This is the published version of a paper published in Nordic Social Work Research.

Citation for the original published paper (version of record):

Persons with certain functional impairments apply for parenting support: a study of personal assistance assessments in Sweden
Nordic Social Work Research, 12(1): 46-58
https://doi.org/10.1080/2156857X.2020.1756387

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:
http://urn.kb.se/resolve?urn=urn:nbn:se:lnu:diva-93423
Persons with certain functional impairments apply for parenting support: a study of personal assistance assessments in Sweden

Ann-Sofie Bergman, Ulla Melin Emilsson & Ulrika Järkestig Berggren

To cite this article: Ann-Sofie Bergman, Ulla Melin Emilsson & Ulrika Järkestig Berggren (2022) Persons with certain functional impairments apply for parenting support: a study of personal assistance assessments in Sweden, Nordic Social Work Research, 12:1, 46-58, DOI: 10.1080/2156857X.2020.1756387

To link to this article: https://doi.org/10.1080/2156857X.2020.1756387

© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

Published online: 24 Apr 2020.

Submit your article to this journal

Article views: 549

View related articles

View Crossmark data

Citing articles: 1 View citing articles

Full Terms & Conditions of access and use can be found at https://www.tandfonline.com/action/journalInformation?journalCode=rnsw20
Persons with certain functional impairments apply for parenting support: a study of personal assistance assessments in Sweden

Ann-Sofie Bergman, Ulla Melin Emilsson and Ulrika Järkestig Berggren

Centre for Social Work, Department of Sociology, Uppsala University, Uppsala, Sweden; Department of Social Work, Linnaeus University, Kalmar, Sweden; School of Social Work, Lund University, Lund, Sweden

ABSTRACT
In Sweden, personal assistance is one form of support for persons with certain functional impairment. The aim of personal assistance is to give compensatory support to individuals so that they can enjoy the right to live a life like anyone else. This article explores what kind of support parents who have functional impairments and apply for personal assistance may need when they have underage children. The article is focused on the following: What support needs in parenting are expressed in personal assistance applications and by whom? How are the expressed needs in parenting met by the intervention personal assistance, i.e. how do the decisions correspond with the expressed needs? The article is based on qualitative and quantitative document-analyses of 100 randomly selected applications for the right to personal assistance submitted to the Swedish Social Insurance Agency by applicants who were parents with children 0–17 years of age, during the years 2014–2017. The central concepts resulting from the analyses of the empirical material were support and care. The results show that in many cases the children were invisible in the material studied. In several investigations, there was no information at all about the applicant’s children. Many applications for assistance were refused. Few parents received assistance in their parenting role. In the documents, we found the following themes in statements about needs for support related to the role as a parent: practical support, care and supervision, support with communication, emotional support and safety, and support to be involved in the children’s lives.

KEYWORDS
Personal assistance; disability; parents; children; support; care

Introduction

When a parent suffers from a serious physical illness or functional impairment, the whole family, not least underage children, are affected. Younger children are totally dependent on their caregivers for safety, care and maintenance. To fulfil these tasks, a parent with functional impairment may need support. This article explores what kind of support people with serious functional impairments need in their role as a parent in everyday life when they live with underage children. There is need for deeper understanding about the lives and needs of children and parents when parents are affected by impairment (cf. Aldridge 2008).

In 2009, the Swedish government decided on a national strategy for developing support for parents. This was a part of a long-term strategy to promote health and prevent ill health among children and young people (The Public Health Agency of Sweden 2014). A basic idea of the Swedish welfare policy is to offer good living conditions to parents, as these are perceived as a prerequisite for good parenting (The Public Health Agency of Sweden 2014). In the Swedish society, there is
a general system of support for families with children, including child allowances (barnbidrag), parental benefits (föräldrapenning), and access to free child healthcare, preschool and education.

For disabled persons, there is also a designated system with individualized support. In recent decades, the Swedish disability policy has been directed towards inclusion and increased participation in society (Nirje 2003; SOU 2008, 77). The Law regarding Support and Service for persons with certain functional impairments (LSS, SFS 1993, 387) was implemented in 1994 as a part of the support system. One form of support within this system is personal assistance. The aim of personal assistance is to give compensatory support to individuals with serious functional impairment so that they can enjoy the right to live life like anyone else (LSS, 5§). One aim of the LSS reform is for people with serious functional impairment to be included as citizens in the society with the opportunity to shape their own lives and get support in their own homes (Government Bill 1992[1993], 159). The LSS reform was implemented during a period of de-institutionalization in society (Lindqvist 2000). Personal assistance was developed with inspiration from the independent living movement in the USA, which started in the 1960s in order to strengthen disabled people’s power over their own lives (Egard 2011).

In Sweden, there is a lack of research on the situation of families with children when parents have functional impairments. When discussing the issue of parenting and disability, it is often about the parents’ care for their disabled children (Committee Directive 2016, 40; Government Inquiry 2018, 88; Gustavsson Holmström 2002). With this article, we intend to make a contribution to the field; our aim is to analyse what kind of support parents who have functional impairments and apply for personal assistance may need when they have underage children to take care of, so that they can get the chance to have a family life like other citizens in Swedish society. As the need for support in parenting can be expressed by the parents themselves and by their family members, representatives, and professionals, the study also analyses who raises the needs. The article is focused on the following questions:

**What support needs in parenting are expressed in personal assistance applications and by whom?**

**How are the expressed needs in parenting met by the intervention personal assistance, i.e. how do the decisions correspond with the expressed needs?**

This article is intended to contribute with a deeper understanding about the needs for support in order to meet the needs of children and parents. The study is limited to applications processed at the Swedish Social Insurance Agency (henceforth SSIA).

**Previous research**

When a parent suffers from a serious physical illness or functional impairment, the whole family and not least underage children are affected. Previous research has demonstrated that children may experience psychosocial stress and anxiety related to the uncertainty and caregiving tasks imposed by a family member’s functional impairment or illness. Stressors may include separation from the parent during hospitalization, altered family roles, increased responsibilities and emotional uncertainty (Spath 2007). Other stressors can be increased economic pressure due to the long-term impact of a parent’s illness/functional impairment that also affects the children, as well as difficulties in getting help with schoolwork and leisure activities as a consequence of the parent’s lack of energy (Järkestig Berggren and Hanson 2013, 2016). In some cases, family roles and functioning can be disturbed, possibly resulting in children taking on significant caregiving responsibilities as young carers for parents, siblings and the home (Ireland and Pakenham 2010). This responsibility often exceeds what is typically expected of a child (Becker 2007).

Previous studies, undertaken in the Young Carers Research Group in the UK, about children who become young carers, indicate that potential triggers for caring are parental illness or disability combined with other significant factors such as lone parenthood, low income or poverty, and lack of
adequate services and support (Aldridge 2008, 2018). Swedish as well as international studies show that disabled parents more often than non-disabled parents face economic strain that affects the living conditions also for the children (NBHW 2010; Reinders 2008).

Research about parents’ experiences of being a parent with functional impairment involve mainly two themes. One is that difficulties are experienced as a consequence of the disability. The other is that the societal discourses about disability exclude parenthood as a possibility. From the parents’ perspective, there are experiences of demeaning attitudes and having their identity of being a parent questioned by persons in authority as well as the general public (Duvdedany, Buchbinder, and Yaacov 2008; Malacrida 2009). Grue and Lærum (2002) study shows that mothers experience that other people react to their motherhood and that they are more closely monitored in their role as a parent. They feel that they have to work hard in order to convince other people that they are capable and good enough parents. The fear that their children can be taken away from them plays an important role in some parents’ everyday lives.

In Sweden, research is limited on experiences of parenthood with a serious functional impairment. Research from the parents’ perspective shows that parents perceive a division between ideology and reality when they as parents are faced with prejudice and expectations that are not faced by non-disabled parents (Gustavsson Holmström 2002). The parents encounter conceptions in the society about disabled people being unthinkable or inappropriate as parents. They are often looked upon by others as receivers of care and not as carers (Gustavsson Holmström 2002).

Alongside these circumstances are the political intentions to offer full equality and participation in society so that disabled persons can live ordinary lives, including family life, like everyone else (The UN Convention on the rights of persons with disabilities, CRPD, article 23). The experience of being questioned can lead to a strategy of trying to conceal the effects of one’s injury or disease (Gustavsson Holmström 2002).

Selander’s (2015) study about physically disabled parents using personal assistance shows that the assistants are important for the parents; they are enablers that support them to be more active and caring parents able to take part in their children’s everyday activities. Parents in the study described different experiences depending on when in life they became disabled, which also had an impact on their strategies about assistance and the assistant’s relations with children in the family. Parents who were injured as adults had experiences of a life before and a life after the accident or illness. Personal assistance enabled them to recapture some of the abilities they had lost. The study shows that family support also was important. The participants in the study received extensive informal assistance from family members, and even children took part in helping their parents. In interviews with children, some of them expressed that they developed a sensitivity to their parents’ needs when they felt that the assistance did not work well enough, and therefore, the children would develop a readiness to step in and give help when required in acute situations. International research on the experiences of children and parents shows a need for implementing various forms of support in their everyday life (Järkestig Berggren and Hanson 2016; Spath 2007).

**Parental care, societal responsibility and the rights of the child**

What is perceived as sufficiently good parenting is contextual; it differs depending on time and place. During the previous century, there were major changes in the conceptualizing and the experience of childhood and parenthood in the western world. The reduction of child labour along with the gradually increased school attendance for children resulted in an extended childhood. A proper childhood should be separated from the adult world. To a higher age than previously, children became an economic expense to their families rather than a potential source of income. Children became dependent on their parents for a longer time, which could be spent in play, education and gradual preparation for adult life. Good parenting in large measure consisted of preserving and prolonging the children’s childhood. Parents were expected to provide care, while children were expected to receive care (Cunningham 2005).
In recent decades, since the ratification of the UN Convention on the Rights of the Child (UNCRC) in 1989, children’s rights have been strengthened in society. The convention was incorporated into Swedish law on 1 January 2020 (www.government.se). According to the convention, children have extensive rights, such as, rights to life, survival, development, health, education, social security, leisure, play and protection from exploitation (Articles 6, 7, 24, 26, 28, 31 and 36). According to the Swedish Parental Code (PC, SFS 1949, 381), children have the right to care, security, and nurturing and to be treated with respect (PC 6:1). The parent or other person who has custody of the child is responsible for ensuring that the rights of the child are respected (PC 6:2). However, the responsibility for the child is shared between the parents/guardians and the state. The boundary between public and private has shifted in a way that the welfare of children has become a public concern to an increasing extent. If the welfare of a child is threatened, the social services have the responsibility to enter in order to provide protection and support to children and their parents (Social Services Act 5, 1).

When assessing parental capability, the social services should take into account children’s needs for basic care, stimulation and guidance, emotional availability and security (NBHW 2015). According to a handbook for social workers from The National Board of Health and Welfare (NBHW) the society has an important role to play in supporting and, if necessary, supplementing the parents during the child’s entire upbringing. The purpose is to offer parents the support and assistance they need to manage their parenthood better. In the handbook, the NBHW expresses that applying for support can be a way for guardians to fulfill their parental responsibility (NBHW 2015).

Growing up as a child in a family when a parent has a serious functional impairment implies a childhood with experiences that sometimes differ from those of children in other families where there is no disability. Children in this position are described as ‘next of kin’. This position is an authoritative concept, according to which the Social Services Act (SFS 2001, 453) grants support to adults who are next of kin and care for a loved one. Underage children, however, who are next of kin, are not included in this text and hence are not granted the right to support. To date, according to the Health Care Act (SFS 2017, 30), underage children are granted rights to have their needs for information and support assessed when their parent has a serious physical illness or injury.

In Sweden, there is the widespread idea that a well-developed welfare system exists, protecting children and preventing them from becoming caregivers. A study conducted by Gould (1995) showed that few people thought it was likely that children with physically disabled parents would be young carers because of the available resources for this group of parents. However, studies show that young carers do exist and that their problems are not always addressed (Gould 1995; Järkestig Berggren et al. 2018; Kallander et al. 2018a, 2018b; Nordenfors, Melander, and Daneback 2014).

The government bill to the LSS in the 1990s raised the importance of parents with impairments receiving support and assistance in various forms so that they can cope with their parental role. Mainly, attention was paid to the situation of parents with very young children. During the child’s first phase in life, the parent would receive assistance with the care of the child. For disabled parents without the right to personal assistance, it was expected that other forms of support from the municipality would be offered. The legal text stated the importance of developing knowledge and awareness of the disabled parents’ situation and needs for support (Government Bill 1992[1993], 159). However, the latest Government Inquiry (2018, 88) takes account of the various roles of disabled adults, and the role as a parent is not among them. When the situation for children and parents is discussed in the inquiry, it is about when a child has an impairment (Section 6).

**Method and material**

The data analysed for this article was obtained from a research project about parenthood in personal assistance assessments carried out by the Swedish Social Insurance Agency (SSIA). The article is based on qualitative and quantitative document-analyses of 100 randomly selected applications for the right to personal assistance by parents who have children 0-17 years of age,
during the years 2014–2017. Assessments of the need for assistance for disabled persons involves integrity-sensitive material. This study has been approved by the regional ethical review board in Linköping (ref. 2017/149-31). The files were made available by the SSIA after the study had obtained ethical approval.

The files included the parents’ applications, assessments by SSIA, and in several cases medical certificates as well as statements from occupational therapists, counsellors and social workers. Occasionally, the files could also include previous assessments by the social services and correspondence from the applicants or their family members.

The person applying for personal assistance received a form that was sent home from the SSIA to enable the applicant to be prepared for the meeting with the public official. The form contained the following question:

If you are a parent, do you need any help and support to take care of your child or your children? In such cases, describe what you need help with and how much time it takes.

These descriptions about needs were central to the analysis of this study. It is important to think about documents, in this case, applications and assessments, in relation to their production (Atkinson and Coffey 2011). In their applications, the parents argued for their needs in order to get access to the kind of support they felt they and their children needed. This article reports how parenting was documented and what needs of the applicant were related to parenting.

Sample

To be eligible for personal assistance, the applicant must be covered by the Law regarding Support and Service for persons with certain functional impairments (LSS). Support pursuant to LSS is aimed towards individuals in the following situations: 1) mental impairment, autism or autism-like conditions; 2) significant and lasting intellectual disability after brain damage at an adult age caused by external violence or physical disease; 3) other permanent physical or mental disability that is obviously not due to normal ageing, if such disability is major and causes significant difficulties in daily life and the person thereby has a significant need for support and service (LSS, SFS 1993:387, 1§).

The study concerns applicants who were parents with underage children. In their applications, the parents described various kinds and degrees of functional impairments and a range of everyday challenges in meeting their own and their children’s needs. The most common diagnoses stated in the applications were related to physical disability (n = 65). Other diagnoses were cognitive (n = 15), palliative (n = 10), multiple (n = 4) and mental illness (n = 2). Among the applicants, there were more men (n = 58) than women (n = 41). The age interval most common was 41–60 (n = 71), while 17 applicants were in the age range of 22–40, and 11 in the age range of 61–64. The most common country of origin was Sweden (n = 50), followed by origin outside Europe (n = 37), and Europe (n = 3). The majority of applicants were married or cohabiting with a partner (n = 63), others lived apart from their partner (särbo) (n = 4), lived with a friend or relative (n = 6), or were single (n = 21).

Analysis – the concepts of care and support

The files have been analysed by two researchers independently using the same data analysis protocol that included themes such as the number of children in the family, the children’s ages, applicant’s gender, life situation, documented needs for support that could be related to parenting, and what support in parenting was included in the decision on personal assistance. The central concepts resulting from analyses of the empirical material were support and care. The analysis focused on discourses about needs for support in parenting and how these needs were met with support. The definition of the concept of support was inspired by Malecki and Demaray (2002) who define support
as an individual’s perception of support from people in their network which enhances their functioning and/or may buffer them from adverse outcomes. In this study, support was defined in a broader sense and included support provided by institutions in society. The analyses were focused on expressed needs of support, perceived needs of support, as well as received support (cf. Reinhardt, Boerner, and Horowitz 2006).

Care is a relevant concept as the article is focused on the applicants’ needs for support in their role as parents and caregivers for underage children. The concept of care can be viewed as 'a species activity that includes everything that we do to maintain, continue, and repair our “world” so that we can live in it as well as possible' (Tronto 1993). Caring is largely defined culturally and will vary among cultures. What is regarded as adequate care varies between different cultures and depends on factors such as time and place, class, gender and age. Fisher and Tronto (Tronto 1993, 2010) have identified four analytically separate but interconnected phases of caring as a process – caring about, taking care of, care-giving and care-receiving. In the process, the concerns and needs of the other person make up the starting point for action. The first phase, caring about involves the recognition that care is necessary, noting the existence of a need, and making an assessment that this need should be met. Taking care of is the next and second phase in the caring process; it involves taking responsibility for the identified need and determining how to respond to this need. Taking care involves the recognition that one can act to address unmet needs, involving notions of agency and responsibility in the caring process. If one believes that nothing can be done, there is no appropriate taking care of. The third phase in the process, care-giving involves the direct meeting of needs for care, while care-receiving is the fourth and final phase of the caring process. The person cared for will respond to the care received and evaluate how well the care provided has met the perceived need. In this study, caring about and taking care are relevant in the analysis. A dilemma in bureaucracies is that those who decide how needs will be met are often far away from the actual care-giving and care-receiving. Care-receivers might have different ideas about their own needs from those of the public officials. As a result, the received care may not be good enough from the care-receiver’s perspective (Tronto 1993, 2010).

Results

Expressed needs for support in parenting

One result from this study was that in many cases the children were invisible in the material studied. In several cases (N = 31) there was no information at all about the applicant’s children. There was no data available even though it was a selection criteria that the applicant had children under the age of 18. When the needs for support in parenting were described in the applications, the needs were expressed by the applicants themselves, their family members, and in written statements by professionals such as doctors, occupational therapists and counsellors. We have found the following themes in the parents’ and professionals’ statements about the applicants’ needs for support related to their role as a parent: practical support, care and supervision, support with communication, emotional support and safety, and support to be more involved in their children’s lives.

Practical support

In the documents, there were examples about needs for practical help in the household. Parents expressed their need for help with domestic chores such as shopping, cleaning, laundering, cooking and dish-washing. Some parents also needed help in contact with authorities and help to pay bills. Other parents needed assistance with driving and picking up their children from school and leisure activities. The following quote was about a single mother with a son in preschool age. In the file, one could read that she needed practical support. Her doctor wrote in a certificate that she had ‘an explicit need for help seven days a week, from early morning to late evening’.
She has a son and she wants to take care of him in the best way. To be able to be a mother for him, it is important that not all her energy is spent on shopping, picking up and leaving the child at preschool, cooking and cleaning.

This mother needed practical help in order to have the time and energy to take care of her young child. She wanted to be a good mother for him. The public official at the SSIA stated in the assessment that the woman’s disability caused difficulties in exercising parenthood. Another example was about a single mother with a son nine years of age. During a meeting, she expressed her needs for practical help, which had been written down in the application by the SSIA official:

She needs assistance so that the housework gets done, so that her son can live a normal life.

This quote makes a reference to the possibility of living a ‘normal life’, which can be related to normalized living conditions not only for the applicant herself, but also for her young child.

**Care and supervision**

There were parents who needed help with care and supervision of younger children. In the documents, there were a lot of expressed needs related to childcare, such as lifting, feeding, dressing, helping young children with hygiene, helping young children to wake up in the morning and go to bed in the evening, and helping children get to school and do their homework. The following example was about the perceived needs of a father with a daughter in preschool age:

He wants to be the parent he has always been for the child, and therefore needs assistance with giving food to the child, help lifting up the child and protecting the child from danger, help getting down to the floor to play with the child, and help noticing if the child calls for him.

This father wanted support that compensates him so that he could be the father that ‘he has always been’. He received an injury as an adult and had the experience of being a parent and living a life before and after the impairment. The needs were expressed by the applicant himself and by an occupational therapist.

**Support with communication**

Assistance with communication was a need for some parents. The following excerpt was from the application of a father with a son eight years of age. This man had a trustee and a wife who both helped him to apply for assistance, partly because he had difficulty communicating with others as a consequence of the disability:

I want help in communicating, taking part in family life and the household, as well as acting as a good parent and a model for my son.

In this case, the family members experienced a communication problem. The applicant was disabled because of traumatic brain injury. His wife described that both she and the child had health problems and needed support to handle the new situation for the family.

**Emotional support and safety**

There were parents who applied for assistance to improve the sense of safety for themselves and their children. One single mother with a daughter ten years of age applied for assistance during the night for her own and her daughter’s safety:

She is applying for someone to be there all night because of her own and her daughter’s safety. The daughter thinks it’s scary to be alone [with the mother] because of her cramps and if anything would happen.
The mother expressed a perceived need for support in case something would happen, which means a form of preventive or proactive support so that someone would be there when needed for herself and her daughter. Another mother expressed perceived needs for assistance so that her daughter would get to school safely:

My daughter needs support getting to and from school by car, as she suffers from panic attacks.

The mother explained that she had tried to drive her daughter to school herself, but that she could not do it anymore because of her disability and multiple illnesses. In this case, the child was 14 years old. Children of that age are generally expected to be able to get to and from school themselves. However, this girl suffered from mental health problems that might be related to the problems her family lived with as the mother had a functional impairment and multiple illnesses, and there was a lack of support for the mother and the family (cf. Spath 2007).

**Support to be more involved in the children’s lives**

Some parents applied for personal assistance to be more involved in their children’s lives. The following example was about a mother with a daughter in preschool age. An occupational therapist wrote about the mother’s situation and needs for support in a statement:

She feels great sadness that she cannot take a more active part in her daughter’s everyday life. She lacks the opportunity for independence and self-determination over her own life/. . ./. She says that she wants to be part of her daughter’s life, not just one who is watching.

Parents who expressed that they wanted support to be more involved in their children’s lives wanted assistance to be able to attend meetings in the children’s school and take part in their children’s leisure activities. Parents also expressed that they wanted support to be able to play with their children, participate in activities together with them, and be able to participate more in the care of their children.

**Received support – decisions on personal assistance**

Above, we have seen what kinds of support parents applied for to be able to provide care for their children. Parents applying for support can be related to the concept *caring about* (Tronto 1993, 2010) as the parents, family members and professionals recognized the existence of a care need that they meant should be met. Then how were the applications for support addressed? This study shows that many of the parent’s applications were refused. Among the 100 cases studied, 30 were deemed eligible for personal assistance, but four parents were so severely ill that they died during the assessment period. Therefore, 26 applicants received personal assistance, and among them there were 18 men and 8 women. This result is in line with the national statistics; the applications are to a high degree refused and more men than women receive personal assistance in Sweden (NBHW 2018; SSIA Statistics 1994[2017]). This study also shows a higher proportion of refused applications among parents whose country of origin was Europe or outside Europe (82%) than among parents from Sweden (57%).

Many applications (n = 42) were refused with the justification that the applicant was not deemed to belong to the group of individuals with rights covered by the LSS (LSS 1§). Other applications (n = 22) were rejected as the public official assessed that the applicant did belong to the group, but did not require assistance more than 20 hours per week for ‘basic needs’. In order to be granted assistance from the SSIA, the applicant is expected to have basic needs for more than 20 hours per week. Basic needs are defined as requiring assistance with washing oneself, putting on clothes, bringing food to one’s mouth, going to the toilet, communicating with others, or other support that requires thorough knowledge of the person in need of assistance (LSS 9a§). When the public officials determine that the applicant does not have these extensive basic needs, they do not assess the need for support in parenting, which is referred to as ‘other personal needs’.
There were few parents who received assistance in parenting; only nine parents received help explicitly for support in their role as a parent. Their needs were to some extent recognized, which could be related to the concept taking care of where one shows some responsibility and action to meet identified needs (Tronto 1993, 2010). Among these nine parents, there were six men and three women. However, there was a larger proportion of women than men among those who applied for assistance in parenting. As Table 1 shows, 31 percent of the parents in the sample applied for support in their role as a parent, and among them there was a larger proportion of mothers than fathers.

One explanation for the larger proportion of women than men applying for support in the parenting role may be that more women in the sample were living as single parents with underage children, implying conditions in everyday life where there is no other parent who can take the main parental responsibility. These single parents may be even more dependent on access to support from society. Another explanation to the larger proportion of women among those who applied for assistance in parenting may be that care for children to a high degree is gendered. Childcare has often been described as a responsibility of women (Tronto 1993). In Sweden, it is most common that children who do not live with both parents live with their mothers (Statistics Sweden 2019). It is more common for women than men to stay at home with parental allowance when a child is born, as well as with temporary parental allowance for the care of a sick child (Statistics Sweden 2018). The statistics also show that Swedish women are spending more time on unpaid care work than Swedish men (Statistics Sweden 2018).

Even though a larger proportion of women than men lived with their children, and a larger proportion of women than men applied for support in parenting, it was more common for men to get support in their parenting role. One explanation could be that women’s childcare is taken for granted, while men’s childcare is encouraged. In recent decades, the Swedish social policy has tried to increase men’s responsibility for the care of children and make fathers more present in children’s lives (Eklund and Lundqvist 2018; Eriksson 2003). Efforts to involve and support fathers might be at the expense of mothers who tend to be seen as natural carers (Eklund and Lundqvist 2018).

The material analysed for this study indicates that many parents have severe impairments. The applicants that received personal assistance in their role as a parent (N = 9) got assistance in the range 67 to 137 hours per week, and two of them received assistance 24 hours a day. The time allocated for care of children was limited, in the range of one and a half to seven hours a week. In most cases, this kind of support was aimed at being able to participate in the children’s lives, such as for leisure activities, and in other cases, care and supervision; see Table 2.

It is important to note that there might be more parents with needs for support in their parental role, as in some cases the issue was not addressed at all and there was no complete application in the SSIA file. Needs for support in parenting young children were not always considered. For some parents, it could also be difficult to talk about their needs for support in parenting for reasons of sensitivity. The felt need could be different from the expressed need (Bradshaw 1972).

### Table 1. Men and women applying for and receiving personal assistance (PA).

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Applied for PA</td>
<td>58 (59%)</td>
<td>41 (41%)</td>
<td>99 (100%)</td>
</tr>
<tr>
<td>Applied for PA in parenting</td>
<td>15 (26%)</td>
<td>16 (39%)</td>
<td>31 (31%)</td>
</tr>
<tr>
<td>Received PA</td>
<td>18 (31%)</td>
<td>8 (20%)</td>
<td>26 (26%)</td>
</tr>
<tr>
<td>Received PA in parenting</td>
<td>6 (10%)</td>
<td>3 (7%)</td>
<td>9 (9%)</td>
</tr>
</tbody>
</table>

Discussion

In this document analysis of Swedish SSIA files, one result was that many applications for personal assistance were refused. In many cases, the applicant’s needs were not cared about; the existence of a need in their parenting role was not even noted. In other cases, the need was noted, but not taken care of. When persons applying for personal assistance are parents, the decisions about assistance
are relevant for the children in the family. In the documents studied, we have found statements about needs for support with practical help, care of children, supervision of younger children, support with communication, emotional support and safety, and support to be more involved in the children’s lives. These needs correspond largely with the needs that the social services should take into account when assessing parental capability, i.e. needs of basic care, stimulation and guidance, emotional availability and security. Applying for support can be a way for parents to fulfill their responsibility, and the society has a responsibility to support children and parents (NBHW 2015).

However, the construction of the LSS does not take the parenting role as a valid need for support. Support in parenting young children is not regarded as a basic need; instead this kind of need is regarded as ‘other personal need’ that does not qualify for support from the SSIA if the applicant does not have ‘basic needs’ more than 20 hours per week. When support for the disabled parent is lacking, there will be consequences not only for the parents themselves, but also for their children. Some parents described in their applications that they were dependent on support from family members, relatives and friends. In the documents, there were descriptions of families living under severe stress. The lack of support may lead also to consequences for the other parent in cases when the applicant is married or cohabiting. In the applications, there were examples where the other parent had to take a great responsibility for the care of the disabled parent as well as all the housework. In some cases, even the applicant’s children were described as resources for their parents without any consideration for the consequences on the children’s health, well-being and development. The lack of support may affect the whole family system in a negative way.

One option for parents when their application to SSIA is refused is to apply for support from the municipality’s social services. In recent years, the assistance from SSIA has decreased, while the assistance from the municipalities has increased (NBHW 2018; SSIA Statistics 1994[2019]). However, one mother expressed that she did not want to be in contact with the social services as she was worried that they might investigate if her child could still live together with her. This finding is in line with previous research (Aune 2012). For some parents, it could be difficult to talk about their needs for support in parenting as it might be a sensitive subject, for example, because of fear of being regarded as an inadequate parent. According to previous research, there are disabled parents who experience that they are more closely monitored and questioned than parents in general (Grue and Lærum 2002; Molden 2014; Swain and Cameron 2003).

One conclusion from this study was that the applicants’ needs for assistance to take care of their responsibilities as parents in many cases were ignored. In the files, it was common that the children’s situation was not documented at all. The general perception in Sweden that the welfare state protects children may contribute to a lack of recognition. There is a risk that children may become young carers in Sweden due to the construction of the welfare system that is individual-based and lacking in a child perspective and family perspective in the distribution of welfare rights. Children’s caregiving is here understood as unpaid work, necessitated by needs of the parent that are not met by the societal welfare system, health care or by the other parent (Becker 2007). Caring responsibilities can have negative impact on children’s self-esteem, their education, relations with friends and transition into adulthood, especially when the caring becomes long-term (Becker 2007; Cheesbrough et al. 2017; Ireland and Pakenham 2010).

<table>
<thead>
<tr>
<th>Kind of support</th>
<th>Applied for PA, men (N = 15)</th>
<th>Applied for PA, women (N = 16)</th>
<th>Received PA, men (N = 6)</th>
<th>Received PA, women (N = 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practical support</td>
<td>2</td>
<td>6</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Care and supervision</td>
<td>2</td>
<td>8</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Communication</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Emotional support and safety</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>To be involved in child’s life</td>
<td>11</td>
<td>6</td>
<td>5</td>
<td>1</td>
</tr>
</tbody>
</table>
Structural factors, such as cuts to welfare support, and poor and ineffective services, increase the risk of children being drawn into inappropriate caring roles (Aldridge 2018). The consequences for children who become young carers when their disabled parents do not receive adequate support will be further discussed in another article.

**Implications for policy and social work practice**

More attention is required from policymakers and practitioners concerning the situation and needs of children and parents when a parent has a functional impairment. When disabled parents apply for support, the review process should take into account a child perspective, since the files commonly do not document the children’s situation at all. It is also important to be aware of the gender and equality perspectives, as the study indicates different treatment according to the applicant’s gender and ethnicity.

Early identification and preventive interventions are crucial, so that children do not have to provide care. In previous research, young people have expressed that the best way that social services could support them is to give adequate support to their parent they care for (Moore and McArthur 2007).

To implement children’s rights (UNCRC) and rights for persons with disabilities (CRPD), it is necessary to acknowledge the parenting role for disabled people, the child’s right to his or her parent and the parent’s right to support.

**Implications for research**

This article focuses on parents’ needs for support. Further research should include how affected children express their needs, as parents and children can have different views on caring and family life when parents are impaired by illness or disability (Aldridge 2018). Thus, more studies are needed about care and support from the children’s perspectives.

**Disclosure statement**

No potential conflict of interest was reported by the authors.

**Funding**

This work was supported by Försäkringskassan [grant number 070576–2016].

**ORCID**

Ulrika Järkestig Berggren http://orcid.org/0000-0002-1325-9965

**References**


Barn som är anhöriga till föräldrar med allvarlig fysisk sjukdom eller funktionshindring

Child & Youth Services


Child Care in Practice

Moder and the Handling of Fathers’ Violence]. Diss., Uppsala universitet, Uppsala.

Om stöd och service till vissa funktionshindrade [On Support and Services for Persons with Certain Functional Impairments]. Stockholm: Socialstyrelsen.

Committee Directive. 2016. Översyn av insatser enligt LSS och assistansersättningen [Review of Services according to LSS and the Attendance Allowance].


LSS is an abbreviation for Lag om stöd och service till viss funktionshindrade (LSS).


SFS. 1949:381. Föräldrabalken [Children and parents code].
SFS. 1993. Lag om stöd och service till vissa funktionshindrade (LSS) [The Law Regarding Support and Service for Persons with Certain Functional Impairments], 387.
SFS. 2017:30. Hälso- och sjukvårds lag [Health and Medical Services Act].