This way the two of them were able to work collaboratively on exploring and defining Ella's preferences. In Ella's case, personal assistance turned out to be a key resource that allowed individualisation in the sense that Ella was able to live a life that looks like her (Vehmas and Mietola, 2021).

Participation is also dependent on physically getting to the hobbies. In this sense, transport services are an important piece of the service puzzle that makes leisure participation a reality (see Tarvainen and Hänninen, 2021). According to legislation, the municipality must provide a person with a severe disability adequate transport, with a minimum—that often in practice is the maximum—of 18 one-way trips per month for everyday affairs, including leisure. This is typically arranged as a taxi service. In relation to leisure time, both the extent of the service (how many trips are allocated to a service user) and the way it is organised influence participation (Huttunen, 2020; Ministry of Education and Culture, 2014). If a person experiences that the transport service is difficult to use and unreliable, they are more likely to use it less, which typically affects leisure participation and thus social relations (Huttunen, 2020). While transport shortages are likely to impact equality, particularly in less populated areas where the distances are longer and accessible public transport is less available, problems related to transport services are also repeatedly raised in advocacy work in bigger cities (e.g. It-lehti, 2020). In addition, Kivistö and Hokkanen (2021) note that while the services can administratively be understood as separate entities drawn from separate sections of the Finnish Disability Act and responding to separate needs of the service user, in practice these are connected. They cite a case where a service user got a positive decision concerning a PA for leisure activities, but a negative decision concerning transport service that in practice made it impossible to use the PA to support their participation in their hobby.

The state can grant financial assistance for the acquisition of assistive devices necessary for particular activities, for example for outdoor activities or hiking. The problem with these, however, is often that there is no official route to try an assistive device—or therefore the activity it is needed for—before applying for assistance in buying it. In addition, while families and persons with disabilities themselves can often receive information and guidance in how to access and apply for institutional services and support, there is a general lack of official support for finding hobbies or leisure activities. Persons with disabilities and their families often describe disability services staff as unaware of, uninterested in or unable to provide information on

accessible leisure activities in their area. Instead, many persons with disabilities find what hobbies they have through the grapevine of acquaintances and NGOs (Eriksson and Saukkonen, 2022).

Overall, both researchers and discussions on the field have repeatedly raised the issue that leisure participation depends not only on the availability of public support but also on finding out about it. This requires specific resources from persons with disabilities or their families. Thus, differences in social, cultural and material capital can create differences in opportunities (Eriksson, Armila and Rannikko, 2018). One needs to be aware of one's rights, the disability service system and forms of support as well as the local availability of accessible leisure activities. This becomes apparent in a study on families of children with intellectual disabilities, where one of the interviewed parents stated that where there is a will there is a way (Niskala, 2018). This statement not only highlights the agency of the families but also makes visible the persistence required to access opportunities. It seems that an active life requires exceptional initiative, investments and resources from persons with disabilities and sometimes from their families: making participation a reality requires a great deal of information gathering, insistence with public services, planning and arranging transportation and assistance (*ibid.*; see also Pulkkinen, 2021). Tarvainen and Hänninen (2021) have conceptualised the subject position formed by these requirements as service-jungle citizenship: a citizen capable of making sense of their rights and the service system as well as of demanding and applying for the services. This level of agency requires social capital, meaning networks for sharing information about the service system and strategies, cultural capital, meaning the capacity to acquire and process information and make use of it, and economic capital (see also Eriksson and Saukkonen, 2022). Thus far the availability of public support in the form of disability services and monetary support has not been able to reduce differences in participation and inclusion resulting from these differences in capital between persons with disabilities themselves or their families.

Meaning and value attached to having hobbies and vibrant leisure activities

As mentioned earlier, hobbies and sports increase the well-being of the person on many different levels. Our ethnographic observations suggest that it is common to emphasise these benefits to legitimise leisure activities and the use of resources for them. This way, hobbies become means to achieve goals rather than valued goals themselves. For persons with intellectual disabilities, the importance of social relations and achieving community participation is typically emphasised in the context of hobbies—although as we have outlined above, segregated groups remain the norm. This instrumental approach to leisure activities was revealed in studies where professionals and family members of persons with disabilities have been asked about the

meaning and value of hobbies. It is typical for them to underline the benefits of active leisure time, such as an overall increase in activity and well-being, strengthening of self-esteem and, most importantly, prevention of exclusion (e.g. Vuorela, 2014; Väänänen, 2016).

This instrumental approach is somewhat challenged by persons with disabilities themselves. While they might attach similar goals related to physical and mental health and social relations to hobbies, when talking about their personal lives and views, persons with disabilities are more likely to view having hobbies as valuable in itself. For example, in a survey of young people with reduced mobility, the respondents highlighted four significant aspects related to hobbies: hobbies produce joy, increase the experience of success, maintain functional capacity and improve fitness and allow you to spend time with friends (Hakanen, Myllyniemi and Salasuo, 2019). In studies on the views and values of adults with disabilities concerning hobbies and vibrant leisure time, the participants valued self-determination, the freedom to choose their hobbies; participation, being part of the group; and experiences of success (Heikkilä and Veijalainen, 2015; Laitainen, 2020; Mustajärvi, 2014). In comparison to the large-scale national surveys discussed above, the views and values that persons with disabilities have concerning leisure seem very similar to those of their peers without disabilities: leisure time is seen as an important area of life for fulfilment, self-expression and social engagement (see Statistics Finland, 2021; Zacheus, 2008; Zacheus and Saarinen, 2019). We would argue that the approach where having a hobby is considered valuable in itself fits the rights paradigm where the emphasis is on equality rather than benefits related to health, integration or inclusion.

Regarding the rights paradigm, recent study raises interesting notions concerning the relationship between leisure activities and rehabilitation (Eriksson and Saukkonen, 2021). For many persons with disabilities, especially those with more severe disabilities, state-sponsored rehabilitative physiotherapy is often their most common and longest standing form of everyday physical activity. Rehabilitative physiotherapy—or ‘demanding medical rehabilitation’ (*vaativa lääkinällinen kuntoutus*) to give it its proper legal name—can be granted to those who are deemed to need it by a doctor in the public health services (KELA, 2022). In addition to ‘traditional’ physiotherapy, such rehabilitation can take certain other forms, of which aquatic therapy and equine-assisted therapy are very common.

Being a part of an individual’s rehabilitation programme, the continuous public backing of any form of physiotherapy is contingent on the highly medicalised goals of rehabilitation—such as upholding movement ranges, improving posture or reducing pain states. Often mere maintenance of health and functioning is not deemed enough to justify continued public support for an individual’s rehabilitation effort, but rather it should result in a continuous improvement. This can be hard to quantify or demonstrate, especially for persons with profound intellectual and multiple disabilities who may lack the communicative means to articulate their physical and mental

state. Physiotherapy is also distinguished from physical exercise as a hobby by the fact that it is obligatory to a larger degree, both in the sense that repeated nonattendance would result in a reduction of state support, and in that it is usually necessary for persons with disabilities to maintain health and functioning on a level that is not true for persons without disabilities.

In interviews with parents and grassroots rehabilitation professionals, values attached to forms of physiotherapy go far beyond the goals of medical rehabilitation. Both family members and professionals can see physiotherapy as an important site of social interaction, self-expression, building self-confidence, getting outdoors and trying new things. Physiotherapy can in other words act as a hobby, just like any physical activity for any person (Eriksson and Saukkonen, 2021, 2022). In addition, for persons with very limited possibilities of ‘getting outdoors’, meaning spending time outside of their housing unit or day activity services, activities arranged under the label of ‘therapy’ might offer the only opportunity, backed up with relevant resources such as assistance and transportation, to actually take part in ‘hobby-like’ activities (Vehmas and Mietola, 2021).

A great example of the various ways that rehabilitative physiotherapy becomes meaningful is ‘Teemu’, a young man with profound intellectual and multiple disabilities whom the first author got to know during his fieldwork. Teemu’s physiotherapist had been working with him for years and was clearly a very important person to him, whose company he very much enjoyed. Teemu’s physiotherapist regularly visited him in school and at home for physiotherapy sessions, in addition to pool therapy roughly once a week, assisted by Teemu’s grandmother. At school, the physiotherapist insisted—initially in contrast to his class teacher’s suggestions—that Teemu should not move to a separate room for the duration of the session but should instead remain in the classroom so he could follow the class. This demonstrated her conviction that sociability was at least as important as the medical effects of physiotherapy. Meanwhile all who knew Teemu considered the weekly pool therapy to be of great importance to him. His physiotherapist emphasised the ways that buoyancy in the water allowed Teemu a greater range of self-determination and self-expression than his everyday life otherwise did. Teemu could propel himself unassisted in the pool, he could manipulate objects more easily—in the words of his physiotherapist, Teemu ‘gets to intend something’ in the water. Meanwhile in an interview, his grandmother was insistent that pool therapy was not just rehabilitation but a proper hobby for Teemu. But this, Teemu’s mother swiftly and half-jokingly reminded her, must never be said aloud to the officials making funding decisions about Teemu’s rehabilitative activities. No, his grandmother concurred, ‘nothing should be enjoyed! It must not produce good feelings, that’s no criteria at all!’

Teemu’s example and several other cases from the study pointed to the fact that within Finnish disability services, the social, creative and pleasurable potential of activities conducted within the framework of rehabilitation continue to be dismissed. While for many persons with disabilities, physiotherapy

is an unavoidable fact of life in a way that ‘hobbies’ as commonly understood are not, we contend that it is a great waste of potential not to treat physiotherapy as a socially and psychologically meaningful activity, given its prevalence among persons with disabilities. Therefore, while the importance and multiple meanings of vibrant leisure time are baked into Finnish legislation with the ratification of the CRPD and clearly acknowledged by actors at the grassroots, there remains a critical gap in the middle level of bureaucratic practice in public services. At this middle level, a medicalised outlook continues to dominate how the lives of persons with disabilities are viewed, even in leisure time.

Concluding remarks

Ensuring that citizens enjoy vibrant leisure time has been a sustained policy goal in Finland and is considered a part of the wider welfare policy. Building a society with participating citizens who ‘fare well’ is a crucial to the ethos of the Finnish welfare state. In this effort, equality is a key concern at the policy level and has long been a central consideration in directing the allocation of state resources in the leisure sector.

Despite this emphasis, the knowledge base concerning the inclusivity of leisure and the participation of persons with disabilities is limited, which makes it difficult to monitor the achievement of policy goals in this sector (per the CRPD) or developments in participation. In the current situation, sports can be considered as the best monitored field of leisure activity—but is this systematic?

We have seen that leisure activities in Finland are traditionally organised through the collaboration of the public sector and non-profit third-sector associations, with the former providing funding and infrastructure and the latter in charge of organising the activity. On both sides of this collaboration, inclusion goals outlined in the CRPD are being incorporated into operational logics. In addition, many popular leisure venues such as cinemas, art galleries or gyms are run by private enterprises. While services in this sector are also subject to accessibility regulations, the incentive to develop more inclusive and accessible services also comes from growing demand (see Teittinen and Vesala, 2021).

An effort to allow persons with disabilities the chance to participate in leisure activities within inclusive settings is thus underway, at least in sports, but there is still a long way to go. Progress towards this objective is being slowed due to lingering prejudices and a lack of accessible spaces and especially of expertise. This is particularly the case in smaller and more rural municipalities. In addition, information continues to be a critical factor. This includes availability of information about suitable and interesting hobbies and services as well as of information about services supporting participation, whether personal assistance, transport services or assistive devices. Increased complexity in needs for assistance multiplies the amount of work necessary in finding, applying and re-applying for forms of assistance and

means that a denial or breakdown of service somewhere in this complex web can render other, already granted forms of assistance useless.

In this jungle of services, the time, energy and resources of individuals and families are subjected to something of a stress test. This means that persons with disabilities from families with greater social, cultural and economic resources are often better off, producing inequality among persons with disabilities. For those families with fewer resources leisure—arrayed alongside more unavoidable and routinised parts of life such as education and the maintenance of bodily health—is often the sector where compromises tend to be made first. This is a loss especially for persons with disabilities past their school years, as unemployment tends to be the norm, and thus, the quality of ‘leisure time’ arguably plays an even bigger role in quality of life.

Our discussion here has attempted to provide a description of the multiple barriers to achievement of inclusion in leisure that still exist and thus underlines the complexity of equality in leisure. This complexity refers to the layered nature of different barriers (see Katsui and Mesiäislehto, 2022). As mentioned at the beginning of our chapter, there is still a lot to do even in relation to the physical accessibility of leisure services. Thus, while a person with disabilities is seemingly free to take part in leisure activities such as going to the theatre or cinema, the built environment can make this difficult or impossible (see Rautiainen, 2021). In addition, this freedom is nonsensical if one’s agency is limited by a lack of funds, with poverty being one key factor impacting the social participation of persons with disabilities (Vesala, Teittinen and Heinonen, 2014). For some, participation depends on availability of different forms of support, like transport services or personal assistance (Kivistö and Hokkanen, 2021). While getting persons with disabilities to the same level of participation as their peers without disabilities remains a priority, inequalities between persons with disabilities resulting from differences in resources, needs or even municipalities of residence need to be considered.

These inequalities cannot be resolved only by investments in funding, policy and monitoring of accessibility and support systems. Actually, in Finland the legislation related to equality and disability rights is considered to be up to date. Making these equality commitments reality is rather dependent on recognition of equal rights (see Chapter 10 in this book). In practice this means that work still needs to be done to change the cultural image of a person with a disability: what life with disability can and thus should look like (Rautiainen, 2021). Only by changing this image does it become possible to challenge systems of priority where leisure activities are seen as less important than meeting other ‘needs’ related to everyday living. Kalle Könkkölä (2013: 19), the most well-known Finnish disability activist and initiator of The Threshold Association, clearly describes this layered nature of barriers:

When a person with severe disabilities wants to include some kind of meaningful activities into their life by for example taking part in popular

education—where there is a multitude of opportunities—they first have to figure out how to get out of their own home or whether to use all of their transportation services on studying Spanish, how to get into the room where the teaching takes place or in the toilet at the educational institution. When they have successfully solved all of these questions, they bump into a brisk citizen who asks ‘does one really need to get everywhere’.

We started by asking whether hobbies make people happy. The fact that leisure is included in social policy is a strong argument supporting this link, meaning that people who have hobbies make a happy nation. However, the Finnish welfare strategy has followed the idea that equality is a prerequisite for national well-being. Thus, while Finland keeps topping the charts in the World Happiness Reports, the inequalities related to participation, also in leisure, keep questioning achievement of the related policy goals. If a hobby nation is a happy nation, there is still room for improvement in happiness by investing in making the leisure sector more inclusive and turning equality of opportunities into actual equality of participation.

Acknowledgements

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Note

1 While also including some Master’s theses, the main body of this literature consists of theses written in polytechnics. These institutions are responsible for training professionals for social and health services while also working in close collaboration with local actors. Thus, it is understandable that the development of inclusive leisure activities is also focused on the work of the institutions, which is reflected by the theses focusing on the topic.

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10 Spiral of progress

Disability activists' perception of the societal and political position of disabled people in Finland

Pekka Koskinen, Aarno Kauppila, and Reetta Mietola

Introduction

How to counter injustices in relation to disability remains a key theme both on a theoretical level in disability studies and on a practical level in the disability movement (Campbell & Oliver 1996). As James Charlton (1998) showed in his seminal work, the global disability rights movement has fought for changes to counter injustices on three levels: laws and legislation; practices and conventions; and symbols and meaning. Charlton argues that resistance to injustices requires changes in political and economic structures and cultural belief systems. Taking Finland as the geographical context, we utilize interviews with disability activists to scrutinize how they regard the current societal and political position of disabled people, and where they see the critical struggles over injustices. Our chapter questions the grand narrative of Finland as a model country of equality, especially when it concerns disabled people's involvement in policy and decision-making. Although we do acknowledge the relative successes in certain areas of disability politics, we suggest that making rights a reality in the daily lives of disabled people remains a struggle.

Our study in this chapter is part of a research project studying disability activism and movement in Finland. Utilizing the project interviews with disability activists, we scrutinize the relationship between Finnish society and disabled people. Our focus is on how disability activists perceive disabled people's current societal and political position in Finland.

To examine this, we apply feminist theorist and political scientist Nancy Fraser's ideas about the politics of redistribution, recognition and representation. We view Fraser's three-dimensional conceptual toolbox as appropriate for acknowledging disabled people's efforts and accomplishments without falling for naïve optimism about self-evident progress in disability policy and disabled people's societal position. Our chapter proceeds as follows: we begin by unpacking our theoretical perspective and explicating how we have utilized the concepts of redistribution, recognition and representation. After

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that, we introduce our interview data and the principles of analysis. Our findings are presented in three separate sections according to our theoretical perspective.

Fraser's theory of injustices and disability

Feminist theorist and political scientist Nancy Fraser's well-known theory of different types of injustices offers three concepts: politics of redistribution and politics of recognition, and later she expanded these with politics of representation (Fraser 2003, 2005). She starts from the notion that various political struggles include 'a new constellation in the grammar of political claims-making' (Fraser 2000: 108). Fraser notes how 'old' social movements used to mobilize around class with redistributive claims to counter injustice. They are accompanied today by 'new' social movements, which mobilize around claims of recognition over one's identity and dignity. Temporality is certainly incorporated in the 'recognition redistribution dilemma', as Fraser and Honneth (2003: 1) argue that after the Second World War, redistributive justice was well suited to analyzing labor struggles. However, since the 1970s we have witnessed struggles over 'injustices that cannot be remedied by redistributive claims' (Fraser 2000: 109).

Redistribution refers to liberal democratic theories of justice such as Rawlsian theories of distributive justice. As Fraser's example of labor struggles suggests, a politics of redistribution sees injustices rooted in the political economy, and this type of injustice should be targeted with claims over economic, cultural and social resources and changes in the production of labor. Indeed, economic relations and disabled people's position in the capitalist mode of production were key sources of injustice in Mike Oliver's theory of disablement (Oliver 1990).

Recognition refers to the type of injustice that has its roots in cultural value systems. While redistributive injustices are rooted in the economic structure of society, recognition injustices are rooted in the status order of society. For example, in Fraser's thinking, sexual minorities face injustices not solely on economic terms—such as family-based social welfare—but more from a heteronormative status order of society (Fraser 2003: 19). These cultural value systems eventually deny the self-worth and dignity of people who are lower in the status order as equal and valued members of society. These systems operate based on norms and ideals, for example about 'proper' embodiment and abilities. According to disability studies scholar Bill Hughes (2020: 89), these deep cultural beliefs 'constitute a vision of good life in which impairment is misrecognized as a deficit of body, soul and cultural competence'. As Hughes argues in depth, ableism should be seen as a crucial element in structuring the status order of society alongside racism and sexism.

Regarding representation, Fraser (2005) sees injustices in economic and cultural spheres are intertwined with injustice in the political sphere. By

political sphere, Fraser means official political processes such as voting but also more abstract political processes, which determine who is entitled to make justice claims on one another. On the one hand, Fraser sees the lack of or exclusion from political participation as a source of economic and cultural injustice which causes misrepresentation. On the other hand, some economic and cultural barriers need to be tackled before people can participate in the political sphere on equal terms. Fraser's politics of representation is thus concerned with membership and procedure: who is considered a legitimate member of political community where political claims are made, and how the procedure of political domain is structured in order to people to state their claims.

Finally, it should be acknowledged that the discussion around recognition or redistribution continues to be contentious. While many share the premise that, on a theoretical level, an adequate analysis of harms and means to address injustice requires both aspects, much has been debated about how users of this theory tend to construct dichotomies such as old/new, past/present or cultural/economic (Butler 1997; Fraser 1997). The recognition-redistribution dilemma concerns which politics—of recognition or redistribution—is more suitable or preferable for which cause (Hugemark & Roman 2007). Indeed, the term dilemma points toward interpretation that it should be solved by favoring one over another. Keeping these imperfections in mind, we feel the dilemma offers a suitable tool for analyzing the evolving position of disabled people in Finnish society. Instead of analyzing claims of recognition and redistribution as a dilemma to be solved, or taking a normative stance while aiming to find the best solution to injustices related to disability, we see both aspects as irreducible and utilize them to capture the dynamics of disability policy. Thus, our analysis shows how certain 'victories' open up new political questions to be addressed by new tactics.

Data and analysis

To analyze disabled people's political and societal position, we utilize 17 semi-structured interviews with disability activists. The interviews were conducted as part of a research project, 'Performing disability activism'. The research project studies the present and past of disability activism and the disability movement in Finland. Two members of the research group carried out the interviews in 2021. We recruited participants through our project's webpage and social media accounts. In addition, we used the snowball method and direct contact with people who we thought would be willing to participate in interviews.

As our project is about centering disabled people's views and voices, we sought participants who are disabled, but it was up to our participants to define their own relation to disability. Each interview was conducted online because of the COVID-19 pandemic. Consent and data protection were discussed before the interviews, and we emphasized voluntariness before

and during the interviews. Our impression is that people were willing, and even eager, to share their views and experiences, since many contacted us at the start of our project stating their willingness to take part in interviews. Interviews were structured loosely around different themes, for example the person's own trajectory, ways of doing activism, or perception of the state of disability policy. During the interviews, the interviewers gave space for the interviewees to steer the discussion toward topics relevant to them. This flexibility allowed the interviewer to take interviewees' preferences into account, if an interviewee might express discomfort in focusing on a specific topic. All interviews were recorded and fully transcribed, and citations were translated from Finnish by the authors, and the extracts here were edited for clarity.

Our interviewees represent different generations: some of them have been actively involved in disability advocacy since the 1970s to the present day, while others have only recently started engaging with disability activism. While some interviewees identified themselves solely as disability activists, others, due to their various backgrounds in different (or overlapping) political arenas, considered themselves more as advocates who work around disability policy in different disability organizations and other non-governmental organizations. Thus, it is difficult to categorize our participants and their political activity with one term. Our interviewees' ambivalent relation to terms such as activism, advocacy or civic participation resembles findings from Finnish social movement studies, which point out that it is not straightforward for people to self-identify through a single term (Monti & Purokuru 2018). The fact that our participants' experiences span different decades enables us to analyze continuities and transitions in disabled people's evolving societal position and participation.

One theme we discussed with disability activists and advocates in the interviews was how they viewed the societal position of disabled people, and what issues they saw as 'progressing' or 'regressing' over the years. When we started the preliminary analysis of our interview data, we noticed a similar kind of narration among interviewees. This type of talk could be characterized as 'yes things have progressed but...'. Despite similarity, the issues and sectors where our participants saw progress happening varied.

To conceptualize these similarities and differences in our interviewees' narration, we utilized Fraser's three-dimensional conceptualization of politics of redistribution, recognition and representation. Hence, we focused both on where (what field or issue) the interviewees see the critical struggles over injustices and what the outcomes of these struggles (progress, stagnation or even backlash) were, in order to capture the complexity of social and political change. As the title of this chapter suggests, progress from one target to the next is not linear; change might require multiple returning efforts and work done simultaneously across different fields. This means that the relationship between disabled people and Finnish society changes according to issue discussed. Progress in one area, such as legislation, does not automatically mean similar change in another, such as attitudes. By analytically

differentiating redistribution, recognition and representation, we revealed multiple yet not mutually exclusive answers to our question concerning disabled people's societal positioning in Finland. In the following sections, we illustrate these answers with extracts from our data.

Narrating progress through history and emerging redistributive claims

In their social historical study on disability in the Finnish welfare state and the status of disabled people, Heli Leppälä (2014) describes a history of expanding policy goals. Leppälä identified three phases: the 1940s preventative welfare agenda to reduce social harms shifted toward an expanding rehabilitative ideal in the 1960s, followed by normalization through supportive policies to promote disabled people's equal status in the 1970s. Our interviewees' narration of the progress in disabled people's societal position in the long run can be read alongside these expanding goals of Finnish disability policy. In interviews, activists commonly narrate progress in disabled people's societal position and state that disability activism has played a role in this by advocating legislative and material progress. The progress story is commonly told by talking about redistribution, such as developments in education, housing, and disability services.

Narration of progress includes highlighting previous generations' struggles for societal change. For example, many of our interviewees from different generations highlighted how Kalle Könkkölä (a well-known Finnish disability activist from the 1970s to the end of the 2010s) and his generation of activists improved the societal position of disabled people in general. In this type of narration, today's progress is established by comparison to a previous repressive situation where disabled people lacked many rights that we tend to take for granted today. As noticeable markers of progress, our interviewees mention development of disability legislation and improvements in disability services.

And if we think for example about a disabled person's life in the 1960s in Finland, and what it is now, what our legislation is with UN convention ratified and so on. So of course, in the long run, things have progressed. We are no longer in the back of a room tied to a bed, so to speak. So of course, change is happening. But when you live that change, it is difficult to notice all the things happening.

This interview extract illustrates how a story of progress is told by making reference to repressive history. Putting the development in a historical perspective works to make change visible, and one of our interviewees belonging to the oldest generation ponders whether change can be acknowledged only afterward, 'in the long run'. To illustrate small but symbolically significant victories, our interviewees mention the European Accessibility Act (EAA) which the European Union enacted in 2019 (Directive [EU] 2019/882). The

EAA requires public and private sector actors to guarantee the accessibility of certain everyday products and services for disabled people. The Ministry of Social Affairs and Health is currently preparing a proposal on the transposition into Finnish legislation. Few would dispute the notion that the disability movement's political focus on material redistribution, whether via disability legislation or services, has had its positive effects.

While recognizing the achievements on policy level (see Introduction in this book), some of our interviewees raised critical insights about policy implementation and its effects on the daily lives of disabled people. It became rather clear in our interviews that over time the political struggle has expanded or even totally shifted from legislative issues to policy implementation.

But then again, about the personal assistance system. I have been talking about the lack of hours for almost 15 years. It is a constant struggle, this same issue. Municipalities are against, either they don't understand or they don't want to understand.

The extract above illustrates how redistributive developments in the daily lives of disabled people remain debatable. Although the personal assistance reform is much appreciated and the efforts to gain it recognized, activists now need to fight for the implementation of that reform, namely assistance hours. Debate concerning personal assistance illustrates how the political struggle over redistributive claims is constantly evolving. Currently, the Finnish disability act is being reformed, and the question of disabled people's right to personal assistance is under political negotiation again. The present negotiation concerns who is entitled to personal assistance, and on what basis.

Claims over redistribution to improve disabled people's societal position have been a distinctive political strategy in the modern disability movement. This has been true particularly in the UK where the strategy of focusing on barrier removal is anchored to the social model of disability (Shakespeare 2006: 30), which has its origins in disability activism and which later became the 'big idea' in disability studies (see Oliver 1990). Despite its significance, the social model of disability has met criticism.

Carol Thomas (1999), among other disability theorists drawing from feminist theory, criticized the social model both as a theory and political strategy. In Thomas' formulation, the social model was suited to capturing the *barriers to doing* but failed to give accurate account of the *barriers to being*. Thus, removing material barriers was not enough. A sufficient political strategy (and accurate theory) should include removing barriers to being. Rather than rejecting the strategy of removing material barriers, Thomas calls for us to acknowledge how attitudinal barriers are also real and efficacious (see also Hughes 2020). In the next section, we explore how disability activists and advocates view the current recognition of disabled people's being and its importance in their activism.

Articulating material issues through recognition and becoming legitimate political subjects

Although claims over material redistribution and cultural recognition are often dissociated from one another in theoretical discussions, Fraser (2003: 8) notes their overlap in the struggles to counter injustices. Recognition can thus be seen as a precondition to enjoying the established material redistribution. For example, physical access to buildings is of little use if the institutional atmosphere inside them is hostile to disability (Apelmo & Nordgren 2022; Titchkosky 2011). Nevertheless, physically inaccessible spaces presumably hamper efforts to gain recognition as disabled people remain invisible in society.

Despite the relative success of reforms concerning material redistribution, our analysis shows that redistribution is on a continuum with recognition. Below are two examples of certainly redistributive questions which are portrayed as questions of recognition: the first about employment and the second about services.

And whether a disabled person is worth hiring, can they be hired, all this employability question. Why can't people just hire disabled people? We wouldn't seek those jobs unless we were qualified to do them.

But somehow officials and their attitudes, that is something I want to try to affect because things would be much better. I see, in my job also, how disabled persons claim services and get so angry sometimes about social workers. I mean how much do people have to convince just to get services? I feel it is offensive how much people's need for services are questioned. So these people's attitudes are what I want to try to change.

In the first extract, disabled people's barrier to the employment is narrated as a question of employer's attitudes. Changing the attitude to see disabled people as 'worth' hiring has been key in Finnish disability policy alongside structural labor market policies to enhance disabled people's employment. The second extract highlights social workers' role as gatekeepers to services. For this interviewee, the barrier is not the lack of adequate services, but the attitudes of the people who grant these services.

To tackle attitudinal barriers, some of our interviewees act to raise awareness about disability in various sectors and with various actors. These actors can be seen as the guards of plenty who have a major impact on how disability issues are discussed and addressed, for example in schools.

[Do you feel your activism has had an impact?] Yes, I do. Like for example I have regularly done these 'expert by experience' lectures. I keep getting invitations repeatedly because the issues I discuss are considered important.

This lecturing in schools is awareness raising advocacy and part of the politics of recognition, as it aims to make disability-related issues visible to the general public. While the outcomes of this kind of advocacy are often vague and difficult to detect, it is worth highlighting how the authority of disability has shifted. From being solely a medical issue with professionals in the authoritative position, disability has become a question of lived experience with disabled people having the epistemic authority.

The flipside of awareness raising is that it can become obligation, making disabled people solely responsible for ‘educating’ non-disabled people. One interviewee described how responsibility for accessible events is becoming acknowledged more thoroughly by event organizers.

Somehow it has become more mainstream, like for example some years ago someone asked how to make this event accessible. Nowadays it seems these issues are considered more widely and systematically and things are done more professionally.

Interviewees like the one cited above underlined how disability and disabled people have become more visible in society during the last few decades and how this can foster awareness that produces concrete improvements in the form of recognition of disability rights and obligations related to this.

Discussion concerning disability representation had two sides. On the one hand, interviewees stressed that today much more attention is paid to how disability and disabled people are represented in public debate. On the other hand, interviewees were critical toward representations of disability as something extraordinary, not as a banal part of society.

Well, if I think for example about the importance of disability, I think it has increased, like there is talk about disability representation. It has gained political weight.

Still, it is considered as a big thing if a disabled person does something. I’d hope for representation, in for example TV series where disabled people would have different forms of relationships or something instead of nothing. I’m so sick of glorifying disabled people for doing literally anything. In my dream world it would not be a huge issue.

The first quote portrays a positive picture of disability representation, and how it has rightly become a political question. The second highlights the critical stance toward ‘inspiration porn’ where disability is cast as a thing to overcome, and where even the most everyday things done by disabled people can often be capitalized on as a lesson to non-disabled people (Grue 2016). Of course, disabled people have been critically countering and calling out such uses of disability for a long time. As a response to charity representations that cast disabled people as objects of non-disabled people’s pity, the disability movement urges people to ‘piss on pity’ (Shapiro 1994).

Ownership and ethics of representation

In the previous section, we analyzed how our interviewees regarded the position of disabled people as legitimate political subjects entitled to make justice claims concerning disability issues and society more broadly. Despite their shortcomings, international treaties and years-long advocacy have changed, and the political landscape is moving toward meaningful participation. While disabled people's own views and concerns are still bypassed in policy processes, the idea of meaningful participation has enabled disabled people to criticize and politicize policy processes that ignore their views and voices. In this section, we use concept of representation (Fraser 2005) to explore how disabled people's own self-representation clashes with the historical idea of representation embedded in Finnish civil society. We also discuss the ethical aspects of diversity among disabled people and representation.

To highlight disabled people's leadership and voice, many scholars have analytically distinguished between organizations *of* and *for* disabled people (Oliver 1990). This has especially been the case in the UK, where disabled people's own organizations emerged from the criticism of established charity organizations run by professionals and parents (Barnes 2002: 313). In comparison to the UK, discussion about organizations' ownership has not been widely, or at least publicly, debated in Finland. However, some of our participants raised the importance of self-representation in disability organizations. In the following excerpt, one younger interviewee describes the difficulty of gaining authority in organizations run by (often non-disabled) parents of disabled children and young people:

Interviewer: You mentioned COVID restrictions but are there some other things that you consider as a barrier to your activism? What has hindered you from doing the kind of activism you'd wish to do?

Interviewee: Well of course the lack of accessibility to spaces, it's always a barrier when I'm invited to speak at an event if you can't be sure how accessible those places are. Another thing that comes to my mind is that the organization I'm involved with, so in the board of that organization the others are mainly parents of disabled children and young people.

Interviewer: I see.

Interviewee: So it's quite difficult to voice your opinions when it isn't run on the 'from us to us' principle, you know.

Interviewer: Okay.

Interviewee: For example, I would like to bring out the issue of social exclusion and its consequences and stuff like that, but so far it hasn't been on the table. So yes, I would welcome a more 'from us to us' attitude.

Interviewer: Yes, so your own voice?

Interviewee: Yes, exactly. Most of the parents are non-disabled so often it is quite difficult to have an impact on the agenda.

The discussion cited here is about barriers related to doing activism. At the time of the interview, face-to-face encounters were almost impossible due to the COVID pandemic, which affected our participants' activism and advocacy, as this interviewee notes. Besides the impact of lockdowns, the interviewee states that the lack of accessibility to spaces still poses a barrier that requires some sort of managing and planning in advance. The discussion quickly turns into being on a board that mainly consists of parents of disabled children and young adults. As the interviewee states, this can cause friction in setting the organization's agenda (Griffiths 2022). The main friction according to our interviewee is that non-disabled parents have a very different understanding about relevant issues, for example concerning social exclusion, and thus the overall agenda of the organization. As was noted by Hugemark and Roman (2007), this friction in agenda setting is also about representation and who should be the legitimate speaker of what disabled people consider worth advocating.

The above extract is illustrative of the culture in the Finnish civil society sector, especially concerning disability organizations. According to Mähönen (1996: 200), Finnish disability organizations were historically organized into different impairment groups, and the emphasis on self-representation of these groups varies in different historical phases. For example, deaf people set up their own organizations earlier, at the end of the nineteenth century. Although various organizations had gained a firm position in the Finnish civil society sector by the 1960s, it is important to note that many of them profiled themselves as service providers and experts rather than political representatives of their members. To explain this profiling in Finnish civil society, Risto Alapuro (2005: 388) has coined the term 'descriptive vision of representation': that is, organizations represent different social groups according to their specific interests and needs.

The extent and depth of descriptive representation varies in Finnish disability organizations. The Threshold Association, founded in 1973, is an exception: since its early days it has profiled itself as an activist organization focused on advocacy and awareness raising, and the depth of descriptive representation extends to its employees. The phrase 'from us to us' raises at least two important aspects in relation to disabled people's self-representation in disability organizations. First, it reflects the role of non-disabled people in disability organizations, which our interviewee noted above. Second, it could reflect the mismatch between older and younger generations' interests. 'From us to us' can thus be understood to mean that descriptive representation should extend to all levels of disability organizations. In Finnish disability organizations, this issue of descriptive representation remains yet to be politicized.

Gaining the legitimate position of representative authority opens up a new dilemma. We describe this as the ethics of representation. The ethical dilemma arises when representation work collides with the fact that disabled people are a heterogeneous group. In the following extract, one interviewee describes the possible dangers of a few people always talking on behalf of all disabled people:

Now that there is a lot of activism and the field has broadened, we should be aware not to end up in a situation where the same people are always talking about disability, and we should acknowledge our own privileges. I'd wish we would have for example more people with intellectual disabilities voicing their own views and concerns, and people who communicate in non-verbal ways. It shouldn't be that because I'm so 'brave' and all that so it's me who always speaks on behalf of all disabled people. In a way, it is quite dangerous if you think like that.

Disability scholars have proposed that in the early days of modern disability movement, issues of diversity were downplayed for political unity (Barnes & Mercer 2010; Bê 2012). To appear united was thought to secure stronger political claims. Feminist disability scholars such as Jenny Morris (1996) and Carol Thomas (2001) are known for addressing these issues. The historical aspect can be read from the extract above, as it starts by stating that compared to the past, nowadays 'the field has broadened'. It does not deny the fact that disabled people have always been a heterogeneous group but rather states that it is crucial to start acknowledging this in activism and advocacy. The lack of intersectional thinking might result in younger generations of disability activists to advocate their cause through other human rights movements focusing for example on gender and sexual diversity (Koskinen 2022).

Concluding remarks

I have to remind myself that it is a spiral, the progress I mean. Sometimes the movement resembles a circle, that we are just going round and round. But no, it also rises, the societal position of disabled people I mean.

In our chapter, we have explored disability activists' and advocates' experiences and views about the societal and political position of disabled people in Finland. We have used Nancy Fraser's concepts of politics of redistribution, recognition and representation as an analytical tool to illustrate the narration that 'yes things progress, but'. Instead of viewing the question of redistribution and recognition as a dilemma to be solved, or as a teleological process where achievement of redistributive objectives makes room for claims for recognition, we have captured the dynamics of both in the evolving societal position of disabled people in the Finnish society. This draws attention

to how redistribution and recognition overlap, with advocates and activists making claims to both in order to make societal change a reality. Yet, this dual strategy highlights the continuous work that needs to be done, and how in the long run key achievements of the disability movement become not endpoints, but important milestones. As the cited interviewee proposed, these dynamics could be described as spiral. Yes, there are backlashes but also improvement in the societal position of disabled people.

There is a lively theoretical and political debate concerning the status of the disability movement as a social movement and whether it should attach its political claims to economic redistribution or cultural recognition (see, e.g., Hugemark & Roman 2007; Waldschmidt et al. 2015). Based on our analysis, activists use both types of claims to counter the injustices disabled people encounter and to advocate for improvements in their societal position. Whereas Marie S epulchre (2018) has noticed that in Sweden claims are more centered on recognition, our analysis suggests rather equal emphasis on recognition and redistribution. The disability activists and advocates we interviewed seem to understand that certain redistributive enhancements fixed in legislation do not mean that there is no need for other redistributive claims in other areas. Rather, improvements on certain issues open the space to discuss new ones. Previous generations' activism and advocacy has widened the sphere of possible political claims, although these achievements cannot be taken for granted.

As Bill Hughes (2020: 86) notes, although the politics of redistribution has been at the center of disability movement's political strategy, many scholars and activists see the politics of recognition as valuable for the politics of disability.

Sometimes barriers that are redistributive by nature include barriers that are characterized by recognition. The lack of recognition of disabled people as potential employees can hamper the effectiveness of labor market policies. The fact that access to employment and services were articulated as matters requiring cultural recognition does not mean that the distribution of resources in employment and services is equal. It might be, as Rannikko (2018) has observed, that the current individualistic ethos is more receptive to political claims articulated in the language of recognition and self-worth than to calls for complex structural changes.

Although this does not yet go far enough, it has become politically contestable to bypass disabled people's voice and experiences in decision-making and policy development. Disabled people actively use the idea of meaningful participation written into the UN Convention on the Rights of Persons with Disabilities to criticize political processes bypassing their voice (L ove, Traustad ottir & Rice 2019). While the question of representation has so far not become politicized within the disability movement in Finland to the extent it has in the UK, our data refers to a growing sensitivity to the question of who speaks on behalf of whom. This representational question can in turn influence how the Finnish disability movement looks at its past achievements

in relation to redistribution and recognition and the current positioning of disabled people in Finnish society.

Our interviews question the current position of disabled people in Finnish society. Our participants seem to be justly doubtful about the sustainability of successes in combating the injustices they face. Indeed, anticipating possible backlashes is embedded in the metaphor of spiral; the political landscape and priorities could take an unfavorable direction for disabled people. Much work needs to be done in ‘making rights a reality’ (Vanhala 2011) as many successes in policy and legislation have not fulfilled their promise in the daily life of disabled people. Viewing disabled people as subjects of policy instead of objects also requires commitment beyond symbolic involvement to truly enhance disabled people’s political participation. Disability inclusion cannot be based on benevolence.

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11 ‘Second Class Citizens’

Challenges with truth and reconciliation process of deaf people and the sign language community in Finland

Maija Koivisto and Hisayo Katsui

Introduction

In the government programme of Prime Minister Antti Rinne in summer 2019, the Finnish government committed to a state reconciliation process regarding the violations of human rights against deaf people and the sign language community in Finnish history from 1900 to date. This process is the first of its kind in the world to try to reach reconciliation between the sign language community and a government. The process was launched by the statement made in the government programme, after which the study was commissioned to our research team in 2020–2021. Our team conducted a study on the history and the current situation of human rights violations against this community (Katsui et al., 2021). The authors were part of the team of the now-completed Signed Memories research project, which extensively investigated human rights violations from the early 20th century to the present and their impact not only on the sign language community but also on Finnish society today. The research project provided the knowledge needed to plan and implement the truth and reconciliation process based on the conducted online survey, individual interviews and group interviews (N = 150 in total). One of the findings of the study is that the knowledge and understanding of the reconciliation process is weak in both the community and the government (Katsui et al., 2021, 168–172). This is the reason for our seventh recommendation, ‘Training must be provided to key players in the process before agreeing on the details of the truth and reconciliation process’, and eighth recommendation, ‘The establishment of a truth and reconciliation commission is possible when that commission is given the opportunity to act independently and autonomously’ (Katsui et al., 2021). In the study, we focused on violation experiences and recommendations for the reconciliation process, while many questions were left unanswered. Reasons for lack of knowledge of the process among community are particularly focused on and re-analysed in this book chapter.

In the Signed Memories report, as well as in this book chapter, we approach the sign language community as diverse and heterogeneous, including deaf people, deafblinds, people who are hard of hearing, hearing children of deaf

adults and a wider range of hearing relatives or those connected to the community. We are careful to respect the identities of the study participants (Katsui et al., 2021, 33). In this book chapter, we use the word ‘deaf’ to represent the whole range of non-hearing people, because it is widely used in Deaf Studies. More than half of the non-hearing people (N = 54 out of 98) who responded to our online survey defined themselves as ‘deaf’ (see, e.g., Rainò’s attachment in Katsui et al., 2021). Another reason is the fact that deaf people encounter more injustices than hearing signers due to their deafness and/or disability. Thus, we focus on deaf people in this book chapter based on the collected personal and group interview and online survey data collected in the middle of the COVID pandemic.

We use internalized oppression theory, which is particularly related to power, to critically analyse the truth and reconciliation process of the deaf people and the sign language community. We use a multidisciplinary approach to Deaf Studies, Disability Studies and Human Rights Studies. Appreciating and respecting deaf peoples’ knowledge and experiences was important in this study. Therefore, the research questions for this chapter are as follows: (1) *what are deaf people’s perceptions and expectations of their truth and reconciliation process?* And (2) *what are the opportunities and challenges of the truth and reconciliation process?* Next, we pave the way by introducing the Finnish deaf movement and the background to launching the process. After this, we answer the key research questions.

Background to the truth and reconciliation process of deaf people and sign language community in Finland

In this part, we introduce how the truth and reconciliation process of deaf people and sign language community in Finland started. And then we present the findings of the Signed Memories study and why we recommend to continue the process. A professor of history and social studies in education, Jan Löfström uses the term ‘institutional apologies’ to refer to official and politically motivated apologies for the past, i.e. apologies by a state, church, economic or other actor of social power for morally reprehensible events, actions or phenomena in the recent or more distant past. This is better known as the ‘truth and reconciliation process’. This process of reparation and restitution has become increasingly widespread since the 1980s, when political actors around the world mobilized to ask for forgiveness from those sections of the population who had gone through injustice experiences. The best known example of dealing with the wounds of recent history is the process that started after the fall of the racially segregated Apartheid regime in South Africa (see Ahonen, 2018, 16–17; Löfström, 2012, 11–13).

In November 2016, at the board meeting of the Finnish Association of the Deaf (FAD), a deaf signer, Outi Ahonen, called for the Finnish state to apologize to the deaf community for the long-term oppression it has experienced.

The discussion was influenced by the truth and reconciliation process of children who were mistreated in foster care and the apology made by the former Minister of Social Affairs and Health, Juha Rehula, in 2016 (see Ministry of Social and Health Affairs, 2016). The following year, a long-time deaf activist, previous CEO of FAD and president of World Federation of the Deaf, Liisa Kauppinen, made a proposal to the board of the FAD that the association should start collecting signatures for a citizens' initiative demanding a state apology. The board of the FAD decided to do so at the FAD meeting in 2017 (FAD, 2017, 2019c).

However, the FAD later decided to deal with the injustices by other means, namely through cooperation with the Finnish League for Human Rights. In October 2018, the Finnish League for Human Rights, together with the FAD and the Finnish Association on Intellectual and Developmental Disabilities (FAIDD), held a seminar on the history of the injustices to promote the dialogue between the groups and the government, and to achieve the aim of a state apology. The speakers represented different minority groups, such as the Roma people, people with intellectual and developmental disabilities, signers and the Sami people who are indigenous people in Northern Finland (FAD, 2019c). Koivisto, one of the authors of this chapter, was an invited panellist at the seminar. After the seminar, she wrote an article on the Finnish League for Human Rights' blog entitled, 'Many wounds remain unhealed – Historical injustices against sign language users have not been acknowledged and continue to shadow the present day' (Koivisto, 2018), after which Timo Harakka, a member of parliament and the child of deaf adults, invited first author's name to talk to the parliament's sign language network about the history of injustices against the deaf people and signers. FAD representatives Markku Jokinen (Chief Executive Officer) and Laura Pajunen (director) accompanied Koivisto to the discussion. After the discussion, the sign language network of the parliament, on Harakka's initiative, approached the parliamentary groups and asked whether the government could initiate an inquiry into the history of the injustices as a step towards reconciliation (see FAD, 2019a).

In the winter of 2019, some TV programmes on the history of these injustices were aired. Two programmes focused on eugenics as well as the forced sterilization in Finland, including an interview with deaf women. On January 17, 2019, the FAD published a press release that demanded the Finnish government to start an investigation into the injustices of the forced sterilizations of deaf people and to apologize to the victims (FAD, 2019c). Shortly after this, delegations of Deaf Clubs discussed the history of the injustices and the state apology at their conference in February 2019, where it was unanimously agreed that a process should be initiated, referred to at the time as the apology process and the reconciliation process (FAD, 2019b). The Finnish Deaf History Society held a seminar on the history of the injustices in 2019, after which the Society's board made a statement claiming that the state should investigate the injustices experienced by the deaf (Finnish Deaf

History Society, 2019). Harakka responded to these in his personal account on social media with an open post as a child of deaf parents:

The fundamental right violations against deaf people, familiar to me in my childhood home, but unspoken—such as prohibitions on the use of the mother tongue, forced sterilisations, restrictions on marriages—finally have to be dealt with at the government level.

(Harakka, 2020)

Harakka has obviously been one of the key actors behind the programme approved by Prime Minister Antti Rinne's Government on June 6, 2019, which included the clause, 'The State Council will start a national reconciliation process regarding the violation of human rights against deaf people in the history of Finland' (Finnish Government, 2019, 88).

Since the birth of the sign language community, in mid-1800s to date, clear evidence of injustices has been recorded (Katsui et al., 2021). More precisely, the eugenic ideology has influenced the sign language community in Finland since the end of the 1800s to the present. This ideology led to oralism penetrating teaching practice and the use of sign language being banned in schools for the deaf from the late 19th century until the 1970s (Salmi, 2010). Using sign language was punished at schools, often corporally. According to the experiences of many of the study participants, the most common way was to repeatedly smack the pupils' fingers with a pointer. Pupils were corporally punished not only for using sign language but also for not understanding speaking-based teaching.

I went to (the name of the school in the 1950s). The school was completely oralistic and sign language was forbidden—the teaching was only through speaking. I was probably 8–9 years old (...) I wrote on the board 'a fox jumps over the ditch', I remember it well (...) the teacher wiped it off and asked me to memorize it by saying it (...) I said 'the fox jumps'—then I couldn't remember the rest and the teacher got angry and slapped my cheek and I burst into tears (...) If the teacher had signed the sentence, I would have understood for sure (...) you had to memorize things even if you didn't understand everything (...) the sentence and speaking was important (...) also in maths you had to memorize and then recite from memory the next day (...) even if you didn't understand the content.

Our data shows that the lack of a common language between the pupils and not only school staff but also other adults, such as family members, has had profound negative effects that may have increased the risk of violence against deaf people. Because there was no common language with adults, deaf children could not tell them about the injustices they encountered, which eventually impacted their lives and resulted in internalized oppression (Katsui

et al., 2021). We discuss this in more detail in the section on internalized oppression.

The goal of the eugenic ideology against the deaf people and the sign language community was not only to prohibit the use of sign languages by deaf people but also to reduce the number of deaf people overall (Salmi & Laakso, 2005, 144–148, 200). Almost 50 years of oralism, from the early 1920s to the late 1970s, and eugenic-based laws such as the Marriage Act (1929–1969) and the Sterilization Act (1935–1970) impacted the community. The aim of the two acts was to eliminate the reproductive health rights of those deemed unfit for society, so that children with disabilities, including deaf children, would not be born in Finland and burden society (see Koivisto & Katsui, 2021; Mattila, 1999; Salmi & Laakso, 2005). In 1929, the Marriage Act (234/1929) was enacted in Finland and prohibited marriages between congenitally deaf people, which led to marriage bans. To restrict marriage among deaf people, the later Sterilization Act (227/1935) required deaf women to consent to sterilization, for example, in order to obtain permission to get married. The reason for sterilizations and abortions was the prevention of deafness (Katsui et al., 2021, 59–66). Numerous attempts to rehabilitate or cure deafness were also made. For instance, experimental ear surgeries were performed on 37 deaf pupils of the Oulu School for the Deaf in the 1960s. Reports have also revealed that hospital wards kept deaf children for many weeks without their parents in the 1970s and 1980s. Deaf children underwent various examinations to which they had not consented (Katsui et al., 2021, 68–72).

There was little possibility for deaf children and hearing children of deaf adults (CODA) to study in their mother tongue of sign language in Finland. This impacted Finland-Swedish signers in particular, many of whom moved to Sweden to seek education opportunities (see Lindberg, 2021). The Ministry of Justice (2016) stated that the Finland-Swedish sign language (FinSSL) would be extinguished in ten years without revitalization measures. This shows how a continuum of the eugenic ideology continues to have negative impacts on practices even today, but in a more nuanced, subtle way.

Key words, theoretical frameworks and methodology

In this section, we first attempt to conceptualize the sign language community. We then proceed with our theoretical frameworks and methodology, including ethical questions.

When discussing the sign language community today, it is important to understand the complexity of its issues around identity and membership, including the lack of accurate statistics on the number of signers. According to the statistics of The Social Insurance Institution of Finland (Kela), in 2019, a total of 2835 persons were entitled to interpretation services for persons with disabilities and used Finnish sign language (FinSL) or Finnish with sign support, and 116 persons used FinSSL or spoken Swedish with sign support

(Rainò & Vik, 2020). These statistics are only approximations, as they do not consider hearing signers such as children of deaf adults whose mother tongues are also sign languages. It has been possible to declare sign languages as a mother tongue in the population information system since 2008, but according to data obtained at the end of 2020, 683 people in Finland had Finnish (N = 532), Finland-Swedish (N = 8) or another sign language as their mother tongue (Rainò, 2021, 23). This figure is clearly lower than Kela's statistics. The same phenomenon can be observed among the Sámi: 'Only one in five Sámi declare their mother tongue to be Sámi' (Yle, 2019). According to the government's report on the application of language legislation issued in 2017, FinSL is used by approximately 4000–5000 deaf, deafblind or hard-of-hearing people as their mother tongue. In addition, approximately 6000–9000 hearing people use FinSL as their mother tongue, as a second language or as a foreign language. It is estimated that there are only about 90 deaf users of FinSSL, and most of these are older people (Finnish Government, 2017; Andersson-Koski, 2015). As can be seen, the identity, self-identity and membership of the sign language community are highly complex issues and therefore also contested among the community itself. 'Deaf' means much more than those who are medically categorized as deaf (Katsui et al., 2021, 38–44).

We use internalized oppression (Katsui, 2005; Campbell, 2009, 16–29) as an analytical and conceptual tool to unravel the opportunities and challenges of this truth and reconciliation process of deaf people and the sign language community. The many layers of injustice, both in the past and the present, are manifested in the form of internalized oppression (Katsui, 2005; Campbell, 2009): many deaf people have internalized the idea that they are 'second class citizens' due to their deafness and sign language. This is our next theme. Internalized audism is particularly relevant in Deaf Studies (Ladd, 2003; Ladd & Lane, 2013; Gertz, 2003)—it is defined as a form of audism that tacitly accepts dominant hearing norms and privileges. It is not so much the absence of consciousness as an impaired consciousness or distorted way of thinking about deaf consciousness. Consequently, a deaf person is often unable to fully recognize oppression and cannot resist the existence of hegemonic forces (Gertz, 2003, xii–xiii). In the Finnish context, Koivisto (2010) has described internalized oppression through the decolonization process as a theoretical frame of reference.

Throughout the studied period from 1900 to date, deaf people have experienced a variety of injustices. The past and present are reflected in the aforementioned perception of the second-class citizens as well as the normalization of oppression and discrimination. In the report, we pointed out that internalized oppression can also be described as a vicious circle, where negative thoughts and their consequences are a continuum. In the vicious circle, prejudices against deafness and sign language lead to low expectations of deaf people and sign language speakers and consequently to low opportunities. These societal prejudices and attitudes are internalized as internalized

oppression of deaf people and sign language community, followed by low self-esteem, which can lead to isolation and passivity (Katsui et al., 2021, 135–138). It was aptly described by one participant:

(...) trauma passed down through generations. For example, for some [deaf] people some things are normal, for my parents it [oppression] is normal, and that [internalized] attitude has been passed on to me.

The data we collected for the Signed Memories research project that we used for this book chapter consisted of (1) individual interviews of old deaf signers (N = 10), (2) group interviews of experts and representatives from the sign language community (N = 16) that took place in autumn 2020 and spring 2021, (3) an online survey of members of the sign language community (N = 124). In total, information of the 150 respondents are used in this book chapter. Recruitment of these research participants was done through many different means, including TV coverage, information dissemination of representative organizations, research project social media and existing networks of deaf people. The interviews and online surveys were in four different languages, namely FinSL, FinSSL, Finnish and Swedish. Some interviews were held only in the sign languages, especially when all participants signed. Finland-Swedish signers had their own group interview, because of their position as a linguistic minority within a minority, in which identity and language play important roles. Due to the overall small number of deaf population in Finland, references to more specific characteristics of the respondents were deliberately not added to minimize the possibility to reveal their identities.

All the interviews were conducted using the thematic interview method. Among other things, we asked about people's relationship with the sign language community, personal experiences of rights violations and perceptions on the reconciliation process. The interviews mainly took place on the ZOOM platform, which enabled recording and was signing-friendly. Our material consisted of notes taken during the group interviews, and some

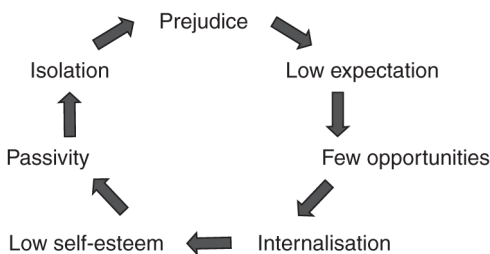


Figure 11.1 Internalized oppression and vicious circle.

Source: Katsui (2005: 90).

illuminating arguments and examples were transcribed verbatim. Individual interviews were first translated from the sign languages into Finnish and then transcribed in full. The open-ended question answers were saved in Excel. First, we analysed the qualitative data thematically, based on recurring content (Eskola & Suoranta, 2000, 62, 174). Next, we conducted researcher triangulation by cross-reading the preliminary thematic analysis. Two other researchers also cross-checked selected themes and modified or confirmed them to increase the validity of the analysis.

Ethical issues were central throughout this study. First of all, anonymity was an important part of our research. The Signed Memories study was commissioned to investigate the injustices against deaf people and the sign language community. This community is small, and people know each other. As this study deals with highly sensitive injustices against vulnerable people, we paid special attention to assuring the anonymity of the study participants. In order to protect their privacy, we removed sources of information and any identifiable information from the citations.

When collecting our data, we carefully took our positionality as researchers into account, due to potential power relationships between us and the study participants. In Deaf Studies, it is considered important to be open about the positions of researchers (see, e.g., Kusters et al., 2017), i.e., their relation to the sign language community. Koivisto is a deaf signer working on a dissertation about how the eugenics ideology has affected the sign language community and deaf women in Finland. Katsui is a hearing, non-signer researcher of disability studies, deaf studies and human rights studies. Both were in the Helsinki University team of the Signed Memory project, whose work was to study the injustice experiences of deaf people and the sign language community. We also had to take into account any possible implications of interpreters accompanying the researchers. Due to the sensitive themes of the research, the interpreters signed a confidentiality agreement in advance.

As interviewing deaf people in an ethically sustainable manner during COVID-19 was not yet well established in academia, we made a great effort to strive for this. An important ethical issue in research is that the participants have the opportunity to share their personal experiences in their own language without the influence of interpretation and/or presence of hearing a researcher whenever possible. In order to minimize the effect of interpretation in remote interviews, the interpreters turned off their video when they interpreted from sign language(s) into spoken Finnish. It was also agreed in advance that the interpreters would not interrupt the interviews to, for instance, check details, but that they would announce aloud any shortcomings in the interpretation to the researchers after the interviews. This enabled us to write down our interpretation of the interview recordings in text form and to check any missing points from the recording in sign language(s) after the interview. Koivisto being a deaf researcher and belonging to the community helped minimize any possible power relationships in the interviews, because on an emotional level, a hearing researcher might represent the majority behind the discrimination,

injustices and violations of the interviewees' rights, no matter how carefully the researcher has evaluated their own role.

Research participants' perceptions and expectations of the truth and reconciliation process

Many of the study participants were aware of these historical and present injustices against them. However, as regards their knowledge of the truth and reconciliation process, both the community members and the government officials lacked sufficient knowledge (Katsui et al., 2021, 209). Community members do not yet have very well-structured views on what the process should be like. Even though many of the group interviewees were representatives and staff members of different organizations, they knew very little about the process, and even when they were interviewed twice for this study, their lack of knowledge of the process had not changed greatly in the second interview. At the time of the first interview, it was more than a year since the government programme was launched, and almost four years since the start of the debate on the official apology among the leadership of the representative organization.

Example 1
Researcher: We met in the autumn and has your knowledge [of the process] increased since then?
Study participant: (Silence and smiling)
Researcher: The topic is clearly difficult for many. (The others nod)
(Second round of group interview in spring 2021)

The data shows that the process is not discussed in depth in the community and that the discussion often drifts into injustices. The participants asked the researchers the following questions: 'Could you tell me the mission and position of the commission?' 'Could you tell me what happens in the process?' As for the individual interviews (N = 10), only less than half were able to discuss the process. Some said that they had heard of it but did not know anything about it, and others had never heard of it. In those individual interviews, the discussion about the process focused on compensation, restitution and apology, rather than on the outcome of the process itself.

Researcher: About the reconciliation process (...) what do you know about it?
Study participant: What?
Researcher: (spells the RECONCILIATION PROCESS and explains the examples of the Sámi people and South Africa) So, maybe something similar for the deaf is about to start in Finland. So, what would you think if the Government apologized?

Study participant: Hard to say (...) yes (...) the deaf have suffered a lot for many years, yes, if the Government (...) it would be good to apologize (...) but the compensation, I don't really agree with that. I hope services improve, or that television would get subtitles and interpretations (...) that all services would be fixed (...) it's also important to apologize but the state doesn't know about these (...) I guess this study will give them information.

Example 1

Study participant: This discussion about the selection of the commission is important, but the problem is that you, researchers, are asking about issues that have not been discussed in the community and have not been resolved. You are taking too big a step here, even though you shouldn't. I don't want anything said in this group to be put in the report. You can't do that. There must be a discussion in the community first—you have to think about how to get the group together.

Example 2

The community has not yet started a discussion about the process, what it would be like. This is challenging, experts and researchers have talked about it, but people must be involved in discussing the course and character of the process.

The two recent quotes indicated that some participants see that discussions about the process did not start properly within the community. It also suggests that the topic is challenging enough that the community has not created a space for discussion. This is reflected as caution during the interviews, in one of which one participant brought up possible bias and preconception of the researchers in Example 1. It is quite understandable that many community members lacked knowledge of this process, as it has only just begun, and there is no precedented example of a process between a government and the deaf people and the sign language community anywhere in the world. As other truth and reconciliation processes around the world, such as those of the indigenous people in Canada and black people in South Africa, are contextually and substantially different, understanding the process has been difficult in general. Nevertheless, the researchers discussed the importance of the way in which deaf people often communicate using concrete examples to explain new issues, such as the Canadian and South African processes. It is also worth noting that the process began in the middle of the pandemic, which has also restricted meetings and discussions on the issue among the community members.

Only a minority answered the open question in the conducted online survey about their expectations of the process, which indicates little knowledge of the process among the respondents. They believe that the process is about setting up a truth and reconciliation commission in the same way as was done for the Sámi truth and reconciliation process (Katsui et al., 2021, 168–169).

Among the study participants, only a few people had a clear vision of the process itself as follows:

Example 1

Regarding the process, first the truth must be found, in which case the state will get to know the facts and at the same time consider the wrongdoings. Then the state will apologize, so we must discuss how the apology will happen, and in practice, the question is whether reconciliation will happen. An apology would be in the middle of the process, not at the end. An apology would take place concretely through, for example, changes in the law (...) when we are satisfied, some kind of agreement will be made.

Example 2

The Sámi have Sámi assemblies. The (FAD) federal assembly could be there. The board of FAD or deaf people could propose suitable names for the Commission. (At the FAD meeting) we elect the representatives, which is how we get the support of the community—this way the community has the power to choose.

Some expressed strong needs to share the injustice history with the whole of Finnish society because the way in which society undermines deaf people's experiences has affected deaf people's self-esteem. Conversely, many study participants felt that it was also important to move away from the position of victim in order to be equal with hearing people (Katsui et al., 2021, 170–171). When we tried to stimulate discussion about models of process, the discussion frequently turned to the experiences of injustices and why it was felt that process was needed. The material reflects the community's hope to be empowered through the process. It was considered important by the respondents that the society in general, hearing majority in particular, is made widely aware of the injustices against deaf people and sign language community.

Example 1

This [injustice history] must be made public so that [we understand that] what happened is true. A deaf friend's hearing parents didn't believe that (name of deaf person) had been sterilized. They considered it impossible! Although it's a fact that it was so hard and cruel then, they think it can't be true. It's because they are hearing. Among the deaf, it's known, but it's not

talked about. Doctors don't talk about it (...) women were just sterilized and nobody talked about it and nobody else in Finland knows about it. Those who are hearing it can't believe this and say that it's a lie and I say that it's true (...) and this makes them think about it (...) it was impossible for them [to believe this fact] (...) but this is how it is.

Example 2

It's reasonable to admit possible mistakes and injustices honestly and openly. Making injustices publicly [known] can comfort [deaf] people and encourage even those people who don't dare or don't want to bring their own stories to the public.

Example 3

We become stronger. If they really took the matter under investigation, if the state admitted it and compensated for it, then our self-esteem would improve.

Revealing the truth is considered empowering and a key element of the process—this was repeated in our data. This issue of empowerment is strongly interlinked with internalized oppression, which is the next theme.

Position of victim—The impact of eugenics and internalized oppression

Example 1

It's good to point out problems, but it would be good to get rid of the frame of reference of a victim.

Example 2

The most important thing is to be aware that not all us signers even understand how we have been discriminated against. We're so used to discrimination that we might think it doesn't concern us [as discrimination reality has been normalized]. Not everyone even understands what this reconciliation process is. So, it takes time for people to understand it.

Oralism and eugenics have contributed to the fact that many, especially older deaf people, have internalized the negative attitude that sign language is evil and something to be ashamed of. In the narratives of the study participants, the complicated and largely negative relationship with sign language and the difficulty of forming a positive identity were associated with shame and fear, as well as repeated and inexplicable anxiety. Deep and coerced shame has prevented deaf people from being aware of the injustice and ill-treatment they have suffered, which can make it difficult to understand and explain the causes of these subconscious feelings of negative self-esteem. In this way, historically constructed, internalized oppression is still negatively impacting the daily lives of deaf people and sign language community members today, as is explained in Figure 11.1.

The deaf people and members of the sign language community described the feeling of inferiority as an internalized oppression for which they could not name the cause. It can be manifested in the form of low self-esteem as a deaf person and signer language user.

In our case, deafness arises through the language issue, that is, our situation corresponds to other minorities, sometimes deafness is a bad thing and sometimes language is.

The real issue here is that deaf people often experience multiple forms of discrimination, both direct and indirect ones. This is because laws such as the UN Convention on the Rights of Persons with Disabilities (CRPD) and the Sign Language Act and different guidelines for signers are good on paper, while their implementation depends on their interpretation by responsible duty-bearers. This makes it hard for deaf people to recognize discrimination, even though reality and these laws have great discrepancies.

Invisible discrimination is hard to define precisely. Prejudice and attitude is profound. Deaf is not good. Deaf is bad and not healthy, not adjustable. This is there on the surface, and it has to be deconstructed. The power relationship is there.

Many study participants did not always know how to question the injustices they encountered. It is not easy to be active in their own affairs and act as full citizens with the right to self-determination (Sen, 2009, 228–230; Sen, 1999, xii–xiii; Nussbaum, 2011, 18). For instance, some individual deaf interviewees described their lives as ‘normal’, although they did encounter othering treatments such as discrimination against them for their education, employment or marriage. Many deaf respondents still have personal barriers in their everyday lives today. In this way, injustices against them have been normalized over many generations. This is important information and should be considered when discussing how the truth and reconciliation process can also include these people who are less aware of the injustice they have experienced.

Discrimination has existed for so long that it's difficult to start [our discussion].

There is a clear link between internalized oppression and the lack of discussion in the community. Internalized oppression reinforces the status quo, in which it may be hard for community members to step out of their victim position and take an active role in the truth and reconciliation process—their repeatedly and intergenerationally perpetuated low self-esteem prevents this.

Example 1

In meetings, some people tend to say ‘excuse me’ when asking to speak. I’ve seen it often—people don’t dare say they disagree because they’re afraid of criticism.

Example 2

When discussing laws, etc., a layperson cannot keep up [with the content of the discussion].

During our interviews, the theme of the truth and reconciliation process too frequently drifted and changed into the theme of historical injustices and discrimination.

Example 1

Feelings are not enough here—you also have to be able to present and examine the facts and push the issue.

Example 2

When it comes to the need for education (...) psychosocial support is important for dealing with trauma, etc., but in addition to this, the state must demand that we receive language awareness training (...) so how do we know how to demand our rights? When you’ve been discriminated against so many times, you don’t recognize it or it’s hard to know or you just can’t bear it. Many deaf people tend to say ‘let it be’ and wait for the Association of the Deaf to do something about it so that they don’t have to do anything themselves. An attitude change needs to happen here. In order to claim our rights, we need to know what the complaints are about.

Example 3

We think that this process belongs to politicians or decision-makers, but it is needed at the grassroots level, ordinary people need to [be part of this].

Based on the analysis of the collected data, we argue that this internalized oppression is incredibly profound due to the intergenerational discrimination history and can be an enormous challenge to the actual process if it does not receive enough attention.

Conclusion—Discussing the truth and reconciliation process as a way forward towards social change and deconstruction of intergenerationally internalized oppression

In this section, we want to return to our research questions and look to discuss deaf people’s perceptions and expectations of the truth and reconciliation process, and from this, we will go on to look at the opportunities and challenges of the truth and reconciliation process.

The fact that the truth and reconciliation process for deaf people and the sign language community has been included in the government programme is a huge step forward and a concession from the government. The government has acknowledged that human rights violations have taken place in Finland and is ready to move forward with the matter. Acknowledgement was something that our study participants expected. This acknowledgement enabled us to finally bring things into the public discussion in society, to draw attention to injustices that have been ignored for decades, especially eugenic-based practices, and to combine them with internalized oppression. We want to highlight the impact of eugenics-based discrimination: the experience of being unwanted in society as a deaf person and whole community as well.

In theory, a truth and reconciliation process is an important tool for the community members, who have internalized their social positions as second-class citizens due to many generational injustices, and have thus lacked sufficient opportunities to make a social change. When the truth and reconciliation process is based on the community members' historical understanding of injustices, structural barriers and their psychosocial impact on them on the one hand, and the general population's and the decision-makers' understanding of these on the other, the process can empower the sign language community and finally dismantle these many layers of injustice. This truth and reconciliation process for deaf people and the sign language community is globally the first of its kind and can provide an example and pave the way for others to follow to achieve social transformation, which many study participants have expressed. Or it can fail, if careful attention is not paid to the internalized oppression.

The challenges are many. The aforementioned findings and analysis reconfirm the Signed Memories study results (Katsui et al., 2021, 161–172) that the knowledge and perceptions of the truth and reconciliation process among many community members, key stakeholders, as well as government representatives, are poor. In our interviews, only a few were able to discuss the process and its direction, especially critically. Few had a clear vision, which are similar to the Sami people's truth and reconciliation process. It has become clear that it is difficult for study participants to deconstruct their position as a victim, which explains why the interviews often focused on injustices and personal experiences rather than the process itself. This phenomenon can be explained by the *intergenerationally experienced internalized oppression*. The Finnish society has to understand this phenomenon for moving forward with the process. Even if one does not personally experience more egregious human rights violations, the historical and present experiences of community members do have an impact. Clearly observed, intergenerationally internalized oppression has caused a lack of activism. Consequently, the community members have given the decision-making power over this process to others, especially to the leadership of the representative organizations who formed a working group of the process.

The Prime Minister Orpo's government proposed a budget of 358,000 EUR for the truth and reconciliation process for the deaf people for the year 2024 (Ministry of Finance Finland, 2023). Nevertheless, decisions about the model of the process have not been disclosed yet, neither by the government nor by the working group member organizations. In this regard, the process could end up becoming 'a negotiation model' instead of a 'collaboration model', as is discussed in Chapter 12, in which the whole of society has ownership of this issue and it will change as a whole. Better knowledge and awareness-raising are needed in the government, among the community members, and among the Finnish people in society in general. Without this process, there is a great risk that we will end up with another signed rhetorical document which looks impressive on paper but cannot change reality. At present, discussions are taking place within a small circle (see Katsui et al., 2021, 171–172). Without true participation and critical discussion on the truth and reconciliation process, people will remain victims and miss opportunities to actively be part of the process. History will unfortunately be reinforced. The process also requires genuine transparency and accountability beyond 'a negotiation model', in which a few representatives of each party negotiate and make decisions for the sake of official reconciliation. Tokenistic representation has to be questioned, when the majority of the community members are not an integral part of the process. Many more people in the community, in the Government in particular, and in society in general need to be informed of this process, and their capacity for genuine participation must be increased, before essential decisions are made on the model of the process. The ultimate aim is a better Finnish society for all, including for deaf people and the sign language community.

The truth and reconciliation process will take place only once, when a government is committed to launch such a process. No more opportunities will come along. It is thus extremely important that this process carefully considers the different aspects discussed above so that it can achieve the desired change in justice and human rights for deaf people and sign language community members, today and in the future. The process entails both opportunities and challenges, as we presented above. The opportunities lie at different levels, including the chance to deal with past injustices, which was not previously possible due to many layers of legal, social and politically environmental barriers and personal capacity, including the psychosocial impact of the past on the present. When social transformation towards equal rights is the ultimate goal of the process, it presents an excellent opportunity. The process is meant to mobilize the whole of society to achieve the goal. The process is in its initial stages at the time of writing of this chapter. We shall closely follow its development when analysing and theorizing the real significance of the process for the daily lives of deaf people and sign language community members in our future research.

Although taking into account the perspective of those who have experienced injustice is a prerequisite for a successful truth and reconciliation process, a

successful process will also require ownership and genuine engagement, not only of the deaf people and sign language community but also of Finnish society as a whole. To achieve this, we recommend 'a collaborative encounter model', in which the sign language community and the general public come together in a meaningful way to move towards social transformation through, for instance, cultural and artistic activities. The process belongs to each one of us as a member of society. It is important that members feel that they have a genuine opportunity to participate in the debate and the process in general. That would be part of the integration and reconciliation process.

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12 Examining cooperation-based advocacy between government and disability activists in transnational advocacy networks

Mina C. Mojtahedi and Hisayo Katsui

Introduction

The history of the global disability movement and international cooperation is relatively short. It goes back to the 1960s and 1970s in many parts of the world when the disability movement was created first nationally and, quite quickly after, also internationally (see Katsui and Chalklen, 2020). Local disability movements recognized international cooperation and transnational activism as strategies to take advocacy for the rights of persons with disabilities further, as States failed to do so (Johnson and Soldatic, 2020: 333). As the United Nations treaties had not referred specifically to disability and persons with disabilities, they were largely left behind in the political discourse as well as its implementation practices. To respond to this recognized gap, disability was mainstreamed with the UN Declaration on the Rights of Mentally Retarded Persons and the Declaration on the Rights of Disabled Persons, adopted in the 1970s (Lord et al., 2010), and with the UN International Year of Disabled Persons in 1981. In the 1970s, the World Health Organization established its definition of impairment, disability and handicap and conceptualized social disadvantages as a direct consequence of individual impairment (Oliver, 1990). This exemplifies what is later called the medical model of disability. The agenda of the UN International Year and the following International Decade of Disabled People was naturally set in the framework of medicine, prevention and institutional treatment and the discussion was dominated by medical doctors and professionals (Hasler, 1993; Katsui and Chalklen, 2020; Series, 2020). In this conjunction, Disabled People's International was established in the same year in 1981 for the disability movement to 'horizontally and globally network among disability movements across different countries' (Katsui and Chalklen, 2020: 9–10). As persons with disabilities are a minority in absolute number in any country and marginalized, thus preventing them from raising their voices locally, international cooperation was quickly picked up as a strategy of activism and advocacy.

One of the turning points is the making of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006). Prior to the adoption of

the Convention, existing human rights instruments were not adequately realizing the rights of persons with disabilities nor addressing specificities related to disability (Quinn and Degener, 2002). The UN Convention on the Rights of the Child (1989) includes an article specifically addressing intersections with disability, albeit limited in scope. Thereby, the Convention reaffirms the rights of persons with disabilities, does not introduce new rights and complements other human rights instruments with specifics on how to protect the rights of persons with disabilities (see Sabatello, 2014).

This Convention is a paramount example of international cooperation (Lord et al., 2010). In 2001, an ad hoc committee was established for this Convention with the UN General Assembly resolution. Many disability activists from many countries also from the Global South were part of the drafting of the Convention, which resulted in the adoption of the Convention in 2006. Unlike previous treaties, as much as 80% of the final text of the Convention came from civil society representatives operationalizing the slogan of ‘Nothing about us without us’ (Series, 2020). This participatory process for drafting the Convention has set a model for future human rights treaties (Series, 2020). In the past, human rights were too often framed and conceptualized as national issues. Today, human rights, especially the rights of persons with disabilities, are increasingly an international concern (Katsui and Chalklen, 2020; Series, 2020). One example cited in an article on transnational advocacy in the Canadian context highlights the opportunities for the making of, ratification of and reporting on the Convention, particularly Article 32, and has created for national disability activists to engage in and advocate for disability-inclusive international cooperation (Stienstra, 2019). A similar pattern can be seen in Finland, as we show in this chapter.

When it comes to Finland, Finnish disability activists have been active members of Disabled People’s International and in the making of the Convention, as will be briefly described below. In this process, which will be examined in this chapter through the concept of transnational advocacy networks (Keck and Sikkink, 1998), not only non-governmental organizations but also governments have gradually become integral to the disability sector, for instance as Member States of the UN and State Parties to the Convention. The Finnish government is thereby one of the significant stakeholders and duty-bearers regarding the rights of persons with disabilities. In fact, the Finnish government, particularly the Ministry for Foreign Affairs (MFA) of Finland, is one example of how States can play a proactive role in global disability policy discourse and advocacy work and how they do this with close collaboration with organizations of persons with disabilities (OPDs).

The MFA’s advocacy and cooperation with OPDs and other donors have given visibility to disability rights and positioned the Finnish government globally as an important stakeholder in promoting the rights of persons with disabilities today. As a result of advocacy and pressure from Finnish disability activists, Finland has increasingly prioritized the rights of persons

with disabilities in its foreign policy. In order to concretely implement its obligations stated in the Convention Article 32 on international cooperation, the MFA has set realization of the rights of persons with disabilities as a development policy outcome, and it has integrated disability inclusion as a cross-cutting objective throughout its development policy and cooperation.

This book chapter focuses on Finnish international cooperation as an emerging strategy of transnational disability advocacy networks and discusses its opportunities and challenges as a form of advocacy based on examples from Finland. The research questions are: (1) How has international cooperation among disability activists and government as a modality of transnational advocacy networks developed in Finland? (2) What are promising examples of cooperation-based advocacy in transnational advocacy networks? (3) What are the possible challenges of a cooperation-based modality of advocacy in general and in transnational advocacy in particular?

The chapter starts with a description of the methodology used, explains our methodological choices and presents the authors' epistemological background. Subsequently, we answer the set research questions based on analysis of relevant literature and interview findings using case examples. In conclusion, we discuss opportunities and challenges of international cooperation as a modality of advocacy in transnational advocacy networks.

Methodology

This chapter is based on literature regarding international disability rights and the MFA's role in this area as well as personal interviews with key informants who have played a significant role in Finland's international cooperation to promote the rights of persons with disabilities. Literature includes 'gray literature' such as policy papers and reports. Some interviews conducted for other studies with Kalle Könkkölä and other disability activists (Katsui, 2005, 2008a, 2008b, 2012) were used in this study. In addition, a total of six personal interviews were conducted with leading global disability activists (Judy Heumann and Vladimir Cuk) and key former and current Finnish government officials (Satu Lassila, Katariina Sario, Timo Voipio and Riina-Riikka Heikka). The interviews took between 1 and 2 hours, on average about 70 minutes, and were conducted online during April–May 2022. Interview questions aimed at gathering information on the advocacy roles and relationships of disability activists and the MFA as well as on processes in which both participated to promote the rights of persons with disabilities. Ethical issues were cleared by informed consent to the voluntary participation and appearance of the interview by their names as publicly known figures. The collected information filled in gaps as well as complemented existing literature and gray literature. When sources are not specifically mentioned, the information provided is based on interviews, both from the interviews for this book chapter and previously conducted interviews. We will use civil society theories (Katsui, 2005; Korten, 1990), social movement

theories (Katsui and Chalklen, 2020; Keck and Sikkink, 1998; Johnson and Soldatic, 2020; Stienstra, 2019) and theories around a human rights-based approach (Degener, 2017; Katsui and Chalklen, 2020; Office of the High Commissioner for Human Rights [OHCHR], 2006) to analyse the Finnish case examples.

The aim of this chapter is to analyse Finnish international cooperation and transnational activism through a few illuminating examples and discuss opportunities and challenges of international cooperation and transnational activism as a modality of advocacy for global disability rights.

It is important to refer to the background of the authors. Both authors have worked in the field of international cooperation and have worked closely with and for OPDs: Mojtahedi was formerly the Senior Advisor on Non-Discrimination at the MFA and Katsui an Associate Professor in Disability Studies at the University of Helsinki. The Professorship was established with support and funding from the Finnish OPDs to the University of Helsinki. Therefore, both authors have close proximity to both the local and global disability movement in the past as well as in their current positions.

Theoretical frameworks

We use social movement theories (Katsui and Chalklen, 2020; Johnson and Soldatic, 2020) as analytical and conceptual tools to unravel the opportunities and challenges of the Finnish international disability activism. Toch (1965: 5) defined a social movement as ‘an effort by a large number of people to collectively solve a problem they feel they have in common’. Giddens’ (1993: 746) definition is a large grouping of people who have become involved in seeking to accomplish, or block, a process of social change. Johnson and Soldatic (2020: 329) argue that activism addresses past injustices and pushes for change in the future, their ‘sense of urgency about the issue’ driving them into action. Katsui and Chalklen (2020) elaborate on social movement theories in the context of disability as follows: the collective identity of a group is often central in forming a social movement in general (Beckett, 2006; Johnson and Soldatic, 2020; Ritzer, 2005). On a personal level, individuals frequently form their identity as ‘others’ (McRuer, 2006: 158) when their experiences deviate from socially constructed norms, namely people without a disability. In other words, awareness of ‘relative deprivation’ (Pettigrew, 2002) explains the initial part of a social movement. When these individuals start to become aware of their collective social experiences as a group beyond their individual differences, a collective identity is formed, and the aim of social transformation becomes equal citizenship (Beckett, 2006: 749) in the form of a social movement. This process requires formalization and representation, often in the form of OPDs (Johnson and Soldatic, 2020). As collective and individual actions are interconnected, Johnson and Soldatic (2020) argue that both are essential for achieving change. In this book chapter, we use social movement theories to critically analyse Finnish international disability activism.

International disability activism can be conceptualized as a form of social movement where local advocacy extends beyond borders to form transnational advocacy networks, as described by Keck and Sikkink (1998). These are networks that go beyond territorial borders and comprise actors that have shared values and a common discourse and that work together to influence policy outcomes and social change. Actors can be from civil society, media, religious, scientific or economic institutions and even parts of government. Typically though, transnational advocacy targets governments, institutions and corporations (*ibid.*).

For an analysis on modalities of advocacy and how these can develop, we use Korten's theory (1990) as a basis. Korten (*ibid.*) describes how civil society organizations (CSOs) progressively develop and mature in four generations (for a summary, see Katsui, 2005: 7):

First generation: Relief and Welfare – CSO is a doer for some immediate shortage targeted to individuals and family

Second Generation: Community Development – CSO is a mobiliser for community project

Third Generation: Sustainable Systems Development – CSO is a catalyst for regional or national wide policies and institutions

Fourth Generation: People's Movement – CSO is an activist or educator for national or global issues

(Katsui, 2005: 7)

In reality, CSOs do not develop in such a linear way but can co-exist in an inter-generational manner and are often more complex. Korten's theory and analysis as such do not take into account the much more diversified and globalized nature of CSOs today. Yet, an interesting aspect of Korten's theory is that social movements are conceptualized as a form of maturity or development of CSOs.

Similar to types of CSO generations, we present modalities of advocacy used by CSOs. Negotiation-based advocacy and confrontation-based advocacy have been described in detail previously (Katsui, 2014). Briefly, these advocacy modalities depend on the context as well as power relationships and asymmetries between rights-holders represented by CSOs on the one hand and duty-bearers represented by governments on the other hand. CSOs carefully observe their roles, positioning and environment in order to select the effective modalities for achieving change (see S epulchre and Lindberg, 2020). In some contexts, where space for CSOs is limited, negotiation-based advocacy is commonly used so that CSOs can survive and operate in the limited space. Confrontation-based advocacy is the modality often used when CSOs have a better capacity to confront duty-bearers and when the environment has sufficient space for CSOs to operate.

In the global disability movement, a human rights-based approach (Degener, 2017; Katsui and Chalklen, 2020; OHCHR, 2006) has become mainstream in disability discourse, especially after the adoption of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006. The making of the Convention was a clear sign of the global disability movement moving towards a human rights-based approach. The visibility brought about by the Convention on disability issues has been phenomenal in global policy discourse, as the Convention has been ratified by as many as 185 UN Member States to date. A human rights-based approach to disability identifies duty-bearers and rights-holders. This dichotomy can increase the risk for confrontations between parties and further dichotomize them (see Johnson and Soldatic, 2020; Katsui, 2008b). In the context of disability, a human rights-based approach can sometimes be confrontational, while at other times it can be negotiation-based, depending on the capacity of the stakeholders and their environments.

In this chapter, we propose an additional modality of advocacy, namely advocacy that is non-confrontational and is based on cooperation between rights-holders and duty-bearers. We aim to show that cooperation-based advocacy can bring not only civil society actors from across State borders together but also government actors who share common goals. Through our analysis we propose that when modalities of advocacy are non-confrontational and cooperative by nature between civil society and governments, transnational advocacy networks will not only target governments but can expand to include them. We also discuss the opportunities and challenges of a cooperation-based approach to global transnational disability advocacy.

Case examples from transnational disability advocacy networks and government engagement

Finnish disability activists have played a crucial role over several decades in developments that led to the MFA's global positioning as a disability advocate. In interviews and discussions with MFA officials, each interviewee stated that this would not have been possible without the pressure and advocacy from individual persons with disabilities, notably Kalle Könkkölä, and their strong international networks with disability activists. The impact of the personal commitment and profound credibility of key disability activists cannot be overstated (see Katsui, 2008a).

The MFA actively advocates for the rights and inclusion of persons with disabilities at international fora and through its policy influencing. In fact, the MFA's strong advocacy has led to it being profiled as a leading disability rights advocate at the global level. For example, a recent evaluation of the MFA's policy influencing in multilateral organizations found that 'Finland was considered a defender of human rights (...) and to possess experience, expertise and credibility especially related to (...) the rights of

persons with disabilities' (Ministry for Foreign Affairs of Finland [MFA], 2020: 23). Similarly, the review of the European Disability Forum (EDF) (2021) substantiates the strong commitment of Finland to disability inclusion:

Finland has gone to considerable lengths to lay the foundations for disability inclusion throughout its development cooperation and humanitarian action – from its external influencing, to its theories of change, to its programme management – with further positive developments in the pipeline. (EDF, 2021: 1)

This internationally high profile on disability rights grew over time. Finnish disability activists are well known and active in the international disability movement and the MFA has increasingly become recognized as an advocate of the rights of persons with disabilities in international fora, such as in the making of the Convention. Finland's ratification of the Convention in 2016, and the subsequent national action plan for the implementation of the Convention, solidified the MFA's role and objectives for disability policy in international cooperation. A positive cycle developed as a result of the advocacy of Finnish disability activists: as the MFA's reputation on disability rights in international cooperation grew, so did measures to advance disability inclusion strengthen and more attention was paid also internally in the MFA to mainstream disability inclusion.

Rights and inclusion of persons with disabilities are currently a priority in Finland's human rights-based foreign policy. This is applied to development policy and development cooperation objectives for better realization of the rights of persons with disabilities (MFA, 2021). Furthermore, disability inclusion is one of the MFA's cross-cutting objectives, i.e. disability-inclusive approaches should be applied throughout all sectors and MFA funding instruments, and the implementation is monitored using disability markers and disability disaggregated data. The focus on the rights of persons with disabilities can be seen, for example, in the MFA's participation in the Human Rights Council, even more so now during its current membership.

The following sections explore the cooperation between Finnish disability activists and the MFA in advocacy for the rights and inclusion of persons with disabilities. A few specific cases of transnational advocacy networks will be examined to exemplify these connections, namely the Global Partnership for Disability and Development (GPDD), the UN Partnership on the Rights of Persons with Disabilities (UNPRPD), the Global Action on Disability (GLAD) Network and the Global Disability Summit. These examples of transnational advocacy were selected by the authors for analysis because of the important and prominent role that the cooperation of the MFA with Finnish disability activists played in them. It is important to recognize that these case examples are only snapshots that result from long-term advocacy and are interconnected with many other significant collaborations and initiatives.

Disability activists form transnational advocacy networks: case example from the Global Partnership for Disability and Development

Global disability advocacy grew from individual, like-minded, local disability activists becoming internationally connected with each other and, over time, forming a global transnational disability activist network. Collaborations between Finnish and international disability activists initiated transnational disability advocacy networks, similar to other contexts. In Canada, for example, international development cooperation supporting the rights and inclusion of persons with disabilities was born from the advocacy of key disability activists (Stienstra, 2019). However, in Finland's case, the collaboration led to the involvement of not only civil society but also Finland's MFA, other governments as well as the World Bank and UN agencies.

Transnational advocacy networks often start with activists facing blockages in advancing their agenda, such as human rights, in their domestic context, and then gaining strength from counterparts across territorial borders, which in turn supports their domestic advocacy towards their respective governments, i.e. the so-called boomerang pattern described by Keck and Sikkink (1998). This strategy is also used among transnational disability advocacy networks (Montgomery and Baglioni, 2022: 129). An example, which is significant for Finland's context, comes from the collaboration between Judy Heumann and Kalle Könkkölä, both prominent disability rights activists in their respective countries. In the 1970s, Heumann, Deputy Director of the Center for Independent Living in California, USA, and Könkkölä, founder and Executive Director of the organization of persons with disabilities Threshold Association in Finland, met at a Red Cross camp in Norway. Both recognized the structural barriers in their societies that prevented persons with disabilities from fully enjoying their rights equally with others. In an interview with Heumann, she reflected on the significance of what they learned from each other and how this contributed to their individual growth as activists, feeding back to their domestic advocacy. Where Könkkölä's organization became part of the independent living movement, Heumann gained insights from Könkkölä's unique engagement with the MFA and international development cooperation to promote disability rights globally. Both Heumann and Könkkölä continued their activism throughout significant milestones in the course of the global disability rights agenda (for further historical information on disability rights see e.g. Series, 2020).

The exchange between individual activists and their domestic agendas can extend to a global agenda. Heumann writes in her autobiographical book (2020) how visiting other countries and meeting disability activists opened new perspectives to global discrimination and challenges that persons with disabilities face everywhere. Könkkölä was a co-founder of the organization Disabled People's International in 1981 and chairperson during 1990–1998. With MFA development cooperation funding Könkkölä travelled to different parts of the world to learn about the situation of persons with disabilities

in various countries. Typical to transnational advocacy, disability activists recognized the possibilities of working collaboratively to have a bigger impact vis-a-vis duty-bearers and global policy makers such as in the UN. This led to several international cooperation initiatives, one of which was the GPDD. Some of these initiatives are described later in this chapter.

The GPDD was the first platform of its kind for a broad range of actors working towards a common goal of ensuring that the rights of persons with disabilities would be advanced through international cooperation. It had key characteristics emblematic of transnational advocacy networks: a platform to share information and ideas, bringing together CSOs with more powerful actors, such as governments and international organizations, in order to leverage policy change and hold duty-bearers accountable (Keck and Sikkink, 1998). In a GPDD report (2010) to the Office of the High Commissioner on Human Rights on the Convention Article 32 on international cooperation, the GPDD was introduced as follows:

The Global Partnership for Disability and Development (GPDD) is a global initiative to strengthen international cooperation to advance the inclusion of disability issues and considerations into mainstream social and economic development efforts. The GPDD's membership is an unprecedented alliance of government ministries, bilateral and multilateral donors, United Nations (UN) agencies, NGOs, Disabled People's Organizations (DPOs), national and international development organizations, and other organizations committed to enhancing the rights of people with disabilities and inclusive development. The Global Partnership for Disability & Development was created in response to the recognition that poverty alleviation in developing countries and genuine progress toward achieving the Millennium Development Goals (MDGs) requires that people with disabilities be explicitly taken into account in national and international economic development efforts.

(Global Partnership on Disability and Development [GPDD], 2010: 4)

The establishment of GPDD during 2002–2008 was made possible through collaboration between key disability rights advocates in international organizations and government ministries of both the Global North, such as Könkkölä, and the Global South, such as James Mwandha of Uganda. Heumann played a crucial role in their capacity as the first disability focal point at the World Bank. The GPDD was funded by three government donors, one of which was Finland's MFA, as a result of Könkkölä's advocacy (Katsui, 2008a). It had an active mailing list administered by Heumann at the World Bank for exchanging information on global disability rights and for coordinating meetings in conjunction with other global events such as the unprecedented World Bank Conference on Inclusive Development in 2004 that focused on disability.

One significant achievement of the GPDD was the Convention Article 32 on international cooperation, which was strongly advocated for by the GPDD to be included in the Convention as a stand-alone article. The content of the article, such as knowledge sharing and networking, shows that the Global South was also an integral part of this discussion according to the interview with then-Ugandan Member of Parliament, James Mwandha (Katsui, 2009). Article 32 outlines the obligations of States to protect and promote the rights of persons with disabilities in their international cooperation:

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:
 - (a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;
 - (b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;
 - (c) Facilitating cooperation in research and access to scientific and technical knowledge;
 - (d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.
2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.
(United Nations, 2006, Article 32)

Although the GPDD ended in part due to the lack of support from the new President of the World Bank at that time, the transnational advocacy networks formed through the GPDD carried forward and continue to influence international cooperation for the promotion of the rights of persons with disabilities. For example, Heumann moved on to the position of Special Advisor on International Disability Rights at the United States Department of State under Obama's presidency. In addition, the World Bank regional consultants have since played major roles as e.g. the UN Special Rapporteur on the Rights of Persons with Disabilities (Catalina Devandas-Aguilar) and a senior advisor at the UN Children's Fund (UNICEF; Rosangela Berman-Bieler).

As described above, the GPDD is a prime example of a transnational disability advocacy network. It included a wide range of stakeholders and, importantly, committed individuals as the driving force of disability activism (Katsui, 2009). Together with powerful actors, individual activists and

civil society can influence global policy, as in the case of the formulation of Article 32 in the Convention. However, individuals and their affiliations are not static, and thus, dependence on individuals and their networks is not sustainable in the long run. In interviews, disability activists remember an informal meeting of like-minded individuals who had been active in the GPDD. They recognized the importance of institutional support and government roles in international cooperation. An important lesson was, therefore, that transnational advocacy can be more effective when it includes institutional support beyond individual commitment also from government and powerful international organizations.

*Government donors engage in transnational advocacy networks:
Case examples from the UN Partnership on the Rights of Persons
with Disabilities and the Global Action on Disability Network*

As the transnational advocacy of disability activists was taking effect globally, like-minded governments with international disability policy agendas and funding for promoting disability rights became more engaged in transnational advocacy networks. This led to the formation of transnational advocacy platforms where disability activists, international organizations and governments could coordinate efforts towards common goals. As both tangible commitments as well as sustainable funding were needed to advance the rights of persons with disabilities in international cooperation, the role of government donors in transnational advocacy networks became more significant. Similarly to the initiation of the GPDD, individual disability activists played a crucial role in mobilizing governments. In this case, domestic disability advocacy and cooperation-based advocacy led to resources for international cooperation, which in turn further strengthened transnational advocacy networks.

First, the advocacy of Finnish disability activists led to funding for development cooperation implemented by Finnish OPDs. In Finland, through his work as a Member of Parliament 1983–1987 and on the Helsinki City Council 1985–2004, Könkkölä had strong and expansive networks with Finnish politicians across political parties. These domestic networks played an important role in advocacy towards the MFA and in securing targeted funding for disability rights in international cooperation. In 1989, Disability Partnership Finland (formerly Finnish Disabled People's International Development Association) was established by seven member OPDs, including Könkkölä's Threshold Association. This non-governmental organization supports OPDs in the Global South to promote the rights of persons with disabilities. A review in 1996 of Finland's development cooperation recommended establishing a new funding channel for grassroots level initiatives (Paasio, 1996). Funding was then directed to thematically important areas, namely disability, human rights and the environment. Based on the recommendation and Könkkölä's personal connections to influential

politicians, including the Minister of Development and the Environment of that time, Abilis Foundation was established in 1998. Abilis Foundation is a non-governmental organization that provides small grants to OPDs and collectives of persons with disabilities in the Global South for improving the lives and rights of persons with disabilities. Approximately 70% of Finland's disability-targeted official development assistance (ODA) is channelled through Finnish and international OPDs (MFA, 2018: 13).

Second, through transnational advocacy networks, a global fund to support the realization of the rights of persons with disabilities in the Global South was established. Mobilization of resources and building of larger investments in disability and development was and continues to be a major challenge in development cooperation. The UNPRPD grew from the transnational advocacy networks and cooperation-based advocacy of disability activists, advocates and government donors. Interviewees stated that, prior to the UNPRPD, funding to support the implementation of the Convention was challenging. They found that significant government funding for disability-inclusive development at the country level would not have been possible without the formation of the UNPRPD.

The UNPRPD was established in 2011, it is a multi-partner trust fund based in the United Nations Development Programme (UNDP), and it is funded by government donors. It is a unique fund that specifically supports the implementation of the Convention in the Global South and disability-inclusive development. Not only does the UNPRPD exemplify cooperation-based advocacy but cooperation between OPDs, UN agencies and governments is a core principle in all grants awarded by the fund (UNPRPD, 2022). Furthermore, international disability organizations strongly influence the UNPRPD agenda and strategy.

Lastly, after the end of the GPDD, members of transnational disability advocacy networks recognized that a platform for exchanging information and ideas and for discussion on disability and development issues was still needed. Based on a proposal from the International Disability Alliance, which is a global organization representing persons with disabilities established in 1999, the GLAD Network was formed in 2015 for like-minded bilateral, multilateral and also non-governmental donors to work together to promote international cooperation in accordance with Article 32 of the Convention. The focus of the GLAD Network is on coordination among members to achieve common goals on disability-inclusive development. The GLAD Network is one of the continued practices of international cooperation and, similarly to the GPDD, another prime example of a transnational advocacy network. However, unlike the GPDD, the GLAD Network is intended to be a platform for donor organizations, be it government, UN agencies, World Bank, private sector or independent foundations, with representation of civil society from the International Disability Alliance and disability and development organizations (Global Action on Disability Network [GLAD], 2022).

A significant outcome of cooperation in the GLAD Network is the establishment of the Global Disability Summit, which is a high-level conference, intended to catalyse commitments and implementation of the rights of persons with disabilities (Global Disability Summit [GDS], 2022). Members of the GLAD Network have been instrumental in organizing the Global Disability Summit, first hosted by the UK and Kenyan governments in London in 2018 and then by the Norwegian and Ghanaian governments in Oslo in 2022. The next Summit is planned to be hosted by Germany and Jordan in Berlin in 2025. OPDs from both the Global North and Global South play a central role in the Summit, shaping the agenda based on known gaps in disability-inclusive development. The Summit is yet another space for CSO advocacy borne out of cooperation in transnational advocacy networks between disability activists and government actors.

Cooperation between OPDs and the government in transnational advocacy networks is an interesting phenomenon identified in the global disability movement as a relatively new strategy of advocacy. As government donors have begun to take more prominent roles in transnational advocacy networks, such as in the GLAD Network and in the Global Disability Summits, the nature of transnational disability advocacy networks has changed. It is no longer only individual disability activists and civil society actors using networks to strengthen their advocacy. In collaboration with civil society actors, advocacy and policy influencing of governments in these networks aim at influencing the realization of the rights of persons with disabilities in other States. This continues to be relevant today, as many governments still do not fulfil their obligations to implement the Convention even after ratification. For instance, the COVID-19 pandemic and responses to the pandemic have revealed the extent of exclusion and discrimination that persons with disabilities face in many countries (United Nations [UN], 2020).

Discussion on opportunities and challenges of cooperation-based advocacy in transnational disability advocacy networks

Katsui (2014) describes negotiation-based and confrontation-based modalities of advocacy. Using the case examples described in this article, we examine the opportunities and challenges of a third modality of advocacy, cooperation-based advocacy, within the context of transnational disability advocacy networks. We also discuss conditions that can support or hinder effective cooperation-based advocacy. The modalities of advocacy are examined through six distinct characteristics summarized in Table 12.1: the capacity of rights-holders, the power of duty-bearers, the objectives of advocacy, the extent of space for civil society to operate in and strengths and weaknesses of the modality.

First, it is important to recognize that Finland's level of democracy, transparency and space for civil society to operate (Organisation for Economic Cooperation and Development [OECD], 2021: 100–106) is a significant

Table 12.1 Summary of three modalities of advocacy

<i>Modalities of advocacy</i>	<i>Negotiation-based</i>	<i>Confrontation-based</i>	<i>Cooperation-based</i>
Capacity of rights-holders	Weak	Strong enough	Strong
Power of duty-bearers	Very strong and unequal power relationships between duty-bearers and rights-holders	Strong	Strong and equal power relationships between duty-bearers and rights-holders
Objective(s) of advocacy	Policy changes to be made by duty-bearers	Policy changes to be made by duty-bearers	Policy changes to be made by duty-bearers and others, such as international organizations and institutions, other States
Space of civil society	Limited	Large enough	Large and enabling
Strengths	When careful, CSOs can survive in the limited space of civil society.	A legal approach can solve problems. Duty-bearers are pressured to make necessary policy changes.	Strengths of both duty-bearers and rights-holders complement each other to have a larger impact.
Weaknesses	CSOs use self-censorship in an undemocratic environment. The goal of CSOs cannot often be achieved.	Dichotomization between duty-bearers and rights-holders might take place, at least in the long run.	The political decision-making power remains in the hands of duty-bearers. Financial dependency might affect the autonomy of the rights-holders. Without policy, continuation is easily jeopardized when the cooperation relies too much on individuals.

contributor to Finnish cooperation-based advocacy. CSOs have good support from society and they ‘perceive themselves as having a relatively good level of input’ (OECD, 2021: 103). Finland’s strong commitment to strengthen civil society applies to both its domestic policy and development cooperation (OECD, 2021: 118). The space that Finnish CSOs have to function in Finland lays the foundation for effective cooperation-based advocacy between disability activists, OPDs and the MFA. In our examples of transnational advocacy networks, cooperation between disability activists and government is characterized by a large and matured space for civil society and by the duty-bearer’s democratic approach to power. The large environment for civil society enabled disability activists to develop initiatives that were then funded by the MFA, e.g. funding to Disability Partnership Finland and Abilis Foundation for implementing international development cooperation.

In Finland, the space for civil society to operate independently is partly due to Finland’s commitment to strengthening civil society participation and inclusion of rights-holders as a core principle of human rights. At the same time, space for civil society also contributes to rights-holders being able to demand their right to participation. The Finnish disability movement has systematically demanded ‘nothing about us without us’ from government duty-bearers. Participation of persons with disabilities in decision-making and maintaining ownership has been a consistent advocacy message from Finnish disability activists. Persistent and effective advocacy from Finnish disability activists and their international counterparts has indeed opened opportunities for them to join official delegations and discuss global disability rights issues at the same table with decision-makers. In fact, financial support from the MFA was earmarked for disability diplomacy and Könkkölä was appointed by the MFA as a representative of Finland on many occasions, including at UN Conferences such as the High-level Meeting on Disability and Development in 2013 with the Minister for Development. Having a person with disabilities representing and discussing disability rights was an advantage for Finnish engagement in transnational advocacy networks, and it also contributed to the MFA’s positive reputation on disability rights as the MFA did not have a high-ranking diplomat who themselves were a person with disabilities to represent Finland.

Another significant characteristic of CSOs, specifically OPDs, and their cooperation with the government is the very strong capacity of rights-holders. Interviewees mentioned that Finnish disability activists’ capacity to influence is an example of CSOs’ impacts at its best and showcases why support for civil society is at the heart of Finland’s human rights-based foreign, security and development policies. The capacity of disability activists is strong in part due to the exchanging of information and ideas through transnational advocacy networks. We show in the case examples how disability activists, such as Heumann, Könkkölä and Mwandha, used their transnational networks to learn from others on the situation of persons with disabilities in other

States, including in the Global South, and also on how each other advocate for rights of persons with disabilities in their contexts. This sharing of information and ideas strengthened their capacity to advocate both domestically and globally. Ideally, rights-holders' and duty-bearers' capacity and knowledge can complement each other, thus making cooperation-based advocacy more effective. The GPDD and the GLAD Network are further examples of how various actors with common values and advocacy objectives can strengthen each other's capacity and extend the networks to a broader range of stakeholders, such as governments.

Fragmentation or polarization of the disability movement and OPDs lacking proper representation can be an indication of poor capacity of rights-holders and it can undermine effective advocacy. Disability movements often comprise organizations representing various impairments and sometimes these organizations are not unified in advocacy and may in fact compete against each other for a voice and/or for resources (see Katsui, 2008a; Pleyers, 2010). Some OPDs are human-rights-oriented organizations whereas others are service-based organizations. It is challenging, for example, for duty-bearers, who are not well-versed in disability rights or familiar with the disability movement, to understand the plurality of disability movement representatives and intersections with gender, age, sexual orientation, ethnicity etc. Furthermore, at the same time, disability movements may exclude or do not adequately represent gender equality and diversity among persons with disabilities (Vernon, 1999), for example rights of women and girls with disabilities (Katsui, 2008a), or of persons with disabilities identifying as a gender or sexual minority (Smith et al., 2022: 55). This can be prevalent regardless of whether the prevalent advocacy modality is negotiation-based, confrontation-based or cooperation-based advocacy. In the case of Finland and the cooperation-based advocacy with the MFA, intersectionality is recognized at the policy level but not adequately enough at the representation level.

Nevertheless and despite the strong capacity of Finnish disability activists and OPDs, and their positive impacts to influence policy changes, MFA interviewees reported sometimes facing challenges in taking concrete action based on the advocacy of disability activists, even when they were in agreement. Effective advocacy enabled discussion between rights-holders and duty-bearers, but despite that decision-makers were willing to act, they also expected and needed concrete suggestions and data in order to make justifiable evidence-based decisions. Globally data and evidence on disability issues, violations of rights of persons with disabilities as well a tracking of the implementation of the Convention exist but there are major gaps in most sectors (Abualghaib et al., 2019). For example, the recent emergence of the transnational disability advocacy in climate change and climate action is hampered by the scant data available on climate change impacts on the rights of persons with disabilities (see Jodoin, Ananthamoorthy and Lofts, 2020). Data and concrete proposals can make a difference in cooperation-based

advocacy leading to action by institutions and decision-makers, as we see from the aforementioned example of the formation of the GLAD Network.

Cooperation-based advocacy brings not only civil society and rights-holders to advocate together but also, in certain conditions, can decrease the dichotomy between rights-holders and duty-bearers, thus creating transnational advocacy networks comprising like-minded actors from both civil society and government. Not unlike developments in Sweden's disability movement, where advocacy strategies have been rupturable, interstitial and symbiotic, as described by Sépulchre and Lindberg (2020), our examples suggest that confrontation-based characteristics existed earlier in the development and maturity of the relationship between disability activists and government. For example, although the GPDD had government funding, an enabling foundation in the World Bank and strong disability activists, the GPDD fell apart after leadership and the political environment changed in the World Bank. The GPDD lacked institutional support. However, we also suggest a development or maturity in the modality of advocacy and thereby a shift towards a stronger cooperation-based advocacy, as evidenced in the GLAD Network, the Global Disability Summits. In these latter transnational advocacy networks and platforms, governments started to have larger roles, i.e. they began to be not just donors but also partners in advocacy. As the government's role in transnational advocacy networks grew larger, there has been a shift from right-holders' advocacy domestically towards both rights-holders' and duty-bearers' joint advocacy objectives extending to influencing policy changes in e.g. other States and in international organizations and institutions.

A major concern and potential weakness in cooperation-based advocacy is financial dependency on the government and its relationship with the autonomy of CSOs. In many countries, government institutions are the primary source of funding for CSOs, especially in development cooperation. This has been discussed extensively globally (e.g. Fowler, 2000) and in Europe, including in Finland (e.g. Nijs and Renard, 2009; Numerato et al., 2019). Financial resource asymmetry can be a significant weakness in cooperation-based advocacy. The financial situation of CSOs in Finland has been deteriorating leading to CSOs suffering a lack of stability (OECD, 2021: 112). The Finnish government's budget cuts in 2015 hit the development sector hard, resulting in a substantial decrease in funding for development cooperation of CSOs, with negative impacts on the continuity of CSOs that were largely dependent on government funding. Although ODA has gradually increased since then, the government budget for CSOs has not increased as a percentage of total development cooperation (OECD, 2021: 119). Similar findings have been reported when a change in the Canadian political environment led to major budget cuts for development cooperation (Stienstra, 2019). As a result, Canadian OPDs lost their funding for disability-inclusive development cooperation and transnational activism. Austerity measures can also create competition among CSOs for funding and

undermine cooperation-based advocacy and participation in transnational advocacy networks (Montgomery and Baglioni, 2022: 118–134). Therefore, autonomy and cooperation-based advocacy between duty-bearers and rights-holders might become more complicated depending on the political support for development cooperation.

Another challenge of cooperation-based advocacy is that CSO's ownership of the agenda does not necessarily lead to overall decision-making power. Ownership of agenda does not equal ownership of political power. The political decision-making power continues to remain in the government and not with disability activists or OPDs, even with close cooperation between disability activists and the government. An example comes from development cooperation funding to the private sector. In Canada, despite effective disability rights advocacy in other areas, disability-inclusive development was not mainstreamed by the private sector (Stienstra, 2019). Similarly in Finland, gaps exist in ensuring that disability-inclusive criteria are applied also to private sector grants (EDF, 2021). For instance, Finnfund, which independently manages MFA funding for private sector development cooperation, has not implemented disability-inclusive programming, despite significant progress in gender equality and despite disability inclusion being an MFA development policy priority.

A concern in development policy in general is the continuity of the policies despite changes in political environments. For example, despite significant results achieved by cooperation between disability activists and the MFA, the MFA still lacks a strategy specific to disability in international cooperation and an explicit policy on OPD participation and engagement with mainstream development programming, i.e. which is not disability-targeted development cooperation (EDF, 2021). The lack of a strategy or policy can undermine long-term progress and funding for advancing disability rights in international cooperation, as has reportedly happened in Canada (Stienstra, 2019). If political priorities were to change in Finland, sustainability of the MFA's advocacy and funding, for example to the UNPRPD, may weaken. As other government donors, such as the UK and Norway, have recently adopted strategies for disability-inclusive development cooperation, the question remains how the MFA will be able to maintain its position as a global advocate of disability rights. In short, there are still many steps before Finland becomes the happiest country in the world from the point of view of international cooperation.

Conclusions: Looking towards the future

The positive reputation of Finland is an important contributing factor that enables effective policy influencing. On disability issues, Finland's strength has been its persistent and strong disability activists and their international networks, combined with the MFA's consistent and long-term policy influencing disability issues.

Mutual recognition of the important roles both disability activists and MFA officials have played in transnational advocacy networks exemplifies the modality of cooperation-based advocacy proposed in this chapter. As described extensively, Finnish disability activists have played a vital role in building the MFA's disability-inclusive international cooperation and strengthening the understanding of disability rights. International disability activists interviewed for this chapter identified also key MFA officials who were not only receptive to cooperating with disability activists but also committed to advancing disability issues within the MFA as well as globally.

Based on the analysis of case examples of Finnish international cooperation, a cooperation-based approach between duty-bearers and rights-holders in transnational disability advocacy is an opportunity. However, specific conditions should be met to enable cooperation-based advocacy. When it comes to international cooperation, this chapter describes the central conditions for Finland to become 'the happiest country in the world'. First, it is fundamental in transnational advocacy networks that stakeholders should share common values, goals and objectives, which in this case are the realization of disability rights, whereby all parties benefit from the cooperation. Ownership and autonomy of rights-holders should not be jeopardized by cooperation with duty-bearers nor by decreased funding for CSOs or dependency on funding from duty-bearers. Space for civil society to function independently is an important enabler. Lastly, institutional support is needed for the continuity of policies and implementation of rights, and continuity within the disability activist movement is needed to garner institutional support.

Future research using comparative analysis could shed light on whether Finland's cooperation-based advocacy is a result from a unique situation or if this is a model that is applicable in other contexts. Comparative studies on this topic are too few (e.g. Katsui, 2008a). Further research could also explore whether a reversal in the conditions for cooperation-based advocacy could result in the advocacy devolving into negotiation- or confrontation-based modalities. Importantly, analysis of Finland's transnational advocacy on disability rights raises interesting questions on whether the conditions for effective policy influencing and disability activism could be replicated and further scaled up elsewhere and in other human rights issues.

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Concluding remarks

Hisayo Katsui

Finland from the critical perspective of disability

In early 2023, when we were finalising this book's manuscript, Finland was re-selected as the happiest country in the world for the sixth year in a row (Helliwell et al., 2023). The Nordic Welfare State Model has often been considered superior to other models in terms of equality (see Kangas and Karonen, 2022), which is an important aspect to bear in mind to understand disability at both the policy and practice levels. However, the overall impression of Finns as the happiest people in the world, generously protected by the welfare state regime, does not in fact extend to everyone living here: Many persons with disabilities do not necessarily experience this happiness, not only because of the sustainability challenge posed by the ageing population, but for many other reasons. Our excellent, illustratively diverse book chapters look at Finland from the critical perspective of disability and show that the country does not seem to deserve the status of the happiest country in the world. For too many persons with disabilities, inequality and poverty are an integral part of the disability phenomenon in Finland in many ways, in their personal daily lives and across diverse sectors. Our studies show that disability is manifested on a number of levels in the lives of persons with disabilities, as emotional, social, political, and structural layers.

The individual needs of children and youths with disabilities in educational institutions are too often undermined in both compulsory education (see Chapter 5) and higher education (see Chapter 2). According to the analysis of Chapter 5, Finnish compulsory school is not very inclusive. Among other things, the vague definition of inclusive education in policy documents has led to varying inclusive educational arrangements, as the ways in which municipalities, principals, and teachers interpret the policy differ greatly. In addition, the extent and use of separate schools, classes, and a small-group pull-out model raises the question of whether the Finnish interpretation of inclusive education in fact contradicts the notion of inclusive education recognised in Article 24 of the UN CRPD.

In other educational institutions, too, especially those in higher education, inclusion is only partially realised. The fact that a significant proportion of students have disabilities is not taken into account. Too often, the

educational environment is *disabling* rather than enabling: many students with disabilities are left with no access to necessary support or reasonable means of accommodation. Extended compulsory education until high school is already problematic for many pupils with disabilities (Aalto, 2022). Crip experiences (McRuer, 2006) are extremely profound for many students with disabilities (see Chapter 2). The Helsinki University students with disabilities studied are too often left alone to deal with their socially created difficulties as well as the inconveniences caused by the effects of their impairments (Thomas, 2007). This is on top of their responsibility to arrange their disability services based on their needs according to Chapter 2. When dependency is seen in a very negative light (see Chapter 3), the students even refrain from asking for support. Moreover, some students simply do not know of the university support services available to them, while others feel that the services are not accessible in a timely manner. Only individual friends and teachers sometimes voluntarily attend to the disability-related needs of these students. Reasonable accommodation is not systematically implemented in the practices of education institutions. Many persons with disabilities experience diverse poverty (Pohjolainen, 2021) which causes them to discontinue their studies (Vesala and Vartio, 2018).

Similarly, most persons with disabilities also go through crip and disabling experiences in employment. In Finland, disability often means living on a disability pension or other social benefits. There are no precise statistics, but the employment rate of persons with disabilities has been estimated at roughly between 15 and 20 per cent (Vesala, Klem and Ahlström, 2015: 53; Vesala and Vartio, 2018: 12). This means that 80 per cent, or even more, of persons with disabilities are excluded from paid work. Those with intellectual and developmental disabilities in particular are routinely granted a disability pension and are unable to practise their right to self-determination (see Chapter 8) as it is not recognised (see Chapter 10). The people with intellectual disabilities interviewed were highly motivated to work but were seldom offered employment opportunities and almost automatically became disability pensioners according to the findings of Chapter 8. Many structural and attitudinal problems were identified in the equal employment opportunities for persons with disabilities (Kyröläinen, 2020).

When it comes to the politically less focused realm of leisure time, the situation is frankly alarming. Even though leisure and physical activities are an independent right recognised in Article 30 of the UN CRPD, many children, youths, and adults with disabilities have enjoyed this right to a much lesser extent than their peers without disabilities (see Chapter 9). As we have shown, inclusion is understood in highly diverse ways (see Chapter 5), and this, in addition to the lack of public support in the form of personal assistants, assistive devices, and transportation services, as well as the lack of family members' resources (see Chapter 9), makes many persons with disabilities unable to enjoy their right to leisure and physical activities. Finnish society does not conceptualise the significance of these activities for persons with

disabilities as a priority in terms of their social belongingness and well-being according to the findings of Chapter 9, even though it recognises them as essential for building social bonds and identity for those without disabilities (Hanifi, 2021; Zacheus, 2008). Too often, the medical aspect is considered important here, and only activities that come under rehabilitation services are available to the majority of persons with disabilities, if any are available at all (Chapter 9; Eriksson and Saukkonen, 2021).

The COVID-19 crisis has further limited the social relations of many persons with disabilities, whose social relations were already limited even before the pandemic (see Chapter 1; Chapter 4; Nurmi-Koikkalainen et al., 2021). Loneliness through emotional and social isolation is one of the paramount forms of the embodied, lived experiences of disability for many persons with disabilities in Finnish society (see Chapter 1). The study of Chapter 1 indicated how profound the negative impact of Finnish society is on the psychosocial status of not only persons with disabilities but also that of their families: ‘Profound, long-lasting loneliness diminishes agency.’ This negative psychosocial effect of disability is also observed in other chapters of this book (see Chapters 8 and 11). In these multi-layered processes of life experiences in our ableist society, many persons with disabilities construct and reconstruct their identity as unwanted others (see Chapter 1). Barriers to doing but also to being, and thus attitudes (Thomas, 1999), are a huge issue in Finland. The loneliness and social isolation experienced by many persons with disabilities are an enormous part of their experiences of disability in Finland, the so-called happiest country in the world. The pandemic made the already poor situation of many persons with disabilities too often worse by widening the gaps between those with and those without disabilities (see Chapter 4). As a result of all these diverse aspects of life, assumed normality (Barton, 1993) is deeply rooted in ableism (Campbell, 2009). Ableism is widely compounded to personal experiences, and eventually the self-esteem of many children and youths with disabilities is profoundly and negatively impacted. This internalised oppression overshadows the well-being of many persons with disabilities (Campbell, 2009; Katsui, 2005; Chapters 1, 8 and 11). In short, for too many persons with disabilities, it is hard to argue that Finland is a happy country, let alone the happiest country in the world.

Why crip experiences?

Why are the experiences of many persons with disabilities so different from those of others without disabilities in Finland? Chapter 11 by Koivisto and Katsui is insightful: it unravels the historical background and explains why current reality is what it is. According to the Marriage Act (1929–1969) and Sterilisation Act (1935–1970), which were valid until quite recently, persons with many types of disabilities were prohibited from marrying and having children, although many of them wished to. Children with disabilities were considered unfit and a burden to Finnish society and were eliminated (see,

e.g., Koivisto and Katsui, 2021; Mattila, 1999; Salmi and Laakso, 2005; Chapter 11). Many attempts to rehabilitate and medically treat disabilities have been made in recent history in Finland (Katsui et al., 2021). Deaf people were not allowed to use their mother tongue—Finnish and Finland Swedish sign languages—at their schools until recently. The eugenic ideology was strong before and after World War II and still causes deep, intergenerational trauma in our society (Katsui et al., 2021; Chapter 11).

Against this historical background, structural and attitudinal barriers are, in fact, a natural consequence and serve to perpetuate ableism and the eugenic ideology, which has favoured ablebodiedness over disabled bodies for many decades in Finnish history. Conceptual confusion is obvious today: historically deeply rooted ideologies are still present, yet at the policy level, human rights discourse has become mainstream. It is thus not surprising that the conceptualisation of ‘inclusive education’ among different education stakeholders is inconsistent at the very least, and in the worst case, even practically based on ableism (see Chapter 5). The chairperson of the teachers’ union, Katarina Murto (2022), also acknowledges the fact that some municipalities use the inclusive education as an option to save money by relocating children with disabilities from specialised education institutions and classes into mainstream schools and classes without the necessary support. When key stakeholders do not understand inclusion and attitudes, it is extremely difficult to make genuine inclusion a reality in schools, especially when austerity is simultaneously greatly affecting the education sector and many other sectors.

Media representation of disability has certainly not dramatically improved, even though organisation representatives acknowledge slight, gradual changes in attitude (see Chapter 6). The media representation of disability is a good example to underline the diverse approaches to disability that co-exist in Finnish society. A medical approach is still predominant, and the media also often fail to give a multidimensional picture of disability, as they often reduce persons with disabilities into the roles of objects or superheroes. In both ways, persons with disabilities are categorised as stigmatised others and are not considered part and parcel of society (Grue, 2016; Chapter 1). Furthermore, market-oriented, neoliberal ideology has been widely spread in society and causes pressure to label many persons with disabilities as others and as deviants from the mainstream (Katsui, 2022; Meekosha and Shuttleworth, 2017). Women with disabilities are particularly neglected by the media (Wilde, 2022). As the media is in a great position to either contribute to social change or to continue reinforcing the status quo, media production teams should include persons with disabilities to create a much more diverse picture of disability (see Chapter 6). Persons with disabilities are under-represented in our society in too many sectors: the media is only one of these.

At the structural level, changes are only beginning to take place, which partly explains why Finnish society still predominantly approaches disability

from the medical framework and treats people with disabilities as objects of care and charity in the UN CRPD era (see Chapters 6 and 7). Disability pension has been largely based on an old-fashioned understanding of persons with disabilities as objects of care and protection. The very assumption that persons with disabilities are not able to work must change dramatically in order to stop the opportunities of persons with disabilities being limited, even though there are always those with, for example, severe intellectual and multiple disabilities who cannot do any work at all. The right to self-determination is too often jeopardised by incorrect assumptions in Finnish structures. Interdependence (see Chapter 3), supported decision-making, and co-agency (Mustaniemi-Laakso et al., 2022) are important key concepts and steps forward.

Many laws and policies are increasingly written in the human rights framework that complies with the UN CRPD and will change at the beginning of 2025 to move away from the previous care paradigm. The two diagnosis-based laws will become one Disability Service Act (Government of Finland, 2022). As the new law more seriously takes individual needs into account, many practices will need to change accordingly. We are at an important crossroads. At the same time, disability services have been increasingly framed in the social investment paradigm, for instance, to support the employment of persons with disabilities, and to eventually alleviate the pressure on the welfare state regime caused by the ageing population (Kangas and Karonen, 2022). This conversely means that active citizenship will become increasingly important, which could further marginalise many persons with disabilities through the aforementioned ableist assumption that they are unable to work (see Barton, 1993). In this conjunction, it will be interesting to follow and monitor the implementation of the new law and to see whether or not it really secures the individually different needs of persons with disabilities, including persons with intellectual disabilities. Another aspect of the implementation of this law is the intersection of disability and ageing, as discussed in Chapter 3. Older persons with disabilities have mostly been left to fall into the gap between the two laws of disability and old people, and there is a risk that this will be perpetuated.

The health and social services reform also aims to cut the budget. This does not bode well for meeting the principal, individual needs of many persons with disabilities, which were unmet even before the reform (Hoffrén, 2019; Vesala and Vartio, 2018; Katsui et al., 2023), as discussed throughout this book. Finnish society is disabling in so many ways that universal rights do not sufficiently ensure that the individual needs of persons with disabilities are met, and disability-specific laws still neglect many persons with disabilities (see Chapter 7). Chapter 10 analysed this phenomenon through the concept of redistribution (Fraser and Honneth, 2003) and presented a context in which the number of services had to be negotiated even when they had been granted. Thus, without careful implementation strategies, laws and policies can continue to restrict the human rights of persons with disabilities (see Mustaniemi-Laakso et al., 2022).

When these multi-layered, disabling barriers are manifested in the everyday lives of many persons with disabilities in Finland, the impact of the psychosocial effect of disability is hard, as Thomas (2007:73) describes:

Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.

This explains the *crip* experiences and the subsequent emotional and social isolation of many persons with disabilities in Finland (see Chapter 1).

Activism and advocacy as a solution? More sophisticated, innovative approaches are needed

How then, can persons with disabilities counteract these observed, experienced injustices? Are there ways to aim for social transformation? At the individual level, despite these collective experiences of disablism at some or many stages in the lives of countless persons with disabilities in Finland, (Katsui et al., 2023) they have also shown great agency in today's disabling environments. For instance, the students with disabilities interviewed at the University of Helsinki also navigate the highly disabling academic environment with their own agency even when little support is available or accessible in a timely manner (see Chapter 2).

At the organisational level, one of the interviewed activists described current disability activism as follows (see Chapter 10):

I have to remind myself that it is a spiral, the progress I mean. Sometimes the [disability] movement resembles a circle, that we are just going round and round. But no, it also rises, the societal position of disabled people I mean.

Some progress has been observed over history, although it is not always linear or self-evident. In all the areas that Chapter 10 analysed, namely, redistribution, recognition, and representation, room for improvement was identified in the Finnish disability movement. For instance, even representation within so-called disability organisations was questioned and politicised (Chapter 10), not to mention societal representation (see Chapter 6). As the injustices and problems are many and exist on multiple levels, counter activism and the ways to impact social transformation have also diversified over the years. The 'conventional' disability movement alone is not enough to counteract injustices and make a difference.

One of the new modalities in the disability sector is the truth and reconciliation process of deaf people and the sign language community, which was launched in the Government Programme of Antti Rinne in 2019 (Chapter 11). This process aims for social transformation and future equality

by acknowledging past injustices as truths and finding measures to reconcile the stakeholders. It was established when the conventional deaf movement and activism were not sufficient for facing the painful past and changing the reality based on ableism, oralism, and audism. It remains to be seen how the process will develop and attend to the diversity of the sign language community and the painful injustices over many generations. Whether a new modality of disability activism will arise in Finland and beyond is an interesting issue to explore in future studies.

Another relatively new modality of advocacy is transnational advocacy (see Chapter 12). In history, the disability movement has required the government to strive for equal opportunities and human rights for persons with disabilities, to enact laws, and to subsequently be accountable for and transparent in their implementation of them. Over recent decades, transnational advocacy has also facilitated networking among different actors, both governmental and non-governmental, and had a greater impact on disability inclusion at the global level. The UN CRPD is a paramount example of the fruit of such transnational advocacy. The Finnish Ministry for Foreign Affairs has actively engaged in transnational advocacy work in collaboration with organisations of persons with disabilities. Increasingly more actors, including other ministries of the Finnish government, are needed to bring about radical changes in the practices of Finnish society towards ensuring equal rights for persons with disabilities. A responsive state and people are needed (Heikkilä, Katsui and Mustaniemi-Laakso, 2020) to genuinely make Finland a country with the happiest people, including persons with disabilities.

Further research areas

Unlike the medical and social models of disability that underpin clear causal relations of biological conditions and society respectively to the phenomenon of disability, Finland has traditionally taken a much more nuanced approach to disability. In this book, the Finnish scholars have been investigating disability by paying attention to the diversity of persons with disabilities and understanding the changing positionality of them in relation to different people in their different contexts that are both enabling and disabling or even somewhere in between. The relational approach to disability, which has been long-standing as a Nordic Approach to Disability (see Traustadottir, 2009), is still present, as it has been observed in this book. Careful insight into the context, relationships, and times including historicity has enlarged our perspectives in critically understanding the current Finnish society with the disability lens. This book has critically scrutinised the realities in Finland from the perspective of disability and thus demystified Finland in terms of a diverse range of thematic areas, from law and policy to individual experiences, and to activism and advocacy at different levels. Through our analysis of embodiment, the critical disability perspective has given us the

opportunity to move away from the objectification of the Eurocentric and neoliberalist understanding of independent able-bodied individuals to the conceptualisation of the more interpersonal relationships located in both the local and global fabrics of inequalities and power relations (Katsui and Mesiäislehto, 2022; Mesiäislehto, 2023). We have tried to keep our focus on disability, but to also appreciate such great diversity. We have particularly listened to the voices and experiences of persons with disabilities of different age groups (Chapters 2, 3 and 9), the deaf and the sign language community (Chapter 11), and persons with intellectual and developmental disabilities (Chapter 8). Many of the authors themselves are or have family members who are persons with disabilities. We acknowledge that diversity also includes persons with different impairments, women with disabilities, immigrants with disabilities, persons with disabilities and other characteristics such as ethnic, religious, and/or sexual minority backgrounds. It is important not to assume that all persons with disabilities in Finland are originally from Finland, heterosexual or Christian. Intersectional aspects were not the main focus of this book but are an absolutely integral part of our research interests. Areas that were not covered in this book will be elaborated on in our future books and publications.

As for the methodological aspect, the participatory research approach (Barnes, Mercer and Shakespeare, 1999; Katsui and Chalklen, 2020) was applied in the studies of Chapters 2 and 11, whereas the co-creation of knowledge was used in the research project described in the study of Chapter 10. Disability studies was created to counteract the previously predominant medical approach to disability and has affected the kinds of research data and methods that are used. Disability studies has primarily focused on personal accounts and used qualitative research methods. This was also the case in this book. More methodological innovation is needed in future disability studies in Finland.

This book benefited from theories of disability studies such as the social model and the human rights-based approach to disability. These approaches are undoubtedly human centric, even though humans are only part of the bigger picture. Thus, another area for future disability studies is a much more globally environmental perspective (Katsui, 2022), because the problems stemming from, for example, ableism, prejudice, and discrimination are not only Finnish problems, they are global (UN Special Rapporteur on the Rights of Persons with Disabilities, 2020). As neoliberalism, growthism, and ableism have become deeply interconnected (Katsui, 2022), degrowth thinking will be relevant for linking not only environmental issues but also the global disability discourse to increasing the well-being of people, consciousness of the environmental impact, and economic stability from the global perspective (Andreoni and Galmarini, 2013). This link is an area for further research, as Finland is located in a global context. It is high time that we critically rethink happiness as being not only the privilege of the average person of a country—we need to go further, to more consciously think about the well-being of

‘others’ as well as that of our whole planet. This book is a step towards such an effort.

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Index

Note: entries refer to Finland and Finnish unless otherwise stated. Page locators in **bold** and *italics* represents tables and figures, respectively.

- Abilis Foundation 245, 248
- ableism 13, 14, 92–3, 160; internalised 42, 160, 166, 169, 171; narratives 15, 24
- accessibility, lack of 3, 182, 184, 208, 209
- accident at work 59–60
- accommodation 30, 34, 37, 38, 99, 140
- Act on General Upper Secondary Education (2018) 85
- Act on Intellectual Disabilities (1977) 49, 50–1
- Act on Public Procurement and Concession Contracts (2018) 152
- Act on Services and Assistance for Persons with Disabilities (Disability Services Act 1987) 6, 7, 140, 141, 150–1, 260
- Act on Special Care for Persons with Intellectual Disabilities (Special Care Act 1977) 7, 111, 140, 141
- Act on the Care of Invalids (1946) 140
- Acts on Disability Services and Assistance 49, 50–1, 111, 151
- ageing policies, public to private sphere 58
- ageing population 48, 256
- age-related restrictions 49, 50, 51
- ‘apologies, institutional’ 216, 217
- apprenticeship training institutions 85
- assistive devices, financial assistance for 188
- Association of Physically Impaired 159
- Association of the Deaf (FAD) 216, 217
- Association on Intellectual and Developmental Disabilities (FAIDD) 71, 217
- athletes with disabilities 112, 130
- Attention Deficit Hyperactivity Disorder (ADHD) 36
- attitudes of society 30
- austerity measures 149, 153, 154
- autism spectrum disorder (ASD) 36, 89, 130
- autonomy and own money 165
- barriers: attitudinal 13, 20, 125, 205, 206; communication 52; to doing and to being 205, 209; to employment 162, 206; to getting help 59; to inclusion in education 97–100; multi-layered 261; physical environment 34–5; to political commitment to organizing services 147; and public policies 8; at University 43
- Basic Education Acts 86, 91; reforms and amendments 86, 87
- belonging and unbelonging 16, 17, 23, 171, 172
- bullying 19, 20, 84
- bureaucracy: dealing with 42; cutbacks 152; difficult 58; nomenclature of 99
- capabilities: basic rights 69; definition 69; equal importance 80
- care system, long-term 50
- carers 57
- child of deaf parents 217, 218, 219
- child-centred approach in education 90, 91, 94, 97, 98, 100
- children with disabilities, right to live with a family 141

- children with special educational needs 99
- civil society organizations (CSOs) 238; government budget for 250
- Clogston and Haller 115, 116, 130
- community based solutions 147
- Constitution of Finland 29
- Convention on International Cooperation 4
- Convention on the Rights of Persons with Disabilities (CRPD) *see* UN Convention on the Rights of Persons with Disabilities
- cooperation-based advocacy 250, 251, 252; financial dependency 250; in transnational disability networks 246–51; weakness in 250
- coping alone 57–8
- Council of the European Union, The 83
- COVID-19 4, 68, 69; causing anxiety and depression 77; changes in living conditions 72; criticism of restrictions 73–4; experiences 70–5; and health care system 80; increased dependence on family members 81; lockdown 69, 75, 80; negative consequences 68, 74, 75–7; restrictions on movement 70; separation from loved ones 76; services disintegrated 70; services rolled back 72, 74–5; social contact restrictions 72–3, 76, 77, 79; at University 44
- crip experiences 32–7, 40–1, 258–61
- crip theory 29–32, 33, 42
- critical disability studies 31
- cultural activities 180, 186
- cultural value systems 201
- curriculum, freedom to interpret 92
- Daily Life and Autonomy of Disabled People 15, 16
- dance group for persons with disabilities 185
- Deaf Clubs 217
- deaf community, experienced oppression 216
- Deaf History Society 217–18
- deaf movement 216
- deaf people: encounter more injustices 216; experimental ear surgeries 219; forced sterilizations 217, 218, 226; internalized audism 220; low expectations of 220, 221; low self-esteem 221; prohibited from using sign language 259; right violations against 218; unable to fully recognize oppression 220; as unwanted in society 229
- ‘deaf’ representing hearing limitations 34, 216
- Deaf Studies 216, 220, 222
- decision-making by people impacted 80
- Declaration on the Rights of Disabled Persons 234
- deinstitutionalization 7, 141, 144, 147, 150, 153
- demanding special support 89–90, 98–9; network 90, 102
- dementia 51
- dependency: fear of 56–8; reciprocal 56, 59, 60
- dignity 23
- disability: acquired 20–1; advocacy 8, 203; allowance system 161; definition 114; as identity issue 115; as ‘incompleteness’ 19; legislation reform 111; living with 8; media representations 115–16; and old age intersection 52–3; as ‘otherness’ 113; percentage reported 48–9, 55; psychosocial effects 261; seen as 31–2; shifted authority 207; women with 259; theorists 205
- disability activism: and advocacy 8; goals 204, 237; international 238
- disability activists 5–6, 193, 200, 204, 235–6, 239, 241; capacity to influence 248; cooperation with government 248; deaf 217; forming transnational advocacy networks 241
- Disability Benefits Act 111
- Disability Forum 84, 113, 159
- disability models and approaches 115–16, 119, 120, 124, 128–9; affirmative 115, 119, 125, 129; biopsychosocial 114, 119, 125, 128; business 116, 119, 125, 128; capability 114–15, 119, 125, 128; charity-based 119, 124, 125, 128; consumer 116, 119, 125, 128, 130; contradictory 130; cultural pluralism 116, 119; global 126; heroic 117, 126; human-rights-based 115, 119, 123, 128; individual 119; legal 116, 130; medical 116, 119, 124, 125, 128, 234; minority/civil rights 116,

- 119, 125, 129; moral 119, 121, 125, 129; neutral 123, 126; Nordic relational 119, 128; political 115, 119, 128; progressive 116, 121, 124, 127, 130; relational 115, 126; social 114, 118, 119, 124, 125, 128, 205; social constructionist 113; social pathological 116, 119, 124, 125, 129, 130; socially oriented 63; supercrip 116, 119, 124, 129; traditional 116–17, 121, 124, 127, 130
- disability movement 3, 7, 52, 234; early days of 210; fragmentation or polarization of 249
- disability organizations 118
- Disability Partnership Finland 244; funding 248
- disability pension 164, 168, 260; decision 162, 167, 168; given up right to 164, 167
- disability pension system 159, 161; discontinuation 161; earnings in addition to 161; failure to listen 173; lack of self-determination opportunities 175; pension-employment decision 160; ‘pension trap’ 159; as rigid and complicated 167, 168, 173; study 169
- Disability Policy Programme VAMPO 144, 149, 150, 151
- disability rights 240; activists 241; advocates 242
- Disability Service Act 6, 7, 140, 141, 150–1, 260
- disability service study 143–54; documents included 144–6
- disability services: access to information 58, 188–9; age-related restriction 61; budget cuts 6, 49, 145; building of 6; definition 142, 150–1; development of 146; to enable inclusion and support independent living 139; individual and personalized 152; responsibility for 174; staff 188–9; as tools to enable inclusion 151; users of 49
- disability’s repressive history 204
- disability-targeted official development assistance (ODA) 245, 250
- disabled people: as heterogeneous group 210; inadequate representation of gender equality and diversity 249; internalised expectations of capabilities 168–9; political and societal positions study 202–5; self-representation 208–9; speaking as to a child 20
- Disabled People’s International 234, 235, 241
- disablism 261
- discrimination 30, 84, 111, 131, 227; normalized 226, 227, 228; positive discrimination 29, 142, 149, 151; at University 38
- Diskurssi* magazine 31
- distance learning 35, 44
- duty-bearers 239, 247, 249, 250
- dyslexia 36, 37
- education: basic (comprehensive) 83, 85; commitment to free 83; discrepancy between inclusion and excellence 93; discrimination in 111; equal access to 84; funding for 88; higher 28, 29, 31; inclusion in 83–4, 85–9; institutions’ attitudes to persons with disabilities 30; level of 28; performance gap 83–4; policy ambivalence 90–7; and poverty 30; secondary 85; segregated 86, 93–4; shift from special to general 87; tiered system 86, 87
- Emergency Powers Act 69
- emotional detachment 17, 18
- emotional isolation 16–17, 18, 19, 22
- employability 206
- employment: difficulties moving into 30; discrimination 30; rates of persons with and without disabilities 111, 159, 257; short periods of 164; types 5
- equal opportunities 142, 149; lack of 30
- equal recognition before the law 143
- equality: access to social services and housing 149–50; advisors 38; in education 29–30
- equity definition 85
- ethical considerations 164
- ethical values 118, 121, 210
- eugenics 217; discrimination 229; ideology 218, 219, 222, 259; and internalized oppression, impact of 226–8; laws 219
- European Accessibility Act (EAA) 204–5
- European Disability Forum (EDF) 240
- European Social Fund project 70
- European Union Statistics on Income and Living Conditions (EU-SILC) 28; database 158–9

- Eurostat surveys 12
 examination time extensions 34, 37
 exclusion 13, 84
 experimental ear surgeries 219
 experts by experience 206–7
- family support and lack of 57–8, 59,
 170, 172; separation from 17, 18
 fear of prejudice or discrimination 39, 186
 Federation of the Visually Impaired 28,
 159
 feminist care ethics 53
 feminist disability scholars 210
 fetal alcohol spectrum disorders (FASDs)
 121
 Figurenotes system 186
 financial burden feeling 172
 Finnfund 251
 fitness to work 168
 forced sterilizations of deaf people 217,
 218, 226
 Fraser, Nancy 200, 206; theory of
 injustices and disability 201–4
 freedom of movement 70
 friendships breaking down 20–1
 ‘from us to us’ principle 208, 209
- gap between policy and practice 43, 141
 Global Action on Disability (GLAD)
 Network 240, 245, 246, 249
 global disability movement 5, 200, 234,
 239
 Global Disability Summit 240, 245
 Global Partnership for Disability and
 Development (GPDD) 240, 242, 243,
 249, 250; case example 241; end of
 245, 250; membership 242
 Global South 242, 243, 245, 249
 government acknowledgement of human
 rights violations 229
 gratitude, pressure for 36
 ‘gray literature’ 146, 236
 group expectations 14
 group homes 7, 75; residents 80, 81;
 support workers 75
- Harakka, Timo 217, 218
 harassment 38, 111
 Health 2011 survey data 28
 hearing children of deaf adults (CODA)
 217, 218, 219
 help: barriers to 59; from children
 57–8; deserving of 56, 62; lack of
 knowledge 58; seeking and justifying
 58–60
 Heumann, Judy 241, 242, 243, 248
 higher education: challenges faced 31;
 completion 28, 29
 hobbies 179; lack of financial support
 184; lack of knowledgeable personnel
 or volunteers 184; outside the home
 180; requiring assistance 187;
 significant aspects of 189; study, of
 183; value of 189–92
 HOHTO project 102
 hospital experiences 17
 housing for persons with intellectual
 disabilities (KEHAS) 68–9, 70, 144,
 150
 Human Rights Council 240
 human rights defender 239
 Human Rights Office High
 Commissioner (OHCHR) 237
 human rights violations, government
 acknowledgement 229
 human rights-based approach to
 disability 239
- identity: collective 237; as ‘others’ 237
 impairment groups 209
 impairments: increased because of
 old age 50; unrecognized 201;
 progressing 57; visible and invisible
 35–6; *see also* disability
 inclusion 31; definition 85; in society
 143
 inclusion in education 83–4, 85–9;
 adequate resources 97; barriers to
 97–100; education policy ambivalence
 90–7; multifaceted nature of 84;
 negative climate towards 100;
 paradox 94; recommendations 101;
 to save money 259; schools’ freedom
 to interpret and include 95; support
 89, 100; teacher training 97; teachers’
 attitudes 96–7; UNESCO education
 report 101; vicious circle of ambiguity
 100
 ‘inclusive equality’ 142, 147, 153
 income, importance of 173
 independence: definition 53; fear
 of losing 61; personal 52, 53;
 professional understanding 53
 Independent Living (IL) movement 5,
 52–3, 143
 ‘independently dependent’ 52

- Individual Education Plan (IEP) 87
 inequality, regional 174
 injustices 218, 220; history of 217;
 questioning 227; against sign
 language users 217
 'inner stories' 15, 16
 'inspiration porn' 122, 207
 Institute for Health and Welfare 118,
 183
 institutional living, ending 7, 141, 144,
 147, 150, 153
 integrated workshops 161; activities
 165, 171–2
 interdependence 63
 internalized oppression 42, 216, 218,
 220–1, 226, 227; intergenerational
 221, 228, 229
 International Decade of Disabled People
 234
 International Disability Alliance 245
 International Disability Rights 243;
 literature 236
 interpretation services 141, 219
 invisibility of persons with disabilities
 32, 40

 job coaching 162, 163, 167, 168
 job history deemed as 'successful' 168
 journalism guide 131
 journalists, ethical obligation 112

 KEHAS housing 68–9, 70, 144, 150,
 151
 KELA social insurance 28, 42, 61, 167,
 219
 Könkkölä, Kalle 152, 193–4, 204, 236,
 241, 244, 248

 labour market, insufficient information
 170, 171
 lack of choice 169, 175
 language, passivating, medical 122, 124,
 129
 laws: of disability and old people,
 gap 260; on disability services,
 reformation 139, 149; eliminating
 reproductive rights 219; history 140;
 and implementation of 227; restrictive
 161
 League for Human Rights 217
Learning and Schooling Support 87, 89
 leisure activities 75, 77–8, 179,
 180, 181; organisation of 183;
 socio-economic status 181; *see also*
 hobbies
 Life of Disabled Persons in Finland
 15–16
 Literature Society (SKS) website 16
 living alone 13
 loneliness: causes of 13; located in
 childhood 17; longing for meaningful
 relationship 22; sense of difference 20;
 signs of 14; as social and emotional
 isolation 12, 14; solitude 14; as
 stigma 14; studies 13, 15–24
 loss of meaningful other 18

 mainstreaming 153
 marriage prohibition 258
 McRuer, Robert 31–2, 42; crip theory
 42
 'Me itse' job coaching 162, 163
 media: ability/power to normalize
 131; confrontations with 122–3,
 124; as influencers of attitudes 112;
 negative and changing attitudes 132;
 power structures 130; preferred
 123; recommendations 127, 128–9;
 representation of disability 113, 118,
 120, 124; trust in 112
 media study 117–31; questions for 120;
 results 121–31
 Millennium Development Goals
 (MDGs) 242
 Ministry of Education and Culture 89,
 90
 Ministry for Foreign Affairs (MFA) 235,
 239, 240, 262
 Ministry of Social Affairs and Health
 (MSH) 6, 70, 143–6, 205; guide 150;
 inclusion working group 152
 MMR vaccination controversy 130
 modalities of advocacy 238;
 confrontation-based 238, 239, 246,
 247; cooperation-based 239, 247;
 negotiation-based 238, 239, 246, 247;
 summary of 247
 model of narrative circulation (MNC)
 12, 15, 17
 mother tongue, prohibitions on the use
 of 218
 motives behind wanting to work 165–6,
 165; lack of 164
 Music Centre Resonaari in Helsinki 186
 Mwandha, James of Uganda 242, 243,
 248

- National Advisory Board on the Rights of Persons with Disabilities (VANE) 159
- National Core Curriculum (NCC) 91, 92, 101
- National Institute for Health and Welfare (THL) 60, 145, 146, 148
- neurodiversity 37
- neurological disabilities, students with 35
- 'nobody cares' 17–18
- Non-Discrimination Act (2014) 29–30, 111
- non-discrimination Ombudsman study 30
- non-governmental organisations (NGOs) 71
- Nordic Network of Disability Research 3, 4
- Nordic Welfare State Model 2, 3, 256
- normality: denaturalising 84; description 160; questioning the idea of 4
- normalization ideology 115
- 'nothing about us without us' 235, 248
- Occupational Safety and Health Act 111
- offensive behaviour 20
- Office of the High Commissioner for Human Rights (OHCHR) 237
- official development assistance (ODA) 245, 250
- older persons with disabilities study 54–61; participant information 54
- Older Persons' Services Act 50–1
- Oralism and eugenics 226
- Organisation for Economic Co-operation and Development (OECD) 1, 84
- organizations of persons with disabilities (OPDs) 235, 237, 244, 246, 249; cooperation with government in transnational advocacy networks 246
- 'othering' 171, 237
- Otus Foundation 32
- pain of separation 17
- Paralympic Committee 183, 184, 185
- parents: death of 18; disconnections from relationships 21; non-disabled 209
- peer support 39, 61
- 'pension trap' 159
- personal assistant (PA): entitlement to 7, 141; for leisure time 187, 188
- personal assistance services 205; ineligibility for 49–50; insufficient 30; users 13
- personal budgeting 7, 153; experiment for persons with disabilities 152
- persons with disabilities: attitudes towards 112; dealing with bureaucracy 42; employment rate 111, 159, 257; as experts by experience 122, 131; low expectations of 168; obstacles to employment 111; pacing 42; participating in sport 183; portrayed as heroes or victims 122; representing and discussing disability rights 248; service assessments 141; support to make themselves heard 154; views prioritized over experts' 125, 131
- persons with intellectual disabilities (ID) 7, 68; changes due to COVID 75; entering labour markets 159; exclusion and inclusion 71; and family members and support workers 71; in group homes 71; as 'incarcerated' 76; in institutions 7; as passive objects 112; study 162–75, 163; and supported housing 71
- persons with visual disabilities 28, 159
- physical activities opportunities research 182
- physiotherapy: aquatic and equine-assisted 189, 191; more than medical rehabilitation 191; medicalised outlook domination 192; obligatory 190–1; rehabilitative 189; sociability importance of 191, 192
- pity 122, 125, 207
- policy/practice gap 43, 230
- policy processes: disabled people excluded 202, 208, 211; injustice in 201–2; intentions 147; levels of impact 140; meaningful participation 208, 211
- political struggles 201, 203, 205
- politics: of recognition 201, 207; of redistribution 201; of representation 201, 202
- positive discrimination 29, 142, 149, 151
- poverty affecting education 30
- prejudice of society limiting opportunities 160
- privacy 164

- professional identity and pride 173
 program for arranging housing and related services (KEHAS) 68–9, 70, 144, 150, 151
 Programme for International Student Assessment (PISA) 83; studies 1
 prosthesis 20
 psychological strain and malaise 77–8

 RARE Media guide to journalism 131
 RARE X Diversity research project 112, 130, 131
 Rawlsian theories 201
 redistributive developments 205
 rehabilitation, medicalised goals of 189
 representation, ownership and ethics 208–210
 research: in disability activism 200; ethics in 148; priority over teaching 43; on reformed services 149; on residential care homes 6
 restrictions: on marriages 218; on movement 72–3; self-restriction 73
 right to learn 98, 101
 right to work 158
 rights implementation in everyday life 111
 rights and needs, tension between 153
 rights-holders 247, 248, 249, 250
 Roma people 217

 Salamanca Declaration 83, 91, 94, 101
 Samhall system 174
 Sámi people 217, 220; assemblies 225; truth and reconciliation process 225
 Sanna Marin program (2019) 152
 Scandinavian Journal of Disability Research 3
 schooling, compulsory 85, 86
 schools freedom to interpret and include 95
 ‘second class citizens’ 20, 220
 segregated placement 89
 self-determination 118, 120, 154, 160; lack of opportunities in work life 171; rights of 142, 152; within the pension system 166
 self-esteem, low 160, 221
 self-sufficiency 52
 sense of belonging 14
 sense of normalcy 171–3
 service systems: changes in politics 151; ignoring people 59; ‘jungle’ of 189, 193; lack of knowledge about 59; participation in planning 152–3; reform of 174; separate for disabilities and ageing 49
 Shakespeare, Tom 115, 116
 Sheppard, Emma 41–2
 sick leave 59
 sickness allowance 167–8
 sign language 34, 218; associated with shame and fear 226; banned 218; Finnish (FinSL) 219, 220; Finland-Swedish (FinSSL) 219, 220; interpreters 39; as mother tongue 220; network 217
 Sign Language Act 7, 227
 sign language community today 219, 220
 Signed Memories research project 215, 216, 221, 222; ethical issues 222; interviews and online surveys 221
 social and emotional relationships 18
 social and health service (SOTE) reform 7
 social connectedness 14
 social exclusion 20, 172
 social inclusion and equality, right to 145, 146
 Social Insurance Institute of Finland (KELA) 28, 42, 61, 167, 219
 social isolation 16–17, 19–21
 social media to break stereotypes 130
 social movements, old and new 201, 237, 238
 Social Science Data Archive (FSD) 12, 15, 16, 54
 Social Services Act reform 140
 social skills 35
 Social Welfare Act (2014) 49, 51, 145, 150
 social workers 206
 societal participation, importance of 173
 Special Care Act (1977) 7, 111, 140, 141
 special care districts 145, 151
 special education: funding 88; reform 86–8; services 85; socioeconomic influence 89
 special educational needs (SEN) 88, 91; children with 15, 16, 99; discourse 97–8; students 98; vague concept 98
 Special Education Strategy 86, 87
 special schools 93, 95
 sport: competitive 186; participation in 183

- sporting opportunities, lack of 185
 sports activity research 182–3
 sports associations 183, 184, 185
 Sports Empowers Disabled Youth' projects (SEDY and SEDY2) 185
 staring, 19, 20, 21, 22, 23
 stereotypes, challenging 130–1
 Sterilization Act (1935–1970) 219
 stigma 38
 students with disabilities 29, 31, 89:
 coping strategies 37–9; needs, physical and mental 36
 study psychologists/counsellors 38–9
 subsidized pay 170, 171
 substance experts 162, 163, 172
 Support Networks of Families with Special Needs Children 15, 16
 support, insufficient 142
 support system, tiered 90, 98
 supported housing 74, 75, 80–1
- teachers at University 36–7, 42
 teachers' attitudes to inclusion 96–7
 theory of injustices and disability 201–4
 Threshold Association, The 5–6, 16, 193, 209, 241
 'toxic waste' 59
 transnational advocacy networks 236, 240, 244, 245, 249; Government donors 244–6
 transportation services 51, 60–1; rights to 140; shortages 30, 188
 Traustadottir, Rannveig 3
 'truth and reconciliation process' 215, 216; apology process 217, 225; of children mistreated in foster care 217; 'collaboration model' 230, 231; of deaf people and sign language community 215, 216–19, 220, 230; indigenous people in Canada and South Africa 224; interviews, focused on compensation, restitution and apology 223, 224; lack of knowledge 223, 224, 225; perceptions and expectations of 223–8; as way towards social change 228–31
 Työkanava Oy (Work Channel Ltd) 174
- UN Convention on the Rights of Persons with Disabilities (UNCRPD or CRPD) 6, 29, 139, 166, 179, 234, 239; definition of 'inclusive equality' 142, 147; implementation of 30; language of 99; ratification of 7, 143, 158
 UN Convention on the Rights of the Child (1989) 235
 UN Declaration on the Rights of Mentally Retarded Persons 234
 UN Development Programme (UNDP) 245
 UN International Year of Disabled Persons (1981) 234
 UN Partnership on the Rights of Persons with Disabilities (UNPRPD) 240, 245
 UNESCO education report 101
 universal and structural solutions 149
 University of Helsinki 29, 31;
 accessibility 31, 35; accommodation measures 36; barriers 43; and COVID-19 pandemic 44; crimp experiences 42; culture of 41; disability experiences 31, 33, 34; discrimination 38; discussing experiences 41–3; equality in 31; feeling alone 40, 41, 43; harassment 38; hybrid teaching 44; ignorance of rights 43; lack of information 40; limited support 41; mental health arrangements 38; needs not met 40; peer support 39; policy/practice gap 42; student activities 35; student organizations not inclusive 35; student stress 40; students' presence required 37, 44; study 32–44; teachers 36–7, 42
 unwanted social attention 22
- Valteri schools 90
 Valtti programme 185
 VETURI project 89
 vicious circles: of ambiguity of inclusion in education 100; in disability pension system 160, 170, 172; of internalized oppression 42, 216, 218, 220–1, 226, 227
 video calls 79
 violence suffered 30
 VIP network 90, 102
 vocational rehabilitation 28
 vocational schooling, segregation 98–9
- welfare cuts 61, 62
 Welfare State reforms 5
 willingness to work 166, 170; motives behind 164, 165–6, 165

women with disabilities 259
words used for persons with disabilities
122, 124, 126
work capacity, partial 168, 174
work created a sense of belonging 171
work experience 165
World Bank Conference on Inclusive
Development 242

World Happiness Report 1, 12, 179,
194
World Health Organization 234;
International Classification of
Functioning, Disability and Health
(ICF) 114
Zoom 35, 221



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