



Elisabeth Hästbacka

Equal participation in society?

Perspectives on the opportunities of persons
with disabilities in Finland



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in Finland

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Abstract

Societal participation for persons with disabilities is central for disability policies globally, and in a Finnish setting, and it is firmly anchored in the welfare state's commitment to create equal opportunities through for example disability services. In addition, it is dependent on other prerequisites, such as accessibility and an inclusive labour market. However, the welfare state's commitments have become increasingly important through efforts of strengthening the rights of persons with disabilities and they are often dependent on political decisions (that should be) based on knowledge and research. Furthermore, professionals, such as social workers within municipal disability services, implement the political decisions by providing services and support for persons with disabilities. On the grassroot level, disabled persons' opportunities to societal participation are often dependent of the service and support available. In addition, the lack of different barriers, such as prejudices, and the availability of different facilitators like accessibility, are equally crucial.

The aim of this doctoral thesis is to study how the opportunities for participation in society are constructed in relation to persons with disabilities in Finland, and how this can be understood and problematized from a theoretical standpoint of equality. In order to distinguish which barriers and facilitators affect it, and to see how it can be enhanced, this thesis includes four perspectives: the research field's perspective, the political perspective, the professional perspective, and disabled persons' personal perspective. The empirical part is based on the qualitative content analysis of studies from a scoping review, a parliamentary debate as well as interviews with both social workers and persons with disabilities. The findings show a strong emphasis on equality and self-determination as well as on disabled persons' labour market participation and participation in decision-making. Furthermore, facilitators, barriers, and suggested actions for enhancing societal participation were all interrelated. Negative attitudes and inaccessibility were for example often highlighted as barriers, whereas disability rights and services were seen as important facilitators. In order to enhance the societal participation of persons with disabilities the disability service system was regarded as in need of increased flexibility and resources. Increased accessibility, inclusive attitudes and improved employment opportunities were also called for. For reaching equal opportunities to societal participation, many actions are still needed in society, and these are also required by the UN Convention on the Rights of Persons with Disabilities, which Finland has committed to.

Abstrakt

Delaktighet i samhället för personer med funktionsvariationer är en central del av funktionshinderpolitiken, såväl globalt som i Finland och det är starkt förankrat till välfärdsstatens åtagande att skapa jämlika möjligheter genom till exempel funktionshinderservice. Även andra faktorer, såsom tillgänglighet och en inkluderande arbetsmarknad är avgörande. Välfärdsstatens åtaganden har blivit allt viktigare genom eftersträvanden att stärka funktionshindrade personers jämlikhet och rättigheter och de föregås ofta av politiska beslut (som borde vara) baserade på kunskap och forskning. Sedan är det professionella, såsom socialarbetare inom kommunernas funktionshinderservice som implementerar de politiska besluten genom att bevilja service och stöd för personer med funktionsvariationer. På gräsrotsnivån är funktionshindrade personers möjligheter till delaktighet i samhället ofta beroende av tillgången till service och stöd. Därtill är frihet från hinder, såsom fördomar, samt olika möjliggörande faktorer, såsom tillgänglighet av avgörande betydelse.

Syftet med denna doktorsavhandling är att studera hur möjligheter till delaktighet i samhället konstrueras för personer med funktionsvariationer i Finland, samt hur de kan förstås och problematiseras i relation till en teoretisk utgångspunkt av jämlikhet. För att urskilja vilka hinder och möjliggörande faktorer som påverkar delaktigheten, och hur den kan främjas, omfattar avhandlingen fyra perspektiv: forskningsfältets, politikens, de professionellas och funktionshindrade personers eget perspektiv. Den empiriska delen baserar sig på kvalitativ innehållsanalys av studier ur en litteraturöversikt, en riksdagsdebatt, samt intervjuer med både socialarbetare och personer med funktionsvariationer. Resultaten visar en stark betoning av jämlikhet och självbestämmande, samt funktionshindrade personers deltagande i arbetsmarknaden och beslutsfattande. Därtill framgår en sammankoppling mellan olika möjliggörande faktorer, hinder och föreslagna sätt att främja delaktighet i samhället. Negativa attityder och otillgänglighet framhölls till exempel ofta som hinder, medan funktionshindrade personers rättigheter och service sågs som viktiga möjliggörande faktorer. I syfte att främja funktionshindrade personers delaktighet i samhället ansågs funktionshinderservicesystemet behöva mer flexibilitet och resurser. Därtill efterlystes ökad tillgänglighet, inkluderande attityder och bättre sysselsättningsmöjligheter. För att jämlika möjligheter till delaktighet ska nås, behövs ännu många åtgärder i samhället, vilket också förutsätts i FN:s konvention om rättigheter för personer med funktionsnedsättning, som Finland förbundit sig till.

Tiivistelmä

Vammaisten osallisuus yhteiskunnassa on vamma politiikan keskiössä sekä maailmanlaajuisesti, että Suomessa ja se kytkeytyy tiiviisti hyvinvointivaltion sitoumukseen luoda yhdenvertaisia mahdollisuuksia esim. vammais palvelujen avulla. Lisäksi osallisuus on riippuvaista myös muista edellytyksistä, kuten esteettömyydestä ja saavutettavuudesta, sekä osallistavista työmarkkinoista. Pyrkimykset vahvistaa vammaisten henkilöiden yhdenvertaisuutta ja oikeuksia ovat tehneet hyvinvointivaltion sitoumuksista yhä tärkeämpiä, ja ne ovat usein riippuvaisia poliittisista päätöksistä, jotka perustuvat (tai joiden tulisi perustua) tietoon ja tutkimukseen. Ammattilaiset, kuten kuntien vammais palvelujen sosiaalityöntekijät puolestaan toimeenpanevat näitä poliittisia päätöksiä myöntämällä palveluja ja tukea vammaisille henkilöille. Ruohonjuuritasolla vammaisten henkilöiden mahdollisuudet olla osallisina yhteiskunnassa ovat usein riippuvaisia palvelujen ja tukien saatavuudesta. Lisäksi vapaus erilaisista esteistä, kuten ennakkoluuloista, sekä erilaiset mahdollistavat tekijät, kuten esteettömyys, ovat myös yhtä lailla olennaisia.

Tämän väitöskirjan tarkoituksena on tutkia, millaisina mahdollisuudet osallistua yhteiskuntaan näyttäytyvät vammaisille henkilöille Suomessa ja miten ne voidaan ymmärtää ja problematisoida yhdenvertaisuuden teoreettisesta lähtökohdasta. Erilaisten esteiden ja mahdollistavien tekijöiden vaikutusten selvittämiseksi, sekä sen, miten osallisuutta voidaan edistää, tämä väitöskirja sisältää neljä näkökulmaa: tutkimuskentän, poliittisen, professionaalisen ja vammaisten henkilöiden oman näkökulman. Empiirinen osa perustuu laadulliseen sisällönanalyysiin kirjallisuuskatsauksessa valituista artikkeleista, eduskunnan lähetekeskustelusta, sekä sosiaalityöntekijöiden ja vammaisten henkilöiden haastatteluista. Tuloksissa korostuivat voimakkaasti yhdenvertaisuus ja itsemääräämisoikeus, sekä vammaisten henkilöiden osallistuminen työmarkkinoille ja päätöksentekoon. Lisäksi esteet, mahdollistavat tekijät ja ehdotetut toimet yhteiskunnallisen osallisuuden edistämiseksi olivat yhteydessä toisiinsa. Kielteisiä asenteita ja ympäristön esteellisyyttä korostettiin esimerkiksi usein esteinä, kun taas oikeuksia ja palveluja pidettiin tärkeinä mahdollistajina. Yhteiskunnallisen osallisuuden edistämiseksi vammais palvelujärjestelmään kaivattiin lisää joustavuutta ja resursseja. Lisäksi peräänkuulutettiin laajempaa esteettömyyttä, osallistavia asennetta ja parempia työmahdollisuuksia. Yhdenvertaisten osallistumismahdollisuuksien saavuttamiseksi tarvitaan edelleen monia

muutoksia yhteiskunnassa, ja näitä edellyttää myös YK:n yleissopimus vammaisten henkilöiden oikeuksista, johon Suomi on sitoutunut.

List of articles

Article 1.

Hästbacka, E., Nygård, M. & Nyqvist, F. (2016). Barriers and facilitators to societal participation of people with disabilities: A scoping review of studies concerning European countries. *ALTER - European Journal of Disability Research* 10 (3) 201–220

Article 2.

Hästbacka, E. & Nygård, M. (2013). Disability and citizenship. Politicians' views on disabled persons' citizenship in Finland. *Scandinavian Journal of Disability Research*, 15 (2), 125–142

Article 3.

Hästbacka, E. (2014). Samma lagstiftning – varierande praxis? Socialarbetares syn på funktionshindrades delaktighet i Österbotten, *Janus* 22 (2) 138–155

Article 4.

Hästbacka, E. & Nygård, M. (2019). Creating capabilities for societal participation in times of a welfare state in change? Experiences of people with disabilities in Finland, *ALTER - European Journal of Disability Research* 13, (1), 15–28

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1. Introduction

1.1 Background

Participation in society is considered important for everyone. On the one hand, most people want to take actively part in different areas of life, and on the other hand, they are expected to participate and contribute to society. The opportunities to participate are however, not the same for everyone, since different circumstances might make it harder for some groups of people. Persons with disabilities constitute such a group. They face many different challenges, not only related to their impairment, but more often due to the fact that society is not being inclusive enough in terms of both design and attitudes (e.g. Vehmas 2005). Therefore, this doctoral thesis discusses and problematizes societal participation of persons with disabilities as a way of understanding what this conveys in practice, and sheds light on it from different perspectives within a Finnish context. Despite acknowledging the tension within disability studies between the concepts ‘persons with disabilities’ (emphasising ‘people first’) and ‘disabled persons’ (emphasising society’s oppression of said group) (e.g. Kiuppis, 2018), these concepts are for reader friendliness used as synonyms in this thesis. Societal participation is used here broadly as a concept referring to the capacity to participate in different and crucial areas of society and different areas of life, such as the labour market or leisure activities (e.g. van Wel & Landsheer, 2012). Different perspectives on disability and the concept of societal participation will be further presented in chapters 2 and 3, respectively.

Disabled persons’ formal rights to societal participation might not be enough if the practical opportunities are lacking or being insufficient. These opportunities are conditioned by many factors, both barriers such as discrimination or different forms of inaccessibility, and facilitators that enable and enhance societal participation, such as positive attitudes or different forms of disability services. The presence or absence of these factors, as well as the way the society is designed and works, is to a great extent dependent on political decisions as well as on resources available. The equal right to participation is one of the fundamental principles of disability policies both in Finland and on an international level. The United Nations Convention on the Rights of Persons with Disabilities (hereafter UN CRPD), for example, emphasises the “[f]ull and effective participation and inclusion in society” (United Nations, 2006). The right to participation for persons with disabilities

is also one of the main principles of the Finnish disability policy, alongside the right to equality and necessary service and support (e.g. Ministry of Social Affairs and Health, 2010).

In addition to political aims and legislated rights, disabled persons' opportunities to participate in society and different areas of life are dependent on the resources available, the institutional structures and the implementation of legislation. Therefore, for example the increased austerity policies following the financial crisis in 2008-2009 and the continued efforts to reform the health and social services in Finland might directly or indirectly affect disabled persons' opportunities to participate equally in society. In chapter 4 a broader contextual background is given regarding the disability policies, as well as the situation of and the service and support to persons with disabilities in Finland.

As mentioned above, disabled persons' opportunities to participate equally in society are dependent on political decisions. Ideally, these decisions are based on and supported by research findings. The international field of research has therefore an important role as a foundation for disability policies and decisions concerning disabled persons' societal participation. Political decisions, in turn, set the rules and determine the resources for professionals, such as social workers, who are responsible for providing services that enable and support the societal participation of persons with disabilities on a local level. Yet, given that every nation sets up certain political aims, legislation and disability service provisions, disabled persons' real-life experiences of societal participation are still influenced by many different and sometimes contingent factors. Using Finland as an example, regardless of the existence of nationally legislated disability rights, we can observe that there are differences between regions and municipalities regarding the access to services for persons with disabilities (e.g. Hoffrén, 2017; Ministry of Social Affairs and Health, 2018a; Nurmi-Koikkalainen, Hintsala & Voutilainen, 2020; Rätty, 2010). This is mainly due to the varying resources of municipalities responsible for the service provision. Furthermore, despite legislation against discrimination, many persons with disabilities find it difficult to access the labour market due to for example prejudicing attitudes among employers (Finnish Disability Forum, 2019b; Hoffrén, 2017; Kyröläinen, 2020; Non-Discrimination Ombudsman, 2016). Therefore, it is crucial for persons with disabilities to get their own voice heard too, especially in matters concerning their daily lives.

1.2 Previous research

In addition to have become a fundamental part of disability policies, there is an increased research interest regarding questions concerning the societal participation of persons with disabilities, even though there is no clear consensus of the meaning of the concept. The term participation is in itself complex, since it is closely related to and has common elements with partially similar concepts such as inclusion and involvement (e.g. Isola et al. 2017). Societal participation can also be seen as an opposite to marginalisation (Raivio and Karjalainen, 2013). The research about the societal participation of persons with disabilities has, especially within disability studies and social sciences, so far often focused on some specific area of participation in society and/or some specific group of persons with disabilities. In addition, there is some research about how the societal participation of persons with disabilities is related to for example subjective well-being (e.g. van Campen & Iedema, 2007) or to the use of disability services, such as personal assistance (e.g. von Granitz, Sonnander, Reine & Winblad, 2021), or housing with special services (e.g. Svanelöv, 2020).

Regarding different areas of participation in society, there has been a much research focusing on for example disabled persons' participation in education, labour-market and/or entrepreneurship (e.g. Achterberg, Wind, de Boer, & Frings-Dresen, 2009; Ballo, 2019; Langørgen & Magnus, 2018; Maritz & Laferriere, 2016; Solstad Vedeler & Mossige, 2010; Trezzini, Schuller, Schüpbach & Bickenbach, 2021; Östlund & Johansson, 2018). Another much-studied area of societal participation has been disabled persons' political participation and active engagement in decision-making (e.g. Kjellberg & Hemmingsson, 2013; Schur & Adya, 2013; Sépulchre, 2018, 2019). Disabled persons' participation regarding other areas has been studied too, for example their inclusion and participation in sports activities (e.g. Ballas, Buultjens, Murphy & Jackson, 2020; Darcy & Dowse, 2013; Kiuppis, 2018; Svanelöv, Wallén, Enarsson & Stier, 2020). Furthermore, there have been studies focusing on their participation in terms of information and communication technology, and web accessibility (e.g. Ferri & Favalli, 2018), as well as access to public spaces, such as shopping malls (e.g. Swaine, et al. 2014).

Instead of (and in addition to) focusing on some area of participation, some of the research has focused only on a limited group of persons with disabilities, for example in terms of their age or life situation, such as students with disabilities in higher education (e.g. Langørgen & Magnus, 2018). Some studies

have also focused on persons with some specific form of disability, such as intellectual/learning disabilities (e.g. Arvidsson, Granlund, & Thyberg, 2008; Darcy & Dowse, 2013; García Iriarte et al. 2014; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009a, b), rare disabilities (e.g. Jaeger, Røjvik, & Berglund, 2015) or some very specific form of disability (eg. Sverker, Thyberg, Valtersson, Björk, Hjalmarsson & Östlund, 2019).

In terms of internationally published articles, the specific research on disabled persons' societal participation in a Finnish context is rather scarce and tends to focus either on participation in some specific area and/or on persons with some specific disability (e.g. Hermanoff, Määttä & Uusiautti, 2017; Järvikoski, Puumalainen & Härkäpää, 2015; Raisio, Valkama & Peltola, 2014). In addition, there are a few recent doctoral theses shedding light on the participation of persons with disabilities. One of them is Rasa's (2019) doctoral thesis focusing on participation in terms of family life and parenthood of persons with physical disabilities. In her doctoral thesis, Lindqvist (2014), in turn, focuses on the participation of persons with learning disabilities in relation to citizenship and especially in the context of housing. The focus of Kivistö's (2014) doctoral thesis is the participation of severely disabled persons especially in relation to the disability services in Finland. During the last couple of years, there has also been a national project, called the VamO-project, for researching and developing the client participation of persons with disabilities in relation to disability services in Finland (eg. Heini, Hokkanen, Kontu, Kunttu, Lindroos & Ronimus 2019). Based on this, we can conclude that there is a need for more research that uses a broader approach in terms of disability while simultaneously focusing on Finland (this is discussed more in detail in the paragraphs on contribution in the next subchapter).

1.3 Aim, research questions and contribution

The overall *aim* of this doctoral thesis is to study how the opportunities for participation in society are constructed in relation to persons with disabilities in Finland, and how this can be understood and problematized from a theoretical standpoint of equality. Thereby this thesis also aims to contribute to the scientific discussion about the current state, challenges, and future of disability policies. This is done by studying the meaning and fulfilment of disabled persons' opportunities to societal participation from four different perspectives in order to get an overview and to distinguish which barriers and facilitators affect it. The four perspectives included are the research field's

perspective, the political perspective, the professional perspective, and disabled persons' personal perspective. These perspectives can also be seen to provide viewpoints from two different levels where the interview studies with the professionals and with the persons with disabilities represent the grass root level and the studies from the research field's perspective and the political perspective can be seen as more representing the societal level. This combination of different perspectives and levels can then in turn provide indications of how disabled persons' equal participation in society can be enhanced.

The overall aim can be divided into three more specific *research questions*. In relation to both the theoretical background of this thesis and the empirical findings from each of the four studies, the first question asks:

1. How is societal participation of persons with disabilities portrayed and problematized in terms of theories of equality?

This relates to different perspectives on disability and to the question whether persons with disabilities are seen as equal members of society. If they are, what are the underlying premises for the equality and the goals when it comes to the societal participation of persons with disabilities? Are the motives related to the benefit of persons with disabilities and their human rights or to the benefit of the society for example in terms of pushing persons with disabilities into the labour market?

The second research question is:

2. What are the main barriers and facilitators regarding societal participation for persons with disabilities, and how can societal participation be enhanced?

Thirdly, the societal participation of persons with disabilities takes place in a context and it is affected by prevailing values and political ideologies, aims and interests. Therefore, the third research question asks:

3. How can findings from the grass root level regarding the societal participation of persons with disabilities be understood in relation to the findings from the societal level as well as in relation to the ongoing changes in the Finnish society, and in relation the UN CRPD?

Regarding this research question, the differences and similarities between the grass root level and the societal level are scrutinised. This question relates also to the effects of the political and ideological shifts that tend to downplay the role of the state as the provider of welfare services in favour for other (private) alternatives. Furthermore, it relates to how the ongoing changes in

the society, such as the current ambitions to reform the health and social services in Finland, is likely to affect the societal participation of persons with disabilities. Last, but not least, what is the role of the human rights declared in the UN CRPD, which Finland recently has ratified?

This thesis *contributes* to the scientific understanding of the societal participation of persons with disabilities since it provides an overview by combining four perspectives. Previously, as mentioned, the research has mostly focused on participation regarding some specific area of life, and/or on persons with some specific disability. This thesis contributes for its part to filling the gap regarding research with a broader perspective on the societal participation of persons with disabilities. Furthermore, this kind of research from a Finnish perspective has been rather scarce, so the thesis will contribute to the knowledge about the current state and challenges for disability policies and provide guidance for the future as well. Since many of the barriers and facilitators, influencing disabled persons' societal participation, are not nation-specific, but more of a universal character, this increased scientific understanding can also contribute to the enhancement of equal opportunities to societal participation for persons with disabilities, not only in Finland, but also in an international context.

The UN CRPD is crucial in defending disabled persons' equal rights to societal participation. Finland signed the UN CRPD in 2007 and ratified it in 2016. Safeguarding equal opportunities to societal participation for persons with disabilities is especially essential in times of structural changes, such as the ongoing reform of the Finnish social and healthcare system, as well as with an ongoing process of revising the Finnish disability legislation (e.g. Ministry for Foreign Affairs, 2019; Ministry of Social Affairs and Health, 2015; National Institute for Health and Welfare, 2021a). Furthermore, an increased trend of austerity policies challenges the welfare state both in Finland as well as in many other countries. As in many other Western European countries, also the ageing population increases the needs of accessibility and disability services and diminishes the number of persons in the labour market. On the other hand, this might support seeing persons with disabilities as a resource and as being able to contribute to society if, and when, they are enabled to participate.

1.4 The articles included

This thesis includes four published and peer-reviewed articles, one for each of the four earlier mentioned perspectives on the societal participation of persons

with disabilities: the research field's perspective, the political perspective, the professional perspective, and disabled persons' personal perspective. The first article provides the international research field's perspective through a scoping review of recent studies about the societal participation of persons with disabilities. The second article studies disabled persons' participation in society from the political perspective through a content analysis of a Finnish parliamentary debate. As to clarify, the focus of the political perspective in this thesis is on politicians' views on the societal participation of persons with disabilities, not on disabled persons' political participation (other than it being a part of societal participation in a broad sense). The third article provides the professional perspective through an interview study among social workers, whereas the fourth article provides the disabled persons' own perspective through an interview study among persons with disabilities. The articles are listed in table 1.

Table 1 Presentation of the four articles.

Article 1. Research field's perspective	Hästbacka, E., Nygård, M. & Nyqvist, F. (2016). Barriers and facilitators to societal participation of people with disabilities: A scoping review of studies concerning European countries. <i>ALTER - European Journal of Disability Research</i> 10 (3) 201–220
Article 2. Political perspective	Hästbacka, E. & Nygård, M. (2013). Disability and citizenship. Politicians' views on disabled persons' citizenship in Finland. <i>Scandinavian Journal of Disability Research</i> , 15 (2), 125–142
Article 3. Professional perspective	Hästbacka, E. (2014). Samma lagstiftning – varierande praxis? Socialarbetares syn på funktionshindrades delaktighet i Österbotten, <i>Janus</i> 22 (2) 138–155
Article 4. Disabled persons' perspective	Hästbacka, E. & Nygård, M. (2019). Creating capabilities for societal participation in times of a welfare state in change? Experiences of people with disabilities in Finland, <i>ALTER - European Journal of Disability Research</i> 13, (1), 15–28

As mentioned earlier, all the perspectives in the four articles are interrelated and dependent of each other. Research can (or should) be the foundation to political decisions, whereas these often set the frames for the professionals such as social workers in the disability services. Furthermore, the professionals, in this case the social workers, can be seen as the gatekeepers for the provision of different forms of disability services, which are crucial for enabling persons with disabilities to participate equally in society (e.g. Raunio, 2004). Therefore, this thesis provides an overview of the societal participation

of persons with disabilities by binding these four perspectives together as illustrated in Figure 1. The purpose of the figure is however to provide a somewhat simplified analytical and visual tool for understanding the research setting and the order of the articles included. The reality is, however, more complex regarding for example interdependence and dialog existing between all the four perspectives, and even in relation to other perspectives not included here.

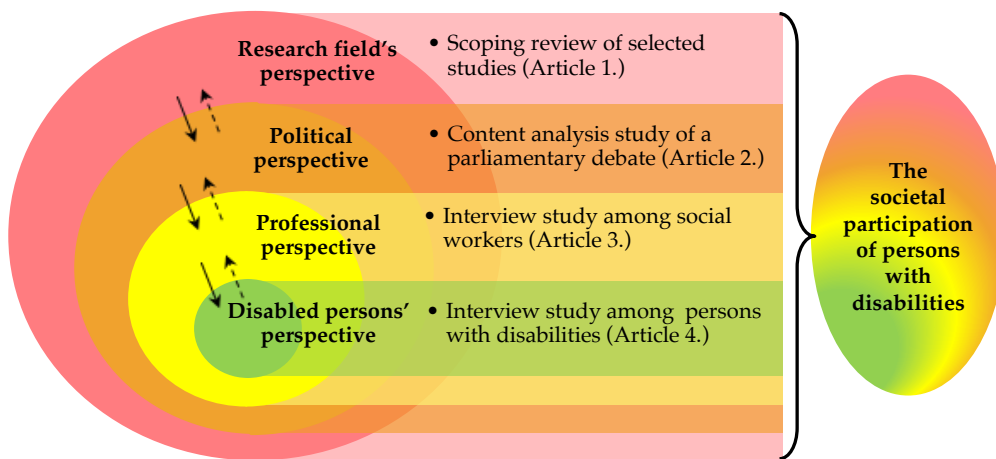


Figure 1 Illustration of how the four perspectives on societal participation of persons with disabilities and the four articles included in the thesis are related to each other.

1.5 Structure of the thesis

This thesis is structured as follows. The next chapter (with the subchapters 2.1–2.4) gives first a brief historical perspective on disability and thereafter presents different models of or perspectives on the concept of disability. The following third chapter (with subchapters 3.1–3.4) provides a theoretical frame for the thesis by viewing societal participation through the lens of the capability approach, and as a not only a narrower concept of participation, but also as closely linked to the concepts of equality and citizenship. The fourth chapter (with subchapters 4.1–4.4) provides a contextual frame for the Finnish disability policies, as well as a shedding some light on the living circumstances of persons with disabilities in Finland. The fifth chapter (with subchapters 5.1–5.3) begins with a description of the articles’ authors’ contributions. This is followed by a summary of the methodology including the data collection processes, the different data sources and the analytic methods used in the four

articles, i.e. qualitative content analysis. Data was collected through interviews, through downloading a transcription of a Finnish parliamentary debate and selecting scientific articles through a scoping review. The fifth chapter ends with a discussion about reliability, validity, and the thesis author's role as a researcher. The main findings from the four different perspectives on the societal participation of persons with disabilities are presented and discussed in the sixth chapter. The last chapter of the thesis (with subchapters 7.1–7.3) provides concluding remarks alongside a discussion about the interpretation of the findings, limitations, and some suggestions for future research. The original versions of the four articles are to be found in the end of the thesis.

2. Perspectives on disability

Disability is a complex and constantly evolving concept since the meaning of it has changed over time due to changes in the perspectives on disability and persons with disabilities (e.g. Calais von Stokkom & Kebbon, 2000; Mitra, 2006; Nurmi-Koikkalainen et al. 2017; WHO, 2011). The perspective depends on whether it is being defined by focusing on the individual with an impairment, on the surrounding (and possibly excluding) society, or a combination of these. The definition of who is seen as disabled and thereby entitled to some specific disability rights, services, or benefits, varies depending on the service or benefit in question (e.g. Lindqvist, 2009). In addition to, and due to, the lack of a clear-cut and commonly shared definition of disability, it is difficult to count the number of persons with disabilities (e.g. Mitra, 2006; Savtschenko, Suikkanen & Linnakangas, 2010).

The following subchapters illustrate the change and development of different perspectives on the concept of disability. Even though the focus of the thesis is not on a historical perspective, the next subchapter will highlight some glimpses from the history regarding the situation of and views on persons with disabilities as a background for the more recent and current perspectives.

2.1 A brief historical review on disability

From a historical perspective, and despite the diversity regarding this phenomenon, the concept of disability has often been related to meanings of individual tragedy or some kind of a punishment for the individual and the family, but sometimes even for the whole community (e.g. Vehmas, 2005). Persons with disabilities have been largely in a marginalised position, hidden away, struggling under stigmatisation and discrimination often leading to oppression, exclusion and poverty (e.g. Hughes, 1998, Vehmas, 2005). Persons with disabilities have often been among the poorest in society and have been seen as a burden due to their limited opportunities to work and earn their own living. To survive, most of them have been dependent of the support from their families, the church and charities (e.g. Hughes, 1998, Vehmas, 2005).

Persons with disabilities have also often been exposed to cruelty and violence. For example, during the period of classical antiquity, babies born with disabilities were often killed, especially in Sparta (Vehmas, 2005). Through the emergence of Christianity, and notably Jesus' emphasis of everyone's equal value, the love towards one's neighbour, as well as the empathy for the poor,

sick and less fortunate in society, changed the view on persons with disabilities into a more merciful and charitable one (Vehmas, 2005). However, in the Middle Ages, persons with disabilities were still sometimes accused of witchcraft and exposed to various attempts to “cure” them. This occurred even though they mostly were living with their families and participating in work according to their abilities. If they for some reason did not have the support from their family, they became objects of charity like any other group among the poor ones in society. Lindqvist (2009) points out, though, that within the heterogenic group of poor people, disabled persons have often been seen as more “deserving poor” than some others, i.e., being more entitled to get support from the society.

Instead of theological and superstitious views on disability that had become more common during the Middle Ages, Vehmas (2005) points out that The Age of Enlightenment brought a more medicalised perspective on disability. This led to various attempts to explain and categorise persons with different kinds of disabilities, and this was especially the case with persons having learning disabilities. In addition, the process of industrialisation changed and intensified the labour market, which in combination with the increased urbanisation made families less able to care for their disabled family members. Therefore, the medical perspective led to the establishment of institutions where persons with disabilities lived separated from the rest of the society. Furthermore, with the medical perspective’s emphasis on rehabilitation, some of the first schools for persons with specific disabilities were established in Finland in the end of the 19th century, for example for the blind or deaf persons. These were often boarding schools, separated from regular education system. Furthermore, Vehmas (2005) points out that on an international level, the medical perspective also led to seeing disability as a eugenic threat in the late 19th century and during the first half of the 20th century. Consequently, persons with disabilities were in many countries denied the right to marry and were even forced to sterilisation. Some of the most brutal cruelties took place during World War II, when approximately 200 000 –275 000 persons with disabilities were killed in the name of eugenics (Vehmas, 2005).

2.2 The individual/medical model of disability

As mentioned above, the roots of the medical model of disability can be found in the historical views on disability (e.g. Hughes, 1998; Vehmas, 2005). Since the medical model is based on a bio-physiological definition of what is ‘normal’,

it sees disability as an individual problem or tragedy. Furthermore, it focuses on what is 'wrong' with the individual, i.e., on the specific impairment as explaining and causing the disability (e.g. Hughes, 1998; Lindqvist, 2009; Oliver, 2004; Vehmas, 2005). This paradigm can be seen normative since persons with disabilities are dictated a so called 'sick role' and seen as not able to function as a 'normal' persons (Lindqvist, 2009; Vehmas, 2005). Therefore, the possible interventions focus on the individual in terms of medical ways to 'cure' and/or 'normalise' the person with the impairment for example through rehabilitation, which the individual is expected to comply with. The medicalisation of disability has therefore put medical and care professionals in a very powerful position on the expense of the voice of persons with disabilities themselves. Even nowadays this is often the case since a diagnosis and/or a medical certificate is needed for being entitled to many forms of disability benefits and services (Lindqvist, 2009; Nurmi-Koikkalainen et al. 2017; Vehmas, 2005).

The medical model does not highlight the various barriers persons with disabilities face in society. On a societal level, the priority is therefore primarily to provide access to healthcare and rehabilitation services (e.g. Lindqvist, 2009; Mitra 2006). Nor does the medical model acknowledge the expertise of persons with disabilities regarding their own lives (Nurmi-Koikkalainen et al. 2017). Since the medical model considers disability primarily as an individual problem, it can cause a lot of shame and stigma for those affected, resulting in persons with disabilities being hidden away and being marginalised in society. Instead of being active members in society, the medical model destines them to be passive receivers and dependent of charity (e.g. Hughes, 1998; Oliver, 2004).

Since the last decades of the 20th century, the previously dominating medical model of disability has been increasingly criticised for the idealisation of an able-bodied person as the 'normal' and for the attempts to 'normalise' persons with impairments through medical interventions and rehabilitation (e.g. Barnes & Mercer, 2004; Hughes, 1998). It is also seen as one of the main reasons as to why persons with disabilities become discriminated, oppressed, and excluded in society. The critic towards the medical model, often advocated by disability movements and organisations, has therefore led to a paradigm shift and a new perspective: the social model of disability (e.g. Barnes & Mercer, 2004; Mitra 2006).

2.3 The social construction and social model of disability

Disability can be seen as socially constructed and thereby dependent of beliefs and values in a certain time and context (Lindqvist, 2009; Vehmas, 2005). Vehmas (2005) points out that language shapes the social construction of disability and how it is defined (often in negative terms primarily by others, not by disabled persons themselves). In addition, the way in which disability is socially constructed and defined can also affect, for example, the design of the physical environment in terms of (in)accessibility. According to Lindqvist (2009), the social construction of disability is linked to stigma on an individual level. Consequently, the expectations on persons with disabilities tend to be low on a societal level. This can in turn, have a negative effect on the disabled person's self-esteem on the one hand, and have a hampering effect on society on the other hand, for example in terms of prejudices against persons with disabilities on the labour-market (Watson, 2004).

On an individual level, the disabled person can however strive at changing the perceptions of disability through, what Lindqvist (2009) calls, (re)negotiation together with, for example, different (healthcare) experts. On a societal level, the social construction of disability is linked to discipline, which means that society has tried to normalise, but at the same time also to control and make persons with disabilities obedient, for example in the form of hard-working, taxpaying citizens (Lindqvist, 2009). Furthermore, the social construction of disability is linked to the social construction of gender. According to Lindqvist (2009), gender differences exist on a practical level, for example in terms of disabled men having better access to services and rehabilitation supporting an active life, and in terms of disabled women's hesitation to claim disability services due to an experienced need to prove themselves as capable of motherhood.

In contrast to the view of the medical model, the social model does not see disability as primarily an individual attribute (e.g. Oliver, 2004). The model distinguishes the individual (medical) *impairment* (i.e., for example the lack of a limb) from *disability*, where the latter refers to the collective experience of different systematic and institutionalised barriers in society resulting in some persons to be disabled (e.g. Lindqvist, 2009; Vehmas, 2005). The focus of the social model is on these environmental and institutional factors that make some persons disabled and hinder equal participation in society (e.g. Hughes, 1998; Lindqvist, 2009; Mitra 2006; Oliver, 2004; Vehmas, 2005). These factors are also related to each other. For instance, Oliver (2004) argues that the

problem of unemployment among disabled persons is related to factors such as transport and education. In other words, a society that is designed solely from a perspective dominated by 'normal' able-bodied persons' perspectives, easily fails to provide appropriate services and meet the needs of everyone and as a result some persons are/become disabled. Thereby disabled persons are oppressed and discriminated in more or less all areas of life for example as their social and cultural recognition is denied (Watson, 2004). Since the focus is switched from the individual to the society, the social model calls for a change by arguing that interventions need to be targeted towards the factors in the society that influence disability, for example sensory, attitudinal, cognitive, physical, and economic barriers and the need of accessibility (e.g. Barnes & Mercer, 2004; Hughes, 1998; Mitra 2006; Oliver, 2004).

The initiative to switch the focus from the individual limitations to the barriers in society came from the grass root level. Central in this respect, were the disability movements and organizations in the 1960s and 1970s, such as the *Independent Living Movement* in USA and *Union of the Physically Impaired Against Segregation* (UPIAS) in the U.K. (e.g. Barnes & Mercer, 2004; Oliver, 2004; Vehmas, 2005; Watson, 2004). The social model has from the beginning been functioning as an empowering political tool in the quest for *equality* for example in terms of equal rights, as voters, consumers, or workers as well as an overall claim to enhance *participation in society*. These processes have also further united persons with disabilities (e.g. Barnes & Mercer, 2004; Oliver, 2004; Vehmas, 2005; Watson, 2004). Moreover, it has played a crucial part in academia for contemporary disability studies (especially in the UK) as well as for disability policies on both international and on national levels (e.g. Barnes & Mercer, 2004; Vehmas, 2005; Watson, 2004). When it comes to uniting persons with disabilities, Lindqvist (2009) also mentions the *affirmative model* of disability (originally presented by Swain & French, 2001), which is based on the personal lives and experiences of persons with disabilities. As a continuation from this perspective, Lindqvist (2009) points out that persons with disabilities can also be seen as sharing a disability culture of their own, at least when it comes to deaf persons sharing the sign language as a cultural foundation.

As mentioned above, disability used to be defined mostly from a medical perspective in the past, attributing the cause of disability to the individual, who was also seen as the target for possible interventions such as rehabilitation (e.g. Mitra, 2006; 2018; WHO, 2002). The social model of disability, on the other hand, sees the society as disabling, which means that disability can be regarded

as a result of, for example, inaccessibility, discrimination or segregation. Accordingly, the social model considers society as the target for interventions instead of the individual. The social model presented above, has however, not escaped criticism. Alike the medical model, it has been accused of being one-sided, but also for neglecting the impact of the impairment in itself, as well as disregarding health-related issues (e.g. Lindqvist, 2009; Vehmas, 2005). Oliver (2004) claims, though, that this is a misinterpretation since the social model did not originally intend to portray for example individual rehabilitation as being counterproductive.

Some critics of the social model have also considered it to be too simplifying since it does not consider the personal experiences as well as the variations among persons with disabilities in a sufficient way. The same goes for the variation regarding the barriers in society and everyday life (e.g. Hughes, 1998; Lindqvist, 2009; Oliver, 2004; Vehmas, 2005; Watson, 2004). According to Watson (2004), this can be seen as a consequence of the social model's emphasis on materialistic barriers and desired interventions, while it overlooks aspects related to personal experiences, interpersonal relations and disability as affecting one's identity as well as issues related to social interaction and recognition. Furthermore, the social model has been criticised for not considering the role of other possible overlapping forms of discrimination and oppression, for example in relation to gender or ethnicity (e.g. Oliver, 2004; Watson, 2004). However, in their defence of the social model, both Barnes and Mercer (2004), as well as Oliver (2004), point out that it was originally intended to be, first and foremost, an aid or a tool for widening the understanding disability, not a theory per se. In the beginning, this tool was seen as especially useful for professionals, such as social workers (Oliver, 2004).

2.4 The ICF model of disability and the human rights perspective

Since neither the medical nor the social model of disability can independently provide a sufficient perspective on disability, the United Nations' World Health Organisation has developed a merged model of disability. The WHO International Classification of Functioning, Disability and Health (hereafter the ICF model) represents a combination of the two abovementioned perspectives by suggesting a merged biopsychosocial model of disability (e.g. Mitra, 2006; 2018; Lindqvist, 2009; Vehmas, 2005; WHO, 2002; 2011). Even though the first

version of the WHO's model (International Classification of Impairment, Disabilities and Handicap) that was presented in the 1980s had a strong biomedical emphasis, the more recent version, the ICF from 2001, can be said to integrate the different perspectives more successfully into a biopsychosocial model of disability (e.g. Barnes & Mercer, 2004; Vehmas, 2005).

The ICF defines impairments as the cause of a limitation or lack in body function or structure, activity as the performance of a task and participation as the "lived experience" (Mitra, 2006). According to the ICF model, participation can also be seen as the outcome of the relationship between personal factors (including the impairment) and the factors related to the environment, such as facilitating or hindering factors (Barnes & Mercer, 2004). According to the ICF, disability can therefore be regarded 'as a dynamic interaction between health conditions and contextual factors, both personal and environmental' (Lindqvist, 2009; WHO, 2011: 4). This means that it is an 'umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and contextual factors (environmental and personal factors)' (WHO, 2011: 4; Leonardi et al. 2006). The ICF model of disability also offers a classification system with a capacity to measure a person's ability to execute a task and a performance qualifier measuring the lived experience of a person in the real-life context (Mitra, 2006).

Vehmas (2005) is however sceptical towards whether the ability to perform a certain task can give accurate and sufficient information about a disabled person's life and abilities. Moreover, despite the ICF model's aim to merge different factors defining disability, Vehmas (2005) claims that the medical emphasis is still prevalent when different medical diagnoses are labelling and objectifying persons with disabilities. Furthermore, another of the ICF model's weaknesses is its rather superficial character that leaves quite a lot of room for interpretation, especially when it is been used for example by different professionals (Vehmas, 2005).

Despite the criticism towards the weaknesses on the ICF model, disability is defined in a similar manner also in the UN CRPD since it states that '[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (United Nations, 2006). Therefore, as the perspectives on disability have switched, merged, and developed, the emphasis is nowadays increasingly on the human rights of persons with disabilities thanks to the UN

CRPD, and it has also come to have a significant positive impact in both policy and practice in many countries (e.g. Katsui et al. 2014).

According to Petman (2010), human rights are in general founded on the assumption of everyone having the same capacities and self-sufficiency as competent adults, as well as on the assumption of society being based on a mutual contract of advantage between the citizens and the state. As Petman (2010) points out, there are however, certain groups of people, e.g., persons with disabilities, whose needs are not necessarily considered or sufficiently met in this contract, which creates a need for a specific convention of human rights for persons with disabilities. The UN CRPD aims at including this neglected group into the human rights discourse and recognizes that disability, and especially the rights of persons with disabilities, are a social matter (not simply an individual or medical one), which require actions regarding both social environments, structures, and systems (Katsui et al. 2014; Petman, 2010). Furthermore, the UN CRPD shows the unnatural and unequal power relationship between persons with disabilities and those without, where the latter has the advantage. Thereby it is crucial that the UN CRPD presents persons with disabilities as citizens, social agents, and equal bearers of human rights (Petman, 2010).

The ICF model will be further presented in relation to the societal participation of persons with disabilities in the subchapter 3.4. A Finnish perspective on the (human) rights of persons with disabilities, as well as the implementation of these rights, will be given in chapter 4.

3. Theoretical perspectives on the societal participation of persons with disabilities

In this thesis, the focus is on how the opportunities to participation in society are constructed for persons with disabilities in Finland from a theoretical standpoint of equality. The theoretical framework will therefore have its first starting point in a discussion about the concept of societal participation in subchapter 3.1. Societal participation is a complex concept, since its meanings vary depending on how, where and in relation to whom it is used. It has also an active component, which relates it closely to concepts such as agency, and it involves a subjective feeling of truly taking part in something (e.g. Isola et al. 2017). The second starting point will be a discussion about the concept of equality in subchapter 3.2, since this is a key for understanding, problematizing, and even valuing the degree, or quality of societal participation. The same goes for the concept of citizenship, which is discussed in subchapter 3.3. The fourth subchapter 3.4, finally, discusses what equal participation, and especially societal participation, means when it comes to persons with disabilities.

3.1 The concept of societal participation

The concept of *participation*, and more specifically, the concept of *societal participation* does not have clear-cut boundaries. According to Raivio and Karjalainen (2013), these concepts can perhaps be understood as an opposite to marginalisation. Thereby it has also become a foundation and goal for welfare policies, especially in terms of the enhancement of opportunities to participate in society, as well as in the labour-market (Raivio & Karjalainen, 2013). In this thesis societal participation is viewed broadly covering several areas of life. Van Wel and Landsheer (2012: 793) defines societal participation as “[the] involvement in outside activities in a variety of work, living, educational and leisure settings, and in terms of one's contacts with family and friends”. Societal participation is thus a narrower concept than social participation, since it broadly includes different areas of life such as labour-market participation, leisure, family life and politics, without focusing solely on interpersonal interactions (United Nations, 2006; Levasseur et al. 2010).

Sen's (1999) and Nussbaum's (2011) *capability approach* provides a frame for the concept of societal participation that emphasises individual agency and essential freedoms to choose and strive for the life and goals one values (see

also Isola et al. 2017). On a practical level, the capability approach highlights the so-called instrumental freedoms, i.e., the opportunities that become reality through for example health care, education, social security, and democracy. The interaction and processes for enhancing the individual's capabilities is also emphasised (Isola et al. 2017; Nussbaum, 2011; Sen, 1999). Nussbaum (2011) highlights especially ten basic capabilities, i.e., freedoms that everyone should have the right and access to for enabling participation in society and regarding all areas of life (see also Isola et al. 2017). The first three include the right to *life, bodily health, and bodily integrity*. These are followed by freedoms related to *senses, imagination and thought*, which is supported by for example education and the freedom of religion and ideology. Furthermore, Nussbaum (2011) points out the importance of *emotions*, as well as of *practical reason*. *Affiliation* is also highlighted, i.e., to live with, respect, and care about other people, as well as in relation to *other species* and the nature. *Play*, and *recreational activities* are not forgotten, and last, but not least, Nussbaum (2011) emphasises the *control of one's environment* both in terms of political participation and in terms of material resources. As mentioned, the capability approach will be further presented in relation to equality in subchapter 3.2 and persons with disabilities in subchapter 3.4.

Societal participation refers also to political aspects, for example voting, as well as engagement in different organisations. In addition, it is a personal experience of freedom and power, i.e., individual capability, agency and choice shifting over different periods of life. When the focus is on opportunities to participation, the implementation of the opportunities is ultimately left upon the individual's responsibility. Raivio and Karjalainen (2013) point out though, that there are groups that might need support and services in order to be able to participate in society, for example people who have a reduced ability to work. Enhancing societal participation also affects the welfare state's administration and services, as traditional public administration is replaced by ideas of new public management and new public governance (Isola et al. 2017). Especially the last school does not consider the citizens as mere subordinates or consumers, but as active members of the community that participate in its development. Regarding the Finnish welfare system, Isola et al. (2017) are therefore calling for diversified, and individually tailored forms of service and support that facilitate participation in society, without abandoning universalism.

Societal participation regarding different areas of life can therefore be seen as the core of active citizenship. When it comes to the concept of societal

participation, one of the renowned illustrations of different levels or degrees of citizens' participation (in society) is Arnstein's (1969) *Ladder of Participation* (see Figure 2). She claims that citizens' participation (in decision-making in society) is actually about citizens' power, or more specifically about the (re)distribution of power between the "powerholders" and the 'have-nots' (Arnstein, 1969). The two lowest levels of this eight-step ladder (manipulation and therapy) represent a situation where there is no actual participation in society. Instead, the aim of the power holders is to convince or cure the 'have-nots'. According to Arnstein (1969), the three following levels in the middle of the ladder (informing, consultation, and placation) represent varying degrees of tokenism, i.e., when participation is more just a formality, rather than an actual opportunity. Informing citizens of their rights and responsibilities is fundamental but tends to be only a one-way communication. Even different consultations of citizens, for example through surveys, as well as different forms of placation provide no guarantee that the citizens' opinions, viewpoints, and advice are really taken into account in decision-making. Actual degrees of citizen power can be found at the top-three levels of the ladder in *partnership*, *delegated power*, and *citizen control* (Arnstein, 1969). Partnership suggests that the power holders negotiate with the citizens and share the responsibility of planning and decision-making with them, and if this is done to a great extent it can be seen as a delegation of power to the citizens. Arnstein (1969) sees citizen control to be reached when citizens are fully given the power, as well as the responsibility for resources.

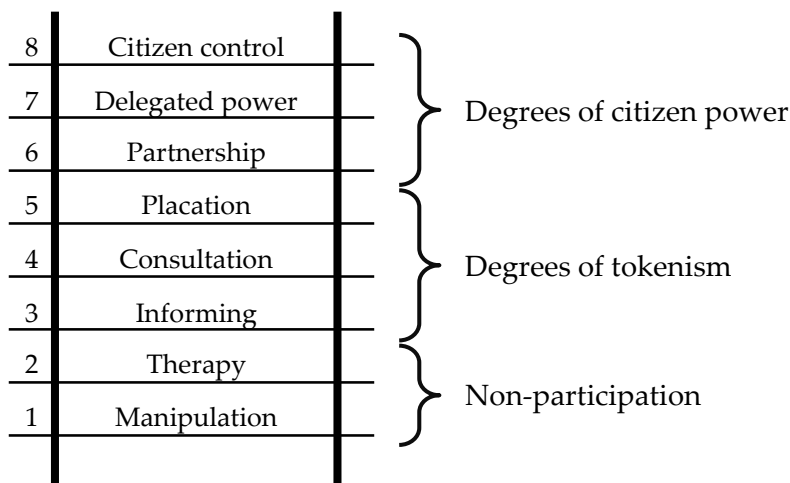


Figure 2 Arnstein's (1969) Ladder of Citizen Participation.

Even though Arnstein's ladder describes various forms of citizen involvement that can be implemented on for example the use of health care services, it has also been criticised for being outdated and insufficient (e.g. Tritter & McCallum, 2006). Accordingly, there is an increasing demand for user involvement in health care services in many countries, for example in the UK, the Netherlands as well as in the Nordic countries. These demands stem from the need for services to be accountable to the users, in their capacities as taxpayers, voters and consumers. Based on their critique, Tritter and McCallum (2006) present a more nuanced model of societal participation. This model argues that user involvement requires different kinds of 'ladders' with varying number of rungs, and that there also needs to be "bridges" between them, i.e., connections between different user involvements. However, Tritter and McCallum (2006) prefer to present the participation of users as a mosaic instead, in order to illustrate the multiple dynamic and complex ways in which different users interact with institutions, organisations and communities. Self-selected engagement is seen as enhancing equality of opportunity since the participants can have an impact through their experiences. Furthermore, Tritter and McCallum (2006) highlight the importance of evaluating the processes and effects of the user involvement in order to get evidence that will encourage further user involvement. They also point out the culture-changing potential in user involvement and its importance when it comes to wide reforms.

In addition to the abovementioned, Isola et al. (2017) points out that societal participation is also, on an individual level, linked to for example self-determination, self-efficacy, motivation, and resilience (Isola et al. 2017). Motivation can for example become hampered by a lack of faith in one's potential and prospects (Ryan & Deci, 1985 referred to in Isola et al. 2017). On the other hand, faith in one's abilities and the real opportunities available can have a crucial role regarding one's self-efficacy (Bandura, 1977 referred to in Isola et al. 2017). Resilience is also crucial for societal participation as it refers to the ability to overcome setbacks in life (Saari, 2015 referred to in Isola et al. 2017).

3.2 Equality as a key to societal participation

Equality can be seen as an enabling key element for societal participation, and this is especially crucial for people whose participation is hindered by for example lack of access, recognition, or resources. Equality, and its counterpart

inequality, are debated concepts in research as well as among the public and in politics (Nygård, 2013; Platt, 2011; Rosanvallon, 2017; Witcher, 2015). Witcher (2015) adds that there is also an inconsistency regarding how these concepts relate to closely linked concepts like discrimination, poverty, and social justice. The actual meaning of equality and inequality is not always clear, but as a simplification Platt (2011) claims that inequalities between people are often, but not always, results of uneven distribution of wealth between individuals and groups in society, i.e., material inequality, or related to bodily differences such as gender, race, or disability. The concept(s) can have various meanings depending on the context and what is measured, and depending on whether we refer to opportunities, outcome, access, entitlement, power, or recognition (Nygård, 2013; Platt, 2011; Witcher, 2015). Furthermore, it is crucial to consider whether (in)equality can be seen to be (un)just, (un)natural, or (un)avoidable, and often many of these aspects overlap or cannot be distinguished from each other (Platt, 2011; Witcher, 2015). This is dependent on whether inequalities result from differences in individual skills and effort, or whether people can be held responsible for the outcomes. Therefore, the amount of 'deservingness' can also vary between different groups in need. Persons with disabilities constitute one such deserving group when it comes to welfare state measures aiming to reduce inequalities (van Oorschot, 2006).

As mentioned above, equality/inequality can be understood either in terms of *outcome* or *opportunity* (e.g. Nygård, 2013; Platt, 2011). Rosanvallon (2017) claims the latter to be the dominating perspective on equality and at the same time also being the justification of inequality regarding the former. On one hand, when equality of outcome is aimed for, efforts are made to even out existing inequalities between people or groups of people without focusing so much on how these inequalities have arisen (e.g. Nygård, 2013; Platt, 2011; Rosanvallon, 2017). Such state intervention can however also be seen as threatening or restricting the individual's freedom, as well as diminishing the reward, and motivation for individual activity (Nygård, 2013; Platt, 2011; Witcher, 2015).

On the other hand, when striving for equality of opportunity, as well as freedom, the assumption is that talents and skills are equally and randomly spread among people and the focus is on creating an equal starting point for all (e.g. Nygård, 2013; Platt, 2011). Therefore, it is important to improve the opportunities especially for disadvantaged groups. But even more so, it is crucial to remove artificial barriers and even out such differences so that a person is not affected or fettered by circumstances that he/she is not

responsible for, or that are out of the person's control (for example circumstances caused by e.g., one's gender, race, or disability) (Platt, 2011; Witcher, 2015). Rosanvallon (2017) sees this as an ambition to remove juridical differences related to inherited social class/positions and to neutralise/correct differences in starting points, for example in terms of resources. Witcher (2015) points out that equal opportunities lose their value if social barriers are hindering some people from using them. Therefore, access to education is crucial for equal opportunities, especially early in life, but also for equipping individuals to tackle barriers like discrimination or glass ceilings that might limit their opportunities later in life (Rosanvallon, 2017; Witcher, 2015).

However, according to Platt (2011), the tricky part is to define this so-called starting point at which the opportunities could be considered equal, if such a point can even be found. From this equal starting point on, i.e., when the equal opportunities are in place, the outcome depends on each and everyone's own talent, effort, performance, and resilience. Some inequalities are therefore allowed between individuals and seen as natural rewards, as long as they are not systematically (dis)favouring some groups. Because if some group is systematically better or worse off, it might be easier to recognise the lack of equal opportunities. Witcher (2015) points out that some inequalities might also be necessary for choice, social change, and diversity. Platt (2011) argues that when it comes to different groups in society, inequalities often exist and therefore equality is called for, if not in terms of outcome, at least in terms of opportunity. The latter is also crucial for enabling social mobility and motivating equal access to education. Inequalities faced by some groups might sometimes also overlap on an individual level and cause multiple layers of disadvantage (Platt, 2011). Regardless of the perspective on equality or inequality, it is closely linked to social justice and considerations of fairness (Platt, 2011, Rawls, 1971; Witcher, 2015). Rawls (1971) has suggested that 'justice as fairness' could be reached if the principles for equality would be set from behind a 'veil of ignorance' that would prevent anyone from knowing which social position, circumstances, resources, talents, intelligence, and strength one would come to have, develop, or lose, in reality (Platt, 2011; Rawls, 1971; Witcher, 2015). Equality and inequality are however dependent of each other since the acceptance of one form or level of inequality requires an agreement of equality on some other basic level that is considered more important (e.g. Sen, 1992 referred to in Platt, 2011; Witcher, 2015).

Equality is also closely connected to freedom. Attempts both to safeguard and to strive for equality (and to even out inequalities) can be seen as either compromising or enabling freedom (Platt, 2011). Freedom in itself is however a complex term, since it can mean freedom (and ability) as a result of equality (of outcome), or freedom from outside interference, i.e., from outside attempts to even out inequalities of outcome through redistribution (Nygård, 2013; Platt, 2011; Witcher, 2015). Freedom, as well as equality of opportunities, are essential elements of the capability approach since it highlights especially freedom as a measurement of welfare, development, and equality in society, i.e., instead of focusing on the (re)distribution of resources (Nussbaum, 2011; Sen, 1999). Because, as Sen (1999) claims, the amount of freedom a person has defines his/her capability to truly live the kind of life he/she values and thereby equally participate in society.

Sen (1999) describes the capability approach by comparing for example a person who is fasting to a person who is starving. They are both malnourished and neither of them is eating, but for the former this is a conscious choice while the latter has no other option. The former is thus 'freer' in a capability sense, although the objective outcome seems to be identical. The freedom or options available determine a person's actions, but they lose their value if a person does not have the practical opportunities to put them into action (Nussbaum, 2011; Mitra, 2018; Sen, 1999). The capability approach distinguishes the so-called capability inputs, i.e., the means consisting of commodities, resources, skills, circumstances, services as well as support from others available to a person, the capability set i.e., the freedom and options available and the actually achieved functioning (e.g. Hvinden & Halvorsen, 2017).

Sen (2010, referred to in Witcher, 2015) also highlights the lived experiences and real-life opportunities of people, which are affected by policies and institutions in society. Therefore, objectivity and information about individuals and the context is needed, as well as the ability to balance, negotiate and compromise, when choosing the form of (re)distribution of resources in society (Witcher, 2015). Furthermore, (re)distribution should not be only about material resources, but also about intangible goods like power, honour, love, knowledge and education, employment opportunities, physical security, and leisure, as well as rewards and punishments, even though it might be difficult for society to distribute them evenly. According to Sen (2010, referred to in Witcher, 2015) any democracy needs to be judged by its ability to give equal voice for different people to be heard and participate. Sen's (1999) capability approach will be further referred to in subchapter 3.4.

Similarly, to equality regarding material resources, cultural recognition, i.e., the positive affirmation of group identity (regarding for example gender, race, or disability), is just as important when it comes to equality and consequently societal participation (Fraser, 1999; Witcher, 2015). Witcher (2015) adds, that equal also can mean equivalency, that is, being different but of same worth. Cultural misrecognition on the other hand, can result in stigmatisation and limited opportunities to participate in society, and at its worst, it can even result in hate crimes due to misrecognition of humanity (Fraser, 1999; Witcher, 2015). Witcher (2015) points out though, that misrecognition of shared experiences of for example discrimination can also be the basis of a shared group identity. In the case of persons with disabilities, misrecognition might often cause the failure to see what should be done in society for equal participation in terms of accessibility (Witcher, 2015).

In opposite to Rawls (1971), Witcher (2015) claims that a perfect understanding of justice does not mean ignorance, but instead knowledge about people's capacity to agency and their circumstances, as well as an understanding through dialogue between different people. As said, the distribution of material resources is important too, since inequality in terms of recognition is often linked to inequality in terms of resources (Fraser, 1999; Witcher, 2015). Therefore, Fraser (1999) points out that both forms of inequality need attention, since resources can enable people to have a voice and influence. Different kinds of welfare benefits and services are important for enabling equality since they can facilitate societal participation in a broad sense. Regarding these benefits and services, Witcher (2015) advocates co-production between providers and receivers, where the voice and knowledge of the recipients can be useful for developing policies and improving services. Co-production loses its value though, if the resources are insufficient (Witcher, 2015).

3.3 Citizenship as a key to societal participation

Citizenship, and the rights it involves, can be seen as a key element in enabling, and to some extent also guaranteeing, equal participation in society. In addition, the active component of citizenship also involves an expectation, or even a demand, of citizens' societal participation, and therefore this concept will be the focus of this subchapter. Similar to equality, citizenship is also a much-debated concept (e.g. Turner, 1993). Traditionally it is often seen as mirroring the historical development of the (welfare) state and signalling a

status of individuals in relation to the society they live in (e.g. Nygård, 2013; Óskarsdóttir, 2007). Citizenship involves different kinds of rights (and responsibilities) for individuals that gradually through history have come equally available for all and expanded to include civil, political and social rights (at least in theory and regarding Western countries) (e.g. Johansson, 2008; Marshall, 1973; Nygård, 2013). Consequently, the rights and responsibilities of the citizens usually affect their opportunities to (societal) participation as well. Marshall (1973) was one of the first to discuss and advocate equal social rights bound to citizenship (instead of for example to social class). Examples of such social rights are services like health care and education, as well as the right to financial support mechanisms (e.g. Johansson, 2008; Marshall, 1973; Nygård, 2013).

Marshall's (1973) notion on social citizenship has been criticised for failing to see that some rights (and responsibilities) are not necessarily bound to official citizenship, but more to for example labour-market position. Furthermore, there is often a difference between formal rights and their implementation in real life (Johansson, 2008; Johansson & Hvinden, 2007b). Perhaps the most dominant criticism towards the social citizenship has been about the (over)emphasising of the importance of rights and the downplaying of the importance of responsibilities, even though Marshall (1973) did not deny their importance (Johansson, 2008). In addition, society has changed radically over the past decades. Today, for example, we have more gender-equal labour market participation, more diversified family structures, and new forms of social risks (e.g. Nygård, 2013). As a consequence, social citizenship has become increasingly criticised for being too generous and even passivating, and a more nuanced and active citizenship has been called for in order to balance the relationship between individuals and the state (e.g. Jensen & Pfau-Effinger, 2005; Johansson, 2008; Johansson & Hvinden, 2007a; Kotkas, 2010; Nygård, 2013; Óskarsdóttir, 2007).

This emphasis on active citizenship has become visible in for example the so-called Third Way in the UK and Germany in the 1990's. This policy paradigm emphasised a balance between social rights and certain duties for citizens (e.g. Giddens 1999, 2000; Johansson 2008; Óskarsdóttir, 2007). Another example is the increased emphasis on social investment policies aiming at enabling and equipping citizens' participation through investments in human capital in terms of for example education (e.g. Jensen, 2010). On a more practical level, citizens are expected to actively participate in society as consumers and voters, and to participate actively in the labour market. Whereas the traditional notion

of social rights sought to shelter citizens from market forces, the active notion of rights, in a way, seek to integrate them in the labour market and to make them more responsible for their own welfare and social security. Different forms of reciprocity are linked to many social benefits, for example unemployment benefits (e.g. Jensen & Pfau-Effinger, 2005; Johansson, 2008; Nygård 2007).

3.4 Societal participation of persons with disabilities from a perspective of equality of capabilities

The formal equality of persons with disabilities, granted through the UN CRPD and legislation, often differs from their experienced/substantive equality regarding different areas of life. As Witcher (2015) points out, persons with disabilities have to a higher extent become for example objects of discrimination, disability-related harassment (physical, sexual, financial, or institutional), and even hate crimes due to the increased polarisation and hardening attitudes. Still, it is important to note that persons with disabilities constitute a heterogeneous group, both in terms of the type of disability and timing, that is, at what point in life one is faced with disabilities (Platt, 2011; Witcher, 2015). Consequently, there are variations in the experiences of inequality among persons with disabilities. Since the incidence of disability in later life can in some cases be related to deteriorated health through aging, it is, according to Platt (2011), difficult to draw a line between ill-health and disability. Furthermore, she points out that mental health problems have not been seen as disabilities, like physical impairments, even though they might be just as disabling and stigmatising, and thereby lead to barriers to participation.

Despite some variations in experiences of inequality, it is common for persons with disabilities to face labour-market inequalities. In addition, they tend to have lower incomes and more often experience poverty, which also applies to families with a disabled child. This might be related to the fact that persons in lower income groups tend to be less healthy than those financially better off (Platt, 2011). When it comes to persons with disabilities, the higher poverty rate is however, mostly a consequence of a lower labour market participation rate. This, in turn, might be because persons with disabilities are more likely to retire earlier or to have difficulties finding employment due to lower educational level, fewer occupational options and/or discriminating attitudes. Even those persons with disabilities who do participate in the labour

market are more likely to end up in jobs requiring lower qualifications and that are paid less and more insecure and/or part-time jobs (Platt, 2011).

As stated earlier, the concept of societal participation is in this thesis seen as something more than simply inclusion and involvement, since these two concepts do not necessarily indicate that a person has an active role in society. Moreover, these two closely related concepts do not guarantee a feeling of truly being part of something, having an impact, and/or making a contribution. As to the ICF model of disability presented in the previous section in subchapter 2.4, no clear distinction is made between social and societal participation. The model does not define participation through different roles of a person, but largely as involvement in life situations in terms of being engaged, accepted, and accessing resources needed (Mitra, 2006). Barnes and Mercer (2004) claim however, that the ICF model sees participation primarily from the perspective of the individual, rather than in terms of social or political participation. The life situations highlighted are divided into nine domains including participation in domestic life, major life areas as well as community, social, and civic life (Levasseur et al. 2010; Mitra, 2006, 2018; WHO, 2002, 2013).

As said, the ICF model distinguishes between a person's performance and capacity, depending on the impact of contextual factors (Mitra, 2006, 2018; WHO, 2002, 2013). These contextual factors include the individual life situation, personal factors like gender, age and social background, environmental factors like the physical environment and climate, services available in terms of for example transportation, health care, and social services, as well as cultural factors in terms of attitudes, and legal and social structures (Mitra, 2006; WHO, 2002). The highlighted factors can be either barriers or facilitators. Barriers, such as different forms of inaccessibility or discrimination, are factors that disable and hinder a person's capacity and functioning and thereby lead to a lower level of societal participation (cf. WHO, 2011). Facilitators, on the other hand, like disability services, assistive technology or inclusive attitudes are factors that enable and enhance functioning and thereby support and increase societal participation (WHO, 2011). Some of these factors can by their absence or presence be either barriers or facilitators, as for example accessibility, or they might otherwise be related to and dependent of each other.

Societal participation for persons with disabilities requires more than formal rights, and as the ICF model shows, it is dependent of many factors, which is also mirrored in the capability approach (e.g. Nussbaum, 2011; Sen, 1999). The capability approach, which is increasingly used in disability studies,

provides not only a perspective on disabled persons' societal participation, but also a perspective on how such participation can be understood, problematized, and even valued from a perspective of equality. The capability approach, as it is understood here, can thus help us to understand what the actual meaning of societal participation for this particular group is, and what facilitators and barriers to societal participation of persons with disabilities there are.

The capability approach highlights the opportunities and capabilities, i.e., the capability sets that people need for being able to live their lives in accordance with their aspirations and goals (Bellanca, Biggeri & Marchetta, 2011; Hvinden & Halvorsen, 2017; Mitra, 2006, 2018; Nussbaum, 2011; Sen, 1999; Trani et al., 2011; Vorhaus, 2013; Welch Saleeby, 2007). The right of self-determination, i.e., a person's effective freedom, is fundamental for the capability approach, and instead of only focusing on people's specific activities or state of being, the capability approach highlights the interests, aspirations, goals, possibilities, and freedoms people have and the extent to which these are fulfilled (Mitra, 2006; 2018; Nussbaum, 2011; Sen, 1999). Therefore, the value of the right to self-determination is not diminished even though some persons with disabilities might need assistance in exercising their freedom of choice (Hvinden & Halvorsen, 2017; Morris, 2005; Nussbaum, 2011; Sen, 1999). Vorhaus (2013) however points out that the capability approach's emphasis on agency and freedom of choice might be problematic for persons with profound disabilities. Accordingly, freedom of choice should not be dependent of the (limited/lack of) ability to perform actions or to express one's will. Every effort possible should be made to assist and involve even persons with profound disabilities in decision-making, especially in matters concerning themselves. If a person – despite these efforts – is still unable to exercise his or her freedom of choice, then the person's well-being should be put first (Vorhaus, 2013).

The capability approach coincides with the ICF in terms of acknowledging the various factors behind and the various consequences of disability. Each person's capability set, and functioning are determined by various factors, as well as the means available. Therefore, the economic causes and consequences related to disability are also highlighted since persons with disabilities tend to have lower incomes due to barriers related to labour-market participation and possible life-long dependence of social benefits (Mitra, 2006; Nussbaum, 2011; Welch Saleeby, 2007). Persons with disabilities may also have limited opportunities to use their earnings or resources for promoting their goals in life (Bellanca, Biggeri, & Marchetta, 2011; Mitra, 2006; Sen, 1999). The process

where a person's means are converted into capabilities and further on to such functioning the person desires and chooses to value is affected by various so-called conversion factors, which can be either hindering or enabling (Hvinden & Halvorsen, 2017; Mitra, 2018). Both the factors regarding the initial conditions or capability inputs, as well as the ones affecting the conversion processes can be personal, social, or environmental factors. Furthermore, these conditions and factors are often interrelated and can vary in scale from the micro level up to the macro level (Hvinden & Halvorsen, 2017). Based on Nussbaum's earlier distinction of ten central capabilities, Hvinden and Halvorsen (2017) focus especially on three fundamental values regarding participation in society: security, autonomy, and influence (Hvinden & Halvorsen, 2017). Equality of opportunities and the potential in each person are also crucial for the capability approach, and the key question is what each person is capable of doing and/or being (Nussbaum, 2011; Sen 1999; Trani et al., 2011). In line with the capability approach, the goal of disability policy should therefore be to increase the options, freedoms, and capabilities of persons with disabilities.

The ICF model has been criticised for putting too much emphasis on a person's performance instead of access to resources and factors enabling participation (e.g. Hammel et al. 2008). It has also been criticised for not considering each person's right to self-determination regarding matters concerning one's own life. Furthermore, there has been critique towards using an objective outside viewer perspective instead of involving the subjective perspective of persons with disabilities. A focus group study by Hammel et al. (2008) for example, provides however such a perspective by showing that persons with disabilities describe participation as 'a complex, nuanced phenomena that can be experienced and play out quite differently for different people on individual, social, community and societal levels' (Hammel et al. 2008: 1449). First and foremost, the respondents in the study of Hammel et al. (2008) stressed the importance of being treated with respect and dignity as equal persons of value. Furthermore, they emphasised self-determination and saw the right to participation to be based on access, opportunity, and inclusion. To have an impact on society and to support others was also seen as important. Participation was seen as a 'personal and societal responsibility that required determination, advocacy and empowerment', and as a means to feel connected with other people (Hammel et al. 2008: 1459).

4. Disability policy and living conditions of persons with disabilities in Finland

Following the theoretical frame presented in the previous chapter, this chapter provides a contextual frame for this thesis. The first of the following subchapters (subchapter 4.1) will therefore present an overview of the Finnish disability policy, while the second subchapter (subchapter 4.2) focuses on service and support for persons with disabilities. The third and fourth subchapter (subchapters 4.3 and 4.4) shed some light on the living circumstances of persons with disabilities in Finland. Disabled persons' use of disability services, their labour-market participation and their experiences of discrimination is also presented. The emphasis in this chapter is especially on those in working age since they are the focus of this thesis, i.e., the services and the situation of for example children with disabilities is not highlighted.

4.1 Disability policy

As mentioned in chapter 2, there is no clear-cut definition of disability, and also in relation to the welfare state there are different definitions and perspectives (e.g. Lindqvist, 2009). Therefore, it is often difficult to count the number of persons with disabilities in different countries, and this is also the case in Finland (eg. Ministry for Foreign Affairs, 2019; Nurmi-Koikkalainen et al. 2017; Savtschenko, Suikkanen & Linnakangas, 2010). The way in which persons with disabilities have been portrayed has also evolved through time, for example from a dominating medical perspective to the emphasis of the equality and (human) rights of persons with disabilities (e.g. Nurmi-Koikkalainen et al. 2017).

Disability policies and legislation concerning the rights of persons with disabilities has evolved too, and especially during the last decade or so, questions concerning persons with disabilities have been increasingly highlighted on the Finnish political agenda. In 2006, the first Government Report on Disability Policy was published, and it was followed by Finland's Disability Policy Programme 2010-2015, as well as some crucial legislative changes made regarding for example personal assistance, and municipality of residence (Ministry for Foreign Affairs, 2019; Ministry of Social Affairs and Health 2006, 2009, 2010). The goal of all these changes and the Disability Policy Programme was the ratification of the UN CRPD, which Finland had signed already in 2007, but did not ratify until 2016. Following the ratification

process, the Advisory Board for the Rights of Persons with Disabilities (VANE) determined 82 long- and short-term measures to be taken in the implementing process and these were presented in the first National Action Plan on the UN Convention on the Rights of Persons with Disabilities 2018–2019 (Ministry for Foreign Affairs, 2019; Ministry of Social Affairs and Health, 2018a). In addition to stressing the importance of for example accessibility and the inclusion of persons with disabilities, the first Action Plan also aimed at increasing the awareness about the rights of persons with disabilities and for them to become mainstreamed in society. Another step regarding the UN CRPD happened in August 2019 when the Finnish Government gave its first report to the United Nations Committee on the Rights of Persons with Disabilities and the implementation of the Convention (Ministry for Foreign Affairs, 2019). The most recent National Action Plan on the UN Convention on the Rights of Persons with Disabilities (2020–2023) was presented in February 2021 (Ministry of Social Affairs and Health, 2021). This Action Plan includes up to 110 measures that the ministries have committed to regarding the implementation of the UN CRPD. Overall, the importance of social inclusion of persons with disabilities is emphasised in the Action Plan, as well as the importance of accessibility as a precondition for the fulfilment of many other rights.

Disability organisations have an important role regarding the Finnish disability policies, since they are often heard and involved in disability related political matters as experts and spokesmen for their members (e.g. Ministry for Foreign Affairs, 2019). In addition, the organisations are important channels for information for their members, as well as in terms of offering peer support (Vesala & Teittinen, 2016). On a national level, there is also the Advisory Board for the Rights of Persons with Disabilities (VANE), which is the coordinating mechanism regarding the implementation of the UN CRPD. It operates under the Ministry of Social Affairs and Health, and has representatives from several other ministries, disability organisations, labour market organisations as well as from regional and local governments (Ministry for Foreign Affairs, 2019). On a local level, municipalities have their own Disability councils (in some cases the councils might be joint with elderly people or with neighbouring municipalities), to involve them in decision-making about disability and accessibility related matters (Ministry for Foreign Affairs, 2019).

Criteria for different forms of accessibility, regarding both the physical environment and digital information and communication, are collected in national guidelines as well as set in the legislation (e.g. Kilpelä, 2019; Land Use

and Building Act, 5.2.1999/132; The Government's regulation on building accessibility, 4.5.2017/241; The Act on the provision of digital services, 15.3.2019/306). However, only 15 % of the apartments are accessible, since the criteria regarding the physical environment tend to be better met in newly built buildings and it takes time before older buildings are renovated to meet the same criteria. In addition, there are still many lacks especially regarding visual and auditive accessibility (Ministry for Foreign Affairs, 2019). According to the Non-discrimination Act (30.12.2014/1325) both the public and the private sector are, when needed, obliged to make reasonable accessibility adaptations for disabled persons' equal opportunities to service, consumption, education, and employment (Ministry for Foreign Affairs, 2019).

Except for the UN CRPD, the disability policies in Finland are also influenced by international co-operation on for example both a Nordic and a European level, as well as through regulations, programmes, and strategies thereof (e.g. Council of Europe, 2017; European Commission, 2010; Nordic Council of Ministers, 2018). The European Union has also come to have various effects on the lives of persons with disabilities and a rather recent example is the regulations about accessibility regarding digital services (Act on the provision of digital services, 15.3.2019/306). Another example is the introduction of a The EU Disability Card (The Social Insurance Institution of Finland, 2019). The idea is that persons with disabilities can use the card as an easy way of proving their disability and/or need of assistance when they, for example, use public transport or participate in sports or culture events.

Since 2013, there has been an ongoing process to renew and collect the legislation concerning service and support for persons with disabilities under a new law (e.g. Ministry for Foreign Affairs, 2019; Ministry of Social Affairs and Health 2015). The aim of renewing the legislation has been to guarantee the equal rights to sufficient and suitable services to persons with disabilities, as well as to strengthen their participation and self-determination (National Institute for Health and Welfare, 2019; 2021a). According to the recent Finnish Government's report to the UN Committee, the new legislation aims also at improving the consideration of the individual needs and circumstances of persons with disabilities (Ministry for Foreign Affairs, 2019). In addition to these original and favourable aims, the process of renewing the legislation came also to involve some aims to cut back the costs of the service and support for persons with disabilities, which were initiated by the Government 2015-2019 (e.g. Könkkölä, 2016). Along the process, the proposition of a new Disability Act has also been revised based on statements given by disability

organisations among others (Ministry of Social Affairs and Health, 2015; 2017). A final government proposal of a new law was submitted to the Parliament in September 2018, and it was planned to enter into force in 2021 (Ministry of Social Affairs and Health, 2017; 2018c). The proposal regarding the reform of legislation about the disability services was linked to the ongoing wider reform of the social and healthcare system (the so-called SOTE reform). However, since this wider reform proposal was cancelled in March 2019 (National Institute for Health and Welfare - Handbook on Disability Services, 2019), this means that also the proposal for new disability service legislation fell. Now, it is in the hands of the new Government elected 2019 to continue the work regarding the reform of legislation about the disability services (Government Programme, 2019).

One of the main goals of the previous Government 2015-2019 was to cut down the obligations of the municipalities. This was to a large extent planned to be done through the previous attempt to reform the health and social services. Even though a new Government has been elected since then reform of the social and healthcare system, there is still a need for reform that would improve the disability services and make them more equally available, as well as simplify the financing of the services (e.g. Ministry of Social Affairs and Health, 2016b). Different austerity policies can be seen as being part of a larger pattern caused by increased neo-liberal influences. The tension between such neo-liberal influences on one hand, and efforts to strengthen rights through the UN CRPD on the other, have perhaps been only partially visible in Finland, but somewhat more for example in welfare to work programmes for persons with disabilities in both the UK and Australia (e.g. Parker Harris et. al. 2014; Randall & Parker Harris, 2012). An opposing signal of attempting to strengthen the rights and especially the self-determination of persons with disabilities can be seen in the current Finnish Government's funding of a national project, as well as a set of regional projects, for developing a proposal for a national model regarding the use of personal budgets within the Finnish disability service system (National Institute for Health and Welfare - Handbook on Disability Services, 2020). The focus of these projects is especially on collecting information through collaboration with clients and professionals. Experiments of somewhat similar new ways of providing disability services through some form of personal budgets has been implemented elsewhere too, for example in the UK (e.g. Dwyer, 2004).

4.2 Service and support for persons with disabilities

The three main principles of disability policy in Finland are the right to equality, the right to participation and the right to necessary service and support (e.g. Ministry of Social Affairs and Health, 2010). The Social Insurance Institution of Finland (Fi. Kela/Swe. Fpa) is responsible for the disability benefits and for financing most of the more advanced medical rehabilitation services. Disability services, as well as some rehabilitation services and aids, on the other hand, are applied for primarily from the local municipalities. The most advanced aids, like motorized wheelchairs, are however provided by the hospitals. The provision of disability service and support is not based on diagnosis, even though a medical certificate is often required and there is partially specific legislation concerning the services for persons with intellectual disabilities (e.g. Ministry for Foreign Affairs, 2019; Rätty 2010). Instead, it is primarily determined by the duration and severity of the person's disability and the individual need, which is evaluated separately for each applicant and for each form of service and support that is being applied for. The disability services are mostly free of charge for the clients, except for e.g., subsidized fees for transportation.

Some forms of support to persons with disabilities, like financial subvention and special assistive equipment for an adapted car, are granted depending on, or within the frames of budgetary resources available in the municipality (e.g. Ministry for Foreign Affairs, 2019; Rätty 2010). Some of the disability services are, however, so-called subjective rights for persons with severe disabilities, for example transport service, personal assistance, and home adaptations. This means there is a legislated minimum level that a client that fulfils the legal criterions cannot be denied based on the municipality's lack of resources. Persons with disabilities have also a legal right to participate in the decision-making concerning themselves through individual service plans, which are (supposed to be) made in co-operation between the municipal disability services and the clients (e.g. Ministry for Foreign Affairs, 2019; Ministry of Social Affairs and Health 2009; Rätty 2010).

Even though the service and support for persons with disabilities is based on a nationally binding legislation (currently e.g. Act on disability benefits, 11.5.2007/570; Disability Services Act, 3.4.1987/380; Law on Intellectual Disabilities, 23.6.1977/519; Regulation on service and support due to disability, 18.9.1987/759), there are local variations in the implementation due to for example varying interpretations of the legislation and use of service

plans. Another reason for variation, is that the financial situation varies between municipalities. Moreover, there have been austerity policies on the local level in the municipalities, which has led to differences regarding financial resources available for disability services. This means, that the municipal social workers are the street level bureaucrats that can be seen as gatekeepers for services (e.g. Lipsky, 2010; Rätty, 2010). They implement the legislation by assessing the clients' individual needs and by providing the services within the frames of the financial resources available. According to Lipsky (2010), street level bureaucrats sometimes exert control on their clients, but Raunio (2004) confronts this by claiming it to be not that common within social work in Finland. As many street level bureaucrats, social workers tend to have a desire to help and support their clients, but also to be trapped between the clients' increasing number and/or needs, the frames set by the legislation and political decisions, as well as limited resources (Lipsky 2010; Raunio 2004; Saarinen, Blomberg & Kroll, 2012).

Due to variation regarding resources, some municipalities have tried to cut down the costs by subjecting some of the disability services for competition, for example regarding transport services and/or service accommodation and institutional care. The discontinuity in services, caused by the frequent changes of service providers, has turned out to be very difficult to handle especially for persons with severe disabilities. Recently, this led to a citizens' initiative aiming to restrict the legislation about public procurement (Citizens' Initiative 2/2018). Even though the concerns in the citizens' initiative were acknowledged by the Finnish Parliament, it has not (at least yet) led to any legislative changes. It did however result in some education about public procurement to be provided for politicians and officials on the municipal level (Ministry of Social Affairs and Health, 2018b). On a national level, an expert group was established in order to try to improve the situation, and the concerns in the initiative will also be considered in the continued work for reforming the legislation concerning disability services (Commerce Committee of the Finnish Parliament, 35/2018).

Since the spring of 2020, the COVID-19 pandemic has, along with the restrictions caused by it, become a major medical and societal challenge, both globally and nationally. As highlighted by several organisations within the Finnish disability policies, as well as experts, the pandemic has in many ways also affected the daily lives persons with disabilities in Finland (Advisory Board for the Rights of Persons with Disabilities (VANE), 2020; Finnish Disability Forum, 2020; Nurmi-Koikkalainen, Hintsala & Voutilainen, 2020; Union of the

Employers of Personal Assistants in Finland, 2020). Not only are many persons with disabilities in the risk group, but the pandemic has also affected for example the provision of different disability services. According to Nurmi-Koikkalainen, Hintsala and Voutilainen (2020), the situation in the municipalities was challenging to begin with, even before the pandemic, since many of them reported having difficulties keeping the legislated time frames for making client decisions and for being able to provide the various services requested. Due to the pandemic, the differences between municipalities increased since some of them partially interrupted the provision of disability services, whereas some partially tried to provide compensating services. Especially in the beginning of the pandemic, the restrictions were also somewhat excessive and even illegal as it turned out (Supreme Administrative Court of Finland, KHO:2021:1), though the situation has improved over time. Nurmi-Koikkalainen, Hintsala and Voutilainen (2020) continue to point out that since the social contacts even to family members have been minimized, and for example the work and daytime activities have mostly been paused, persons with disabilities have overall become even more isolated than before. This, in turn, has sometimes led to feelings of loneliness and insecurity, and to mental health problems. Due to sick leaves and quarantines, there has also been an increased lack of staff in the disability services. The pandemic has with its restrictions in many ways also been challenging for family members and parents to children with disabilities. Furthermore, it is likely that even after the pandemic itself will not pose a major medical threat, it will have long lasting negative effects on the economy and welfare states, and thereby probably also complicate the funding of disability services and support (Honkatukia, 2020; Nurmi-Koikkalainen, Hintsala & Voutilainen, 2020).

4.3 Disabled persons' living circumstances and use of services

As mentioned in chapter 2, the disability is an evolving concept and there is no clear-cut characteristics defining who is disabled or not. Therefore, there is no fully covering register over persons with disabilities in Finland, and in order to get an estimate of the number of people in question, data from several sources has to be combined (Väyrynen, 2017 in Nurmi-Koikkalainen et al. 2017). These include data from for example registers about persons with some specific disabilities and data about receivers of specific disability related benefits or services. There are for example around 18 400 persons that are registered to have a visual disability in Finland (Väyrynen, 2017 in Nurmi-Koikkalainen et

al. 2017). Another group are persons with an intellectual disability, which are estimated to be approximately 40 000 persons (Ministry for Foreign Affairs, 2019).

In order to estimate the number of persons with disabilities and to compare them to the population in general, surveys such as the national Terveys 2011 survey, including questions regarding vision, hearing, mobility, cognitive skills, self-care and communication, have been made. The questions used in the Terveys 2011 survey correspond to those recommended by the so-called Washington Group (Sainio, Sääksjärvi, Nurmi-Koikkalainen, Ahola & Koskinen, 2017 in Nurmi-Koikkalainen et al. 2017). The survey indicated that 13 % of all people over 29 years of age, i.e., an estimate of around 400 000 persons, have some kind of disability or limited ability to function. Having some kind of disability is however highly related to age since the percentage was only 6 % among people aged 29-64 years. The survey allows some comparisons between persons with some kind of disability and the population in general in Finland. For example, according to the survey, persons with some kind of disability seem to be less likely to be in a relationship with a partner than people in general. Furthermore, persons with disabilities tend to be much less likely to have a higher education. This can be seen as one of the underlying reasons as to why the employment rate is relatively low, around 35 %, for persons with some kind of disability. This rate is roughly only half of the rate of over 70 % for people in general. The share of retired was considerably larger among persons with disabilities than among the general population, around 40 % compared to around 10%. According to the survey, persons with some kind of disability tend to find it more difficult to make ends meet, which is likely a consequence of the lower employment rate compared to the population in general (Sainio, Sääksjärvi, Nurmi-Koikkalainen, Ahola & Koskinen, 2017 in Nurmi-Koikkalainen et al. 2017). Related to this, persons with disabilities were more likely to experience the service fees as an obstacle for seeing a doctor, compared to people in general.

Both regarding place of residence and form of housing, the national Terveys 2011 survey showed barely any differences between persons with disabilities and the population in general (Sainio, Sääksjärvi, Nurmi-Koikkalainen, Ahola & Koskinen, 2017 in Nurmi-Koikkalainen et al. 2017). Persons with some kind of disability seemed, however, to be less likely to live in households with at least three persons and more likely to be living alone than the population in general, which might be explained by age increasing the likelihood of having some kind of disability. Regarding social relationships, the survey indicated that

loneliness is about three times more common among persons with disabilities (16 %) compared to the population in general (5 %). Furthermore, the survey indicated that compared to the population in general, persons with some kind of disability participate less frequently in cultural and leisure activities, as well as in outdoor exercise. According to the survey, persons with disabilities did not experience their quality of life to be as good as people in general (Sainio, Sääksjärvi, Nurmi-Koikkalainen, Ahola & Koskinen, 2017 in Nurmi-Koikkalainen et al. 2017).

A description of service usage gives an even broader and more nuanced perspective on the lives of persons with disabilities. However, one needs to keep in mind that the individual need, and the severity of the disability is assessed separately for every service type (Väyrynen, 2017 in Nurmi-Koikkalainen et al. 2017). According to Väyrynen, (2017 in Nurmi-Koikkalainen et al. 2017), there were barely 6 600 users of personal assistance in 2009, when this service form became a subjective right in Finland. By 2016, the number had increased to a bit over 21 000 users of personal assistance and around 15 000 of them were in working age (National Institute for Health and Welfare, 2017). Personal assistance is to be provided in the sufficient extent for the disabled person's daily living, studying and labour-market participation, as well as an additional minimum of 30 hours a month for hobbies, societal participation, and social relationships, unless less can be regarded sufficient (Ministry for Foreign Affairs, 2019). Of all the users of personal assistance in 2016, 53 % used the service less than 10 hours a week and 24 % used it 10-24 hours a week (Ministry for Foreign Affairs, 2019; National Institute for Health and Welfare, 2017; Väyrynen, 2017 in Nurmi-Koikkalainen et al. 2017). Even though the municipalities have the financial responsibility for providing personal assistance, the users can act as employers of their assistants. Alternatively, the municipality can provide the service through a private or third sector service provider or by being the employer of the personal assistants (Ministry for Foreign Affairs, 2019). Since 2010, the share of users of personal assistance who are employers of their assistants has dropped from over 70 % to 57 % in 2016. At the same time there is an increase of the share of users who are provided personal assistance through the private or third sector as well as through service vouchers.

In 2016 the number of users of transport services for persons with disabilities was around 98 100, but less than 40 000 of them were persons of working age (Väyrynen, 2017 in Nurmi-Koikkalainen et al. 2017). Support for informal care is usually given to those who care for a family member. When

scrutinizing the ones that were cared for in 2016, almost 15 000 were under 65 years of age, but only around half of them were in working age, whereas the rest were under 18 years old (Väyrynen, 2017 in Nurmi-Koikkalainen et al. 2017). During the period from 2006 to 2016, the number of persons with disabilities living in service housing doubled from around 3 000 to over 6 000, but the biggest increase was among the ones over 65 years of age. In 2016, around 4 000 persons with disabilities in working age lived in service housing (Väyrynen, 2017 in Nurmi-Koikkalainen et al. 2017).

Specifically, regarding the about 31 000 adults with intellectual disabilities, it's estimated that nearly half of them live in some form of assisted housing (Ministry for Foreign Affairs, 2019; Pitkänen, Huotari, & Törmä, 2018). Among the rest there are about the same number who live independently as to those who live with their parents or other family members. During the past decade or so, the aim has been to decrease institutional living and enhance the opportunities for independent living of persons with intellectual disabilities especially through the KEHAS-project (Ministry of Social Affairs and Health, 2016a; Pitkänen, Huotari, & Törmä, 2018). The project's goal has been that by 2020 no persons with intellectual disabilities would live in institutions anymore. As a result, the number of persons with intellectual disabilities living in institutions has decreased from almost 3 000 in the beginning of the 21st century to roughly 500 in 2019 (National Institute for Health and Welfare, 2021b). During the same period, the number of persons with intellectual disabilities within the assisted living has increased significantly (Väyrynen, 2017 in Nurmi-Koikkalainen et al. 2017).

In 2018, a survey for persons with disabilities was conducted by Finnish Disability Forum for scrutinizing the realisation of disability rights based on the UN CRPD (Vesala & Vartio, 2019). According to this survey, individually tailored disability services are very important for persons with disabilities, as well as the individual service plans and the service mindedness of professionals (Finnish Disability Forum, 2019a; Vesala & Vartio, 2019). The survey highlighted though that there are some regional differences and that the amount of service provision, and/or quality of the services are not always experienced to be sufficient. For example, 70 % of the respondents used personal assistance, but only 57 % regarded the amount of assistance they received to be sufficient. Similarly, 66 % of the respondents used transport services but 41 % experienced the transport services to be insufficient and not meeting their individual needs. Furthermore, 79 % of the respondents reported needing rehabilitation, but around 45 % reported that they had received an

insufficient amount of rehabilitation. In addition, there were some respondents reporting not receiving enough interpretation services, or aids and assistive technology devices they needed (Finnish Disability Forum, 2019a; Vesala & Vartio, 2019).

4.4 Disabled persons' labour-market participation and experiences of discrimination

A recent publication from the Ministry of Economic Affairs and Employment states that by the end of 2019 there were 228 157 persons aged over 16 receiving the disability benefit from the Social Insurance Institution of Finland (Kela/Fpa) (Kyröläinen, 2020). Furthermore 141 000 persons received disability pension from the Social Insurance Institution and 134 000 persons received disability pension from employment pension companies at the end of 2019. In May 2020, there were 64 200 clients with a disability or a partial work ability who were registered at the employment offices and 35 800 of them were unemployed jobseekers.

As said earlier, the labour-market participation of persons with disabilities is significantly lower compared to the population in general. One of the main reasons seems to be discrimination, even though discrimination against persons with disabilities is prohibited in the Non-discrimination Act (30.12.2014/1325), as well as in legislation concerning both employees and officials (Ministry for Foreign Affairs, 2019). Disabled jobseekers have the right to the same employment office services as everyone else, i.e., their labour market participation can be supported by for example vocational rehabilitation or wage subsidies (Ministry for Foreign Affairs, 2019). In addition, the employers of persons with disabilities can apply for financial compensation for possible special arrangements required, for example for making the workplace accessible.

Despite the prohibitions against discrimination and the employment office services available, disabled persons' experiences give a different kind of picture of their labour-market participation. According to for example a survey by the Non-Discrimination Ombudsman for persons with disabilities in 2016, nearly 90 % of the respondents considered a disabled jobseeker to be in a weaker position despite having equal education and skills. Around 67 % of the respondents reported having been discriminated when seeking for employment. Furthermore, around 57 % considered the attitudes at workplaces to be negative or very negative towards disabled persons (Non-

Discrimination Ombudsman, 2016). The survey also confirmed disabled persons' low labour-market participation rate, and regardless of their education-level, an employed disabled person seems to be the exception rather than the norm. Still, persons with disabilities do not tend to report discrimination because they doubt reporting would change anything (Non-Discrimination Ombudsman, 2016).

In another survey for persons with disabilities conducted in 2017 by the Advisory Board for the Rights of Persons with Disabilities in Finland, the respondents experienced the realisation of disabled persons' rights to be rather poor, especially in terms of labour-market participation due to discriminating attitudes (Hoffrén, 2017). The results from the most recently conducted survey by Finnish Disability Forum in 2018, point in the same direction as the other earlier conducted surveys, since around 57 % of the respondents had experienced different forms of discrimination when entering the labour-market or as jobseekers (Finnish Disability Forum, 2019b; Vesala & Vartio, 2019). According to the survey, this was primarily seen to be caused by attitudes and prejudices portraying persons with disabilities as a financial burden for society, instead of picturing them as persons contributing through their knowledge and skills. Finally, the survey showed that nearly 60 % of those respondents in working age (25-65-year-olds) had also experienced poverty during the last two years (Finnish Disability Forum, 2019b; Vesala & Vartio, 2019).

For some persons with (usually intellectual) disabilities, labour-market participation is only made available through work activity as a form of daytime activities. This is a service form for those who are (regarded as) unable to participate in the labour-market, and in 2016 it was provided to roughly 9 800 persons with an intellectual disability and nearly 1 800 persons with other disabilities (National Institute for Health and Welfare, 2017). As said, the daytime activities can also include so called work activity, which means working, usually part-time, either in a special work centre or at a regular workplace. Persons with disabilities participating in this kind of work activity on a regular workplace can get support from a special work coach, but usually it does not mean getting a regular wage or any other work-related benefits, even if the tasks might be the same as for those who are actually employed. Instead, the disabled persons participating in this kind of work activity are paid only a small symbolic sum on top of their disability pension. There has however rather recently been a campaign lead by the Finnish League for Human Rights-organisation to highlight this difference in status between disabled persons

participating in work activities and their employed co-workers (Finnish League for Human Rights, 2019). The Non-Discrimination Ombudsman also initiated a campaign in 2018 for raising awareness about disabled persons' low employment rate (Non-Discrimination Ombudsman, 2018).

Disabled persons' labour-market participation was also highlighted through the previous Government's key project focusing on people with partial workability (Mattila-Wiro & Tiainen, 2019). As part of the project, a report was given on reforming the measures promoting access to employment and rehabilitative work activities for disabled persons (Paanetoja, 2019). According to a recent publication from the Ministry of Economic Affairs and Employment, disability services need to be able to support disabled persons' labour-market participation and job seeking in a more efficient way (Kyröläinen, 2020). In this sense, the municipal differences in service provision need to be minimised and disabled persons need to be able to move in search for a job or studies. According to Kyröläinen (2020), insufficient personal assistance and/or interpreter services should not complicate job seeking, delay a disabled person from taking on a new job, or be a hindrance for entrepreneurship. The right to transport services should also be extended and made more flexible to enable both job seeking and working, as well as combining work life and parenthood (Kyröläinen, 2020; Rasa, 2019). In addition, the disability pension system should be smoother, clearer, and more flexible to enable disabled persons' labour-market participation while also providing a solid personal financial security base. The support system for entrepreneurship should also be better equipped for supporting the entrepreneurship of persons with disabilities. Kyröläinen (2020) acknowledges that some persons with disabilities might need adaptations of the work tasks and/or workload and that health care services enhancing the personal work ability are also essential. Furthermore, the importance of (inclusive) education, study counselling, the opportunities offered by digitalisation, as well as of course the whole range of employment office services for both job seekers and employers are highlighted. Kyröläinen (2020) also points out the importance of information, and the need for employers to be made more aware of how to get different forms of support for recruiting persons with disabilities. Attitudes and discrimination of persons with disabilities are highlighted too, as well as the need for enhancing different forms accessibility and tackling discrimination on a more structural level rather than as individual cases (Kyröläinen, 2020).

Despite the legislation prohibiting all forms of discrimination for example due to disability, many disabled persons in Finland face it in their daily lives and it is not only related to labour-market participation. Ever since the Non-Discrimination Ombudsman's office was established in 2015, disability has been the second most frequent reason for reporting discrimination to the Ombudsman's office, and in 2018 it became the most frequent reason with 20 % of all the reported discrimination (Non-Discrimination Ombudsman, 2018). The reports about discrimination due to disability in 2018 were most frequently related to social- and healthcare services (22 %) followed by other private services (20 %) and other public services (19 %) (Non-Discrimination Ombudsman, 2018). Inaccessibility, both in terms of the physical environment, as well as regarding information, communication, and the digital world, can also be seen as a form of discrimination. The survey conducted by Finnish Disability Forum in 2018 shows that different forms of inaccessibility set some limitations regarding the societal participation of persons with disabilities (Finnish Disability Forum, 2019c; Vesala & Vartio, 2019).

As mentioned, the Non-Discrimination Ombudsman conducted a survey in 2016 especially among persons with disabilities about their experiences of discrimination. In addition to experiences of discrimination in general, the survey focused especially on access to products and services, employment, and digital services (Non-Discrimination Ombudsman, 2016). More than half of the respondents considered the attitudes towards persons with disabilities in general in Finland to be negative or very negative. Only around 14 % considered them to be good or very good and the rest regarded them being neutral. As mentioned, the attitudes were considered to be most negative at workplaces, whereas the most positive attitudes were seen to be found among NGOs in the third sector. The increase of digital services was often seen to make life easier, but they were also reported to be discriminating since around a third of the respondents had experienced difficulties in accessing digital information or digital services due to their disability. Around 64 % of the respondents reported that they had been discriminated in some area of life during the past year (Non-Discrimination Ombudsman, 2016). More than half of the respondents with disabilities had experienced discrimination regarding products and services, most commonly regarding transport services. Still, nearly 80 % had not reported the discrimination to anyone since many respondents considered it to be unlikely to change anything or not severe enough (Non-Discrimination Ombudsman, 2016).

Instead of highlighting only experiences of discrimination, the previously mentioned survey conducted in 2017 by the Advisory Board for the Rights of Persons with Disabilities focused on the realisation of disabled persons' rights in relation to the UN CRPD (Hoffrén, 2017). As said, the respondents in this survey experienced the disabled persons' rights to be rather poorly realized overall. Disabled persons' participation in decision-making, their equality in society, the awareness of disabled persons' rights, accessibility, independent living and participation in the community, mobility, and transport, were considered to be on a rather poor level according to the survey. The respondents therefore called for a change of attitudes through raising awareness in society about disability rights. Disabled persons' standard of living and their social security were also regarded to be some of the most important things in need of improvement. Furthermore, the respondents called for an increased inclusion of persons with disabilities in decision-making concerning themselves and for improved accessibility in society (Hoffrén, 2017). In addition to this, the survey conducted by Finnish Disability Forum in 2018 also highlighted some respondents' experiences of disability related discrimination and mistrust from (health care) professionals regarding their (potential) parenthood and family planning (Finnish Disability Forum, 2019d; Vesala & Vartio, 2019), which is also in line with the findings in the study by Rasa (2019). The survey also showed that disabled women are in a more vulnerable position compared to their non-disabled peers regarding (sexual) violence (Finnish Disability Forum, 2019d).

5. Data and methods

In the first subchapter (5.1) of this section, the contributions of the thesis author and the co-authors' of the four articles included in this thesis is presented. In the following subchapter (5.2) summarises the aims and data for each of the articles, as well as the methods regarding both data collection and analysis (see Table 2). The last subchapter (5.3) presents some reflections on reliability, validity, and the thesis author's personal role as a researcher, as well as the interaction with the respondents in the two interview studies included.

Table 2 An overview of the aims, data and methods for the four articles.

	Aim of the article	Research questions	Data and method
Article 1. Research field's perspective	To explore the meaning of societal participation of working-age people with disabilities, and to map the scholarly understanding of facilitators and barriers relating to this phenomenon	1) What is the meaning of participation in society for persons with dis-abilities, that is, which areas of participation were highlighted in the studies? 2) Whose participation was discussed? 3) What kind of different barriers and facilitators regarding societal participation were highlighted?	32 peer-reviewed articles in English published 2012-2013 and focusing on Europe or some European country
Article 2. Political perspective	To analyse the impact of so-called active citizenship ideas on disability policies in Finland	a) How were people with disabilities portrayed as a group? b) What social rights were seen as essential for disabled persons? c) To what extent was the responsibility for fulfilling these rights delineated to public authorities, the private and third sector or individuals?	A Finnish parliamentary debate held in 16th May 2006 concerning the Government Report on Disability Policy 2006 including 90 speeches by 48 MPs
Article 3. Professional perspective	To shed light on how the social workers working with disability services consider the societal participation of people with disabilities in Finland today	1) What kind of meaning do the social workers give to participation, and how do they construct people with disabilities as a group? 2) What do the social workers see as obstacles for participation of people with disabilities, and what do they consider is needed to be done to rectify these obstacles? 3) What is the role of street level bureaucracy in the disability services in municipalities, and are there great differences between them?	10 face-to-face interviews with social workers from different municipalities in Ostrobothnia in Western Finland (Nov.2012-Jan.2013)
Article 4. Disabled people's perspective	To investigate how Finnish people with disabilities experience capabilities for societal participation in times of welfare state change	a) What are the disabled people's subjective experiences of societal participation? b) What barriers and facilitators are identified in this respect and how could societal participation of people with disabilities be strengthened?	13 individual face-to-face or phone/Skype interviews with persons in working-age with different kinds of disabilities (Sep.-Nov./2015)

5.1 Authors' contributions in the articles

As for the articles included in this thesis, the thesis author is the main author in all articles, and the sole author in article 3. Professor Mikael Nygård co-authored articles 1, 2 and 4, and acted as the supervisor of this thesis and the research during which all the included articles were written. In addition to Professor Nygård, Dr. Fredrica Nyqvist is also one of the co-authors in article 1.

Regarding article 1, all three authors participated in planning and outlining the study. Dr. Nyqvist's previous experience of literature reviews was valuable for the planning of the study, as well as for the selection and analysis of the data. The author of this thesis had the main responsibility for analysing the data and the writing process. Professor Nygård gave valuable input especially regarding the theoretical frame as well as regarding the language. Both co-authors provided also valuable feedback throughout the writing process of the article.

In articles 2 and 4 the thesis author collected and analysed the data and was also the main responsible for the writing process. Professor Nygård participated in the planning, contributed with input to the theoretical frame, and provided valuable feedback throughout the writing process especially regarding the language and structuring of the articles.

5.2 Summary of methodology

The aim of article 1 was to explore the meaning of societal participation of working-age persons with disabilities from a research perspective, and to map the scholarly understanding of facilitators and barriers relating to this phenomenon. Previous research was mapped by using scoping review, without any particular focus on the type of disability or methodological approach (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010). The selection process is illustrated in Figure 3.

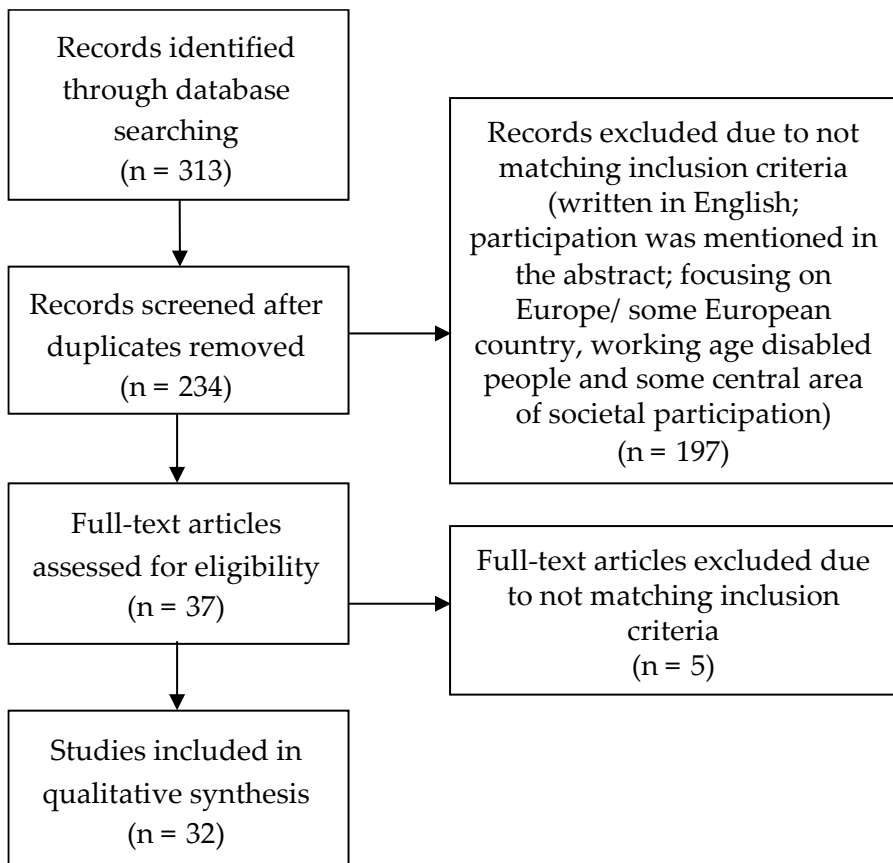


Figure 3 The selection process of the studies included in the scoping review of Article 1.

In accordance with the steps of a scoping review (Arksey & O'Malley, 2005), the articles included were selected by searching six central databases within social sciences¹ with 'participation' and 'people with disabilities' (and synonyms²) as keywords. The search was further limited to peer-reviewed

¹ Academic Search Premier [EBSCO], Applied Social Sciences Index and Abstracts [ASSIA], PubMed, Social Services Abstracts, Sociological Abstracts and Web of Science (limited to the research areas concerning specifically social sciences and social work)

² E.g. 'disabled persons', 'disabled people' and 'persons with disabilities'

studies published in English between January 2012 and December 2013 as well as to studies concerning working-age persons with disabilities. In order to avoid too much diversity regarding the societal contexts, studies focusing on Europe or at least some European country were only included. The database searches were done between December 2013 and February 2014.

The selection of studies in the scoping review included removing possible duplicates and identifying the final studies in accordance with the inclusion criteria. The titles, and abstracts of the remaining studies were thereby scanned by both the article's first author, and co-author Dr. Nyqvist as independent reviewers. Unclear cases were reviewed by the other co-author Professor Nygård as a third reviewer and followed by a consensus decision. Considering the inclusion criteria set, the data of the scoping review came to consist of 32 full-text articles.

The aim of article 2 was to study the political construction of disability policies in Finland through a qualitative content analysis of the parliamentary debate about the Government Report on Disability Policy 2006 in the Finnish parliament (Eduskunta). The debate included 89 speeches of varying length given by 48 of the two hundred Finnish Members of Parliament participating. The data was obtained by downloading the transcribed Finnish parliamentary debate and it was analysed during the autumn of 2009.

Speeches held on the Finnish parliamentary arena follow certain formal structures, such as time limits. Furthermore, they are likely to be influenced by the MPs' own pre-understandings of the debated theme as well as their party affiliation and parliamentary position, i.e., if their party is in office or opposition. The MPs participating in the debate represented both genders and different political parties, both those being in office and those in opposition at the time (see Table 3). There were, however, no conspicuous differences in opinions as to gender or party affiliation to be found, even though the actual political situation in the country was likely to reflect upon the debate. What made this debate exceptional, was that it was one of the first times that matters concerning disability policies became discussed from a very broad range of perspectives. In addition, the debate did not only focus on the state of disability policies at the time, but also on future visions and legislative changes needed. Matters concerning disability policies have of course been debated in the Finnish Parliament several times later too, but these debates have usually been far less extensive.

Table 3 The number of MPs by gender and political party (in office or opposition) in the parliamentary debate (Article 2).

	Number of MPs participating	Number of speeches
Total	48	89
Gender		
Women	23	46
Men	25	43
Political party		
Centre Party	11	19
Christian Democrats	3	4
Finns Party	1	2
The Greens	3	8
Left Alliance	5	9
The National Coalition Party	9	19
The Social Democratic Party	15	26
Swedish People's Party	1	2
Parties in office (Centre Party, The Social Democratic Party, Swedish People's Party)	27	47
Parties in opposition (Christian Democrats, Finns Party, The Greens, Left Alliance, The National Coalition Party)	21	42

Article 3 aimed at shedding light on how social workers handling disability services view the societal participation of persons with disabilities in Finland. This study was conducted by the thesis author as an interview study among social workers from ten different municipalities in Ostrobothnia in Western Finland (including both Coastline-Ostrobothnia and Southern Ostrobothnia). In the selection of municipalities and social workers, the size and language-group affiliation of the population in the municipality (Finnish-speaking, Swedish-speaking and a bilingual) were considered. The title 'social worker' is here used as an umbrella term for the interviewed professionals handling disability issues in the municipal organisation, even though four of them did not have the full educational competence required for social workers by the Finnish legislation.

The potential respondents were contacted by phone, and all of them agreed to being interviewed and were also sent additional information by e-mail. After two pilot interviews, the interviews with the social workers were conducted face-to-face between November 2012 and January 2013. The overwhelming majority of the respondents were women, and the sample of professionals included social workers with a varying amount of work experience ranging from less than a year and up to more than 20 years of experience. For most of the interviewed social workers, tasks related to disability services were the main part of their daily work, but there were also a few for whom these tasks were only a minor part of their daily job.

The aim of article 4 was to investigate how Finnish persons with disabilities experience capabilities for societal participation. Similar to the article on professionals, this study was also conducted as an interview study. The respondents were recruited through an advertisement published in a magazine of a disability organisation that operates as an umbrella organisation on a national level for persons with different kinds of disabilities. In addition, the advertisement was published in a Facebook-group for persons with different kinds of disabilities. This resulted in thirteen individual interviews with working-aged persons with different forms of disabilities. The interviews were conducted between the end of September and the middle of November in 2015. Ten of the interviews were done face-to-face, whereas three were done as telephone or Skype interviews due to a long geographical distance and/or in accordance with the preference of the respondent.

Ten of the respondents with disabilities were women and three were men. At the time of the interviews, the respondents were all between 34 and 64 years, which was in accordance with the aim of the study, i.e., to focus on working-aged people. This phase of life was chosen since the opportunities for societal participation can be considered to peak in terms of work, family life, leisure activities and engagement in organisations and/or politics. Eight of the interviewed persons with disabilities lived in western Finland, three lived in southern Finland in the Helsinki region, one in south-western Finland in the Turku region, and one on the Åland Islands. The group of respondents turned out to also have some variation regarding different forms of disabilities. Seven of them had some kind of mobility impairment, which meant that five of them used a manual or motorized wheelchair and two used other kinds of mobility aids, such as crutches or other kinds of support for walking. Three of the respondents had a visual impairment, one had limited functioning of hands, one had a psychological illness, and one had a mild learning disability. There was

also a variation in terms of the length of experience of living with a disability, since some of the respondents had been living with their disability their entire life, whereas others had been faced with disability at some point later in life.

All the interviews with both the professionals and the persons with disabilities were conducted by the thesis author alone. Furthermore, all interviews were semi-structured, which means that the respondents in each of the studies were asked the same set of questions, but the answers that were given did not follow any certain structure (Kvale & Brinkmann, 2014; Trost, 2010). All interviews were also recorded and transcribed.

All the data in the four studies included in this thesis: the selected articles in the scoping review, the parliamentary debate, and all the interviews with both professionals and persons with disabilities were analysed using *qualitative content analysis* (e.g. Mayring, 2000; Tuomi & Sarajärvi 2002). This is a rather straightforward 'research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns' (Hsieh & Shannon, 2005), and where the researcher still remains as neutral as possible (Mayring, 2000; Lundman & Hällgren Graneheim, 2008; Tuomi & Sarajärvi, 2002). Qualitative content analysis can be applied on various kinds of data, where the aim is to interpret the content, and find possible latent messages (Eskola, 2007; Mayring, 2000; Tuomi & Sarajärvi, 2002).

In accordance with the steps of qualitative content analysis, and in order to get an overview, the process started with some initial readings of the data material for each study. This was followed by the coding/categorisation process, which meant extracting text fragments from the material and organising them into themes/categories and subthemes/subcategories. This step can be done either through a *deductive* approach, where thematic categories are created before scrutinizing the data, or an *inductive* approach, where the data continuously steers the analysing process and the creation of categories (Elo et al. 2014; Eskola, 2007; Lundman & Hällgren Graneheim, 2008; Mayring, 2000; Tuomi & Sarajärvi, 2002). The approaches are however not mutually exclusive but can also be combined, and in all the studies included in this thesis, a mix of both approaches, i.e., a so-called *abductive* approach, was used. This meant, that although the specific research questions for each study set the starting point and an overall frame for the analysis, the content itself was analysed inductively. In both interview studies, the interview questions were also, alongside the research questions, setting the starting point for the analysing process without limiting it though.

In the coding/categorisation process patterns were found and thematic categories were created based on the extracted content of the data material for each of the four studies included in this thesis. The identifiable units of meaning varied from whole paragraphs to specific words or sentences. The number and hierarchy of categories was also sometimes shifting during the process when thematically similar (sub)categories were merged, or broad (sub)categories could occasionally be split. Throughout the analysing process, the data material was continuously checked for accuracy and for the contexts of the extracted text fragments. This process was rather uncomplicated, since the N'Vivo software (versions 9-11) was used as a tool for categorising the data in all studies except when the parliamentary debate was analysed.

In qualitative content analysis the coding/categorisation process is primarily a way of organising the data material, and thereby only a part of the whole analysing process (e.g. Elo et al. 2014; Lundman & Hällgren Graneheim, 2008). Once the data material was coded/categorized, common themes, patterns, emphases and even gaps could be distinguished. These findings provided, in turn, answers to the research questions. When the findings of the analysis were originally presented in the articles, they were illustrated and strengthened by quotes from the data. The quotes from the parliamentary debate and the interviews with the disabled persons were translated from Finnish or Swedish to English by the authors of these articles. In addition, the thesis author translated some of the quotes from the interviews with the professionals from Finnish to Swedish.

5.3 Reliability, validity, and the thesis author's role as researcher

Qualitative research, such as interview studies and qualitative content analysis of (usually textual) data, seeks primarily to reach a deeper and intersubjective understanding rather than to reveal an 'objective truth' (Kvale & Brinkmann, 2014; Lundman & Hällgren Graneheim, 2008; Tuomi & Sarajärvi, 2002). The validity and reliability, i.e., the trustworthiness of qualitative research, like interview studies and qualitative content analysis, is therefore usually and primarily strengthened through the description and justification of each step and choice along the whole process (Elo et al. 2014; Kvale & Brinkmann, 2014; Lundman & Hällgren Graneheim, 2008; Schilling, 2006; Tuomi & Sarajärvi, 2002).

Based on a literature review, Elo et al. (2014) have developed a checklist regarding trustworthiness for each of the phases of a qualitative study: preparation, organization, and reporting of results. In the preparation phase it is therefore important to consider how to collect the data and in the case of interviews the formulation of questions is crucial, as well as the awareness of the possible influence of the interviewer and the appropriate selection and number of respondents (Elo et al. 2014). Just before, or at the start of the actual organisation phase, i.e., the categorisation/coding of the data, the suitable unit of analysis has also to be set. According to Elo et al. (2014), the study's trustworthiness can in the organisation phase be strengthened by describing the creation of concepts and categories, as well as the consideration of interpretation, especially in the case the data is analysed by several researchers. In the reporting phase of a qualitative content analysis, the results should be presented both systematically and carefully, and most importantly, they should answer the study's aim and research questions (Elo et al. 2014). Here, the transferability of the results is crucial for the trustworthiness of the findings, i.e., whether they can be shifted to other and/or broader groups or contexts. Therefore, the trustworthiness and reliability of qualitative studies is usually strengthened by quotes from the data in order to support and exemplify the findings when reporting the results (e.g. Elo et al. 2014; Eskola, 2007). Elo et al. (2014) point out however, that the word limits for articles in scientific journals can be a challenge since the trustworthiness of a qualitative content analysis requires an adequate description of each phase of the process.

Regarding both interview studies as well as qualitative analysis, a certain degree of subjectivity is however acknowledged, i.e., referring to the somewhat unavoidable influence of the researcher/interviewer (Elo et al. 2014; Kvale & Brinkmann, 2014; Lundman & Hällgren Graneheim, 2008; Tuomi & Sarajarvi, 2002). Therefore, a certain amount of self-criticism and reflection is needed throughout the process, since especially the abstraction process can, at least to some extent, be dependent on the insight or intuitive action of the researcher (e.g. Elo et al. 2014). When it comes to disability studies, Watson (2004) points out that even if the research, especially when stemming from the social model, has also had an underlying political agenda, persons with disabilities have often been passive objects of research i.e., non-disabled people have been in charge. Therefore, Watson (2004) calls for a more active role for persons with disabilities and for disability studies to increasingly highlight disabled persons' personal experiences.

As a continuation to the before mentioned, the thesis author's personal role as a researcher doing qualitative research (e.g., interviews) in disability studies will be discussed in this section. This is of importance, since I, as the thesis author, also have a disability. As earlier stated, all the interviews with both the professionals and the persons with disabilities were conducted by me. Since I use a motorised wheelchair and my stature is very short, I had to make sure of the physical accessibility of the place of all the interviews. Therefore, it was clear to all my respondents before the interview that I have a disability myself. Firstly, regarding the interviews with the professionals, I experienced the respondents to be genuine when I encountered them at their offices, even though they were aware of my disability in beforehand, and thereby could have been seeing me as too much representing the clients. Secondly, when interviewing the persons with disabilities I similarly experienced these respondents as being genuine too, since they freely and openly told me about their lives and experiences. Especially in the encounters with the respondents with disabilities, I also experienced that having a disability myself was beneficial in terms of understanding them and gaining their trust. What I did not foresee, however, was that several of the respondents with disabilities seemed to become somehow empowered during and after the interviews when they had been given a chance to speak about their experiences and viewpoints.

The data collection in the other two studies included in this thesis, i.e., the one from the political perspective and the one from the research field's perspective, did not involve any interaction with respondents, since the data was obtained through downloading the transcribed parliamentary debate from the Parliament's website and through systematic searches in scientific databases. As the thesis author and as a researcher my duty is and has been to be as neutral as possible, despite having a disability myself. My personal experience has however to some extent surely contributed to my preunderstanding of disability as a concept, disability policies, and the daily life of persons with some kind of disabilities. This increased preunderstanding has been a benefit and strength when studying the societal participation of persons with disabilities from all four perspectives.

Last, but certainly not least, the trustworthiness of all the studies included in this thesis is shown in the fact that they have all been published as scientific articles. The study from the research field's perspective, the study from the political perspective and the study from disabled persons' perspective have all been published as articles written in English in international peer-reviewed journals. The study from the professional perspective has, in turn, been

published as an article written in Swedish in a national peer-reviewed journal. This means that all four studies included in this thesis have been anonymously peer-viewed in order to be published articles in scientific journals. The key findings from each of the studies is summarized in chapter 6 and further discussed in chapter 7.

6. Main findings

This section presents the main findings from the four articles, which each focuses on the societal participation of persons with disabilities from different perspectives. In addition, a summary of the findings from the articles can be found in Table 4 at the end of this chapter. In chapter 7, the findings are discussed further in relation to the research questions and both the theoretical and contextual frames of this thesis.

As to the key findings from the study from the research field's perspective (article 1), the selected articles in the scoping review focused mostly on persons with disabilities in general (instead of persons with some specific disability) and labour market participation was the most studied area of societal participation. Financial barriers (either on an individual or on a societal level) and negative attitudes were the most highlighted barriers, followed by unemployment and health related issues, or the disability itself. The most highlighted facilitators related to legislation and disability policies, which is no surprise since they are fundamental for regulating many facilitators such as accessibility and the provision of service and support. Other frequently highlighted facilitators were related to support from other people, changing attitudes, and increasing knowledge about disability as well as to employment opportunities for persons with disabilities.

Regarding the study from the political perspective (article 2), the MPs portrayed persons with disabilities as both (potentially) active citizens, and passive dependents of support. Furthermore, they were portrayed in the parliamentary debate as a group with equal rights to societal participation, self-determination and necessary service and support meeting individual needs. Barriers related to disabled persons' education, and employment were very much highlighted, as well as the importance of improving the opportunities for persons with disabilities to study and work. Personal assistance and accessibility in society were seen as crucial facilitators for participation, and regarding these, the MPs called for a more clarified and binding legislation. Municipalities were viewed from the political perspective as having a central responsibility for disability services, but due to the variations regarding resources, increased state responsibility was called for and complementary service producers were also welcomed. The emphasis of employment was a clear sign from the politicians that they favoured an active citizenship perspective and disability benefits were even suggested to be made more reciprocal. Both disability services and efforts for employment were seen to

aim at enabling disabled persons to more actively participate in society and to ensure equality of opportunity.

The key findings from the study from the professional perspective (article 3) show that the social workers saw persons with disabilities as a heterogenic group and both as (potentially) active, and as passive and dependent of support. Participation was seen, in terms of equality, both as a goal and a foundation, and as a human right as well. The social workers emphasized disabled persons' right to self-determination and involvement in planning and decision-making in the disability services, even though only a handful of them brought up the importance of the individual service plans. Negative attitudes and the lack of suitable and/or more rare service forms were seen as barriers for participation by the professionals. Accessibility was on the other hand seen as a crucial facilitator regarding the participation of persons with disabilities. The social workers also requested some improvements of the existing system of disability services in terms of increased flexibility, resources, binding rights and clarification of the disability legislation.

As for the fourth study from the disabled persons' perspective (article 4), the key findings show that the respondents emphasized equality and self-determination when defining societal participation. Many of the respondents felt rather involved in society too. Regarding different areas of participation, the respondents highlighted especially family life, studying and labour market participation, political and societal engagement as well as leisure activities. The most hindering barriers for societal participation were seen to be the bureaucratic, rigid, and often underfunded disability service system, as well as different forms of inaccessibility, negative attitudes, limited study and employment opportunities and health-related factors. Disability rights and services, like personal assistance, transport services and assistive technology, were on the other hand seen as the most important facilitators, alongside support from other people, inclusive attitudes and employment and studying opportunities. In addition to the facilitators, the respondents saw that participation could be further enhanced by increasing flexibility regarding disability rights and services and by increasing the involvement and self-determination of persons with disabilities.

Table 4 A summary of the findings from the four articles.

Findings in the article ↓→		Most highlighted			
	Perspective on persons with disabilities and/or societal participation	Areas of societal participation	Barriers	Facilitators	Ways to enhance participation
Article 1. Research field's perspective	<ul style="list-style-type: none"> • Mostly focus on persons with disabilities in general, but some focus on a certain age-groups or persons with some specific disability 	<ul style="list-style-type: none"> • Labour-market participation • Participation in leisure activities • Different perspectives on and policies related to disabled persons societal participation 	<ul style="list-style-type: none"> • Unemployment, lack of suitable employment opportunities, workplace environments and tasks, insufficient employment policies and support systems • Limited personal financial resources and limited resources within the public sector for disability services • Negative attitudes, stigmatization and discrimination • Discouragement and/or lacking expectations from other people • Lack of power, influence, and participation in decision-making • Unfavourable views on disability or changes in disability and/or welfare policies and benefits • Health-related issues, and/or the disability itself 	<ul style="list-style-type: none"> • UN CRPD, legislation, and disability policies • Support from and collaboration between professionals, decision-makers, family members and employers • Positive attitudes, values, viewpoints, attention, visibility, information, and knowledge • Self-determination, optimism, self-confidence, and participation in decision-making • Personal initiative, skills, qualifications, knowledge, and education • Individually tailored services, including personal assistance and assistive technology • Employment policies and suitable working opportunities • Financial resources and opportunities • Accessibility in the physical environment, transport, communication and information 	

	Perspective on persons with disabilities and/or societal participation	Areas of societal participation	Barriers	Facilitators	Ways to enhance participation
Article 2. Political perspective	<ul style="list-style-type: none"> • Persons with disabilities were referred to as one undifferentiated group: seen as a homogenous group, but with miscellaneous types of individual needs, as both dependent and (potentially) active, as labour-force resource and future taxpayers • Persons with learning disabilities or with mental illnesses were seen to be more dependent of support • Equality in terms of citizenship rights was emphasized and disabled persons should be guaranteed equal opportunities to participate in society, and especially to participate in the decision-making processes concerning themselves 	<ul style="list-style-type: none"> • Participation in decision-making concerning oneself • Participation in the decision-making in society in general • Education and labour-market participation 	<ul style="list-style-type: none"> • Lower educational level and employment rate, obstacles regarding employment • The municipalities tend to have limited resources, which place them in unequal positions when providing disability services 	<ul style="list-style-type: none"> • The right to personal assistance • Self-determination especially regarding choosing place of residence and one's assistants • An accessible environment and access to information • The right to be heard and understood and express one's will, interpretation services, aids, and technological solutions for communication • Financial support through social benefits 	<ul style="list-style-type: none"> • Improving education and employment opportunities, especially in the vocational and higher education • Increased financial responsibility by the state for disability services • More clarifying and binding legislation with subjective rights • Cooperation between public administration, clients, private and third sector • Employment needs to be promoted and the wage subsidy system renewed

	Perspective on persons with disabilities and/or societal participation	Areas of societal participation	Barriers	Facilitators	Ways to enhance participation
Article 3. Professional perspective	<ul style="list-style-type: none"> • Persons with disabilities were seen as a heterogenic group, and both as (potentially) active and as passive receivers of service and support • Societal participation was seen as fundamental and a part of the human rights, meaning to be heard and to be able to affect the decisions concerning oneself and to be able to equally and naturally take part in all areas of life and society 		<ul style="list-style-type: none"> • Inaccessibility in the physical environment • Negative attitudes, prejudices, lack of knowledge, non-disabled people's jealousy of disability services, and hardening values in society • Lack of suitable service forms 	<ul style="list-style-type: none"> • Accessibility was seen as crucial • Transportation service was seen as crucial 	<ul style="list-style-type: none"> • Improvement of the personal assistance system through more flexibility • Clarifications of the disability legislation • More subjective rights, i.e., less dependence of resources • More resources in terms of funding, time, and personnel

	Perspective on persons with disabilities and/or societal participation	Areas of societal participation	Barriers	Facilitators	Ways to enhance participation
Article 4. Disabled persons' perspective	<ul style="list-style-type: none"> • Equal value and right to participate in all areas of life was highlighted and the right to self-determination was seen as central 	<ul style="list-style-type: none"> • Family-life, education, labour-market participation, leisure activities and political engagement 	<ul style="list-style-type: none"> • Disability service and benefit system seen as rigid and vulnerable with complicated bureaucracy, regional differences, and insufficient resources and service provision • Lack of flexibility and understanding from professionals • (Uncertainty regarding) (in)accessibility related to the physical environment and information, which limits life choices • Discriminating, prejudicing or ignorant attitudes • Low self-esteem, feelings of loneliness, exclusion, and being a burden • Limited study and job opportunities • Health-related factors or the disability itself 	<ul style="list-style-type: none"> • The UN CRPD, the national constitution and disability legislation • Disability services, especially personal assistance, transport services, and assistive technology • Social support, acceptance, encouragement, appreciation, and supportive attitudes from close ones, such as family, friends, and peers, as well as professionals and decision-makers • Supportive and inclusive attitudes, and knowledge that are preventing prejudices • Inner strength, confidence, courage, active engagement, resilience, and fighting spirit • Financial resources and security in life • Physical therapy, rehabilitation, and health care services 	<ul style="list-style-type: none"> • Improvements of and sufficient resources for the disability service system • More flexibility in disability services and consideration of individual life situations • More self-determination • Increased accessibility by considering it already in the planning stage • Change of attitudes • More employment opportunities in regular jobs

7. Discussion and conclusions

As presented in the introduction, the overall *aim* of this thesis was to study and clarify how the opportunities to participation in society is constructed for persons with disabilities in Finland, and how this can be understood and problematized from a theoretical standpoint of equality. The aim was furthermore divided into three more specific *research questions*. In this chapter's first subchapter (7.1.) the findings from all four studies will be discussed in relation to the aim for the thesis and the research questions, as well as to the theoretical and contextual frame. In the next subchapter (7.2) the limitations of this thesis will be discussed, while suggestions for future research and disability policy developments will be included in the last subchapter (7.3).

7.1 Interpretation of the findings

The first research question asked how societal participation of persons with disabilities is portrayed and problematised in terms of theories of equality. Furthermore, this relates to how persons with disabilities are portrayed and whether they are seen as equal members of society. Since the introduction of the social model of disability the perspective on disability has shifted to being seen more as a societal matter, instead of just an individual tragedy and/or a medical abnormality (e.g. Barnes & Mercer, 2004; Lindqvist, 2009; Mitra 2006; Oliver, 2004; Vehmas, 2005). Through the more recent ICF model, the perspective on disability has been shifted again into a somewhat merged biopsychosocial model of disability (e.g. Mitra, 2006; 2018; Lindqvist, 2009; Vehmas, 2005; WHO, 2002; 2011). The primarily focus of all four studies included in this thesis was on persons with disabilities in general, instead of only persons with some specific form of disability. According to the findings, persons with disabilities were described as a heterogenous group, but with equal rights like everyone else and especially from the political and professional perspective as both (potentially) active citizens and passive dependents of support.

When it comes to participation and the evolving perspectives on disability, we can find some similarities between in the lack of actual participation at the two bottom levels of Arnstein's (1969) eight-step ladder and the lack of disabled persons' involvement in terms of the medical model of disability. But then again, the plans of introducing personal budgets in the Finnish disability

service system could be seen as a form of power-redistribution, at the top of Arnstein's (1969) ladder, back to persons with disabilities. The societal participation of persons with disabilities is in this thesis seen from a broad perspective, which is also in line with the ICF-model and the aims of safeguarding the rights in the UN CRPD (e.g. Mitra, 2006, 2018; United Nations, 2006; WHO, 2002, 2013), as well as the capability approach (e.g. Nussbaum, 2011; Sen, 1999). The capability approach emphasises especially equality of opportunities that people have to possess in order to be able to live their lives, and to participate in society, in accordance with their aspirations and goals (e.g. Hvinden & Halvorsen, 2017; Mitra, 2006, 2018; Nussbaum, 2011; Sen, 1999). Therefore, the right to self-determination is also fundamental for the capability approach. In line with that, a shared and strong emphasis of self-determination and equality regarding the rights and opportunities to societal participation for persons with disabilities could be found in all four studies included in this thesis. Participation in decision-making was however emphasised especially from the professional perspective, but also from the three other perspectives.

Disabled persons' experiences of inequality do however vary since they are a heterogeneous group, and the labour market is for example one area of life where persons with disabilities still have far from equal opportunities to participate. Consequently, this kind of inequality is also related to lower incomes and even poverty (e.g. Finnish Disability Forum, 2019b; Hoffrén, 2017; Kyröläinen, 2020; Non-Discrimination Ombudsman, 2016, 2018; Platt, 2011; Vesala & Vartio, 2019). Participation in the labour market was also one of the most highlighted areas of societal participation in the studies covering the research, political, and disabled persons' own perspective. The interviewed disabled persons' emphasis of labour-market participation can be interpreted as a clear expression of their desire for equal employment opportunities. The emphasis of labour-market participation can, from the research and political perspectives, be seen as both as a call for equal rights and employment opportunities for persons with disabilities, but also as an expression of an additional underlying goal to increase the employment rate for the benefit, not only on an individual level, but also on a societal level.

Furthermore, the study covering disabled persons' own perspective was, perhaps somewhat surprisingly, the only perspective highlighting family life as a form of societal participation. This indicates that persons with disabilities might be the ones having the strongest faith in their own ability to participate in this area of life as parents. This conclusion is also supported by the survey results highlighting disabled persons' experiences of discrimination and

mistrust from (health care) professionals regarding their (potential) parenthood and family planning (Finnish Disability Forum, 2019d; Vesala & Vartio, 2019). This can also be related to the statistics showing that persons with disabilities tend to be less likely to be in a relationship and more likely to be living alone and/or experiencing loneliness than the population in general (Sainio, Sääksjärvi, Nurmi-Koikkalainen, Ahola & Koskinen, 2017 in Nurmi-Koikkalainen et al. 2017). Furthermore, this can be said to signal a need for more research about societal participation through family life and for changed attitudes in general. Although this has been studied recently from a Finnish perspective by Rasa, 2019, she too, points out the scarce amount of research in this area. Furthermore, her research shows the prevailing attitudes that persons with disabilities are not expected to be parents, and that their ability and competence as parents is often questioned by different professionals, other non-disabled parents, and even by the children's peers. These attitudes, as well as the scarce research, highlight the need for increased awareness and consideration about this form of participation, especially among professionals, researchers and decision-makers.

In relation to the empirical findings from each of the four studies in this thesis the second research question asked what the main barriers and facilitators are regarding societal participation for persons with disabilities, and how societal participation can be enhanced. In line with the theoretical frame presented, especially in subchapter 3.4, the ICF model of disability and the UN CRPD consider the contextual factors (e.g. Mitra, 2006; Petman, 2010; United Nations, 2006; WHO, 2002) and the capability approach distinguishes the so-called capability inputs, i.e. the factors that determine real opportunities available to live in accordance with one's aspirations and goals (e.g. Hvinden & Halvorsen, 2017; Mitra, 2006, 2018; Nussbaum, 2011; Sen, 1999). As seen in the presentation of the contextual frame of the Finnish disability policies, the societal participation of persons with disabilities is affected by many (often interrelated) factors, both barriers and facilitators. This is also supported by the findings from the four studies included in this thesis.

As to facilitators and barriers highlighted in the four studies, attitudes were seen both as potential barriers and facilitators especially from the research, professional and disabled persons' perspectives. To some extent, the attitudes were also seen to be reflected in the experiences of society's (sometimes lacking) faith in disabled persons' potential, as well as their own faith in their abilities, opportunities, and resilience (or the lack thereof) (cf. Isola et al. 2017). The fact that disability has been the most or second most frequent

ground for discrimination reported to the Finnish Non-Discrimination Ombudsman's office is a clear signal though, that negative attitudes are a barrier for the societal participation of persons with disabilities (Non-Discrimination Ombudsman, 2016, 2018). The way the society is structured and fails to include everyone is also a form of indirect discrimination. Inaccessibility regarding both the environment and the (especially digital forms of) information and communication can also be seen as a form of discrimination, which was seen in the surveys by the Non-Discrimination Ombudsman and the Finnish Disability Forum (Finnish Disability Forum, 2019c; Non-Discrimination Ombudsman, 2016; Vesala & Vartio, 2019). Therefore, it is no surprise that accessibility was seen as an important facilitator of societal participation, and the lack of it as a barrier, from all four perspectives included in this thesis.

In line with the capability approach (and the economic causes and consequences of disability it brings up), disabled persons' participation in the labour-market was highlighted from several perspectives included in this thesis. Therefore, barriers related to studying, and even more so to employment, were highlighted especially from the research and political perspectives, but also by the interviewed disabled persons themselves. This can be seen as very justified, since both the educational level and the employment rate are lower for persons with disabilities compared to the population in general (Sainio, Sääksjärvi, Nurmi-Koikkalainen, Ahola & Koskinen, 2017 in Nurmi-Koikkalainen et al. 2017). In addition, several national surveys have recently shown that persons with disabilities often face negative attitudes and discrimination related to labour-market participation (Finnish Disability Forum, 2019b; Hoffrén, 2017; Non-Discrimination Ombudsman, 2016; Vesala & Vartio, 2019). Disabled persons' underdog position in the Finnish labour-market is also apparent based on the fact that many of those persons with (especially intellectual) disabilities who get to participate in the labour market, only get to do so through so-called work activity which does not include a regular salary or other employment benefits (Finnish League for Human Rights, 2019; National Institute for Health and Welfare, 2017). As a kind of contrast to this, the findings presented in this thesis show that persons with disabilities were also portrayed as a labour force resource, both by the interviewed persons with disabilities and the politicians participating in the analysed debate. In addition, were efforts for enhancing disabled persons' labour market participation seen to benefit both society and persons with disabilities. Aside from different campaigns against disabled

persons' labour-market discrimination, the Ministry of Economic Affairs and Employment as well as the Ministry of Social Affairs and Health have recently taken some initiatives aiming at mapping the barriers related to disabled persons' labour market participation (Finnish League for Human Rights, 2019; Kyröläinen, 2020; Mattila-Wiro & Tiainen, 2019; Non-Discrimination Ombudsman, 2018; Paanetoja, 2019).

In line with the capability approach and the economic causes and consequences of disability, financial barriers were brought up both on disabled persons' individual level, and on a societal level, especially from the research perspective and the disabled persons' own perspective. These limited resources on the individual level are often a consequence of the above-mentioned barriers related to disabled persons' labour-market participation and/or insufficiencies in the welfare benefits (e.g. Sainio, Sääksjärvi, Nurmi-Koikkalainen, Ahola & Koskinen, 2017 in Nurmi-Koikkalainen et al. 2017). The financial barriers on a societal level are however often a consequence of the municipalities' varying or limited resources for providing disability services and enhancing accessibility (e.g. Rätty 2010). There has also been signs of austerity on the state level linked to the renewal of the disability legislation and the attempt to reform the social- and healthcare system (e.g. Könkkölä, 2016).

From the research field's perspective, legislation and disability policies were the most highlighted facilitators and seen as something fundamental for the outcome of service and support for persons with disabilities. In line with this, more binding rights and clarifications of the disability legislation were called for especially from both the political and professional perspectives. As mentioned, the process to renew and collect the legislation concerning service and support for persons with disabilities under a new law has been ongoing since 2013 (e.g. Ministry for Foreign Affairs, 2019; Ministry of Social Affairs and Health 2015; National Institute for Health and Welfare – Handbook on Disability Services, 2019; 2021a). Together with Finland's ratification of the UN CRPD in 2016, the renewal of the legislation can at least to some extent be expected to answer to the requests of a more clarified and binding legislation. The importance of legislation and disability rights was also emphasised from the disabled persons' perspective especially in terms of facilitating societal participation, alongside different forms of disability services on a more practical level.

According to the findings especially from the political perspective, the public sector, and especially the municipalities, were seen as crucial for the provision of disability services. As said, there are however some variations in the services

available, and the implementation and interpretation of the legislation. Furthermore, there are varying/limited resources on the local level, and therefore the MPs participating in the analysed Parliament debate requested the state to take an increased financial responsibility for disability services and support. In the Finnish disability service system, there are also other actors involved in the provision of services, both private and third sector actors. As presented earlier, it is sometimes problematic for persons with disabilities if the service providers change very frequently due to reoccurring public procurement processes. The ongoing reform of the health and social services can be expected to bring both some changes and continuity regarding the responsibilities for, and actors involved in the provision of disability services. In the long run, the reform also aims at slowing down the cost increase.

Especially the interviewed persons with disabilities highlighted different forms of disability services as facilitators for societal participation and one of these were personal assistance, which was highlighted from the political perspective too. However, according to a recent survey, all those in need of it, do not seem to get the sufficient amount of personal assistance (Finnish Disability Forum, 2019a; Vesala & Vartio, 2019). Despite emphasising the meaning of certain service forms, the disability service system itself was seen as rigid and bureaucratic from the disabled persons' perspective and therefore also experienced as a barrier for societal participation. Interesting though, the professionals saw most of the barriers for participation to be "outside" of their daily work, i.e., outside the bureaucratic disability service system, which might indicate that they felt they could not do so much about enhancing participation.

Improvements of the disability service system were requested both from the disabled respondents and the interviewed professionals, where the latter especially called for increased resources. The disabled respondents, in turn, requested improvements in terms of increased flexibility and client involvement. These requests and the emphasis on more individually tailored disability services and individual service plans go fully in line with the responses to the survey by the Finnish Disability Forum (Finnish Disability Forum, 2019a; Vesala & Vartio, 2019). The requests could (or should) however be at least to some extent fulfilled already through the current legislation and disability service system, since the service provision should not be based on for example diagnosis, but on individual needs. The disability service legislation states also that the individual service plans should be made in co-operation with the clients (e.g. Rätty, 2010), but apparently there are still gaps in the implementation of this part. The findings from both the professional and

disabled persons' own perspective showed however the value of both the personal experiences among clients, but also the street level perspective among the social workers, regarding ways to enable the societal participation of persons with disabilities.

As presented earlier, especially in chapter 4, the surrounding societal context, with its values and political ideologies, aims and interests, as well as societal changes, such as the repeated and ongoing ambitions to reform the Finnish health and social services and the legislation of disability services, play a crucial role for the disabled persons' opportunities to equal societal participation. Therefore, the third research question of this thesis asked how the findings from the studies included (especially those closer to the grass root level) can be understood in relation to the context of the disability policies in Finland, as well as in relation to the human rights declared in the UN CRPD.

As for the context of the Finnish disability policies, this research question has already been partially touched upon in relation to the two previous research questions. On one hand, questions concerning persons with disabilities have been more on the political agenda in Finland, and there have been some important milestones not only in the form of reports and action-plans, but also for example in the strengthening of the right to personal assistance to a subjective right, and the ratification of the UN CRPD (e.g. Ministry for Foreign Affairs, 2019; Ministry of Social Affairs and Health 2006, 2009, 2010, 2018a, 2021). On the other hand, though, the pace of some developments can be seen as slow since Finland's ratification of the UN CRPD took nearly a decade and the renewal of the disability legislation has been going on since 2013 (e.g. Ministry for Foreign Affairs, 2019; Ministry of Social Affairs and Health, 2018a; National Institute for Health and Welfare, 2019, 2021a). The latter has been, as mentioned, delayed partially due to its linkage to other societal changes, especially the attempts to reform the social and health care system. Furthermore, the tension between strengthening disability rights through the UN CRPD, and weakening them through neo-liberal influenced austerity policies has been visible elsewhere (e.g. Parker Harris et. al. 2014; Randall & Parker Harris, 2012), and this might, at least to some extent, be(come) the case here in Finland as well. In the future, the reformed social- and healthcare system might come to cut down costs as well, which in turn, will in that case, unavoidably come to affect the resources for disability services. Most recently, the daily lives of Finnish persons with disabilities and the disability service system have been hugely affected by the COVID-19 pandemic (Nurmi-Koikkalainen, Hintsala & Voutilainen, 2020). Austerity policies

affecting the welfare state, and probably also the disability services and support, can be expected in the wake of the COVID-19 pandemic due to its negative effects on the economy (Honkatukia, 2020; Nurmi-Koikkalainen, Hintsala & Voutilainen, 2020).

Nevertheless, the UN CRPD is for its part, has been from the beginning, a very important milestone for the empowerment and equality of persons with disabilities and their participation in society. But the very fact that a specific UN convention is needed to safeguard the human rights for persons with disabilities on a global level speaks clearly that persons with disabilities have not been, and still are not, in an equal position in society (cf. Petman, 2010). This seems to be the case here in Finland too, even though the situation here is, from a global perspective, better than in some other countries. As presented earlier in relation to the previous research questions, the findings from all four perspectives included in this thesis also show that some of the rights or themes included in the UN CRPD were more highlighted than others. These were especially for example equality and non-discrimination, accessibility, education, work, and employment, as well as living independently and being included in the community (United Nations, 2006). Still, in spite of Finland having ratified the UN CRPD, Finnish persons with disabilities have at several occasions reported experiences of discrimination (e.g. Finnish Disability Forum, 2019c, Hoffrén, 2017; Non-Discrimination Ombudsman, 2016, 2018; 2019d; Vesala & Vartio, 2019). In addition, the survey conducted by the Advisory Board for the Rights of Persons with Disabilities signalled persons with disabilities experiencing their rights to be rather poorly realized regarding for example participation in decision-making, equality in society, accessibility, as well as independent living and participation in the community (Hoffrén, 2017).

One reason behind this, is probably the rigidity and bureaucracy regarding disability services and support that especially the interviewed respondents with disabilities highlighted. This experienced rigidity shows, in turn, that matters concerning persons with disabilities are still seen as issues to be treated within specific sectors of governance, when a greater, more holistic, flexible, and sector-overlapping view would be needed in accordance with the UN CRPD. Therefore, the UN CRPD has yet to make a stronger breakthrough and paradigm shift in the Finnish society. As Nurmi-Koikkalainen, Hintsala and Voutilainen, (2020) point out, the COVID-19 pandemic has also shown the need for increased flexibility in the disability service system and increased individually adapted services. This is needed in order to better be able to

respond to unexpected situations, needs and changes that for instance a global pandemic brings. In addition, the pandemic has shown the need of sufficient information to be provided in various accessible forms (Nurmi-Koikkalainen, Hintsala & Voutilainen, 2020).

The findings especially from the two interview studies, i.e., the professional's and disabled persons' perspectives go in line with the above-mentioned survey findings in terms of showing that the disability rights are not, or have still difficulties to be, fully realized in the daily life of persons with disabilities. Furthermore, the findings show many similarities between the viewpoints of both disabled persons (i.e., clients) and professionals regarding disabled persons' societal participation, i.e., what the barriers and facilitators are or might be, and how to enhance participation. Common ground could be found also in relation to the findings from the research field and the political perspectives. All these similarities, especially closer to the grass root level, indicate that an increased co-operation between clients with disabilities and professionals could be beneficial for an increased mutual understanding and for finding the best solutions regarding disability services, both on an individual level and a municipal, or even national, level.

7.2. Limitations

Despite shedding light on the societal participation of persons with disabilities from four different perspectives, this thesis has its limitations, as well as the four articles included. Regarding the study from the research field's perspective the data consisted of a selection of articles based on a scoping review. In order to get a manageable amount of data, the scoping review was however limited to a time span of only two years, as well as to articles written only in English and focusing on at least one European country, of which most turned out to be countries in Western Europe. In addition, the search was conducted only in social science databases, which consequently narrowed down the field of research areas. A wider time frame and geographical area, as well as databases covering other research areas might have given a somewhat different selection of articles. Despite these limitations, the selected articles matching the chosen search criteria ended up covering a rather wide range in terms for example both of research methods and areas of disabled persons' societal participation.

The perhaps most significant limitation of the study from the political perspective, in turn, is that the analysed debate took place more than a decade

ago and it might therefore be considered somewhat outdated. Still, it is even until today one of the thematically broadest debates held in the Finnish Parliament concerning disability policy. Furthermore, the political perspective in this thesis did not focus on the political participation or engagement of persons with disabilities. However, as shown in chapter 4, many of the developments in the Finnish disability policy have been rather slow and the analysed parliamentary debate can also be seen as a crucial starting/turning point in the process of Finland signing and ratifying the UN CRPD.

The interview studies from the professional perspective and the disabled persons' own perspective have limitations too. Firstly, as presented in subchapter 5.2 the number of respondents was rather limited in both studies. Furthermore, regarding the professionals, only social workers (used here as an umbrella term) were interviewed, instead of including other professionals as well. The geographical area was limited too, even though the professionals worked in municipalities of varying sizes in both urban and rural areas. As to the interviewed persons with disabilities, there were also a rather limited number of them and due to the chosen sampling method, the ones volunteering to participate in the study might have a stronger tendency to and desire for participation in general too. Therefore, they are not fully representative, even though they came to include a rather various spectrum of different life situations and experiences of having a disability. Still, there were for example no respondents with immigrant background and there was a dominating representation of persons with physical disabilities compared to for example persons with an intellectual disability. The similarities between the disabled respondent's experiences and the results from several of the national surveys indicate though, that the findings from the interviews could be to some extent generalized to a broader level instead of just being seen as a limited and isolated selection of individual experiences.

This thesis itself has also limitations. The theoretical frame in chapters 2 and 3 had to be limited somehow, even though societal participation for instance is a wide concept, which in this thesis too, is seen to include participation in all major areas of life. The contextual frame regarding the Finnish disability policies, the service and support system, as well as the living circumstances of persons with disabilities had to be limited too. On one hand the contextual frame had to be limited in terms of broadness, but on the other hand in terms of changes over time. In addition, it was limited to focus primarily on persons with disabilities in working age. As shown in chapter 4, disability policies and the issues concerning persons with disabilities are not limited to for example

matters related to social- and healthcare, but instead disability policies (should) span over all areas of society, governance, and decision-making. Furthermore, the welfare state, and disability policies within it, has its historical roots and is not something static but rather something constantly evolving. This brings us back to some of the limitations related to the data presented in the four studies included in this thesis. Even though it has been collected already some years ago, it is still relevant, as shown above when mirrored against more recent events. In addition, the data from all four perspectives support each other and contributes to forming a broader and more nuanced picture of the societal participation of persons with disabilities.

The main reason behind the data being collected by now already several years ago, is that finishing this thesis has taken longer than planned. As a continuance to the discussion in subchapter 5.3, it is undeniable that the thesis author's, i.e., my personal disability has played a part in this sense as well. Aside from some issues related to my health, my daily life as a disabled person is in many ways more time and energy consuming, and it requires planning, for example regarding personal assistance. Furthermore, I have also to some extent personally experienced similar barriers as presented here and as highlighted especially by the respondents with disabilities. I have for example sometimes been dealing with complicated bureaucracy to get necessary disability services or aids. On the other hand, I am grateful for having been very fortunate regarding both my studying and labour market opportunities. Especially regarding the latter, I have wanted to grasp the opportunities I have received because they have been interesting job opportunities. But at the same time, I have also been aware of the fact that the job opportunities or options are more limited for me as a disabled person compared to my non-disabled peers. Therefore, I have chosen to take on these unmissable job opportunities and been working more or less full time with other tasks, and working on the thesis on the side for more than the last two and a half years. This has, in turn contributed to delaying the finishing of the thesis.

7.3 Policy implications and suggestions for future research

The aim of this thesis has been to study and clarify how the opportunities to participation in society are constructed for persons with disabilities in Finland, and how this can be understood and problematized from a theoretical standpoint of equality. And as the acquired overview shows, there is still a need for improvement in many different aspects. Disability services are one of the

most crucial facilitators enabling participation, but as noticed earlier, the findings from especially the grass-root level show a need of strengthening the rights of persons with disabilities and developing the disability service system. A renewed and improved legislation is needed, especially to meet the clients' requests of more flexibility, individually tailored solutions, and a stronger voice in the decision-making processes. The renewed legislation is expected to also be welcomed by the professionals in terms of coming to provide a more clarified frame for their work. In terms of the participation of persons with disabilities, the aim of the ongoing process of reforming the legislation of disability services is to involve them and their organisations in several hearing sessions (National Institute for Health and Welfare - Handbook on Disability Services, 2021a). In addition, persons with disabilities have a crucial role in the collaboration with local social workers in developing a Finnish model for personal budgets (National Institute for Health and Welfare, 2020). Personal budgets might become one of the new tools enabling more flexible and individually tailored disability services. There might however be some risks involved for example in relation to for example the redistribution of the responsibilities between clients and professionals. Therefore, if personal budgets are introduced as a new way of service provision, they should be implemented cautiously and only on a voluntary basis, i.e., clients should not be forced or pressured to this form of service provision. In addition to legislative changes, the findings, especially from the grass-root level, showed the disability service system's need of especially increased financial resources for necessary service provision, but also its need of educated personnel.

One of the most important aspects of societal participation is labour-market participation, but in this aspect the opportunities for persons with disabilities are still far from being equal (cf. Kyröläinen, 2020). Sufficient and functioning disability services that meet the individual needs are therefore crucial for enabling both labour market participation, as well as other forms of societal participation. The same goes for accessibility and inclusive attitudes in society since these are also important facilitators for enabling the equal participation of persons with disabilities. Furthermore, accessibility and inclusive attitudes are very much linked together and dependent on increased awareness among decision-makers, professionals, employers, and the public in general. In addition, the realisation of for example different forms of accessibility is dependent of awareness, sufficiently strict legal requirements, thorough planning, and resources. This can, however, at best create a positive spiral where an accessible environment, including accessible information and

communication, enables people to participate in society regardless of their personal characteristics, like (dis)abilities. And the more persons with varying abilities are participating in all areas of life, the more it will raise awareness and expand the norm, which in turn can contribute to a more universally designed society. In the wake of this, attitudes will change too, as persons with disabilities can show their full potential both to others and the society as a whole, as well as to themselves and their peers. The increased active and visible participation in society of persons with disabilities will improve attitudes and for example contribute to mainstream universal design and the consideration of accessibility.

The combination of all four perspectives included in this thesis showed, that the highlighted areas of societal participation, the facilitators, barriers, and suggested actions for enhancing societal participation were very much related to and dependent of each other. Therefore, all four perspectives complement each other, and they all make an important contribution to the overview of the societal participation of persons with disabilities – what it means, what is hindering it, what is facilitating it, and how it can be further enhanced. The complimented picture acquired through the different perspectives also confirms, that increased and improved cooperation between persons with disabilities, i.e., clients, and professionals would be fruitful, as well as with politicians and the research field. The professionals, as well as politicians should have more time to stay up to date of needed and ongoing policy changes and research. But even more so, there also needs to be real opportunities for persons with disabilities to engage in and influence decision-making, disability policy developments, as well as disability research.

As a continuance from this thesis, the societal participation of persons with disabilities could be studied in relations to various areas of life and from more expanded and/or new perspectives too. Disabled persons' participation in terms of parenthood and family life is clearly still an understudied area, even though some recent research has been done (e.g. Rasa, 2019) and especially because many of the disabled persons themselves see this as one of the most important forms of participation. In addition to family life, further research is also needed about other areas of disabled persons' societal participation, for example regarding recreational and cultural activities. Furthermore, the professional perspective could for instance be expanded to include a wider range of different professionals in different positions, working on both a national and local level. Similarly, the political perspective could be expanded to focus on local politicians and/or on an international level, for example MPs

on the EU level. In addition, the societal participation of persons with disabilities could for example be studied from a media and/or social media perspective.

As mentioned earlier, the interviews seemed to have an unforeseen empowering effect on the respondents with disabilities, which made me personally mostly glad, but also a bit surprised and confused. Furthermore, these reactions of empowerment might indicate that some of the respondents with disabilities had rarely been given a similar chance to speak about their experiences and viewpoints. Perhaps most importantly is therefore, to continue to give the voice to people with disabilities themselves both within research and decision-making in accordance with the motto of the disability movement: “nothing about us without us.”

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Equal participation in society?

Perspectives on the opportunities of persons with disabilities in Finland

This doctoral thesis studies the opportunities for participation in society in relation to persons with disabilities in Finland. The thesis includes four different perspectives: the research field's perspective, the political perspective, the professional perspective, and disabled persons' personal perspective. Together these perspectives provide an overview on how the participation in society for persons with disabilities can be understood in terms of equality, which barriers and facilitators affect it, and to see how it can be enhanced.