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# Records of personal assistance applications reveal young carers: Viewed from the rights of the child

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## Abstract

The aim of this article is to investigate how children's care responsibility is recognised in records of personal assistance carried out by the Swedish Social Insurance Agency (SSIA). The article consists of document analysis, examining how caring activities are made visible in the records, and professionals' views and actions regarding responsibilities placed on children. Data consist of 100 cases randomly selected from the SSIA register amongst applicants with children, focusing on parents' descriptions of their needs, the public officials' assessments, and statements from professionals. Recurring themes related to young carers were developed.

## KEYWORDS

children, disability, parents, personal assistance, young carers

## INTRODUCTION

Children living in families with a parent who needs care, support or supervision in his/her daily life due to physical or psychiatric health problems or drug misuse run the risk of having to take on a responsibility for caring for their parent and/or for siblings (Becker, 2007). Children's responsibility for caring is an issue in many developed countries independent of the welfare model; for examples, there are studies about young carers conducted in Switzerland

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(Leu et al., 2019), England (Joseph et al., 2019), Australia (Moore & McArthur, 2007), Norway (Kallander et al., 2018), Sweden (Järkestig-Berggren et al., 2019; Nordenfors et al., 2014), Canada (Stamatopoulos, 2018), Germany (Metzing et al., 2020), Austria (Nagl-Cupal et al., 2014) and the US (Kavanaugh et al., 2015). At the same time, children's rights to care, education, leisure and protection from situations that are harmful for their health or education have been recognised through the UN Convention of the Rights of the Child (UNCRC).

During the last decades, many countries in Europe have been facing austerity measures which challenge the availability of societal support (Brimblecombe et al., 2018; MacDonald & Morgan, 2020; Pinto, 2018). Reduced budgets lead to increased responsibility for care falling on the family and next of kin (Näsman, 2016), further contributing to the vulnerable situation of young carers (Vizard et al., 2019). However, it is not very visible how this affects children in families in need of assistance and support. Sweden has been rather unaffected by the austerity measures following the financial crisis in 2008, but still there are some areas that have been subjected to budget cuts, and one of the most debated the last couple of years is state-funded personal assistance (Altermark, 2018). Personal assistance is a form of compensatory support to individuals with serious functional impairment (The Law regarding Support and Service for persons with certain functional impairments, SFS 1993:387). One aim of PA is that people with serious functional impairment will 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 latest government inquiry in this area (SOU, 2018:88) had the directive to review the legislation and 'create a long-term sustainable economic development of personal assistance and to bring about more effective measures in LSS' (Committee Directive, 2016:40). During the year 2002, about 70% applying for personal assistance were granted support. During the years 2017 and 2018, the proportion had decreased so that <20% of those who applied received state-funded personal assistance (SSIA, 2019, p. 11). Instead, there was an increase of assistance funded by the municipalities (The National Board of Health and Welfare [NBHW], 2020). One option for parents when their application to the SSIA is refused is to apply for support from the municipal social services.

Given that existing knowledge about young carers says that children become young carers when there is a lack of other forms of assistance and other persons to take on the responsibility, and there is no alternative (Cass et al., 2009; Leu & Becker, 2017), it is urgent to gather knowledge about the situation of children who have parents with physical disabilities. Few children who provide support or assistance to family members define themselves as 'young carers', without first getting that acknowledgement from relatives and/or professionals (Cass et al., 2009; Moore & McArthur, 2007). Many of these children and youth see themselves as someone who 'helps out' at home (Cass et al., 2009; Smyth, Blaxland, & Cass, 2011; Svanberg et al., 2010).

In Sweden, there is no general support for children who take on responsibilities for the care of family members. Therefore, professionals who investigate the right to support, such as personal assistance, need to recognise the responsibilities undertaken by the children in the family. The aim of this article is to investigate how children's and young people's (up to the age of 20) care responsibility is recognised in parents' applications and in records of personal assistance carried out by the Swedish Social Insurance Agency (SSIA). In the article, we analyse and discuss what care responsibilities the parents and professionals make visible, and the views and actions of professionals regarding the caring placed on children and young people.

## Personal assistance and parenting

Over the years, Nordic research has concluded that personal assistance provides persons with disabilities the possibility of partaking in society on equal terms, living in their own homes (Giertz, 2012; Larsson, 2008), having a family (Selander, 2015) and obtaining paid employment (Dowler et al., 2011). A systematic review (Mayo-Wilson et al., 2008) concluded that amongst adults with physical and intellectual impairments, personal assistance was generally preferred over other forms of services. The contribution to empowerment in various forms for the recipients of assistance is a debated theme (Bonfils & Askheim, 2014). The relationship between the personal assistant and the client has been simultaneously described as being a friendship and a tool (Egard, 2011).

Few studies have focused on parenting with personal assistance. Wadensten and Ahlström (2009) found that service users with families deemed the support of the personal assistant to be inevitable in order for them to keep living with their family. A study of family members' experiences (Ahlström & Wadensten, 2011) shows that children placed strong emphasis on the aspects of perceived safety and security in the assistance for their parents. For example, changing of assistants and lack of continuity could give rise to perceived insecurity for them. Jacobson (1996) concluded that the partner and children take over care responsibilities when the assistance is insufficient. Selander (2015) also found that parents received care from underage children for support in their daily life when the assistance hours did not cover their needs. Parents also report negative experiences, such as their privacy and family life can be too exposed. Some parents try to moderate and set boundaries for the personal assistants (Järkestig Berggren et al., 2021). In a study about parenting, Bergman et al. (2020) explore what kind of support parents, who have functional impairments and apply for personal assistance, may need when they have underage children. The following themes were found 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 more involved in the children's lives.

## Children's caregiving

The field of research about children's care activities has developed from the 1960s as being described as pathological (psychology) or deviant (sociology) parentification (Winton, 2003). The research paradigm of parentification denotes a reversal of the parent and child roles, creating risks for relation disorder, where children are understood as passive receivers. From the early 1990s, childhood sociology describes children as actors who possess competencies, amongst which is the ability to inform about their own situation (Prout & James, 2003). The research field of young carers views children as actors in their families taking on responsibilities and tasks that are demanded. Children's caregiving is emphasised as a result of patterns in the family due to illness, substance misuse or serious loss, as well as the lack of societal and network support systems (Becker, 2007; Kallander, 2020; Smyth, Cass, & Hill, 2011). In most cases, children become young carers because there is no alternative:

In most families, young carers are drawn into caring because there is no alternative. Their caregiving is an outcome of the interplay between the demands for, and availability of, informal care within any family, community or society; a lack of available or affordable health and social care provision, particularly home-based care for

people with care and supervision needs; and the lack of recognition and support available to meet the parenting needs of ill or disabled parents.

(Becker 2007, p. 34)

Leu et al. (2022) describe young carers as 'a hidden army' of children who provide unpaid care for their parents, siblings and other family members (p. 1). Children's caregiving is understood as forced by needs not met by the societal welfare system, healthcare or social network. Leu and Becker (2017) define 'young carers' as:

young people under the age of 18 who provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or any other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.

(Leu & Becker, 2017, p. 750)

Young carers provide a spectrum of care activities, such as physical care, emotional care, household tasks and helping siblings. In summary, one can say that they do the same as adult informal carers (Chikhradze et al., 2017). Previous research about young carers has been conducted about the prevalence and extent of caring as well as the outcomes of caring for the children and young people.

## Prevalence and extent of caring

The prevalence and extent of children's caring has been studied in several countries. Overall, studies of young carers indicate that they spend more time on caring activities than children in the general population (Kallander et al., 2018; Nagl-Cupal et al., 2014; Pakenham et al., 2006; Warren, 2007). Prevalence rates for young carers younger than 18 years of age in Europe, Australia and the United States vary between 2% and 8% (Becker, 2007; Joseph et al., 2019; Kavanaugh et al., 2015; Leu et al., 2019; Leu & Becker, 2017; Metzger et al., 2020; Nagl-Cupal et al., 2014; Smyth, Cass, & Hill, 2011). A national survey in Sweden amongst ninth-grade compulsory school students found that 7% reported that they provide a very high extent of caring (Nordenfors et al., 2014). It is often difficult to compare results as there are varying age definitions for young carers in different studies (Chikhradze et al., 2017). There are studies that have shown that children in single households are more likely to be involved in caregiving than children whose parents live together (Chikhradze et al., 2017).

## Outcome of taking on care activities

Studies of outcomes for children who are carers report both a negative and a positive impact of caregiving. The negative outcomes have focused on psychological well-being and quality of life (Järkestig-Berggren et al., 2019; Kallander, 2020; Kavanaugh, 2014; Lloyd, 2012; Pakenham et al., 2006; Pakenham & Cox, 2012; Rose & Cohen, 2010), physical health (Nagl-Cupal et al., 2014; Chikhradze et al., 2017) and mental health (Chikhradze et al., 2017; Cree, 2003; Nagl-Cupal et al., 2014; Pakenham & Cox, 2012; Robison et al., 2020; Sieh et al., 2012). Children's

caregiving may also affect their school achievement, including school absence and admittance to higher education (Becker & Sempik, 2019; Chikhradze et al., 2017; Kaiser & Schulze, 2015; Moore et al., 2009; Stamatopoulos, 2018), and their future transition into adulthood (Aldridge & Becker, 2003; Roling et al., 2020). Missing out at school due to caring for family members has recently been addressed in Sweden by the former national investigator of school absence (Malin Landell Gren, DN 200107). According to the state public report about school absenteeism (SOU, 2016:94, p. 163; Hjern et al., 2013), at least one student in each class is absent every week due to caring responsibilities for a family member.

Negative outcomes of caring have been associated with increased caring activities (Kallander et al., 2018; Pakenham & Cox, 2018), lack of time for respite, and when the child perceived a lack of choice in caregiving (Pakenham & Cox, 2018). Children are found to be at risk for experiencing stress whilst undertaking responsibilities and tasks that exceed their abilities and developmental stage (Cheesbrough et al., 2017; Pedersen & Revenson, 2005). Furthermore, poorer parental physical health and unpredictability in the situation concerning the parent's condition also have a negative impact (Pakenham & Cox, 2012).

Children who become young carers are not automatically at risk. Children do also report positive views of caring and are found to develop social skills (Kallander, 2020; Roling et al., 2020; Van der Mijl & Vingerhoets, 2017). Positive outcomes of caregiving have been associated with resilience and self-esteem (Cassidy et al., 2014), early maturity and independence (Chikhradze et al., 2017; Roling et al., 2020). Children may have different experiences of their caring due to the combination of tasks and time spent on caring (Järkestig-Berggren et al., 2019). Their views of caring are also dependent on the responses by parents. Parents' recognition of their work and show of appreciation helps to build a close relationship between the children and parents. When the responsibilities are too demanding, when there is a lack of respite and absence of appreciation from the parents, the children's well-being is affected in a negative way (Pakenham & Cox, 2018). Families may avoid disclosing young caring to professionals because of fear of intrusion in family life, fear that the social services will separate them and take the children into care (Alexander, 2021; Metzging-Blau & Schnepf, 2008; Rose & Cohen, 2010).

## MATERIALS AND METHODS

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). Results from the research project have previously been reported (Bergman et al., 2020; Järkestig Berggren et al., 2020, 2021). For this article about young carers in records of personal assistance applications, we have collected data from 100 records of applications and assessments between the years 2014 and 2017. However, one record was registered as missing, as the application concerned a child that had incorrectly been registered on the mother's social security number. Therefore, the analysis is performed on 99 records of applications.

The records were randomly selected from a national sample by birthdate. Assessments of the need for assistance for disabled persons involve integrity-sensitive material. The records were made available by the SSIA after the study obtained ethical approval from the regional ethical review board in Linköping (ref. 2017/149–31). Data from the applications and assessments were subjected to qualitative thematic analysis (Braun & Clarke, 2006). First, the analysis was carried out on a case by case basis. Thereafter, the analysis focused on the entire material. For this article, we mainly focused on the parts of the applications in which the parents describe their



needs, the assessments in which the public officials describe family life, and the statements in which children are mentioned by parents or professionals. Recurring themes related to young carers were developed. In the analysis of children's care activities, we have started from previous research. Joseph et al. (2009) have constructed a questionnaire for identification of young carers in the UK. They found that caring tasks can be divided into six domains: personal care, sibling care, domestic chores, emotional care, household management and financial/practical support. In this study, the data contained documentation about children performing the following care activities: *personal care, domestic chores, household management, financial/practical support and emotional care.*

## 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 applications and assessments regarding parents. The two main criteria for inclusion were that the applicant was being assessed to decide on his or her right to PA and that the applicant must have 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 parents' physical disability ( $n = 65$ ). Other diagnoses were cognitive ( $n = 15$ ), palliative ( $n = 10$ ), multiple ( $n = 4$ ) and mental illness ( $n = 2$ ). Amongst the applicants, there were more men ( $n = 58$ ) than women ( $n = 41$ ). The age interval most common was 41–60 years ( $n = 71$ ), whilst 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 ( $n = 21$ ). There was information that the applicant had children in the ages 0–20 in about 74% of the cases examined; in the other cases (about 26%), there was no information about children despite the fact that it was a selection criterion that the applicant had children. See [Table 1](#) for sociodemographic data.

Amongst the 99 cases studied, 30 resulted in a right to personal assistance, but four applicants were so severely ill that they died during the assessment period. Therefore, 26 applicants received assistance, and amongst them, there were 18 men and 8 women. See [Figure 1](#). 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, 2022). Gender differences may to some extent be explained by differences in the incidence of different diagnoses. Some diagnoses that are linked to the right to personal assistance are more prevalent amongst men than women, such as developmental diagnosis and autism. At the same time, research shows that girls often are diagnosed later than boys, and that research on for example autism mainly has been carried out on boys whose symptoms have guided the design of the diagnostic criteria (NBHW, 2011, 2022).

**TABLE 1** Sociodemographic data for applicants ( $n = 99$ )

	<i>n</i> (%)
Gender	
Women	41 (41.4)
Men	58 (58.6)
Age (years)	
22–40	17 (17.2)
41–60	71 (71.7)
61–64	11 (11.1)
Country of origin	
Sweden	50 (50.5)
Europe	3 (3.0)
Outside Europe	37 (37.4)
Missing	9 (9.1)
Civil status	
Married/cohabiting with partner	63 (63.6)
Living apart from partner	4 (4.0)
Living with friend or relative	6 (6.1)
Single	21 (21.2)
Missing	5 (5.0)
Parenthood	
Children 0–20 years	
One child	55 (55.5)
Two children	11 (11.1)
Three children	6 (6.1)
Four children	1 (1.0)
Missing	26 (26.3)
Disability/diagnosis	
Physical disability	65 (65.6)
Cognitive disability	15 (15.2)
Palliative	10 (10.1)
Multiple	4 (4.0)
Mental illness	2 (2.0)
Missing	3 (3.0)

However, this cannot explain the gender differences amongst parents in this study, as the most common diagnosis was related to physical disabilities.

## Findings

In this article, we investigate how children's care responsibility is recognised in the applications and records. The results present what was found in the documentation, organised as follows:



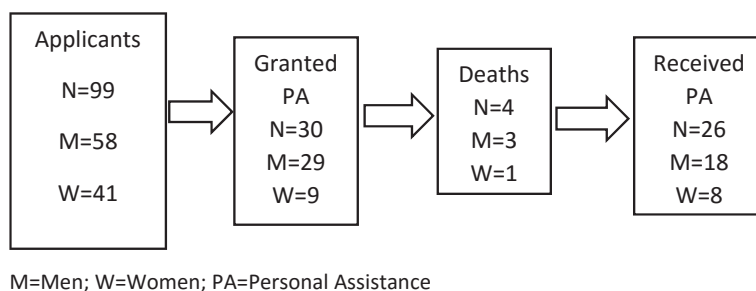


FIGURE 1 M = men; W = women; PA = personal assistance

(i) the extent of the identified caring done by children, (ii) what caring activities children performed, (iii) how parents acted towards their children's caring, (iv) the impact of caregiving on children, and (v) how the SSIA officials recognised and considered the children's caring in the assessments.

## To what extent do children take on caring responsibilities?

As already mentioned in the sample section, it was only in about 74% of the 99 selected records that it was documented whether the applicant had children, which means that data about the applicant's children was lacking in about 26% of the records. Descriptive analysis reveals that in 30% of the records with data about children, it was mentioned that children and young adults (up to 20 years of age) took on responsibility for caring for their parents. These children were in the ages 9–20 years. According to the documentation, children took on responsibilities when they lived with both parents, as well as when they lived only with the parent applying for personal assistance.

## What is documented about children's caring responsibilities?

### Personal care

In the records, there was documentation about children and young adults who helped their parents with personal care. Common care activities within this domain were help with personal hygiene, eating, taking medication, and getting dressed/undressed. In the following case, a son 19 years of age had written the application to the SSIA, where he described the situation in the family. He wrote that he and his brother were helping their disabled mother. The brother's age was not documented in the record.

Me and my brother are helping her; we take care of her hygiene such as showering, visiting the toilet, washing clothes, getting dressed, eating, taking her to her medical appointments, and taking her out to get some air.

In another case, there was documentation about a 15-year-old girl who cared for her mother during nighttime: 'The daughter helps her mother during the night when needed'.

In a third example, the children had to lift their parent. In the family, there was a 15-year-old girl who lived with both parents. There were also three older children in the ages 18–23. However,

the two eldest children had been refused asylum in Sweden and therefore had to leave the country. Thereafter, the younger children cared for the parent. In this case, the children's care work was recognised by a physiotherapist the disabled father had contact with:

He gets a lot of help from the family, wife and children /.../ Sometimes the wife does not manage to lift him herself and then one of the children can help him [when showering].

## Domestic chores and household management

Children performed a lot of care activities related to housework; there were examples such as cooking, washing up the dishes, taking care of laundry, cleaning and changing sheets in the disabled parent's bed. In one case, a doctor, who had contact with the parent, wrote in a medical certificate that the children provided care work:

Food purchases and cooking are done by the children /.../ The children do most of the housework.

There was also documentation about children shopping for food and carrying out other errands for their parents: 'The children provide valuable support to make everyday life function'.

About a 15-year-old boy who lived with a single mother and took care of most of the household chores, the SSIA investigator wrote in the record: 'She gets a lot of help from her son'.

## Financial/practical support

In the records, there was information about children who performed financial and practical care activities like paying bills, reading their parents' mail/letters, and helping their parents with communication in the contact with healthcare and authorities.

The son is helpful when needed; he handles contacts with third parties and pays bills.

In some cases, it was the applicant's young adult children who described the needs of their parent in the contact with the SSIA. They acted as the applicant's representative, and in some cases, also as interpreter. The officials at the SSIA also contacted these young adults to get information about the applicants, according to the documentation: 'I am calling the son'.

## Emotional care

There were children who performed emotional care and safety, for example, being there if the parent needed anything, taking the parent out for some air, or looking after the parent to make sure that he/she would not be injured or fall:

The daughter [15 years of age] has to keep the father company when the wife has to leave the home.

When a parent had a cognitive impairment, for example, due to traumatic brain injury or dementia, the care activities could include tasks such as control, monitoring and supervision:

The son [20 years of age] helps [the father] with planning, organising and prioritising, because he can't remember or follow simple instructions like turning off the stove, finding the way outside the home, or getting to scheduled appointments.

In the following case, the children were the only support. The disabled mother was described as completely dependent on her children, who were expected to act as a kind of personal assistants: 'She is cared for at home by her children who, among other things, carry her to the toilet'. According to the medical certificate, the woman was cared for by her children, who were 15, 16, 17 and 18 years old.

## Parents' actions towards their children's care responsibilities

The documentation reveals that parents could have different views on their children's care responsibilities. Some parents mentioned that their children did personal caring tasks, and there were parents who applied for support so that their children would not need to be the ones to provide care for them. The following example is about a single mother with three children in the ages 16, 18 and 22 years: 'In the current situation, the children are at home helping [the mother], but [the applicant] now desires that they will go back to school and work'.

In another case, the mother's trustee gave information to the SSIA about the children's situation: 'Previously, the children have been home from school and together they helped their mother'. The trustee applied for personal assistance for the woman, and also stated that it was important for the children to go to school: 'The trustee wants the children to continue to go to school'.

A somewhat different approach was taken by the applicant and her spouse who wanted their 18-year-old son to be the mother's personal assistant, even if they wanted another person during the time he was in school: 'As the children go to school during the day, they want to hire an older woman who can help [the mother] during the day'.

In all the examples above, we can see that the parents, and in one case the parents' trustee, addressed the children's need to go to school.

## Impact of caregiving on children

Since the records involve applications and investigations for the parents, they are not complete and reliable as information about the situation for the children in the family. However, there was some documentation that told about the caregiving impact on the children. In the documents, there were examples of young adults in their 20s who moved back home again to help their parents as they lacked personal assistance or other kinds of support. This could lead to setbacks for the young people's work and education. The following quotes were from different investigations:

The son [20 years] has dropped out of education to be able to be at home and help his family.

The son [20 years] helps his mother. He has not been able to work for nine months, because he has to help his mother every day.

In several cases, there was documentation about the problems for children to combine their studies with the care work. An occupational therapist wrote in a certificate: '[The applicant] lives with her adult children who help her. They find it difficult to combine their education with helping their mother'. However, in this case, only one of the siblings was an adult, as the children were in the ages 15, 16 and 20 years old. When there was no support from society, no personal assistance or other kind of support, the children and young adults stepped in to perform care, which affected their own lives, education and work. In one of the cases mentioned above, where a 15-year-old boy took on a major responsibility to support his mother, the mother's doctor contacted the social services to report concern for the child's vulnerable situation:

A report to the social services has been sent as I perceive that her son is harmed by having to take so much responsibility. It is absolutely necessary that she receives assistance as soon as possible.

## **How is children's caregiving recognised and considered in the assessments?**

The themes above show that there was information given in the records about children's caregiving, and therefore the follow-up question is how this information was used and valued in the assessments of the applicants' rights to personal assistance. The short and clear answer is that it was not. Under specific circumstances, the parent applying for personal assistance may also get support in their parental role. This assessment is then based on the parent's explicit application for support in their parental role and without reference to the needs of the child. This is partly to be understood as the intention of the legislation, which only mentions support for parents in reference to their parental responsibilities and limited capacity.

In several cases, it was the physician who documented the children's care work and included this information in the parents' medical certificates. In other cases, the documentation about the children's situation was made by an occupational therapist, physiotherapist or rehab coordinator. In some cases, there was information about the children in the SSIA descriptions from the public officials' meetings with parents and in one case the parents' trustee. Finally, there were also four young adult children who described the situation themselves, as they were the ones helping their parent with the application and the contact with the SSIA. There were situations when other professionals reacted to the children's caregiving as a cause for child protection authorities to investigate the situation of the child. The SSIA, however, did not mention in any record that they had contacted the municipal social services responsible for child protection, although they were the only professionals who had this information about the situation of the parent and the child.

## **DISCUSSION AND IMPLICATIONS**

This article contributes knowledge, in a Swedish context, about how children's care responsibilities were recognised in applications and records of personal assistance, what the records made

visible about children's caring, and the views and actions of professionals regarding the responsibilities placed on underage children. The analysis reveals that in 30% of the records with data about children, it was mentioned that children and young adults took on responsibility for caring for their parents. This is then a proportionally higher figure than children in the general population. In a study, 7% of students in the ninth-grade of compulsory school reported that they were engaged in extensive care work (Nordenfors et al., 2014). In the same study, a small proportion of young people, 1.6% out of 2424 students, reported that they helped parents to get dressed or undressed, and 2.5% said that they helped parents with personal hygiene at least once a month.

This study indicates that there seems to be a lack of knowledge amongst professionals about the risk for children becoming caregivers when parents with disabilities do not get adequate support. Data about children were lacking in many cases, which indicates an unawareness of how children may be affected. When the SSIA officials documented the children's care activities, they seemed to be quite unaware of what they were recording. The officials appeared to document the children's care work in a way that did not problematise the impact on the children, although the youths had difficulties combining care with education and work. Instead, in some of the cases, other professionals or the parents and children themselves recognised the children's vulnerable situations. Similar results have been found in the UK, as studies show that despite the legal duty for local authorities to identify, assess and support children who provide a caring role, a lot of young carers remain unknown and few young carers receive services that change their situation (Alexander, 2020; Kendall, 2021).

According to the UN Convention on the Rights of the Child (UNCRC) that was ratified in 1990, and that since 1 January 2020 is law in Sweden (SFS 2018:1197), children have rights to protection and care (art. 3), development (art. 6), education (art. 28) and leisure (art. 31). According to article 32, governments must protect children from any work that is likely to be hazardous, to interfere with the child's education or to be harmful to the child's health or development. In the situation where a parent has a disability and lacks support, there is a risk that the children have no choice but to take on the care responsibility (Becker, 2007). Previous research shows that there is a widespread idea that a well-developed welfare system exists in Sweden, protecting children and preventing them from becoming caregivers (Gould, 1995; Leu et al., 2022). In a previous Swedish study about children's care activities, Järkestig-Berggren et al. (2019) failed to recruit children who have parents with serious physical illness and possibly personal assistance. The researchers did not succeed in this quest due to the fact that these children do not have support groups, such as organised programmes for children who have parents who use drugs or for children who have experienced violence in the family. This particular group of children stood out as the group that did not have access to such societal support.

In order to implement a child perspective in accordance with the UN Convention of the Rights of the Child, professionals need to pay attention to the children's situation when parents with disabilities apply for personal assistance and other support. They need to identify whether the applicant has children. The child perspective needs to be included in the investigation and assessments. The assessment needs to address children's rights to parental support, as well as their rights not to become carers for their parents. Society should protect children from taking on responsibilities for their parent's personal care and other extended support, which may affect the children's health, well-being, school, work and future in a negative way (Chikhradze et al., 2017). In order to provide adequate support for young carers, it is crucial to increase the awareness amongst professionals of the risk factors when children and young people take on a caring role. Young carers need support that also recognises the

real needs of their disabled parents, so that both the children and the parents can get adequate support and assistance.

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### CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are not publicly available due to ethical and legal restrictions. Permission is required from the Swedish Social Insurance Agency (SSIA) and from the Swedish Ethical Review Authority for this research.

### ETHICS STATEMENT

The study has been approved by the regional Ethical Review Board in Linköping (ref number 2017/149-31).

### PATIENT CONSENT STATEMENT

The study was conducted without the consent from the applicants in the records at the Swedish Social Insurance Agency (SSIA). The research has permission from the regional Ethical Review Board in Linköping (ref number 2017/149-31). Data have been anonymised so that no applicant or other person will be recognised.

### PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES

The Authors have permission to use data for this research from the Swedish Social Insurance Agency (SSIA) and from the Ethical Review Board.

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