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**Creating capabilities for societal participation in times of welfare state
change? Experiences of people with disabilities in Finland**

Elisabeth Hästbacka and Mikael Nygård

Abstract

Societal participation is central for disability policies throughout the world. In a Finnish setting, it is firmly anchored in the welfare state's commitment to create equal capabilities, but it is also dependent on other prerequisites, such as an inclusive labour market. However, these commitments have become both increasingly important through efforts of strengthening the rights of people with disabilities as well as increasingly challenged by crumbling growth and recurrent austerity measures in social policy. This article explores societal participation of people with disabilities in Finland in times of the recent ratification process of the UN CRPD and welfare cuts, and investigates the subjective experiences of societal participation in a changing welfare state context. The data consists of 13 individual qualitative interviews among working-age people with different kinds of disabilities. The findings highlight the importance of state commitment for creating equal capabilities for societal participation and for removing barriers standing in its way. They also suggest that this commitment is becoming both strengthened by the UN CRPD and weakened by the economic crisis and austerity measures and that this may have an undermining effect upon capabilities for persons with disabilities to participate in society.

Keywords: people with disabilities, societal participation, welfare state change, capabilities, interview-study, Finland

1. Introduction

Over the last decade, societal participation has become increasingly emphasised in disability policies. Societal participation refers to the capacity to participate in relevant areas of society, such as the labour market or leisure activities (Van Wel & Landsheer, 2012). The United Nations Convention on the Rights of Persons with Disabilities (hereafter UN CRPD) emphasises the “[f]ull and effective participation and inclusion in society” (United Nations, 2006). However, disabled people’s real-life experiences of societal participation are conditioned by practical factors, which are also called conversion factors (Hvinden & Halvorsen, 2017). These may consist of barriers, for instance inaccessible environments, or facilitators that enable and enhance societal participation, such as education and employment opportunities. As a member of the Nordic welfare state model, Finland has sought to encourage societal participation by providing – for example – legislated services to persons with disabilities and the right to participation is one of the main principles of the disability policy (e.g. Ministry of Social Affairs and Health, 2010). In 2016, Finland also ratified the UN CRPD, which can be seen as a commitment to safeguard and strengthen the rights of people with disabilities.

However, after the financial crisis in 2008-2009, such state commitments have become challenged by crumbling growth and recurrent cuts in social expenditures (Farnsworth & Irving, eds., 2015), which is likely to undermine the opportunities to societal participation. The aim of this article is to investigate how Finnish people with disabilities experience capabilities for societal participation in times of welfare state change. Two research questions are in focus: a) what are their subjective experiences of societal participation, and b) what factors, that can be both or either barriers and/or facilitators are identified in this respect? The latter question also illuminates how societal participation of people with disabilities could be

strengthened. The article is based on 13 individual qualitative interviews with working-age persons with various kinds of disabilities. Using a broad approach to societal participation and disability, the article contributes to the literature by offering a diversified analysis of what societal participation entails for persons with disabilities in a Finnish context. These questions, and especially studies of subjective experiences of societal participation, are inadequately addressed in previous research, and especially in a Finnish context. Some earlier works study participation in a general way (e.g. Hammel et al. 2008), while others focus on participation in some specific area of life (e.g. Solstad Vedeler & Mossige, 2010; Raisio, Valkama & Peltola, 2014) or on people with some particular disability (e.g. Saur & Johansen, 2013).

The article is structured as follows. In the next two sections, we present the context of the study, i.e. the Finnish disability policies and service system, followed by a discussion about theoretical perspectives on the societal participation of people with disabilities. After this, we present our data and methods and thereafter the findings. In the last section, the findings are drawn together and discussed.

2. Disability policy in a Finnish context

The three main principles of disability policy in Finland are rights to equality, participation and necessary service and support (Ministry of Social Affairs and Health, 2010). Disability benefits and rehabilitation are mainly provided by the Social Insurance Institution of Finland, whereas disability services are primarily provided by municipalities. Services are largely conditioned by individual need and some of them, for example personal assistance, are so called subjective rights for people with severe disabilities (Ministry of social affairs and health, 2009). This means that some rights cannot be denied a client due to a lack of

budgetary resources as long as legal criteria are met. People with disabilities also have a legal right to participate in decision-making concerning themselves through individual service plans. These were given a strengthened role in 2009 and are (supposed to be) made in co-operation between the municipalities and the clients (Räty 2010; Ministry of Social Affairs and Health 2009).

Although disability services and support follow nationally binding legislation, there are variations in the local implementation due to discretion and austerity policies, which has led to varying resources available for disability services (e.g. Räty, 2010). The employment rate among people with disabilities is low, since only about a third of working-aged people with disabilities participate in the labour-market compared to around 75% for the population in general according to a survey by the National Institute for Health and Welfare in 2011 (Nurmi-Koikkalainen et al. 2017). Due to variations in the definition of disability statistics specifically about people with disabilities are however challenging to find (Ministry of Social Affairs and Health, 2018; Nurmi-Koikkalainen et al. 2017). Disabled people's labour market participation is only to some extent supported by for example vocational rehabilitation, wage subsidies and compensations to employers for possible special arrangements required. For many people with (intellectual) disabilities labour market participation is only made available through an arrangement where the wage is only a symbolic sum.

During the last decade, questions concerning people with disabilities have become more visible on the Finnish political agenda (cf. Ministry of Social Affairs and Health 2006, 2009, 2010). Legislative changes have been made both in order to prepare for the ratification of the UN CRPD, which took place in 2016, and to collect the legislation concerning service and support for people with disabilities under a new law (Ministry of Social Affairs and Health 2015). These processes have later come to involve also aims to cut costs initiated by the

Government elected 2015 (Könkkölä, 2016). The program of this current Government is much characterized by aims to cut down the obligations of the municipalities and balance the state economy through austerity measures (Prime Minister's Office Finland, 2015). The austerity measures have so far mostly been found on the local level since some municipalities have tried to cut down the costs by repeatedly opening up some of the disability services for competition for example regarding service accommodation. The frequent changes of service providers have led to discontinuity in services which in turn has turned out to be very difficult for people with severe disabilities (Ministry of Social Affairs and Health, 2018). As a part of the process of renewing the disability legislation, the Government suggested for example setting a national age-limit of 75 years for disability services. This was however later withdrawn and replaced by a search of alternative ways to cut down the state expenditures related to disability legislation (Könkkölä, 2016). In addition, the ongoing health and social services reform aims at cutting costs, which will unavoidably affect the resources available for disability services (e.g. Ministry of Social Affairs and Health, 2016). These 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 been visible for example in welfare to work programmes for people with disabilities in both the UK and Australia (e.g. Parker Harris et. al. 2014; Randall & Parker Harris, 2012).

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

The WHO International Classification of Functioning, Disability and Health (hereafter ICF) represents a combination of the previously dominating medical perspective on disability (attributing the cause of disability to the individual, who was also seen as the target for possible interventions) and the newer social model of disability (seeing inaccessibility,

discrimination or segregation as causing disability and viewing society as the target for interventions) (e.g. Mitra, 2006; 2018; WHO, 2002; 2011). The ICF thus suggests a biopsychosocial model of disability, defining it ‘as 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., 2008).

By contrast, participation has varying meanings depending on how, where and in relation to whom it is used. 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 a narrower concept than social participation, since it focuses more squarely on labour market participation, leisure, family life and politics rather than general social interaction (United Nations, 2006; Levasseur et al. 2010). The ICF model defines participation in a more general way, focusing on involvement in different domains of life, such as domestic life, community, social, and civic life (Levasseur et al. 2010; Mitra, 2018; WHO, 2002; 2013). Furthermore, the ICF model distinguishes between a person’s performance and capacity, depending on the hindering or facilitating impact of both personal and environmental factors (Mitra, 2018; WHO, 2002, 2013). 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, such as services, assistive technology or inclusive attitudes are factors that enable and enhance functioning and thereby increase societal participation (WHO, 2011). Some of these factors overlap and may even be related to and dependent on each other.

Societal participation for people 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 (hereafter CA) (e.g. Nussbaum, 2011; Sen, 1999). The CA highlights the opportunities and capabilities that people have 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). Furthermore, it refers to a person's options regarding what he or she can do or be i.e. which functionings he or she can achieve. The options available determine a person's actions, but they lose their value if there are no practical opportunities to put them into action (Nussbaum, 2011; Mitra, 2018). The CA distinguishes the so-called capability inputs (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 options available) and the actually achieved functionings (e.g. Hvinden & Halvorsen, 2017). The right of self-determination, i.e. a person's effective freedom, is fundamental for the CA and its value is not diminished even though some people with disabilities might need assistance in exercising their freedom of choice (Hvinden & Halvorsen, 2017; Morris, 2005; Nussbaum, 2011). Vorhaus (2013) however points out that the CA's emphasis on agency and freedom of choice might be problematic when it comes to people with profound disabilities, which is why a person's well-being should be put first if he or she is, in spite of every effort possible, unable to exercise his or her freedom of choice.

The CA coincides with the ICF in terms of acknowledging the various factors behind and the consequences of disability. Each person's capability set is determined by various factors, as well as the means available. Therefore, the economic causes and consequences of disability are highlighted, since people with disabilities tend to have lower incomes due to barriers related to labour-market participation and life-long dependence of social benefits (Mitra,

2006; Nussbaum, 2011; Welch Saleeby, 2007). People 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 desired functionings 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 those affecting the conversion processes can be either personal, social or environmental factors. Furthermore, they are often interrelated and can vary in scale from the micro level up to the macro level (Hvinden & Halvorsen, 2017). Equality of opportunities and the potential in each person are also crucial for the CA, 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 CA, the goal of disability policy should therefore be to increase the options, freedoms and capabilities of people with disabilities.

The ICF model has been criticised for overemphasising a person's performance instead of access to factors enabling participation and for insufficient consideration of a person's right to self-determination and subjective experiences (Hammel et al. 2008). Therefore, the concept of participation needs to be studied from the grass root perspective, i.e. through the personal perspectives and experiences of people with disabilities. In a study from the grass root perspective by Hammel et al. (2008), participation was described 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). . Furthermore, self-determination and the importance of being treated equally with respect and dignity was emphasised and the right to participation was seen to be based on access, opportunity and inclusion. Participation was seen as a 'personal and societal responsibility that required determination, advocacy and empowerment' and as a way to feel connected with other people.

(Hammel et al. 2008: 1459). Similarly, as Hammel et al. (2008) our study has the grass root perspective too. In addition, this article stresses the centrality of capability, equality and self-determination in the ways that people with disabilities relate to participation. In the following, we investigate whether this is the case with persons with disabilities in the Finnish context.

4. Methods

The empirical study was conducted through 13 individual qualitative interviews with persons with different forms of disabilities. This method was chosen since our research interest here is particularly focused on disabled people's personal experiences of societal participation. The respondents were found through an advertisement in a disability organisation magazine and through a Facebook group for people with different kinds of disabilities. In total fourteen persons announced their interest in participating, but due to difficulties in finding a suitable time and place for the interview, one of the respondents chose not to be interviewed. The interviews were conducted between the end of September and Mid-November in 2015 by using similar questions for everyone (see Appendix 1) (Trost, 2010) with non-structuralised answers. Most of the interviews were face-to-face interviews, except in three cases where telephone or Skype interviews were used due to the long geographical distance and/or the wish of the interviewed person. All interviews were recorded and subsequently transcribed. NVivo software (version 10) was used in the analysing process.

The data was analysed through qualitative content analysis, which refers to a '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, 1278; cf. Mayring, 2000; Tuomi & Sarajärvi 2002). This means that the extracted text fragments were categorised for meaning into different categories and subcategories. The

identifiable units of meaning varied from whole paragraphs to specific sentences. We used a semi-inductive variant of this method meaning that although our research questions and the interview questions set the overall frame for categorisation and analysis, the content within these main categories was analysed inductively. In this vein, the analysis focussed on the meaning and experiences of and the facilitators and barriers influencing the societal participation of people with disabilities.

The respondents constituted a rather heterogenic group in terms of disability, socioeconomic situation and other life conditions. Three were men, ten were women, and they were between 34 and 64 years of age, which corresponded with our aim to focus on persons in working-age. This phase of life can be considered as a peak of a person's opportunities to societal participation, since it usually is the time in life to work, have a family and be politically active. Eight of the respondents lived in western Finland, three in the Helsinki region in southern Finland, one in the Turku region in southwestern Finland and one on the Åland Islands. Seven of the respondents had some sort of mobility impairment and five out of these seven used a manual or motorized wheelchair, while the two others used crutches or other support for walking. Three persons had a visual impairment, one person's hands had limited functioning, one person had a mild intellectual disability and one person had a psychological illness. Some of the respondents had had their disability their entire life while others encountered it later in life. In order to illuminate the experiences and to validate our interpretations excerpts from the interviews are used in the result presentation. These excerpts are translated to English by the authors.

5. Findings

5.1. Meaning and experiences of societal participation

As to the first research question, all respondents described the overall meaning of societal participation first and foremost in terms of equality that is, having the same value and an equal right to participate in all areas of life and contribute to community, such as working, having a family or being politically active. They also saw the right to self-determination as central.

“Participation means that you feel free, and have opportunities, to participate in community alongside other people. You should not be limited to, or be more and less welcome in different contexts, but to be able to be anywhere where there are other people, regardless of whether they are disabled or not.”

(Respondent 3)

On a normative level, the respondents emphasised that people with disabilities should get the help and support they need for participating, since this can be regarded as a baseline yardstick of a just and equal society. The UN CRPD, the national constitution and national disability legislation were brought up as fundamentals for a functioning equality. In terms of personal experiences, most respondents felt rather involved in society and that they were able to participate at least in some areas of life within the frames of what they considered possible. Those who had encountered disability later in life said they sometimes found it hard to adapt, and to find new ways of societal participation. Still, these respondents expected, and hoped, that others would treat them in the same way as before and not be sidestepped in social situations.

Based on the personal experiences of the respondents, the areas of life that were seen as important fields of societal participation were family-life, education, labour market participation, leisure activities and political engagement. All respondents had some kind of

education and at least some experience of labour market participation. Regarding family-life, five respondents lived with a partner and children, and another two had children that were already grown-ups. Parenthood was overall described as giving a feeling of being like everyone else:

“Yes, I’ve experienced that having children has enhanced my participation quite a lot. Through [them] I have had to, and got the chance to, do exactly the same things that everyone else is doing. I do not really know how to describe it, but as I’ve said, that has made me come closer to what could be seen as a normal society.”

(Respondent 1)

5.2. Facilitators and barriers regarding societal participation

The second research question focussed on the conversion factors, i.e. facilitators and barriers related to societal participation. First of all, social rights and services for people with disabilities, such as personal assistance, transport services and assistive technology were put in the front as facilitators. Personal assistance was seen as crucial for participation on an equal and independent basis and for coping in daily life, that is, for studying, working, taking care of one’s home and children, leisure activities and social life. The importance of receiving a personal assistant was emphasized regardless of the variations in the need for assistance both among the respondents and over time. One respondent described it as follows:

“I was thrilled when [the assistant] came and ‘took me out’ [---] because otherwise I would just sit inside. [---] So, the assistant is very important. [---] Thanks to [the assistant], I can get out, which I had not been able to do for many years, and I’m able to go to cafés or to go shopping by myself.”

(Respondent 12)

Transport services and mobility facilitators were also seen as essential for being able to get out of one's home and to participate in society. This includes the right to use disability taxi (a certain amount of times a month within a limited area for the fee of public transport) and/or having adaptations made to one's own car. Transport services were seen as crucial especially for those unable to drive a car by themselves and in the wintertime. It was pointed out though that transport services should be made more flexible and equal nationwide. Furthermore, different aids and assistive technology, such as wheelchairs, crutches, walkers, the white stick, screen reading software for smart phones and computers and enlarging screens for printed text were seen as important. It was pointed out that the aids need to be individually suited and sometimes accompanied by guidance or training.

On the other hand, although legislated social rights and services were seen as crucial for daily living, the actual access to these rights were sometimes complicated by bureaucracy, regional differences in service provision as well as a lack of information when it comes to what kind of service and support one could apply for, or where to get them. The application process was often experienced as a constant struggle:

“It usually becomes such a rush when you need something and you cannot wait for weeks. [---] Some years ago, I knew that I would need certain forms of services [due to a scheduled surgery]. I nagged and nagged about my need of services, but could not seem to get my voice heard, because we could not get hold of the right people at the disability service centre. It felt like a constant struggle, [those responsible for disability services] did not understand the rush of it all. [---] Then the [surgery] day came ... and nothing had yet been resolved. [---] Well, in the end the matter was resolved while I was in the hospital, but if my spouse would not have continued nagging and calling them several times a day; it would not have been resolved.”

(Respondent 6)

These struggles with bureaucracy can be both time and energy consuming, which may result in resignation and a renouncement of entitlements. The Finnish disability service system was to some extent seen as both rigid and vulnerable in the sense of constantly being upheld with minimum staff and resources, which leads to outdrawn decision-making processes. Insufficient funding leads to insufficient service provision, which in turn complicates societal participation. Therefore, the respondents called for improvements of the disability service system in terms of better coordination and increased cooperation between municipalities. Sufficient resources were also called for since many feared a future degradation of services due to funding cuts.

Another barrier related to disability services can be found in the lack of professional flexibility and understanding, especially if persons with disabilities are not acknowledged as experts of their own lives. Many of the respondents had experienced that professionals, such as social workers, did not always understand their individual life situations and needs, their desire for an independent and equal life or what kind of consequences insufficient or delayed aids, adaptations and services had on their lives. For instance, nearly half of the respondents had experienced insufficient personal assistance with complicating effects on their daily living. The most frequent claim regarding how to enhance participation was therefore the request of more flexibility in disability services, and solutions considering individual life situations. In line with this, the respondents emphasised the importance of self-determination of people with disabilities. Sufficient provision of services at an early stage was also pointed out to spare the society from bigger costs in the future.

“There should be more flexible solutions to these things, how to get help and assistance, how to achieve autonomy, so that one gets to articulate the need for help that one has. [---] that they would listen to people's own perceptions of what would be a good solution [---] instead of coming up with solutions by themselves”

(Respondent 7)

However, several respondents brought up that the support from different professionals, such as those within disability services and health care or sales persons in shops, could also be a facilitator for societal participation. In addition, supportive attitudes among decision-makers, i.e. politicians on the local as well as on the national level, were brought up. Nevertheless, the most important form of social support from other people was seen to be received from the closest family and friends. The support and encouragement given by parents had made those respondents who had been disabled from childhood feel as normal and as equal as possible. For some, the parents’ role had been crucial for enabling their studies in a time when disability services were less developed than today. Partners, friends and children had also an important role in providing support and assistance.

“Yes, I was thinking of close ones, how one might forget how important one’s closest network is: your spouse first and foremost, and then, of course, one’s own children, and one’s own parents. [---] ... my mother's encouragement and support was extremely important in my opinion. Somehow, she never questioned my abilities just because I sit in a wheelchair.

(Respondent 1)

As the quote illustrates, the acceptance, encouragement and appreciation from close ones was considered important for one’s self-esteem. Last, but not least, the importance of peer support

was highlighted, as was disability organisations' role for bringing people with disabilities together and defending their rights and interests.

The treatment and the presence or absence of social support from other people are dependent of attitudes, which were also highlighted as a conversion factor related to societal participation. Therefore, supportive and inclusive attitudes emphasising equality, respect and appreciation serve as fundamental facilitators. Furthermore, persons with disabilities need to be acknowledged and appreciated for their value, strengths and potential, which in turn depends on the level of knowledge, visibility, recognition and empathy that they encounter. Even though the respondents saw a positive trend regarding attitudes towards people with disabilities they feared this might be threatened by increasing individualism and selfishness, which might diminish the resources for disability services. Overall the respondents emphasised that knowledge prevents prejudices, while ignorance creates fear.

The respondents highlighted that discriminating, prejudicing or ignorant attitudes are barriers for societal participation. Values focusing predominantly on performance and efficiency were also seen to counteract participation and foster exclusion. For example, some of the respondents said they had been overlooked, excluded, unappreciated, discriminated, labelled, disrespected or even offended by others due to negative attitudes. This was often the case in job interviews:

“...during all these 20 years, I have applied for many jobs and I am often invited to an interview, because my papers are good. But then when they see me, they are quite perplexed and ask me weird things, like ‘do you have a driver’s license?’ or other totally irrelevant things. [---] I mean, they are not asking other applicants those things. I have many times felt compelled to try to explain that it will be all right, I have my

own car and I have the right to assistance and so on, but [---] many times I have not been chosen because of this. I think I usually do well at the interviews but I do not remember how many times I have been put on reserve while they have chosen someone else for the job.”

(Respondent 5)

In addition to job-related situations, people with disabilities often encounter prejudices in social situations. People sometimes fail to see the person behind the disability and ask intrusive questions. Sheer ignorance may also explain inadequate efforts to increase accessibility and the abuse of disability parking spaces. Consequently, the respondents expressed a need to change the attitudes towards accessibility and towards people with disabilities – to see them as a resource in society.

Reportedly, due to negative attitudes and lack of support some respondents had low self-esteem and expressed feelings of loneliness, exclusion and being a burden for others. Therefore, many of the respondents underlined that one’s inner strength, confidence, courage and active engagement are essential for societal participation to become true.

“I have experienced that my disability has put obstacles in my way, I have had to stand up for myself more than one would otherwise have to do. But I'm quite used to that, I have some experiences that others have seen my disability before they have seen me as a person.”

(Respondent 2)

Resilience and fighting spirit was on the other hand seen as essential for overcoming barriers and challenges in life, for example fighting bureaucracy for one’s right to service and support. Finding possibilities and solutions, for example in relation to inaccessibility, requires

stubbornness and can be demanding, but also rewarding as this might inspire others too. Several respondents emphasised that people with disabilities need to join forces and support each other in fighting for their rights. They also had positive experiences from participation in decision-making through organisations, politics, media and social media.

Different forms of (in)accessibility was yet another rather frequently mentioned factor related to societal participation. Even though it is not directly linked to disability services, it can affect to what extent a person needs disability services like personal assistance or transport services. Physical inaccessibility, in terms of for example stairs, can hinder disabled persons from getting into buildings or public transportation, attending events or participating for example in politics or in their children's activities. Inaccessibility can also stem from infrastructural deficiencies such as sidewalks that are snowy or have high thresholds. The experiences of inaccessibility among respondents with sensory impairments were more related to information: they noted that printed information is rarely available in Braille and that information in digital form might sometimes be unreadable with screen reading software. Uncertainty regarding accessibility forces people with disabilities to plan and make inquiries in advance. Inaccessibility may also limit life choices, for example the choice of studying and working opportunities. One respondent had also found the local hospital not to be fully accessible when giving birth to her child, which made her wonder whether people with disabilities were actually expected to become parents. Some respondents had even experienced inaccessibility at home due to delayed adaptations when facing disability later in life or moving. Many of the respondents called for increased accessibility and requested that it should be considered already in the planning stage of public places and transport through consulting people with disabilities. This was seen as a more cost-efficient alternative for society too.

Study and job opportunities were also seen as an important factor facilitating social participation. While studies were seen as important for one's future working life, they may however, often be complicated by an insufficient amount of personal assistance or different forms of inaccessibility. Similarly, it is often difficult for people with disabilities to get a job, and some respondents experienced that the economic crisis had made this even harder. The barriers are not necessarily linked to the disability in itself, but to negative attitudes. The respondents pointed out that in Finland, people with disabilities often tend to be offered employment primarily through special arrangements involving only a symbolic wage on top of their disability pension. This was experienced as discriminating and having a hampering effect on equal employment opportunities. More employment opportunities in regular jobs were therefore called for. Some respondents, however, reported that they had found jobs, which made them feel very happy:

"...I regard employment as one of the greatest opportunities for achieving participation. It gives you the feeling that you are involved, you contribute, you are an important link, you get colleagues like any other person, and you also gain economically, which enables you to participate even more actively."

(Respondent 5)

Work is not only about receiving an income; it is also crucial for one's self-esteem, activity, sense of belonging and contribution to society. It also shapes attitudes in society and thereby has a greater meaning than just being beneficial for the individual. In spite of some negative experiences related to labour-market participation, the respondents expressed their desire to be able to show what they are actually capable of. Even though incomes were not always considered the most important benefit from labour market participation, they were

nevertheless seen as providing a fundamental financial security in life, and even so, if the incomes were low and/or solely disability benefits.

Lastly, health-related factors or the disability itself was also brought up as a hindering factor to participation in terms of for example having chronic back pain due to constant sitting in a wheelchair. Therefore, physical therapy, rehabilitation, health care services and training for visually impaired to move around independently were seen as essential for keeping up one's level of functioning for being able to return to work and ordinary life after facing disability later in life.

6. Conclusions

The aim of this article was to investigate how people with disabilities in Finland experience societal participation and the factors influencing it in times of a changing welfare state. The findings show that the right to equality and self-determination were central in the respondents' conceptualisations of societal participation and in terms of their personal experiences the vast majority felt rather able to participate in society. Self-determination and equality referred most squarely to opportunities of living one's life in the same way like everyone else and to be able to strive for one's dreams and goals in life. This conceptualisation is in accordance with the core idea of an equally and capacitating society (e.g. Hvinden & Halvorsen, 2017; Mitra, 2006; 2018; Nussbaum, 2011; Sen, 1999). One central aspect in this notion of equally shared capabilities is the ability to study and participate in the labour market, not least since this is closely linked to the prevention of limiting economic consequences of disability (Hvinden & Halvorsen, 2017; Bellanca, Biggeri, & Marchetta, 2011; Mitra, 2006; Nussbaum, 2011; Sen, 1999; Welch Saleeby, 2007). Since people with disabilities create a labour force resource, an enhancement of their participation

would benefit both themselves and the society as a whole. The experiences of our respondents show however, that the societal efforts made so far have been insufficient and that they to some extent have fostered segregation rather than inclusion in the labour market. Other highlighted central aspects of societal participation were family life, leisure activities and political participation. Here too, equally shared capabilities are central and most of the respondents felt rather included in this sense, although this was not always true.

In line with both the ICF and the CA (e.g. Mitra, 2006; Nussbaum, 2011; Welch Saleeby, 2007; WHO, 2011), and the discussion about conversion factors (Hvinden & Halvorsen, 2017), the findings show that real opportunities to participate in society are dependent of a number of factors which can be either facilitators or barriers, and that are often interrelated. For example, social support from other people such as family, friends, professionals, decision-makers and peers, was highlighted as an important facilitating factor. As to hindering factors, inaccessibility, discriminating and prejudicing attitudes, limited educational and labour market opportunities, and health-related factors were highlighted. The most highlighted conversion factors, both in terms of facilitators and barriers, were however the disability rights and the disability service system. On one hand disability services such as personal assistance, transport services or assistive technology, were highlighted as crucial facilitators that need to be safeguarded. As presented earlier, some of the recent developments and legislative changes in Finland's (e.g. the ratification of the UN CRPD), indicate constructive government concerns for the safeguarding and development of disability rights and services (e.g. Ministry of Social Affairs and Health, 2015).

On the other hand, the respondents saw the rigidity and bureaucracy of the disability service system, e.g. the lack of flexibility and understanding from professionals, such as social workers, as one of the main barriers for societal participation. In addition, regional differences

regarding both practices in and the resources available for disability services were brought up. Therefore, the respondents called for a more coordinated, flexible, individually tailored and deliberative service system, where the voices and experiences of people with disabilities are heard. In spite of service plans, people with disabilities still seem to be insufficiently involved in decision-making in matters regarding their own lives, as well as in decision-making on a societal level. This means, that even more efforts are needed for the safeguarding and development of disability rights and services, for example through the ongoing renewal of the disability service legislation.

These concerns and ambitions can however be easily surpassed, or even overthrown, by concerns for the overall financial sustainability of the Finnish welfare state and austerity measures following in their wake. The strengthened rights of people with disabilities have come to increase the obligations (and to some extent the expenses) of the municipalities, which has led to increased regional differences and a higher risk of austerity measures – even regarding disability services. This can also be found in the new aims to cut expenditures in the process of renewing the legislation concerning service and support for people with disabilities (Könkkölä, 2016; Ministry of Social Affairs and Health 2015; 2018). Furthermore, one of the aims of the ongoing health and social services reform has been to cut down costs. Based on this, the findings pinpoint a number of important factors that condition the feasibility of societal participation for people with disabilities in a Finnish context. Not only need there to be rights, but also elements ensuring central capabilities for all persons in order for a society of truly equal opportunities to become true (cf. Hammel et al., 2008). A further discussion about how these capabilities are safeguarded in the Finnish society, and how they will develop in the future, needs to take place elsewhere due to sheer volume. Here it perhaps suffices to say that in spite of many positive changes; at least some of our respondents' concerns for the future of disability policies are still justified.

Despite the limitations of this study (e.g. the small number of respondents), it illustrates a surprising richness in conceptualisations and subjective experiences of societal participation as well as the factors influencing it. Another limitation pertains to the sampling method. The selection of respondents through an advertisement might have generated a sample of more active and included persons as compared to people with disabilities in general, which makes it difficult to generalise the findings. As a consequence, further research is needed in order to capture the whole variety and complexity of societal participation from disabled people's perspective.

Our study shows that the experiences of people with disabilities is valuable regarding how to solve problems they face in their daily lives and how to enable and increase their societal participation. In addition to being the experts of their own lives, they tend to be rather well aware of the economic determinants in society and desire to participate and contribute. Therefore, there is a need to listen more carefully to persons with disabilities in matters regarding especially disability services and decision-making, but also to appreciate their experiences and inputs in society in general if their societal participation is to continue to be a corner stone and a goal for disability policies. Because as it is now, some of the ongoing changes in the Finnish welfare state do go against the core idea of the CA, since the aims to cut expenses are threatening some of the facilitators regarding the societal participation of people with disabilities. As effects of the rather recently ratified UN CRPD grow stronger and with the renewal of both the disability service legislation and the social and healthcare system, there are however much potential for a continuation of strengthening and developing the rights, opportunities and capabilities enhancing the societal participation of people with disabilities.

References

- Bellanca, N., Biggeri, M., & Marchetta, F. (2011). An extension of the capability approach: Towards a theory of dis-capability. *European Journal of Disability Research*, 5 (1), 158–176.
- Farnsworth K and Irving Z (2015). Austerity: more than the sum of its parts. In: Farnsworth K and Irving Z (eds) *Social Policy in Times of Austerity*. Bristol: The Policy Press, 9–21.
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J. & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30 (19), 1445–1460.
- Hsieh, H.-F., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15 (9), 1277–1288.
- Hvinden, B. & Halvorsen, R. (2017). Mediating Agency and Structure in Sociology: What Role for Conversion Factors? *Critical Sociology*, First Published January 9, 2017
- Könkkölä, K. (2016). *Vammaispalvelujen vaihtoehtoiset säästöt. Selvitysmiehen raportti*. Sosiaali- ja terveystieteiden ministeriön raportteja ja muistioita 2016:58 (Ministry of Social Affairs and Health). Available online: <http://julkaisut.valtioneuvosto.fi/handle/10024/75554> (Retrieved 1 April 2017).
- Lag angående specialomsorger om utvecklingsstörda*. 23.6.1977/519 (Law on Intellectual Disabilities). Available online: <http://www.finlex.fi/sv/laki/ajantasa/1977/19770519> (Retrieved 11 March 2011).
- Lag om service och stöd på grund av handikapp*. 3.4.1987/380. (Disability Services Act). Available online: <http://www.finlex.fi/sv/laki/ajantasa/1987/19870380> (Retrieved 8 March 2011).
- Leonardi, M., Bickenbach, J., Bedirhan Ustun, T., Kostanjsek, N., & Chatterji, S. (2006). The definition of disability: What is in a name? *The Lancet*, 368 (9543), 1219–1221.

- Levasseur, M., Richard, L., Gauvin, L. & Raymond É. (2010). Inventory and analysis of definitions of social participation found in the aging literature: Proposed taxonomy of social activities. *Social Science & Medicine* 71, 2141–2149.
- Mayring, P. (2000). Qualitative content analysis. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 1 (2), 1–28.
- Ministry of Social Affairs and Health. (2016). *Health, social services and regional government reform: Equal and cost-effective services for all*. Helsinki: Ministry of social affairs and health 9/2016. Available online: <http://alueuudistus.fi/en/fact-sheets> (Retrieved 15 January 2018).
- Mitra, S. (2006). The capability approach and disability. *Journal of Disability Policy Studies*, 16 (4), 236–247.
- Mitra, S. (2018). The Human Development Model of Disability, Health and Wellbeing. In *Disability, Health and Human development*. Palgrave Studies in Disability and International Development. Palgrave Pivot, New York
- Morris, J. (2005). *Citizenship and disabled people: A scoping paper prepared for the disability rights commission*. Available online: <http://www.leeds.ac.uk/disability-studies/archiveuk/morris/Citizenship%20and%20disabled%20people.pdf> (Retrieved 8 March 2012)
- Nurmi-Koikkalainen, P., Ahola, S., Gissler, M., Halme, N., Koskinen, S., Luoma, M-L., Malmivaara, A., Muuri, A., Sainio, P., Sääksjärvi, K. & Väyrynen, R. (2017). *Tietoa ja tietotarpeita vammaisuudesta – analyysia THL:n tietotuotannosta. (Disability-related information and information needs – an analysis of data production activities of the National Institute for Health and Welfare)*. Helsinki: National Institute for Health and Welfare. Discussion Paper 38/2017.

- Nussbaum, M. (2011). *Creating capabilities: The human development approach*. Cambridge, Mass: Belknap Press of Harvard University Press.
- Parker Harris, S., Randall, O., Fisher, K. & Gould, R. (2014). Human Rights and Neoliberalism in Australian Welfare to Work Policy: Experiences and Perceptions of People with Disabilities and Disability Stakeholders. *Disability Studies Quarterly*. 34 (4).
- Prime Minister's Office Finland. (29 May 2015). *Finland, a land of solutions. Strategic Programme of Prime Minister Juha Sipilä's Government*. Government Publications 12/2015
- Raisio, H., Valkama, K., & Peltola, E. (2014). Disability and deliberative democracy: Towards involving the whole human spectrum in public deliberation. *Scandinavian Journal of Disability Research*, 16 (1), 77–97.
- Randall, O. & Parker Harris, S. (2012). 'No Rights without Responsibilities': Disability Rights and Neoliberal Reform under New Labour. *Disability Studies Quarterly*. 32 (3).
- Räty, T. 2010. *Vammaispalvelut: Vammaispalvelujen soveltamiskäytäntö*. Vol. [4. uud. p.]. Helsinki: Kynnys.
- Saur, E., & Johansen, O. (2013). Stepping into the unknown – welfare, disability, culture and theatre as an opportunity for equality? *Research in Drama Education*, 18 (3), 246–260.
- Sen, A. (1999). *Utveckling som frihet*. Göteborg: Daidalos.
- Social- och hälsovårdsministeriet (Ministry of social affairs and health). (2006). *Statsrådets redogörelse om handikappolitiken 2006* [The Government Report on Disability Policy 2006]. Helsingfors: Social- och hälsovårdsministeriets publikationer 2006:10
- Social- och hälsovårdsministeriet (Ministry of Social Affairs and Health). (2009). *Ändringar av handikappservicelagen fr.o.m. 1.9.2009*. Available online: <http://stm.fi/sv/artikkeli/>

- /asset_publisher/andringar-av-handikappservicelagen-fr-o-m-1-9-2009 (Retrieved 11 April 2011).
- Social- och hälsovårdsministeriet (Ministry of Social Affairs and Health). (2010). *Ett starkt underlag för delaktighet och jämlikhet. Finlands handikappolitiska program VAMPO 2010–2015 (A strong basis for inclusion and equality. Finland's Disability Policy Programme 2010–2015)*. Helsingfors: Social- och hälsovårdsministeriets publikationer 2010:12
- Social- och hälsovårdsministeriet (Ministry of Social Affairs and Health). (2015). *Slutrapport av arbetsgruppen för revidering av handikapplagstiftningen*. Helsingfors: Social- och hälsovårdsministeriets rapporter och promemorior 2015:29
- Social- och hälsovårdsministeriet (Ministry of Social Affairs and Health). (2018). *Oikeus osallisuuteen ja yhdenvertaisuuteen. YK:n vammaisten henkilöiden oikeuksien yleissopimuksen kansallinen toimintaohjelma 2018–2019 (Right to social inclusion and equality – The National Action Plan on the UN Convention on the Rights of Persons with Disabilities 2018–2019)*. Helsingfors: Social- och hälsovårdsministeriets publikationer 2018:2
- Solstad Vedeler, J., & Mossige, S. (2010). Pathways into the labour market for Norwegians with mobility disabilities. *Scandinavian Journal of Disability Research*, 12 (4), 257–271.
- Trani, J.-F., Bakhshi, P., Bellanca, N., Biggeri, M., & Marchetta, F. (2011). Disabilities through the capability approach lens: Implications for public policies. *ALTER, European Journal of Disability Research*, 5 (3), 143–157.
- Trost, J. (2010). *Kvalitativa intervjuer*. Lund: Studentlitteratur.
- Tuomi, J., & Sarajarvi, A. (2002). *Laadullinen tutkimus ja sisällönanalyysi*. Helsinki: Tammi.

- United Nations. (2006). *Convention on the rights of persons with disabilities and optional protocol*. New York: United Nations. Available online:
<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> (Retrieved 20 November 2014)
- Vorhaus, J. S. (2013). Capability, freedom and profound disability. *Disability & Society*, 28 (8), 1047-1058.
- Van Wel, T. F., & Landsheer, J. A. (2012). Societal participation: examining the impact of a rehabilitation approach for young people with schizophrenia. *Journal of Psychiatric and Mental Health Nursing*, 19 (9), 792–798.
- Welch Saleeby, P. (2007). Applications of a capability approach to disability and the International Classification of Functioning, Disability and Health (ICF) in social work practice. *Journal of Social Work in Disability & Rehabilitation*, 6 (1–2), 217–232.
- World Health Organization. (2002). *Towards a Common Language for Functioning, Disability and Health ICF*. Geneva: World Health Organization. Available online:
www.who.int/classifications/icf/training/icfbeginnersguide.pdf (Retrieved 4 October 2016)
- World Health Organization. (2011). *World report on disability*. Geneva: World Health Organization. Available online: <http://www.who.int/disabilities/worldreport/2011/report.pdf> (Retrieved 23 January 2015)
- World Health Organization. (2013). How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. October 2013. Geneva: WHO

Appendix 1. Interview Guide

Theme 1: Background

- Gender, age, place of residence, language, type of disability
- Description of life situation
- Description of everyday life

Theme 2 & 3: Your own participation in society / The societal participation of people with disabilities in general

- What does participation mean for you / for people with disabilities in general?
- To what extent do you experience that you / people with disabilities in general are participating in society?
 - To what extent does your perceived participation in the community correspond with your own expectations in terms of your participation?
 - To what extent do you feel that disabled people's real participation in society is consistent with the expectations in society regarding the participation of people with disabilities?
- In which area(s) of life do you feel that the opportunities for participation are the most important for you / that the society mostly prioritizes disabled people's opportunities to participate?
- What do you think is needed for you / disabled people in general to be able to participate in different areas of life? What is the role of different enabling factors?
- Do you think there has been a change over time regarding your participation / concerning disabled people's participation in general, and if so, what kind of change has there been?

- Do you think that different forms of support and service within the disability services are supporting your participation / can support the societal participation of people with disabilities in general, and in which way in that case?
 - Is there any of these support and service forms, or any other factor, that you feel to be especially important for your participation / for the societal participation of people with disabilities in general?
- What potential problems or obstacles do you consider there are for your participation / for the societal participation of people with disabilities in general?
- How do you think the society and disability services should be developed in the future considering
 - ... your participation?
 - ... disabled people's participation in the municipality where you live?
 - ... disabled people's participation in society at large?
- How do you think possible actions to enhance your societal participation / the societal participation of people with disabilities in general should be motivated?
 - Why are they important to you / to people with disabilities in general?

Theme 4: Other

- Is there anything you would like to add?

Closing and thanking the respondent