

Näkökulmia vammaisten ihmisten yhdenvertaiseen osallisuuteen suomalaisessa yhteiskunnassa

Perspectives on the equal participation of people with disabilities in the Finnish society

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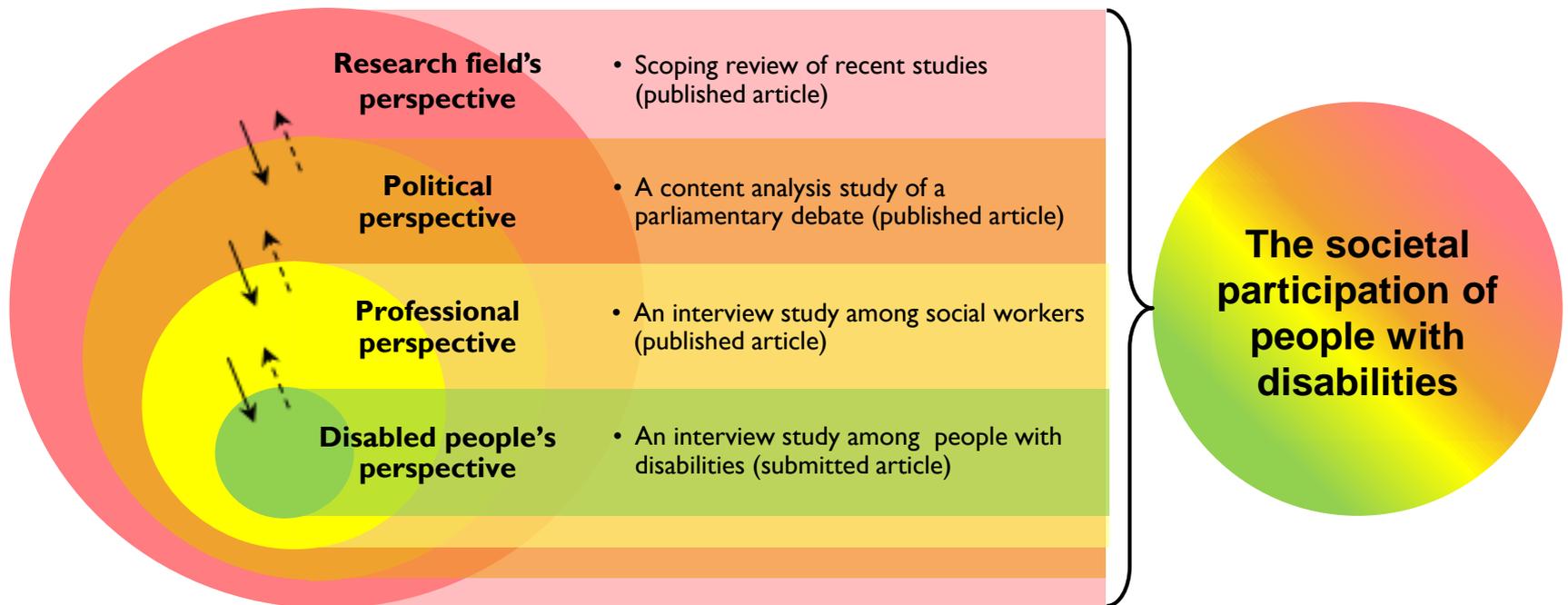
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Introduction and aim

- Societal participation is as a corner stone and a target of the Finnish disability policy and the disability policies internationally
 - e.g. the UN Convention on the Rights of Persons with Disabilities (2006) accentuates (in article 3 e) the “[f]ull and effective participation and inclusion in society”
- In spite of formal rights and political aims to promote participation of disabled people, there are still often different barriers limiting the opportunities to participate
 - e.g. inaccessible physical environments and negative attitudes
- Different facilitators are crucial for disabled people’s participation in society
 - e.g. disability services, assistive technology and inclusive attitudes
- The aim of my forthcoming doctoral thesis is to study and clarify how the opportunities to equal participation in society are constructed for people with disabilities in Finland
 - This is done from four different perspectives in order to get an overview and to distinguish which barriers and facilitators affect it

Studies included

- Research can provide a foundation for political decisions which set the rules and resources for professionals providing services that facilitate the societal participation of people with disabilities
- The studies included in my forthcoming doctoral thesis cover four different perspectives on the societal participation of people with disabilities:



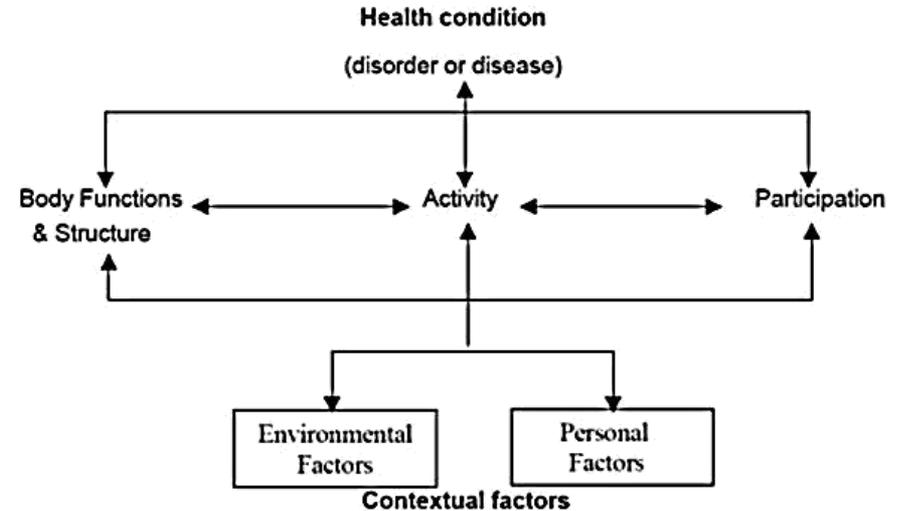
Simplified outline of the doctoral thesis

- Introduction
 - Previous research
 - Aim and research questions
- Different perspectives on disability
 - Medical and social model of disability, the ICF model
- Disability policy internationally and in Finland
 - Disability services (and the street level bureaucracy)
- Theoretical frame
 - Societal participation through the lens of the capability approach
- Methods and data
- Summaries and results of the articles
 - Research field's perspective on the societal participation of people with disabilities
 - Political perspective on the societal participation of people with disabilities
 - Professional perspective on the societal participation of people with disabilities
 - Disabled people's perspective on the societal participation of people with disabilities
- Discussion
- Concluding remarks

Central concepts

Disability

- According to the ICF (by WHO) disability is “a dynamic interaction between health conditions and contextual factors, both personal and environmental”
- The ICF-model is a “bio-psycho-social model” and can be seen as a combination of or compromise between the *medical model* and the *social model* of disability



Participation

- The concept of societal participation is understood and used in a broad sense, referring to different areas of life
 - e.g. decision-making processes, the labour market or leisure activities

Disability policy in Finland (1/2)

- Finnish disability policy is based on three principles which are the rights to:
 - equality, **participation** and the necessary services and support
- Finland's Disability Policy Programme 2010–2015: “A Strong Basis for Inclusion and Equality”
- Ratification of the UN CRPD in 2016
- “Right to social inclusion and equality” – The National Action Plan on the UN Convention on the Rights of Persons with Disabilities 2018–2019
- Disability services are now guaranteed in the legislation and stipulated by
 - the Disability Services Act
 - the Law on Intellectual Disabilities

currently in the process of being merged into a renewed Disability Services Act
- The legislative changes related both to the ratification process and the renewing of disability legislation have later come to involve aims to cut costs
 - The ongoing health and social services reform aims also at cutting costs, which will unavoidably affect the resources available for disability services
 - Tension between austerity policies and efforts to strengthen disability rights

Disability policy in Finland (2/2)

- The municipalities are mostly responsible for providing the disability services and their social workers implement the disability legislation
 - There are variations in the outcome of disability services due to for example differences in legislation interpretation and the amount of resources available
- Disabled people's employment rate is low and labour market participation is only to some extent supported by vocational rehabilitation, wage subsidies and compensations to employers for special arrangements etc.
 - For many people with (intellectual) disabilities labour market participation is only made possible through arrangements where the wage is just a symbolic sum
- Disability organisations and councils have also an important role in promoting the societal participation of people with disabilities

Societal participation through the lens of the capability approach (1/2)

- **The *capability approach* (CA)** sees participation as the capabilities and choices people have in their lives
- Instead of focusing on what people do, i.e. their functions, the CA highlights the aspirations, goals, possibilities and freedoms people have, i.e. their capability set
 - For example, the action, or function of both a person who is fasting and a person who is starving, is not eating, but the former chooses not to eat, while the latter is forced not to eat
- The options available lead to actions, but the options lose their value if there are no opportunities to put them into action
- The right of self-determination is fundamental for the CA and it focuses on which potential each person can reach
 - Key question: what is each person capable of doing and/or being?

Societal participation through the lens of the capability approach (2/2)

- The CA highlights also the economic causes and consequences of disability:
 - “A person who is disabled may have a larger basket of primary goods and have less chance to lead a normal life (or to pursue her objectives) than an able bodied person with a smaller basket of primary goods.” (Sen, 1999 quoted in Mitra, 2006)
- Reduced incomes can make a person even more disabled, and a disabled person is also more likely to have lower incomes
- In line with the CA the goal of disability policy should be to increase the options, freedoms and capabilities of people with disabilities

Research questions

1. How is the societal participation of people with disabilities constructed and defined?
 - What possible barriers or facilitators are related to it and how should it be enhanced?
2. What does societal participation of people with disabilities mean in terms of equality?
 - How are people with disabilities portrayed and are they seen as equal members of society?
 - Are the underlying motives related to the benefit of people with disabilities or to the benefit of the society?
3. How can the societal participation of people with disabilities be seen in relation to the Finnish society?
 - What are the effects of the political and ideological shifts and the ongoing changes in the society?
 - What is the role of the human rights declared in the UN CRPD, which Finland recently has ratified?

Methods and data

- The data consists of
 - 32 peer-reviewed articles in English published 2012-2013 and focusing on Europe or some European country were included in a scoping review
 - A Finnish parliamentary debate concerning the Government Report on Disability Policy 2006
 - 10 face-to-face interviews with social workers from different municipalities in Ostrobothnia in Western Finland (Nov.2012-Jan.2013)
 - 13 individual face-to-face or phone/Skype interviews with persons in working-age with different kinds of disabilities (Sep.-Nov./2015)
- **Qualitative content analysis** has been used for analysing the articles, the parliamentary debate and all the interviews
- The N'Vivo software has been used in analysing the data except for the parliamentary debate

Findings from four perspectives on the societal participation of pwd (1/4)

Elisabeth Hästbacka, Mikael Nygård & Fredrica Nyqvist (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



Findings from the research field's perspective:

- Focused mostly on people with disabilities in general and **labour market participation** was the most studied area of societal participation
- **Financial barriers** (either on an individual or a societal level) and **negative attitudes** were the most highlighted barriers
 - Followed by **unemployment** and **health related issues, or the disability in itself**
- Most highlighted facilitators related to **legislation and disability policies**
 - Lays the foundation to the regulations for many facilitators like accessibility and provision of service and support
 - Other frequently highlighted facilitators were related to **support from other people**, to **changing attitudes and increasing knowledge about disability** as well as to **employment opportunities**

Findings from four perspectives... (2/4)

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



Findings from the political perspective:

- People with disabilities were seen as both (potentially) active citizens and passive dependents of support, as well as a group with equal rights to societal participation, to self-determination and to necessary services and support meeting individual needs
- **Obstacles for education and employment** were very much highlighted, as well as the importance of **improving the opportunities** in this sense
- **Personal assistance** and **accessibility** were seen as crucial facilitators for participation and **more clarifying and binding legislation** was also requested
- Municipalities were viewed as central but due to varying resources, increased state responsibility was requested and complementary service producers were welcomed
- The **emphasis of employment** was the foremost sign of an active citizenship perspective and disability benefits were also suggested to be made more reciprocal
- Both disability services and efforts for employment were seen to aim at enabling disabled people to actively be part of society and to ensure equality of opportunity

Findings from four perspectives... (3/4)

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



Findings from the professional perspective:

- People with disabilities were seen as a heterogenic group and both as (potentially) active and as passive and dependent of support
- Participation was described in terms of equality, both as a goal and a foundation, and as a part of the human rights
- The right to self-determination and the involvement in planning and decision-making in the disability services were emphasized by the social workers even though only a handful brought up the individual service plans
- **Negative attitudes** and **lack of suitable and more rare service forms** were seen as obstacles for participation
- **Accessibility** was seen as crucial for disabled persons' participation
- Some **improvements of the existing system of disability services** were also requested in terms of more flexibility, resources, binding rights and clarifications of the disability legislation

Findings from four perspectives... (4/4)

Elisabeth Hästbacka & Mikael Nygård (submitted article): Creating capabilities for societal participation in times of welfare state change? Experiences of people with disabilities in Finland



Findings from the disabled people's perspective:

- *Equality* and *self-determination* were emphasized in defining societal participation and most respondents felt rather involved in society
- Most highlighted areas of participation were **family life**, **studying and labour market participation**, **political and societal engagement** as well as **leisure activities**
- Most important facilitators were seen to be **disability rights and services** like **personal assistance**, **transport services** and **assistive technology**, **support from other people**, **inclusive attitudes**, as well as **employment** and **studying opportunities**
- Most hindering barriers were seen to be **the bureaucratic, rigid and often underfunded disability service system**, **different forms of inaccessibility**, **negative attitudes**, **limited study and job opportunities** and **health-related factors**
- In addition to the facilitators, participation was seen to be further enhanced by **increasing flexibility regarding disability rights and services** and by increasing the **involvement** and **self-determination** of people with disabilities

Discussion and conclusions (preliminary) (1/5)

- In line with the CA all four perspectives shared a strong emphasis on *self-determination* and *equality* regarding rights and opportunities to societal participation for people with disabilities
- The four perspectives focused mostly on people with disabilities in general, instead of only people with some specific disability
 - They were described as a heterogenic group, but with equal rights, and from the political and professional perspectives as both (potentially) active citizens and passive dependents of support
- In line with the CA, participation in decision-making was emphasized especially from the professional perspective, but also from the three other perspectives
- Family life was only highlighted from disabled people's perspective
 - Indicates disabled people themselves having the strongest faith in their ability to participate in this area of life?

Discussion and conclusions (preliminary) (2/5)

- As to highlighted facilitators and barriers, attitudes were seen both as potential barriers and facilitators especially from the research, professional and disabled persons' perspectives
- Accessibility was also seen as an important facilitator of societal participation, and the lack of it as a barrier, from all four perspectives
- In line with the CA (economic causes and consequences of disability), labour market participation, as well as barriers related to studying and employment, were very much highlighted especially from the research and political perspectives, but also from disabled people themselves
 - From the political and disabled people's perspectives disabled people were seen as a labour force resource and enhancing their labour market participation was seen to gain both society and people with disabilities
- Likewise in line with the CA (economic causes and consequences of disability) financial barriers (either on an individual or a societal level) were brought up mostly just from the research and disabled people's perspectives

Discussion and conclusions (preliminary) (3/5)

- From the research perspective legislation and disability policies were the most highlighted facilitators due to their fundamental value for the outcome service and support for people with disabilities
 - In line with this, more binding rights and clarifications of the disability legislation were called for both from the political and professional perspectives
 - The ratification of the UN CRPD and the renewed disability legislation will hopefully answer at least to some extent to these requests
- From the political perspective the public sector, and the municipalities in particular, were viewed crucial for the provision of disability services
 - Due to limited resources (and local austerity policies), the state was requested to take greater financial responsibility for disability policy
 - There are also other actors involved too in the provision of services and sometimes they change frequently → problematic for people with disabilities
 - The ongoing health and social services reform will also bring changes regarding responsibilities for and actors involved in provision of disability services as well as aims to cut down costs

Discussion and conclusions (preliminary) (4/5)

- From the disabled people's perspective the importance of legislation and disability rights was also emphasized as facilitating societal participation, alongside different forms of disability services on a practical level
 - Personal assistance was highlighted from the political perspective too
- From the disabled people's perspective the system of disability services was seen as rigid and bureaucratic and therefore as a barrier for societal participation and requested it to be improved by becoming more flexible and client involving
 - Improvements of the disability service system were also requested from the professionals, but in addition to flexibility, they called for increased resources
- From the professional perspective most of the barriers for participation were however seen to be “outside” of the social workers daily work, indicating they felt they could not do so much about enhancing participation

Discussion and conclusions (preliminary) (5/5)

- The professional and disabled people's perspective showed the value of primarily the personal experience among the clients, but also the street level perspective among the social workers, regarding ways to enable the societal participation of people with disabilities
- The highlighted areas of societal participation, the facilitators, barriers, and suggested actions for enhancing societal participation were all related to and dependent of each other
 - Therefore all four perspectives compliment each other and each one makes an important contribution to the overview of the societal participation of people with disabilities – what it means, what is hindering it, what is facilitating it and how it can be further enhanced

Kiitos!
Thank you!

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