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CONTESTED AGENCY? EXPERIENCES OF PARENTHOOD AMONG FINNISH MOTHERS AND FATHERS WITH A PHYSICAL DISABILITY OR VISUAL IMPAIRMENT

Marjukka Rasa, Merja Laitinen

Abstract

Parenthood is quite rare among physically disabled adults in Finland, and becoming a parent can be labelled as a taboo act. In this paper, we shed a light on this salient topic by scrutinising the experiences of Finnish mothers and fathers with physical disabilities. The research questions are: (1) How do mothers and fathers describe their agency as parents? and (2) How is their agency constructed within social structures and relations? The analysis is based on qualitative teller-focused interviews with 17 mothers and fathers. The results reveal their agencies as multidimensional, and demonstrate how parenthood is constructed through interaction within institutional spaces. Personal support, peers and NGOs also play an important role in the construction of agency. Interaction can either limit, question or support the agency of disabled people as parents. The results show that the parents have strong agency in using their knowledge, and flexible resources when meeting the demands.

KEY WORDS: physical disability, motherhood, fatherhood, agency, experience, Finland.

Anotacija

Suomijoje suaugusiųjų tėvystė, turint fizinę negalią, tapimas tėvais gali būti nepriimtinas. Straipsnyje autoriai pristato šią svarbią temą, analizuodami suomių motinų ir tėvų, turinčių fizinę negalią, patirtį. Tyrimo klausimai: 1) kaip motinos ir tėvai apibūdina savo, kaip tėvų, savarankiškumą ir 2) kaip jų savarankiškumas konstruojamas socialinėse struktūrose bei santykiuose? Analizė paremta kokybiniais, į pasakotoją orientuotais interviu su 17-ka mamų ir tėčių. Rezultatai atskleidžia jų savarankiškumą kaip daugiamatį ir parodo, kaip tėvystė kuriama sąveikaujant institucinėse erdvėse. Asmeninė parama, bendraamžiai ir NVO taip pat atlieka svarbų vaidmenį ugdant savarankiškumą. Sąveikos kontekste savarankiškumas atskleidžia galimybę paremti neįgaliųjų tėvystės iniciatyvas, kartu paliekama erdvės abejonėms ar net apribojimams. Tyrimo rezultatai atskleidžia, kad tėvai lanksčiai naudoja turimas žinias ir išteklius tenkindami savo vaikų poreikius.

PAGRINDINIAI ŽODŽIAI: fizinė negalia, motinystė, tėvystė, savarankiškumas, patirtis, Suomija.
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Introduction

It largely depends on the society where people with a disability live how their rights are realised. One remarkable debate during the last few decades has focused on a disabled people' right to self-determination and bodily integrity, particularly on their right to become and act as parents (e.g. Kallianes, Rubensfelt, 1997; Grue, Laerum, 2002; Battalova, 2019; Król, 2024). In this paper, we aim to continue this discussion and deepen the knowledge from the viewpoint of Finnish parents, both women and men, with a physical disability or visual impairment. We lean on the idea that disability is a socially constructed disadvantage. As a phenomenon, disability is a culturally fabricated norm concerning the body, like the fictions of race and gender (Garland-Thomson, 2011). Barriers and possibilities of action as well as power hierarchies, overt and covert ways of oppression, and the realisation of civil rights, are socially constructed (Prillertensky, 2004). Hence, disadvantages and barriers in realising one's rights are preventable, and there are multiple ways in which society can support disabled people's rights and agency.

Although societal norms, values and attitudes have changed, the combination of disability and parenthood still bears a historical burden. Structural and attitudinal barriers become visible in the lives of parents with disabilities (Prillertensky, 2004; Battalova, 2019; Xion, Chen, 2024). As a Nordic welfare state, Finland is well known as a model country of the realisation of citizens' rights. However, minorities such as people with disabilities have to constantly confront situations in which their rights and possibilities to live like other citizens are somehow restricted or questioned (cf. Vehmas, 2019). Becoming a parent in this context is a taboo phenomenon. In this paper, we shed a light on this salient topic by scrutinising the experiences of Finnish mothers and fathers, and exploring how they construct their agency as parents in Finnish society. Our methodological approach is Grounded Theory (Glaser, 1978; 1998), and the study also draws on feminist standpoint theory (Harding, 1991; Reinharz, 1992). The research questions are: (1) How do mothers and fathers describe their agency as parents? and (2) How is their agency constructed within social structures and relations? Our research is based on qualitative interviews with parents who have a physical disability or a visual impairment caused by a disease or a genetic process.

In Finland, the status of people with disabilities and their possibilities to act as citizens have developed along with societal and political change (Leppälä, 2014). From a historical point of view, they have been viewed as abnormal individuals who have had to prove that they are human beings (Hughes, 2007). They have been labelled as weak, ill, vulnerable and childish, and defined as non-sexual people who need to be cared for by others and who have difficulty controlling their lives.

They have not been regarded as agents, but as dependent on other people, who pity them or consider them a target of charity (Berger, 2010; Vaughan et al., 2015). Disability has been regarded both as an individual tragedy (Shakespeare, 2008) and as a person's destiny (Shubhangi, 2015). After the Second World War, European welfare states granted services to disabled people (Borsay, 2012). There has been a link between the realisation of social equality and granting human rights to all citizens. The protection of the principles of human rights coincides with the realisation of equality (Hammarberg, 2014.) During the last decades, more attention has been focused on people's rights, their societal status and their agency. People with disabilities are currently seen as individuals who make their own choices as citizens (e.g. Forrest, French, 2014.) Nevertheless, the question whether parenthood can be considered as a realistic choice for them remains in the background.

We can echo Battalovas' (2019) thoughts by noting that nowadays Finnish women with disabilities have produced multiple experiences in a broad context involving the historical, economic and social realities of a place and life therein. Previous research shows that disabled women have only had limited possibilities to earn money, to love, to be loved, and to become mothers (Asch, Fire, 1997). Their bodies have been considered fragile and weak instead of beautiful or attractive, and as such not suitable for pregnancy and giving birth. Furthermore, these women have not been regarded as suitable for the role of mother or caregiver (McFarlane, 2004). They are seen as passive receivers of social services and as targets of other people's help (Grue, Laerum, 2002). Women's reproductive rights have been constrained by the assumption that they are asexual; they therefore lack reproductive health care, contraceptives and information on sexuality. Further, there has been social resistance to disabled women's reproduction and mothering (Kallianes, Rubenfeld, 1997).

We argue that it is important to hear and analyse the parents' own experiences. By doing so, we aim to contribute to research discussions that promote disabled people's rights to self-determination and bodily integrity, particularly their right to become and act as parents. Our interest in this topic can thus be defined as emancipatory and practical. Overall, more knowledge is needed on how to support parents with disabilities in their parenthood and in raising their children (cf. Malacrida, 2012).

1. Parents with disabilities and their agency

There is only a limited amount of research on physically disabled parents (Olsen, Clarke, 2003). Previous research has focused mainly on the viewpoint of mothers (McKeever et al., 2003; Prillertensky, 2003; Prillertensky, 2004; McFarlane, 2004; Molden, 2014; Tefera et al., 2017), whereas fathers (Kilkey, Clarke, 2010) and family life with disability (Clarke, McKay, 2014) have not been analysed to the same extent. The parenthood, parent-child relationships and private responsibilities of people have played a minor role both in family and disability research. Additionally, in research on the social participation of disabled people, parenthood has not been the focus of attention (Höstbacka, Nygård, Nyqvist, 2016). Instead, the research has mainly focused on disabled people as service receivers (Prillertensky, 2004; Parish, Magana, Cassiman, 2008; Clarke, McKay, 2014).

Previous studies show that institutional, physical, social and attitudinal barriers are present in the lives of disabled people (Clarke, McKay, 2014). The social context usually limits and does not support their parenthood. Professionals and non-professionals alike often focus on the limits which are brought by disability, and which are central in the medical model of disability (Parchomiuk, 2014). Mothers may therefore experience bodily and social avoidance (McKeever et al., 2003; McFarlane, 2004). There have also been many employment disincentives concerning parents with disability (Kiesel et al., 2020). However, there is a growing body of research that draws on the social model of disability and argues that disability can be addressed through structural changes. Nevertheless, people with disabilities are still often perceived as victims in society, and their active role in challenging prevailing structures and practices is frequently overlooked (Watson, 2012). Researchers have highlighted ways to support disabled individuals in becoming agents in society (Smits, 2009). These perspectives have served as an important starting point for our research interest in the agency of mothers and fathers.

We lean on the Anthony Giddens' (1984) theorisations of agency, the idea that agency is relational, formed by knowledge and action, and constructed as social activity in the co-presence of time and space. In the formation of agency, relations and interaction are important factors. Relations both limit and enable action. They contain variable and alternating meanings and definitions. Agents cannot be seen on their own without relating to the big picture (Crossley, 2011). Agency can be linked to the three dimensions of time: past, present and future. Historical, cultural and personal factors affect the acts of agents, as well as how people understand their own relationship with the past, present and future (Emirbayer, Mische, 1998). If people accommodate to being disabled, structural factors can affect their agency and enable them to have experiences in the changed situation (Berger, 2010). Giddens (1984) sees that agents have to act and monitor the rationality of their actions. Agents also have to be motivated to perform their acts. Agents and structures are also interdependent. Furthermore, an agent interprets situations and society: the power is inside all acts (Giddens, 1984). People's own action, the surrounding situations and various possibilities affect their agencies. In terms of disabled parents' agency, the salient issue is the daily dialogue between other acts, social and health services, and other institutional and societal structures.

2. Materials and methods

Our research method was Grounded Theory, in which the researcher investigates social and socio-psychological processes, analyses the data, and generates theory based on the findings. Grounded Theory is particularly well suited for research areas where little or no prior knowledge exists (Glaser, 1998, 53). A central element of Grounded Theory is the researcher's theoretical sensitivity, which is shaped by their personality, professional background, and life experience. Theoretical sensitivity develops and deepens as the research progresses (Glaser, 1978, 31; Birks, Mills, 2011, 59).

This study also draws on feminist standpoint theory (Harding, 1991; Reinharz, 1992), with a focus on the epistemic position of parents. Our starting point is interactional and individually oriented research, incorporating a standpoint design in which the parenting experiences of both women and men are central. This approach lets us analyse experiences and meanings from subjective and epistemic viewpoints. The research topic is challenging because the experiences are invisible, deeply personal, and hard to reach. Hence, the study requires sensitivity from the investigators in attempting to reach the diverse perspectives and different versions of the world that emerge from people's experiences that do not entail a single reality or offer a single interpretation. Standpoint design does not seek to universalise a single experience, but to create space for the individual and her/his experience in a specific temporal, situational and historical context. It enables the subjectivity and diversity of knowledge. In addition, interactivity, the personality and involvement of the researcher influence the way knowledge is formed in the research process. Even the researcher is part of people's experiential reality. We lean on the idea that experiences and knowledge are socially placed, because living in a certain place and position shapes them (e.g. Harding, 1991; Reinharz, 1992). The study complies with the Finnish research ethics guidelines (Finnish National Board on Research Integrity TENK, 2023) and special attention has been paid to the sensitive nature of the research in all phases (Fahie, 2014).

The parents were recruited through a national NGO. The invitation to an interview was thus conveyed through physical and virtual forums frequented by parents. The data consisted of interviews with 14 mothers and three fathers with a physical disability or visual impairment. None of the interviewees had intellectual or developmental disabilities. At the time of the interview, the parents had one minor child or more. The interviewees lived in different parts of Finland.

It was up to the parents to decide whether to participate in the interview on the phone, in a café, or at home, and whether to participate together with the spouse or separately. To establish a relationally safe space and to support narration, the main idea was to respect the parents' right to self-determination in all practical decisions (Hydén, 2014). Therefore, the data include both individual and paired interviews. Aiming to gain deep, experiential knowledge, all the participants were interviewed twice. During the first round, the interviewees were given a free space to narrate their own experiences and views about their parenthood. This course of action respected the privacy of the parents, giving them the right to determine what information to provide to the researchers. In the second round of interviews, the discussion was more focused and based on the parents' first accounts.

The data analysis was content-oriented. We first read and coded the data by observing what and how parents speak about their parenthood and themselves as parents. Next, we carried out interpretative reading by paying attention to agency and its construction. We found four dimensions of agency that overlap in the parents' experiences: transformative, flexible, compensating and restrictive. Thereafter, we examined the parents' experiences of constructing their agency within social structures and relations. Based on the analysis, we divided the experiences into three categories: encounters within institutional spaces, personal support as a realiser of one's agency as a mother or father, and peers and NGOs as emotional and social supporters. In the following, we will elaborate on these more precisely. We use data excerpts to illustrate our analysis and interpretation. All excerpts are anonymised and tagged with pseudonyms.

3. Results

3.1. Different dimensions of parental agency

3.1.1. Transformative agency

The starting point for experiences of agency was the change from a woman or a man to a mother or a father and to a parent. The parents experienced the change in agency towards parenthood solely as a positive process (also Grue, Laerum, 2002), although non-disabled people often questioned them, claiming that they were not able to handle a parent's role and cope with the responsibilities engendered by it. Even their close friends and relatives were critical, bewildered or amazed about their decision to become parents and their abilities to act as parents, as described by one of the mothers:

> When other parents' children were small, they were asked, have you slept enough and has the child been given enough food? But in my case, they asked, how do you manage and who cleans your house, and do you get enough

> help, and can your children see? They questioned how we manage and whether the children have inherited this impairment. They slightly either admired or disclaimed my parenthood (Maria, mother, visually impaired from birth).

The parents described their daily lives and parenthood with newborn babies like any other parent. They did not emphasise their own impairments and the constraints brought on by them. The main theme in the parents' accounts was that they creatively modify their agency so that it responds as far as possible to the child's needs. They all stressed that their daily physical environment, the home and various assistive devices, was very important. The environment supported their transformative agency as parents (McKeever et al., 2003), because life with babies was concentrated on the home. Compared to parents with a visual impairment, parents with a physical disability met different challenges in bathing, picking up and putting down the baby, as well as carrying, dressing and feeding the baby. So it was important that they received support from the built environment. The parents did not find time with the baby a specially challenging period. Everyone said that they had to learn new practices and solutions, but they thought that responding to the baby's needs went well. It was also meaningful for them that they were able to live in a setting that they were familiar with. The parents' experiences highlighted the fact that parenthood can alter one's agency (Shubhangi, 2015) and build self-confidence.

3.1.2. Flexible agency

Both the mothers and the fathers brought forth their experiences as parents, and they did not draw a line between gender roles. Their experiences of parenthood were quite similar. This can also be linked with society and values. Gender equality is highlighted in Finland, and fathers are entitled for instance to paternity leave. In many cases, disabled men have not been regarded as caregivers, and the positions of women and men have been unequal (Kilkey, Clarke, 2010; Mi Yeon, 2014).

According to the data, parenthood comprises various elements, and both spouses are caregivers within the limits of their physical capabilities and resources. According to the interviewees, spouses without a physical disability or visual impairment took great responsibility in tending the child and the home. They also looked after outside activities, such as shopping and taking the children to their hobbies.

> I could say that we do quite ordinary things like everyone else. But then my husband plays a clearly physical role in parenthood; he drives the children to their hobbies and spends time there. And in day-to-day situations, like when we went to kindergarten, our boy tripped in the yard and wanted to come

> into my lap, but I cannot carry him, or I do not want to carry him, outside for safety reasons (Anne, mother, muscular disease).

In families where both parents had physical limitations, tasks were divided based on the parents' personal abilities instead of gender. The data included various combinations of parents: a parent with a visual impairment with a spouse without one, a parent with a visual impairment with a spouse who also has one, a parent with a physical impairment with a spouse who does not have a similar impairment, and two parents with a physical impairment. Agency becomes visible in how the parents' roles are negotiated and formed based on the tasks they can do. The parents knew how their impairment affects their abilities to act and what limits it imposes. Based on that knowledge, they divided the parenting tasks and roles.

3.1.3. Compensating agency

According to the interviewees, finding a way to compensate for their lack of agency was important. The parents found the time when the child started to move and explore the environment very challenging. Many parents thought that, for safety reasons, they needed someone's help when they went out with the children, for example if the parent was blind and the child had just learnt to walk but did not listen to or understand the parent's instructions.

> Sometimes the girl was so quiet that we did not know where she was, and then we had to call her and ask. We had to tell the girl that we have go home if she won't listen to us. I had the girl in one hand and the guide dog in the other. And there we sat and wondered which way home was (Joe, father, visually impaired from birth).

For example, it was difficult for parents with a visual impairment to locate their child by listening and to keep the child nearby. When walking outside, the child might tell the parent something about what they can see, and the parent would have to ask the child to describe it exactly. The parents reported that they also used guide dogs that know familiar and safe routes to compensate for their lack of agency.

Parents with a physical impairment can see where their children are and what they are doing. The challenge is that they cannot always prevent dangerous situations when the child is unaccompanied and moves quickly, while they can only move slowly owing to their impairment. For some parents, it was impossible to pick the child up from the floor, to intervene in a difficult situation, or to control the child's behaviour. Verbal instructions were therefore important in guiding the child (Prillertensky, 2004).

The data show that the built environment restricts the places where parents can go with their children (McKeever et al., 2003; Galvin, 2005). The parents came up with proactive solutions to be able to move outside their home. In most cases, the home was chosen because moving outside is easy and, in some cases, based on the fact that it is easy to reach public transport. If the parents owned a car, modifications were made to it. These solutions made life easier for parents with both visual and physical impairments. Many parents said that they went to places that are easy to access. They had to plan everything carefully beforehand, so that they could manage as parents as well as possible, as described by the mother in the following excerpt:

> Maybe an extra stress factor is that I must think carefully, plan and prepare so that the child is not too tired or hungry, because these situations are difficult to manage from a wheelchair. If the child is overtired or hungry, he just screams or kicks on the floor, and I am pretty much powerless. I avoid these kinds of situations, and I have had to control my child verbally (Susan, mother, physically disabled as an adult).

Based on the above, compensating agency enables parents to create strategies that help them cope with social and physical barriers in their daily lives (McKeever et al., 2003). Public spaces are usually planned for non-disabled adults, which requires parents with a disability to think and do things differently.

3.1.4. Restrictive agency

The data show that the agency of a parent with a disability or visual impairment can also be restrictive. Restrictive agency makes them visible in the private sphere of life as mothers, fathers or parents, but not as citizens who are capable of acting outside the home. There were only three parents with a full-time job, and two with part-time jobs, all the others were outside the labour market, even though they were well educated. Nine people received a pension, one was a student, and three women were on maternity leave. Two parents had the possibility to combine a pension and part-time entrepreneurship. Otherwise, the interviewees found it very difficult to broaden their agency to the public sphere, as described by two mothers:

> In Finland, we really have many prejudices, particularly in the labour market […] People just think that if you have an impairment, you are not able to work as well as others. They prefer to hire a healthy person, even if s/he is not as qualified (Jill, mother, CP).

> They saw me in the wheelchair. I never mention it in my job application or in an interview, because it is yet another possibility, if they do not want to hire a different kind of person, to ignore her. Once, I was accused of cheating because I didn't tell them the essential information that I am in a wheelchair (Martha, mother, CP).

Parents’ scarce possibilities to enter the labour market become visible in other studies as well: disabled people are unemployed, underworked, unpaid, and their employment rate is low, which is why millions of disabled families live in poverty (Kiesel et al., 2020). The parents’ experiences revealed that both the mothers and the fathers have had difficulty getting a job (also Galvin, 2005; Kilkey, Clarke, 2010). Hence, compared to families with non-disabled parents, a parent’s disability can be seen as a risk, and may mean that the family must live in poverty (Clarke, McKay, 2014). The parents’ experiences highlight the fact that whatever Finnish society does to support studying among disabled people, it seems that it is not enough to guarantee them a place in the job market.

3.2. Experiences of constructing agency within social structures and relations

3.2.1. Encounters in institutional spaces

The parents in this study were active agents making use of the service system and functioning in various institutional spaces. As active agents, they took responsibility for their own action and collaborated with health and welfare professionals (cf. Watson, 2012). Various subsidies were important to all of them in constructing their agency as parents. Applying for benefits and support and searching for help and services demanded their strong contribution and abandoning the idea that they should manage alone.

> Physically disabled parents should understand that seeking help is not … that you should be proud of it. You do not have to manage all by yourself, get totally tired and burn out. All the energy goes into coping, this is what I have learnt. […] It is also a question of the quality of life, it is not always that you can’t do it, you simply receive help so that you can also do something else (Jenny, mother, visually impaired from birth).

One mother described how she has learned to receive help in daily life. Some of the interviewees still had difficulty accepting their vulnerability, and regarded independent coping as the ideal. In the transition from adult to parent, the social service system has an important role. The parents described encounters with the social service system as bureaucratic in terms of decision making. However, they pointed out that social benefits, support and services behind these bureaucratic practices were underlying factors of their agency as parents. They saw that the focus of social work should be on the entire family instead of the parent. Thereby the requirements for supporting the parent’s agency would be better met.

The parents described broadly various encounters with professionals which they thought were meaningful in terms of their agency both in a positive and in a negative sense. Their experience of professionals in social and health care services, kindergarten and school varied. Regarding positive experiences, the parents reported that professionals listened to them and thus supported their status as agents. In the opposite cases, professionals questioned or ignored them.

> The boy's journey began in an incubator. It was a full-term pregnancy, but the boy had bigger and smaller problems at the beginning. They wondered whether I could leave, as I would need help myself, and I said, 'Excuse me, what kind of help do you need?' I don't need any help other than carrying the child, but they had no knowledge of this disability. So I had to be pretty strict. The nurse was very interested in whether I could drive a car, and I said I could drive and what not, they were so very interested in things that are not directly related to the baby. And one nurse told another one at the turn of the shift that there is such and such a family here, that she has CP, but otherwise acts and thinks normally (Tina, mother, CP).

The parents also shared their experiences of inappropriate behaviour on the part of others, children and adults, in institutional settings:

> When they started in the new kindergarten, they were kind of bewildered and made comments about me. So I went to two parents' meetings and talked about this. It is not our children's responsibility to explain why I walk like this. It felt really dumb every time I picked up my children and they were shouting after me. But it doesn't happen as much any more. I think they have grown accustomed to me in this kindergarten. I spoke first to the staff, and I was given a few minutes to talk to them and it did the trick (Jane, mother, CP).

The excerpt illustrates how a different body can stigmatise and label a disabled parent (Avery, 1999; Svain, Cameron, 1999). Visible impairments can generate disturbing reactions from other people (Galvin, 2005). The excerpt also demonstrates that social encounters may demand strong agency from parents with a disability. The above example is not the only one in the data where the parent instead of the authorities or professionals has had to intervene in a situation of inappropriate behaviour or bullying. It was a burden for the parents that their children would carry the stigma of their difference and be bullied because of it. Overall, encounters in institutional spaces make visible how a parent's value as a human being can be either supported or questioned.

3.2.2. Personal support as a realiser of one's agency as a mother or father

Personal support was vital in constructing the parents' agency. The parents' experiences are in line with the previous research, according to which the significant others and social resources which help living in another way after becoming disabled are very important (Berger, 2008). Personal assistance enables a state in which mothers and fathers are independent agents in relation to their children, and children are not responsible for them as young carers (Olsen, Clarke, 2003; Prillertensky, 2004). The data show that a grounding factor in constructing agency as a parent is that the parent with a disability is not dependent on help given by the spouse or children, and that the spouse's leisure time is not spent attending to family routines and the home.

Sharing agency with a personal assistant required a great deal from the parents. Familiarising oneself with the personal assistant took time and required crossing one's personal boundaries. Sharing one's agency typically meant that the personal assistant performed physical acts which the parent with a disability or visual impairment was unable to perform. Besides sharing bodily boundaries, personal assistance means that the private sphere of the home will also be shared. The interviewees reported that they had considered carefully when and where they need a personal assistant and when they can manage by themselves. It is not an ideal solution that a personal assistant is constantly present at home. Personal space and time are also important for parents in constructing their agency:

> We usually have one, two, sometimes three days in week when the personal assistant is not in our home. I need my own space, so that when we made the employment contract, we agreed that I need help two or three days per week, on weekends with my hobbies. I have said to jobseekers that I will need help five days a week when the child starts to walk, and she nearly does (Emily, mother, CP and visual impairment).

The challenges brought to parenthood by the child's developmental stage also affect the amount of personal assistance that is needed. Parents with babies needed help with physical tending and carrying. Later, the parents utilised help when going out and visiting clubs and children's events. The amount of necessary personal assistance depended on personal preferences and the limitations imposed by the physical impairment.

The parents seldom used public welfare services such as family work or housekeeping services, which demonstrates that they have parenting skills. They needed support, help and compensation when the physical impairment limited their agency, and thus personal assistance was important in terms of their agency. A personal assistant can promote a feeling of comfort and a sense of control, which can maintain the autonomy of personal life. Hence, professional help is an important part of constructing one's agency as a parent with disability (Prillertensky, 2003; Galvin, 2005).

3.2.3. Peers and NGOs as emotional and social supports

Peer support was a significant factor in constructing one's agency as a parent with a disability. The parents mentioned NGOs as notable forums where they can reach people who have various kinds of disabilities and are in a similar life situation. Voluntary groups enabling self-help and providing advocacy connected the parents with other ones (also Shakespeare, 2008). The role of NGOs as sources of informal social security, as well as social and rehabilitation services, was also important to them. Additionally, NGOs were key information providers, as the parents said that they have not always received sufficient information from formal social institutions. The parents said that they started to seek peer support when they were planning pregnancy. They benefited a great deal from peers' tips when the baby was born, and they had to learn how to take care of him/her or when they had to seek suitable assistive equipment and social services. The parents received emotional, social and informative support from peers. First, they were receivers of support, and peer relations were important in constructing their agency as parents. When their child grew up, their role changed and their agency as parents got stronger, so that they could now support others who planned to be parents or who had small children. A possibility to share silent knowledge validated their position as knowing agents (cf. Giddens, 1984).

> I belong to many kinds of groups, and I have been active on Facebook for the last few years, and I get peer support there. I can give links to other people concerning the circumstances of people with disabilities and much other information. I feel that social media gives new insights, I can see things from other perspectives and maybe my own worries look a bit smaller. Sometimes I get peer support there as well (Maria, mother, visually impaired from birth).

According to the parents' accounts, social media has broadened their opportunities to be active agents without the impairment complicating physical access or participation. Getting information from social and other digital media via computer is also meaningful for the parents. Therefore, noticing disabled people and their needs in the development of information technology and social media is important (Kent, Ellis, 2016). Overall, peer-related activities have enabled collective agency, a situation where people unite their resources to achieve their goals (Bandura, 2000).

Conclusions

The results present the parents' agency as multidimensional and constructed in interaction with various social structures and relations (Fig. 1).

The results also demonstrate that the parenthood of the mothers and fathers is constructed in interaction with societal structures, cultural values and attitudes, and social relations. The interaction brings forth practices, attitudes and reactions that can either limit, question or support the construction of the parents' agency. According to the results, the parents have strong agency. They have used the resources of society and impacted the power relations in our society (Giddens, 1984). The parents have had to use their knowledge and flexible social resources in meeting the demands of parenthood and their children's development. Their agency as parents have also required new attitudes and acts from them. The results highlight the fact that creating one's own, active agency is vital for them as mothers and fathers (cf. Watson, 2012).

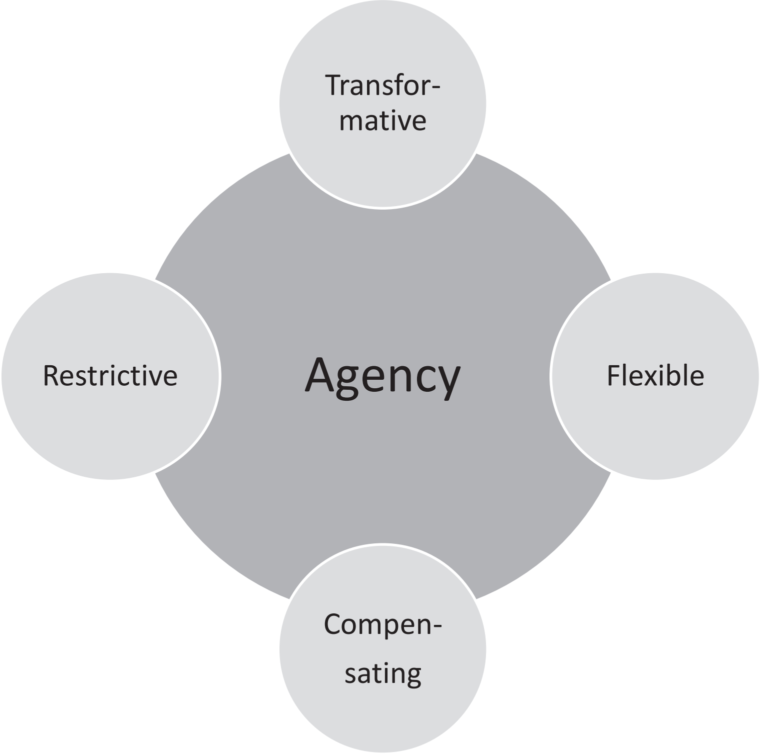

Figure 1. The construction of parental agency

From society, this requires a novel attitude towards disabled parents. At its best, the social service system pays attention to the rights and self-determination of disabled people, and creates more co-equal and equal possibilities for them (Hammarberg, 2014). It also offers places where parents can share their silent knowledge, which can validate their position as knowing agents (cf. Giddens, 1984). The results show that parents have the desire and ability to utilise social services so that they can be parents in spite of the disability. Official help is also important for the construction of their agency (Prillertensky, 2003), and the possibility to share silent knowledge validated their position as parents.

Although Finnish people with a disability nowadays have better possibilities to act as parents than in previous decades, the parents had experienced being evaluated morally and even questioned as agents when making the decision to have a child. While social structures are ready to accept their parenthood, people are not always ready to acknowledge it yet. This is shown by the attitudes that parents with disability or visual impairment often encounter even within professional and institutional settings. Attitudinal barriers still exist, and genuine co-equality and equality are still far from being reality. The clearest example of this are the difficulties in getting a job (also Galvin, 2005; Kilkey, Clarke, 2010).

The agency of parents with a disability or visual impairment is built under the demands of outsiders. The parents utilise existing structures and develop as agents who change strategies to cope with their parenthood. Responding to their children's needs and developmental stages challenges parents to continuously change, update and create their strategies regarding their agency as parents. The forms of their agency demonstrate this multiplicity. In creating the strategies, peers and information received from them are significant, and the strategies are tested against and accommodated to the parents' own agency. Different peer-related activities can also support the parents' collective agency in realising their parenthood (Bandura, 2000). The development of digital technology has enhanced the parents' interaction with other parents and helped in getting information about parenthood and children's developmental stages and needs. Paying attention to the needs and rights of disabled people in developing social media is therefore important (Kent, Ellis, 2016).

Although the research is based on a small sample of qualitative data from Finnish society, it gives a voice to parents with physical disabilities or visual impairment, and raises the point that more research is needed on the topic. For example, cross-national analysis could offer important and broader insights into the subject. However, the research points out the importance of seeing and hearing the experiences of mothers and fathers with disabilities. It is vital to understand the construction of parenthood through interaction between an individual social setting and societal/cultural structures.

Based on the results, we argue that becoming and being a parent with a physical disability or visual impairment is nowadays easier than in previous decades, but it still requires strong will, agency and innovative action from the parents. They construct their parenthood creatively by utilising various environmental, social and societal resources. Through their lived experiences, mothers and fathers with disabilities challenge societal assumptions and moral perceptions about their right to be parents. The moral and social barriers reveal a need to raise awareness and change attitudes.

References

Asch, A., Michelle F. (1997). Nurturance, Sexuality and Women with Disabilities. L. J. Davis (eds.). *The Disability Studies*, 241–259. New York: Routledge.

Avery, D, M. (1999). Talking "Tragedy": Identity issues in the parental story of disability. M. Corker, S. French (eds.). *Disability Discourse*, 116–126. Great Britain: St Edmundsbury Press.

Bandura, A. (2000). Exercise of Human Agency Through Collective Efficacy. *Current Directions in Psychological Science 9* (3)*,* 75–78. DOI: https://doi.org/10.1111/1467-8721.00064.

Battalova A. (2019). Ambivalent subjectivities: experiences of mothers with disabilities in Russia. *Disability & Society*, *34* (6), 904–925. DOI: https://doi.org/10.1080/09687599.2019.1580563.

Berger, R. J. (2008). Agency, structure, and the transition to disability: a case study with implications for life history research. *The Sociological Quarterly*, *49* (2), 309–333. DOI: https://doi.org/10.1111/j.1533-8525.2008.00117.x

Berger, R. J. (2010). Structure and the Transition to Disability. M O´Donnel (eds.). A case study with Implications for life History Research. *Structure and Agency Part*, *3*, 347–374. London: Sage: CPI Anthony Rowe.

Birks, M., Mills, J. (2011). *Grounded Theory. A Practical Guide*. SAGE Publications. Cippenham, Wiltshire.

Borsay, A. (2012). History and disability Studies evolving Perspectives. In N, Watson, A. Roulstone, C. Thomas (eds.). *Routledge handbook of Disability Studies Routledge*, 324–335. Chippenham. Wiltshire: CPI Antony Rowe.

Clarke, H., Mc Kay, S. (2014). "Disability, Partnership and parenting." *Disability & Society*, *29* (4), 543–555. DOI: https://doi.org/10.1080/09687599.2013.831745

Crossley, N. (2011). *Towards Relational Sociology*. Routledge.

Emirbayer, M., Mische, A. (1998). "What is Agency?" *American Journal of Sociology*, *103* (4), 962–1023. DOI: https://doi.org/10.1086/231294

Fahie, D. (2014). Doing Sensitive Research Sensitively: Ethical and Methodological Issues in Researching Workplace Bullying. *International Journal of Qualitative Methods*, *13* (1), 19–30. DOI: https://doi.org/10.1177/160940691401300

Forrest, H., French, P. (2014). Voices Down Under: An Australian Perspective. In M. Sabatello, M. Schulze (eds.). *Human Rights and Disability Advocacy*, 188–208. Philadelphia: University of Pennsylvania Press.

Galvin, R. D. (2005). Researching the disabled identity: contextualizing the identity transformations which accompany the onset of impairment. *Sociology of Health & Illness*, *27* (3), 393–413. DOI: https://doi.org/10.1111/j.1467-9566.2005.00448.x

Garland-Thomson, R. (2011). Integrating disability, transforming feminist theory. In K. Hal (eds.). *Feminist disability studies*. Indiana University Press.

Giddens, A. (1984). *The Constitution of Society Outline of the Theory of Structuration*. Cambridge: Polity Press.

Glaser, B. G. (1978). *Advances in the Methodology of Grounded Theory.* Strategies for Qualitative Research. California: The Sociology Press.

Glaser, B. G. (1998). *Issues end Discussions*. Sociology Press, 2 p. USA: Sociology Press.

Grue, L., Laerum, T. K. (2002). Doing Motherhood: Some experiences of mothers with physical disabilities. *Disability & Society*, *17* (6), 671–683.

Hammarberg, T. (2014). Human Rights and Social Equality. In S. Hessle (eds.). *Human Rights and Social equality: Challenges for Social Work: Social Work – Social Development*, *1*, 9–12. Almeida. Surrey: Routledge.

Harding, S. (1991). *Whose Science? Whose knowledge? Thinking from Women's Lives.* New York: Cornell University Press. Ithaca.

Hughes, B. (2007). Being disabled: towards a critical social ontology for disability studies. *Disability & Society*, *22* (7), 673–684. DOI: https://doi.org/10.1080/09687590701659527

Hydén, M. (2014). The teller-focused interview: Interviewing as a relational practice. *Qualitative Social Work*, *13* (6), 795–812. DOI: https://doi.org/10.1177/1473325013506

Höstbacka, 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*, *4*, 1–20. DOI: https://doi.org/10.1016/j.alter.2016.02.002

Kallianes, V., Rudenfeld, P. (1997). Disabled Women and Reproductive Rights. *Disability & Society*, *12* (2), 203–222. DOI: https://doi.org/10.1080/09687599727335

Kent, M., Ellis, K. (2016). People with disability and new disaster communications: access and the social media mash-up. *Disability & Society*, *30* (3), 419–431. DOI: https://doi.org/10.1080/09687599.2015.1021756

Kiesel, L. R., De Zelar, S., Lightfoot, E. (2020). Equity in Social Work employment: opportunity and challenge for social workers with disabilities in the United States. *Disability & Society*, *34* (9–10), 1399–1418. DOI: https://doi.org/10.1080/09687599.2018.1561354

Kilkey, M., Clarke, H. (2010). Disabled men and fathering: opportunities and constrains. *Community, Work & Family*, *13* (2), 127–146.

Król, A. (2024). Stratified reproduction and ableism: Women with disabilities and navigating reproduction and social control in Poland. *European Journal of Women´s Studies*, *31* (2), 246–261. DOI: https://doi.org/10.1177/13505068241262122

Leppälä, H. (2014). *Vammaisuus hyvinvointivaltiossa. Invalideiksi, vajaamielisiksi ja kehitysvammaisiksi määriteltyjen kansalaisten asema suomalaisessa vammaispolitiikassa 1940-luvun taitteesta vuoteen 1987.* [*Disability in a welfare state: The status of citizens defined as invalids, retards and handicapped in Finnish disability policy from the beginning of the 1940s to 1987*] Turku: University of Turku.

Malacrida, C. (2012). Mothering and Disability: Implications for Theory and Practice. In N. Watson, A. Roulstone, C. Thomas (eds.). *Routledge handbook of Disability Studies*, 390–401. Great Britain: Routledge.

Mc Farlane, H. (2004). *Disabled Women and Socio-Spatial "Barriers" to Motherhood.* Submitted in fulfillment in Phd. Glasgow: University of Glasgow, Department of Geography and Geomatics Facults of Social Sciences. extension://efaidnbmnnnibpcajpcglclefindmkaj/https://theses.gla.ac.uk/1289/1/2004mcfarlanephd.pdf

Mc Keever, P., Angus, J., Lee-Miller, K., Reid, D. (2003). It's More of a Production: accomplish mothering using a mobility device. *Disability & Society*, *18* (2), 179–197. DOI: https://10.1080/096875903100745871

Mi Yeon, K. (2014). Women with Disabilities: The Convention Through the Prism of Gender. In M. Sabatello, M. Schulze (eds.). *Human Rights and Disability*, 113–130. Philadelphia.

Molden, H. (2014). A phenomenological investigation into the impact of Parenthood: Giving a voice to mothers with visual impairment in the United Kingdom. *British Journal of visual Impairment*, *32* (2), 136–147. DOI: https://doi.org/10.1177/0264619613511616

Finnish National Board on Research Integrity TENK. (2023). *The Finnish Code of Conduct for Research Integrity and Procedures for Handling Alleged Violations of Research Integrity in Finland*. TENK 4/2023. Helsinki. https://tenk.fi/sites/default/files/2023-11/RI_Guidelines_2023.pdf

Olsen, R., Clarke, H. (2003). *Parenting and disability. Disabled parents' experiences of raising children.* Great Britain: The Policy Press.

Parish, S., Magana, S., Cassiman, S. A. (2008). It's just That Much Harder Multigraded Hardship Experiences of Low-Income Mothers with Disabilities. *Journal of Women and Social Work*, *23* (1), 51–65. DOI: https://doi.org/10.1177/0886109907310463

Parchomiuk, M. (2014). Social Context of Disabled parenting. *Sexuality & Disability*, 32, 231–242. DOI: https://doi.org/10.1007/s11195-014-9349-5

Prillertensky, O. (2003). A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities. *Sexuality & Disability*, *21* (1), 21–47. DOI: https://10.1023/A:1023558808891

Prillertensky, O. (2004). My child is not my carer: Mothers with physical disabilities and well-being of children. *Disability & Society*, *19* (3), 209–223. DOI: https://doi.org/10.1080/096875042000204185

Reinharz, S. (1992). *Feminist Methods in Social Research*. Oxforsd: Oxford University Press.

Shakespeare, T. (2008). *Disability Rights and Wrongs*. Routledge. Taylor Francis Group. 3rd Ed. London and New York.

Smith, S. (2009). Social justice and disability: competing interpretations of the medical and social models. In K. Kristiansen, S. Vehmas, T. Shakespeare (eds.). *Arguing About Disability: Philosophical Perspectives*, 15–29. Routledge.

Svain, J., Cameron, C. (1999). Unless othervise stated: discourse of labelling and identity in coming out. M. Corkes, S. French (eds.). *Disability Discourse*, 68–78. Open University Press. Buckingham- Philadelphia. Printed in Great Britain by St Edmusnsbury Press. Bury St Edmunds.

Tefera, B., Van Engen, M., Van Der Klink, J., Schippers, A. (2017). The grace of motherhood: disabled women contending with societal denial of intimacy, pregnancy, and motherhood in Ethiopia. *Disability & Society*, *32* (9), 1–24. DOI: https://doi.org/10.1080/09687599.2017.1361385

Vaughn, M., Mc Entee, B., Schoen, B., McGrady, M., (2015). Addressing Disability Stigma within the Lesbian Community. *Journal of Rehabilitation*, *18* (4), 49–56.

Vehmas, S. (2019). Persons with profound intellectual disability and their right to sex. *Disability & Society 34* (4), 519–539. DOI: https://doi.org/10.1080/09687599.2018.1545110

Watson, N. (2012). Researching disablement. In N. Watson, A. Roulstone, C. Thomas (eds.). *Routledge handbook of Disability Studies*, 96–106. Routledge. Printed and bound in Great Britan by CPI Antony Rowe. Chippenham. Wiltshire.

Xiong, Y., Chen, G. (2024). Motherhood Experiences of Visually Impaired Women in China from an Intersectional Approach. *Sexuality & Disability*, *42*, 635–646. DOI: https://doi.org/10.1007/s11195-024-09850-1