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Parenting with Assistance – The Views of Disabled Parents and Personal Assistants

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This qualitative study, based on semi-structured interviews with eight parents with disabilities and five personal assistants, explores two different but interrelated perspectives: how parents with extensive physical disabilities use personal assistants in their parenting strategies and how personal assistants experience assisting in parenting strategies.

The assistance users' parenting strategies are affected by gender, age of the children and whether the disabilities were congenital or acquired later in life. The assistants were seen as enablers, competitors for the child's love or compensators. Access to personal assistance has increased parents' possibilities to be active in their parenting.

However, total adaptation to the assistance user's parenting strategies could be challenging for assistants with different parenting ideals. There is a need for discussions on how assistants can work to strengthen parenting roles as well as receive support to work in a sustainable way.

Keywords: personal assistance; parenting; parenthood; parenting strategies

Introduction

Women and men with disabilities are seldom perceived as parents. On the contrary, they have been discouraged and prevented from parenthood. Claudia Malacrida describes the history as a development from 'eugenics to newgenics' (Malacrida 2020: 467), where 'newgenics' refers to the 'subtle, covert or informal ways' (2020: 468) of preventing and restricting the reproductive choices of people with disabilities. Nevertheless, women and men with disabilities are parents and raise children by themselves, sometimes with support from personal assistance.

Very little is known about how parents with disabilities use assistance in their parenting strategies, and likewise little is known about personal assistants' experiences of supporting parents with childcare. The present article explores these two perspectives, namely, how parents with extensive physical disabilities use personal assistants in their parenting strategies and how personal assistants reflect on assisting in parenting in a Swedish context.

The bulk of the existing research on parenting and persons with disabilities concerns mothers and mothering. Motherhood has been studied more than fatherhood, probably due to the 'master status' of motherhood for adult women in our society (Malacrida 2020). The link between being 'a real woman' and being a mother is one of the more stable, significant and powerful ideas in our culture (Gillespie 2003). Nevertheless, mothers with disabilities are primarily embedded in a discourse of disability and have difficulties being perceived as women or mothers (Grue & Laerum 2002). As disabled adults, women have mostly been seen as receivers of care and not as partners or parents who provide care to others (Lappeteläinen, Sevón & Vehkakoski 2017; Malacrida 2009). Another theme in previous research on mothers with disabilities is a focus on their children as 'young carers'. Such a perspective varies across a spectrum that is, at worst, based on prejudices about mothers who are not seen as competent parents due to their disability and, at best, an analysis of disability as one of several factors affecting the care-giving role (Bergman, Melin Emilsson & Järkestig Berggren 2020; Lappeteläinen, Sevón and Vehkakoski 2017; Malacrida 2009).

Our knowledge about the conditions for fathers with disabilities is limited (Duvdedany, Buchbinder & Yaacov 2008; Kilkey 2007). A British study shows that loss of the ability to be the family's breadwinner could affect men's self-esteem (Kilkey & Clarke 2010). Taking on more 'female' tasks such as attending to children could be meaningful to some men, while others found it hard to accept their new situation as it did not conform to what they considered masculine (Kilkey & Clarke 2010). Another study conducted in Israel concerns Jewish men with physical impairments, focusing on negative social attitudes towards disabilities and how they affect their fathering strategies. It describes their fear

of not being accepted by their children because of their impairments and their strategies concerning their children's education (Duvdedany, Buchbinder & Yaacov 2008).

Studies on fatherhood, motherhood and disability reflect the fact that parenthood is a gendered practice (Malacrida 2020). There are traditional gendered norms for what constitutes good fatherhood and motherhood, where motherhood implies care and nurturing, whereas fatherhood is connected to physical activities and play (Duvdedany, Buchbinder & Yaacov 2008; Selander 2015). More modern norms of parenthood include aspects of being present and participating in children's lives (Wissö & Plantin 2015). Modern parenthood strategies in Sweden are child-focused, and both fathers and mothers have their own special relationship to the child, which is characterized by gendered norms (Bekkengen 2011). The Swedish welfare society has targeted the gendered outcomes of parenting through dual-earner and dual-carer policies that support less traditional gender roles and gender-equal parenting (Korpi, Ferrarini & Englund 2013). In a society characterized by cohabitation instead of marriage, high rates of divorce and separation, the relationship between parent and child constitutes the lifelong relationship, not the relationship between the parents. In an unstable world, the consistent part of family is the relationship between parent and child.

The Swedish legislation does not give parents with disabilities any specific right to support in exercising their parenthood. Care of children is not a task for personal assistants, but the law (SFS 1992/93:159) emphasizes that it is important for toddlers' development that their fundamental needs can be met by a small number of persons. Consequently, the parent's assistants may also provide practical care for the child. Nevertheless, an empirical study of the assessment process concerning personal assistance shows that parenthood is seldom a reason for granting assistance (Bergman, Melin Emilsson & Järkestig Berggren 2020). The non-attention concerning disabled parents' need for support in parenthood is revealed in the last review of the law on personal assistance, where 'parent' is not even mentioned as a role for disabled adults (Bergman, Melin Emilsson & Järkestig Berggren 2020).

Despite the invisibility of children when personal assistance is granted, some parents with disabilities have personal assistants who expand their ability and means to be active as parents (Olsen & Clarke 2003; Selander 2015). Studies on disabled mothers and personal assistance describe how service users create parenting strategies in order to safeguard their mothering role. They make a distinction between emotional care supplied by the parents and practical care provided by other persons (e.g., personal assistants). The assistants handle practical tasks when the children are young, such as feeding or changing nappies, while the mothers with disabilities and the rest of the family provide emotional care, such as comfort and rule setting in everyday life (Aune 2013; Grue & Tafjord Laerum 2002; Prilleltensky 2004). Values regarding what constitutes good parenthood, as well as good childhood, have a great impact on what kind of tasks parents with disabilities want their personal assistants to carry out. The assistant user sets the rules for employment, including parenting strategies, by determining the working conditions and the relation between the user, the child and the assistants.

Work as a personal assistant differs from the labour market at large with regard to the employee's right to be involved in decision-making. The assistants have no clear right to discuss their work tasks or how and when they should be carried out (Falch 2010; Gough 1997). Consequently, they have no influence over their employer's parenting strategies. If there is a conflict between the employer and the employed, the employer decides on whether the employment should continue or end (Gough 1997; Guldvik, Christensen & Larsson 2014).

Several studies have pointed out that working as another person's 'hands or feet' and being expected to 'be invisible' when other persons are close by are emotionally demanding for personal assistants (Egard 2011; Falch 2010; Gough 1997). Personal assistance has increased independence and control for assistance users, and there is an assumption that personal assistants accept playing a subordinated role (Gough 1997; Neumann & Gundersen 2019). The fact that the assistance user both needs personal help and may be the employer or manager makes the situation complex (Falch 2010; Porter, Shakespeare & Stöckl 2020). The risk of blurred boundaries between what the assistants' tasks are and what other family members should do can lead to frustration among the assistants (Porter, Shakespeare & Stöckl 2020). Neumann and Gundersen (2019) critically discuss whether the relationship between an independent assistant user and his/her assistants rely on the invisibility and lack of recognition of the personal assistant. Different opinions concerning parenthood, parenting strategies and upbringing methods between personal assistants and assistance users may lead to complex situations for the personal assistant trying to strike a balance between the assistant user's demands and his/her own values.

Aim

The aim of the study is to explore parenting with personal assistance and two different but interrelated perspectives:

- How do parents with extensive physical disabilities use personal assistants in their parenting strategies?
- How do personal assistants experience assisting in parenting strategies?

Method and Analysis

The article is part of a longitudinal interview study exploring what family life is like for parents who have personal assistance (Selander 2015), including the perspectives of personal assistants working for parents living with families. The article is based on interviews with disabled parents conducted in 2004–2007 and complementary interviews

conducted in 2015–2017, as well as on interviews with personal assistants conducted in 2004–2007. All interviews were carried out by the first author.

The criteria for participating in the study were being a parent who had been granted personal assistance and having one or several children under 18 living at home. Eight parents with extensive physical impairments, six women and two men, were interviewed (see **Table 1**, for more information see Selander 2015). In addition, five personal assistants, four women and one man, were interviewed. With few exceptions, the assistance users and the personal assistants were interviewed twice, with six months to one year between the first two interviews, amounting to 18 interviews with assistance users and nine with personal assistants. Follow-up interviews were conducted about 10 years later with six of the assistance users, as two from the initial group had died. A total of 33 interviews were conducted.

At the time of the first round of interviews, five of the parents lived with a partner. Three of the parents were single and lived part time with their children. The assistance users were between 30 and 60 years, and they had experiences of living with personal assistance between three and 12 years. The amount of granted personal assistance varied between 50 and 192 hours a week. During the 15 years that the study lasted, one of the assistance users was granted expanded assistance hours, and another person received fewer hours for a period of time.

Five personal assistants in the age range 30–55 years were interviewed twice, with six months to one year between the interviews. The assistants all had experiences of working in families. There were four women and one man who had worked between three to seven years. At the time of the second round of interviews, only one of them still worked as a personal assistant and we chose not to conduct any follow-up interviews.

The interviews lasted between 45 minutes to two and a half hours; they were audio-recorded and transcribed by the first author. The quotations have been translated as close to the original as possible. Sometimes a slight adjustment in the language has been made to get closer to what the person wanted to convey (Kvale 1997).

Initially, the qualitative analysis of the interviews, both with the parents and the personal assistants, focused on meaningful text units describing important experiences and opinions. These units were assigned codes, which in turn were grouped together to form overarching themes, which were induced from the empirical data. During the analysis, there was constant movement between the interviews as a whole and the themes to ensure that there was no shifting in the interpretation of the interviews (Melin Emilsson 1998).

The themes induced by the data concerning the parents are personal assistants as ‘enablers’, ‘competitors’ or ‘compensators’. The themes concerning the experiences of the personal assistants carrying out parenting strategies are ‘the relationships to children’, ‘different views of upbringing’ and ‘boundaries of work tasks’.

Ethics

The research was conducted in full compliance with ethical codes of conduct for social science research, including the recruitment of informants, data storing, informed consent, anonymization and publication of data (Swedish Research Council 2017). However, because this study started out already in 2004 when ethical review within social sciences was not required, there is no formal ethical approval. Nevertheless, the ethical codes of conduct for social sciences

Table 1: Assistant users’ age, family situation, children, period living with disabilities, hours of personal assistance per week at the first interview, and 10-years-follow-up-interviews.

	Woman	Woman	Woman	Woman	Woman	Woman	Man	Man
Age	30	30	50	50	45	60	35	40
Family situation	Partner cohabiting	Partner cohabiting	Partner cohabiting	Partner cohabiting	single	Partner	single	single
Children, age and residence	2 sons, 7 and 1 years	1 son and 1 daughter, 7 and 5 years	1 daughter, 18 years	2 sons, 17 and 13 years	1 son and 1 daughter, 16 and 15 years	3 sons and 2 daughters, 18–40 years	1 daughter, 11 years Lives with mother	2 daughters, 14 and 12 years Live with father every other week
Disability experiences	Whole life	Whole life	Whole life	9 years	3 years	10 years	10 years	12 years
Hours of assistance/week	133	168	63	77	50	112	133	192
Interviewed after ten years	Yes	Yes	No	Yes	Yes	No	Yes	Yes

have been applied throughout the process and ethical discussions have been present during the years. Because all informants of the first round of interviews had accepted to be contacted for eventual follow-up interviews, the second round of interviews was seen as a continuation of the study.

The parents were recruited through different organizations. A contact person, who stressed the voluntary nature of participation, made the first contact and provided written information about the study. After approval of contact, the first meeting began with information about the study, stating that the interview was voluntary and that it was possible to withdraw at any time. The interview protocols were sent to the informants, who were given the chance to comment on them. For ethical reasons, we chose not to interview personal assistants who worked in the interviewed families. The personal assistants were recruited through municipal and private assistance organizations and have given informed consent according to the same process as the assistance users. All informants have been de-identified, and their names, place names and other details have been changed to make them unrecognizable.

Parents Using Personal Assistants in Their Parenting Strategies

The use of personal assistance concerning parenting among the interviewees seems to be related to gender and to whether the impairment was achieved before the assistance users became parents or if they were parents when they became disabled. Depending on whether the parents had young children or teenagers when they became disabled, they had different expectations on their personal assistants. The parents in this study can be categorized into three different groups based on their views on how they wanted the personal assistants to support them in their parenting role. The first group consists of the women with congenital disabilities who planned their parenthood carefully. They saw their assistants not only as enablers, but also as possible competitors. The second group is the women who already were mothers when they became disabled. They had elderly children or teenagers and faced challenges concerning the limits of the personal assistants' tasks and responsibilities in relation to their children. The third group is the men with toddlers who got disabled. They were fathers but had not formed their fatherhood strategies when they had their accidents. To them, the personal assistants were compensators for things they could not carry out themselves.

Assistants as enablers – and competitors

Three of the women in the study were born with their disabilities and had known all their lives that they would need assistance both to meet their own needs and to be active mothers. They had already as children expressed a wish to have a family and become mothers, despite the negative assumptions and attitudes expressed by persons in their surroundings at school and sometimes from health-care personnel. As teenagers, they had doubted whether they would find a partner who would find them attractive and who would accept the presence of personal assistants at home. They had had several years to reflect on what kind of assistance they wanted and to exchange views on the subject with their peers. To these women, having personal assistance meant being enabled to play the role they wanted as mothers without being dependent on their partner or other family members. They had friends without access to personal assistance who were forced to sit and watch the non-impaired parent provide care during the child's first years, while they were left to play a secondary role. The help from personal assistants was vital to the women, yet receiving it could give rise to mixed feelings. Britta described her feelings when the personal assistant cared for her first child:

My way of managing on my own is through personal assistance. I haven't reflected more than that. All of a sudden, I was sitting there with my son in my arms; I wanted to do everything for him by myself. I wasn't interested in five or ten persons holding him maybe in a way I didn't like. I didn't want anybody to hold him at all! He was our son, and nobody should come and comment on that. But then I actually had to pinch my arm and say to myself "Hey, I've become a mother, but I still need assistance and I also need assistance for Bosse's sake. Because without it we can't do anything at all together". And I learned to live with that. (Britta, mother with congenital impairment)

The mothers with congenital impairments expressed a fear that the assistants might become more important to the children than they were as mothers. Consequently, they wanted the assistants to avoid eye contact and wanted the children to always be directed to their mother to ask for help or when they needed emotional care of any kind (e.g., had taken a fall, were sad or needed a hug). By instructing the personal assistants on how to relate to the children and how to guide the child's attention towards the mothers, they found a way to create a kind of assistance that made them feel more secure.

Already during the process of recruiting personal assistants, the women informed the applicants that they were not supposed to form any relationships with the children. The applicants reacted in different ways to their demands. Some said that they could not conform to the instructions and were consequently not accepted for the job. Others said they would try, even though they thought it would be hard. One reason for these strict instructions may have been the mothers' earlier experiences of assistants taking on an active role trying to implement their personal views on childrearing.

And then it can be very fun to play with other people's children, as long as they are happy and nice. But the days will come when the children aren't so happy and nice. On those occasions, I don't want the assistants to have the childrearing role because I don't want them to go and maybe say no to the children and set their limits on our children. It's our limitations and our rules and our words that count. (Britta, mother with congenital impairment)

In some of the families, the strict rules implemented for every new assistant gradually softened. In the second interview of the first round with Anna, she described that her position on how the assistants were allowed to relate to her children had changed since the birth of her second child:

And I could, when the assistant changed diaper, enjoy seeing how they laughed together. I felt that, because I had never, I would never have allowed that with Andreas. But I thought that it felt very good with Anton. (Anna, mother with congenital impairment)

The insecurity she felt upon becoming a mother for the first time gradually disappeared when she realized that, as parents, they would be present for the children over the years, representing continuity and emotional care.

Established parents who get personal assistance: Debating limits

The three women who were injured as adults had already formed an identity as mothers and partners before needing assistance. Their reflections on the personal assistants did not concern questions of care or whether the assistants could become rivals for the children's affection. The women's challenges were related to questions about the limits of the personal assistants' tasks and responsibilities in relation to the children. The assistance user and the personal assistants could have different views on at what age the child should carry out different chores him- or herself. Fanny, the mother of two teenage boys, described discussions with her personal assistants about what her boys ought to do by themselves. Fanny wanted her assistants to do things the boys were capable of doing but that Fanny, as their mother, nonetheless wanted to help them with.

And discussions with the assistant who thinks my children should do these things by themselves. That my children are too spoiled and that they actually can cook themselves, while I think that it's too stressful for them since they come directly from school. That the boys don't have the time to do that, and that I think they should do it. [...] When they were younger, we never had these kinds of discussions! (Fanny, injured as adult).

If assistants questioned the mothers' right to use the assistance to cook a meal, clean or do other things for their children, this could be experienced as questioning her right to 'mother' her own children. Several of the families reported wanting to compensate their children for adjusting to their parents' disability in different ways and for sometimes refraining from doing things children of able-bodied parents could do. To some of the parents, helping their teenagers with chores was one way of doing this. Fanny said the following about her two sons:

They know that they have to help out, or that we have to take each other into consideration. They may have learned other things. [...] They have to show consideration in another way. They can't just come and say "Mom, let us go! We have to do these things now". (Fanny, injured as adult)

Assistants as compensators

The two young men who took part in the study had recently become fathers and formed families when they were struck by accidents. Neither of them had changed their way of living despite becoming parents. Until the accident, they continued with their work and their habits just as they had done before the children were born, leaving most of the childcare to the mothers. The accidents changed their way of life dramatically. They both reported that it had taken many years before they had recovered enough to be more active as fathers. They were affected by strong medications and were fully occupied with their rehabilitation and orienting themselves in a new situation.

I was only twenty-three years old at that time. I wasn't so very into these things. The main thing was that it was ok for Camilla. That was most important. Then who took care of her was... I was busy taking care of myself, so to speak. So, for sure, I would gladly have done more and taken care of her if I had had the energy for it. But I was fully occupied with taking care of myself. And she hasn't missed out, luckily. It works quite well now, I think. (Conny, injured as adult)

Both of the men said that their children, during their first years, were primarily taken care of by their partners. The personal assistants were of help now and then, giving practical care as a way to relieve the able-bodied partner. None of the men seemed to have had any thoughts about whether the assistants could have helped them to be more active as fathers during the toddler years. Both of them talked about fathering as being there, playing and being physical with

the children: teaching them to ride a bike, playing ball and so on, but also giving them a hug. They described these activities as a complement to the mothers' role and that they feared that the children might miss out on these things, as they could not provide them. Having assistants around was described as a means to compensate the children for their fathers' physical limitations. In contrast to the women who used the personal assistants to take on an active role as mothers, the men described how they had refrained from demanding this part of the fathering role and accepted, though it hurt, that the assistants could fill this gap to some extent.

I think that you have different roles there as mother and father. I don't mean that a mother can't teach the children to ride a bike. [...] But I think, the father has a role there, that I felt got badly damaged because I can't be physical. [...] Still, I felt a joy that the kids could always go to the assistants to make mischief and be tickled and so on. And I felt that the assistants, they must take my role, no matter how hard it is. The children must get what they need, so to speak. Then I have to take my fight with myself. (Henrik, injured as adult).

The young men did not view the personal assistants as enablers of fatherhood or as competitors. To them, the assistants were more like compensators. The men encouraged the personal assistants and the children to build good relationships. They talked in different ways about their losses, saying they were sorry to miss things they described as fatherly tasks. At the same time, they talked about the advantages their children had in being able to do things with the help of the assistants. The men allowed the assistants to do things on their own with their children, something that did not occur with the assistants of the mothers with congenital disabilities. For example, they could give the child a ride to an activity if their father wanted to stay at home or play a game with the children while the father was asleep.

The parents' views ten years later

Ten years after the first round of interviews with the assistant users, six of the parents were interviewed again about their parenting strategies and the role of the personal assistants. At the time of the follow-up interviews, their children were on the verge of leaving home or had already left home.

The parents' views on how the assistant should relate to their children followed largely the same patterns as before. The mothers with congenital impairments adhered to the notion that it was important that the children turn to them as mothers. Britta has remained as strict in her opinion as before concerning how the assistants should relate to her children. She emphasized that she has viewed the assistants as her hands and feet for the entire time they have worked with her.

And then I want the assistants to be my arms and legs without having relationships with my children when they work, because the children may get angry with us, then they should be angry with us, and not with an assistant who has interfered because she's a friend and has the right to do it. And then I think that if you have clean, straight relationships in order to make it work, then I think that if you're "only assistant" and not a friend, when you work, there won't be any double things like that. (Britta, mother with congenital impairment)

Throughout the interviews, she described problems with a high turnover of personal assistants. Her way of protecting the children from experiences of separation has been to try to avoid the children and assistants becoming attached to each other.

But my children, as well as other children, have enough separations anyway, with pedagogues leaving the pre-school, and teachers leaving school and all the other people who come and go in their lives. It shouldn't also be a separation every time an assistant leaves her job. If things were like that life would be very tough, very often. (Britta, mother with congenital impairments)

The other mother with congenital impairments underlined that she was present almost all of the time and that she and her partner should answer all of the children's questions and provide the emotional care. In most cases, the children were young adults, and they no longer needed practical help from the personal assistants.

Personally, I feel that I have been so intensely present in my children's lives. The personal assistants have certainly not been complements. [...] The boys turn to me for everything and now when they've grown up there are so very few things that we can't do because of my impairment. [...] Today our relationship does not depend on the assistance like it did when I needed the assistants to help me with physical things. (Anna, mother with congenital impairments)

Even though Anna was still of the opinion that the children should turn to her in the first place, she had underlined the importance of the children showing respect for the personal assistants during all of the previous interviews and that they must never take advantage of having personal assistants at home.

With the distance of ten years, most of the assistance users talked about the assistants and their importance to the children. Their views had become more relaxed as the children grew older. In most cases, the assistants were talked about as family members or friends. The parents also reported that the children had become more attached to some assistants than to others.

/My son/ used to say that he's had two mothers. Sally who has worked for a long time. He knows that she's there and can be of help and they know of nothing else because they've learned that there are assistants in the family during the days and that they are always there to help out. (Fanny, injured as adult)

The two fathers reported leaving it to the assistants and the children to form their own relationships. According to the fathers, their grown-up children could even hang out with personal assistants who are close to them in age. "She hangs out a lot, at least with the younger assistants I have" (Conny, injured as adult).

Personal Assistants' Views on Assisting in Parenting Strategies

Five interviews with personal assistants working in families with children have been held. The personal assistants discussed difficulties in relations to the parenting strategies. It concerned (1) their assistance user's opinions on how to develop relationships with the child and (2) contradictory views on upbringing and (3) limits concerning tasks in relation to other family members.

Relationships to the children

Some of the interviewed assistants had experiences of working in families where the assistance users emphasized that emotional care should be provided by the family. The assistants and the children were not supposed to form any relationship of their own. Maria had worked in different families. She described working as a personal assistant for a mother who had very strong views on how the assistants should respond to her children.

She wanted you not to be too personal with the children. [...] She wanted to get help with all sorts of things, but everything should be decided by her. An assistant must never take any initiative towards the child, every initiative must pass from assistant to mother, and to the child. If a child fell and got hurt, she would not want you to lift the child, hug it, and comfort it, ever. Even if she wasn't present, you were supposed to tell her what had happened and then she would decide what to do. It was very important not to take any initiatives on your own. (Maria, personal assistant, PA seven years)

Working according to the mother's instructions put a strain on Maria. Even if she showed some understanding of the mother's motives, Maria used strong words to describe how she herself was affected by adapting to the mother's demands:

Personal assistance in this home was almost like destroying yourself. And it's really about being as invisible as you can. Put on 'the invisibility coat'. Disappear almost! (Maria, PA seven years)

Turning off the natural impulse to respond to a child's actions requires a lot of energy from the assistant. After some time, when the mother felt she could rely on Maria, the restrictions loosened a bit and Maria began adapting to the situation.

Despite the difficulties accepting 'the invisibility coat', Maria also mentioned that working for an assistance user with clear ideas about how the assistance should work was in some respects easier to handle than working with a person who gave unclear or no instructions at all. The limits were clearly established:

And it was very good in a way because there you really just needed to stick to the rules. It was nice in *one* way. (Maria, PA seven years)

Another personal assistant had experiences of working in a family where the father had contracted a progressive illness as an adult. On the contrary, he wanted the assistants to engage in and relate to his children:

He felt very strong in his fathering role, although he was very limited as to what he could do. On the contrary, he really wanted us to have good relationships with the children. (Rebecka, PA five years)

One task to help him take on his fathering part was to accompany him to pre-school to collect his two children in the afternoon. This was a challenge for the assistant, as the man needed her full attention and assistance at the same time as she was supposed to bring him and the children, two and four years of age, back home.

Concerning teenagers in the family, the personal assistants sometimes wanted contact but the teenagers saw them as persons who helped their father or mother. The teenagers were not totally at ease with having assistants at home and stayed in their rooms, passing the assistants without saying hello.

Different views on upbringing

The assistants described different dilemmas, where they either were too loyal to the parent or followed their own ideas about what was right in the current situation. This could be a question of whether to give a child a sandwich after dinner if the parent had said no, which might constitute crossing the line the parent had laid down. Another example was when the personal assistant tried to stop a child from making mischief by saying no. This might cause the parent to take the child's part. Both examples imply that the assistants had passed the limits of the parent's sphere. Åsa had worked as a personal assistant for many years, but in a situation where she tried to stop a child, she became aware of how easily she could lose her job.

In a certain situation she said "If you interfere with my children one more time you will actually have to leave!" [...] And I hadn't thought about it since I had worked in preschool before. [...] It's very good! I think that it's a great thing that they can decide themselves if they want to have somebody in their home or not. But it's very precarious for those doing the work! Because you can be just a little tiresome and then you're not welcome anymore. (Åsa, PA nine years)

Other difficult situations for the assistants were when the assistant thought the parent was rude or harsh towards the children and the assistant wanted to protect them. This could result in a discussion with the parent, where the parent insisted on his or her right to decide what was best in the situation.

And then I felt that there were conflicts also because I thought that Adam, he could be very hard on Axel. And laugh at him if he burst out in anger and it was very hard for me to see that and not be able to enter into it properly. For he made it very clear that "I'm with my kids like I am with my kids and you don't have any right to comment on that!" And I thought that was pretty tricky. (Rebecka, PA five years)

Another source of frustration and discussion was the division between the personal assistants' tasks and the chores done by other family members. Sometimes the assistants were also expected to do various things for other family members, such as washing the dishes after a family party or looking after the children. These things were seen as ways to relieve the able-bodied partner from household work so the partners could spend time together, according to the assistant user. However, some personal assistants were not convinced that these chores were part of their job.

Discussion

Earlier research has shown how difficult it is for women and men with disabilities to be accepted as good parents (Grue & Laerum 2002; Lappeteläinen, Sevón & Vehkakoski 2017; Malacrida 2009, 2020). Parents with disabilities struggle against negative stereotypes, at the same time as many of them are dependent on support to carry out certain aspects of parenthood. In Sweden, personal assistants can help parents with disabilities realize their parenting strategies even though parenthood is seldom a reason for granting assistance (Bergman, Melin Emilsson & Järkestig Berggren 2020).

The study examines how parents with extensive physical disabilities use and direct personal assistants to realize their parenting strategies. Likewise, it studies how personal assistants experience assisting in parenting strategies. Parenting strategies are gendered (Malacrida 2020), and this was seen also in the present study. Some parents constructed their parenting strategies according to traditional male or female norms of parenthood. The fathers' first years with the children, which coincided with their accidents and first years with disabilities, were periods of time when the child's mother assumed the overall parental responsibility. However, this is not only explained by the accident; these fathers also held the view that the mother is the primary care-giver during the child's first years. Later on, when the children were older, the fathers, who linked fatherhood to physical engagement and activities with older children, handed over these tasks to the personal assistants without being involved themselves, thus using the assistants as 'compensators'.

If the fathers' parenting strategies were formed along the way, the mothers with congenital impairments had clear objectives for how they used personal assistance to implement their parenting strategies. They instructed the assistants to focus on practical support, not social or emotional support. They used the assistants as 'enablers', which helped them to be active mothers (cf. Lappeteläinen, Sevón & Vehkakoski 2018). The requirement of the personal assistants to be 'hands and feet' was also a strategy to attach the children to them and not to the personal assistants, implying that they were afraid of the assistants as emotional 'competitors'. The mothers who had accidents as adults and already had children did not discuss the personal assistants as rivals for their children's affection. They were more concerned about being in charge of the tasks and responsibilities in relation to their children.

Follow-up interviews ten years later indicate that the parents kept their parenting strategies. The interviews also bear witness to how all of the parents have processed the difficult fact that they need support in their parenthood. Over the years, the sadness and frustration of not being able to carry out some tasks have led to not only acceptance but also joy that personal assistants can substitute for them and give their children access to things and experiences they want to offer them. The parents were all convinced that they had acted in their child's best interests. The fathers were pleased that the personal assistants could compensate for their physical shortcomings and interact with the children,

and the mothers who wanted their personal assistants to be their ‘hands and feet’ tried to protect their children from separations and being caught in the middle of different opinions.

Arguing based on what is in the child’s best interests might be interpreted as a way to steer away from the discourse of negative assumptions about parenting with disabilities. Referring to the child’s positive development is one way to underline a successful parenting strategy (Lappeteläinen, Sevón & Vehkakoski 2018). The argument that the most important thing is the child’s well-being, not who carries out the practical support, stresses a child-focused parenting strategy that aligns with modern Swedish parenting.

The aim of personal assistance is to give compensatory support to enable the service users to ‘live like others’ (SFS 1993:387 5§). There has been a shift from being dependent on others’ benevolence or support from family and friends to independence and user control through personal assistance. Another ‘independence journey’ implemented by the Swedish welfare state is the provision of public support for parents like day-care centres, paid parental leave, compensation for loss of income due to children’s illness, and so forth. Instead of relying on help from relatives and friends concerning parenthood, there is public support based on a dual-earner model. In a comparative study, Mona Franséhn (2011) argues that Swedes experience planning their family formation as an individual project, where the welfare state provides basic security, instead of seeing it as collective project, which is common in other cultures. Both processes, which emphasize independence, have had an impact on the parents with disabilities in the present study. Their point of departure is that parenthood is their own and their partner’s decision, without being dependent upon relatives. Their parenting strategies are based on access to personal assistance and other welfare support, such as day-care centres.

The personal assistants’ views

The working conditions for personal assistants differ from other employment arrangements in Swedish work life, in that the service user may be the employer and have the right to end the employment. There is also a lack of employee influence over work tasks compared to other jobs. Guldvik, Christiansen and Larsson (2014: 57) point out that ‘the flexibility is structurally distributed asymmetrically between the user and the worker’. The blurred boundaries between service users and personal assistants concerning privacy, friendship, informality, and so forth, are also characteristic of the job (Porter, Shakespeare & Stöckl 2020). Parenting strategies are closely connected to values concerning parenthood and ‘the best interests of the child’, which are imbued with individual opinions on gender, childrearing, human dignity, and so forth. Such values are highly individual, and when personal assistants and service users disagree, it becomes problematic.

Working as a personal assistant in families with small children may be demanding, as assistants have to relate to both parents and children. The assistant is expected to respect the assistance user’s wishes about how to relate to the child. Some assistants working in families where little social contact with the child was required had difficulties not responding to the child’s attempts to make contact. Likewise, they experienced difficulties when parents treated their children in ways that did not align with their own ideas about parenting strategies. The assistants also experienced blurred boundaries concerning work and if they should carry out tasks for other family members, thereby creating more quality time in the family. Such situations reveal the asymmetry of power between user and personal assistance, where critique may result in dismissal (Guldvik, Christiansen & Larsson 2014; Porter, Shakespeare & Stöckl 2020).

The different parenting strategies could be carried out thanks to personal assistance. The variety of different parenting strategies shows that personal assistance does indeed constitute personal and individualized support. It may be used to challenge gendered norms as well as to preserve them. Personal assistance gives users the ability to live their lives according to their own wishes and ideals. There are, however, challenges when such parenting ideals are at odds with the assistant’s own ideas. Formally, the assistant user makes the decisions, but morally this is a strain on the assistant. The interviewed parents have clearly indicated that access to personal assistance has been of great importance to them by increasing their means to be active parents. However, there is a need for continuing discussions about how assistants can work in a way that strengthens parenting roles as well as about how assistants can get support to work in a sustainable manner.

Competing Interests

The authors have no competing interests to declare.

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How to cite this article: Selander, Viveca and Kristina Engwall. (2021). Parenting with Assistance – The Views of Disabled Parents and Personal Assistants. *Scandinavian Journal of Disability Research*, 23(1), 136–146. DOI: <https://doi.org/10.16993/sjdr.775>

Submitted: 23 October 2020 **Accepted:** 06 May 2021 **Published:** 27 May 2021

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