

# Nka™



## Young carers in Sweden

– A short overview

Monica Nordenfors och Charlotte Melander

## Foreword

This short overview ‘Young Carers in Sweden’ is a summary of two reports on young carers in Sweden. The government initiated a wide spreading development work, in which the National Board of Health and Welfare, the National Institute of Public Health, Swedish municipalities and health care regions collaborated to strengthen support to children and young people in families with substance abuse, serious illness or mental ill-health, violence or death of a parent. These two reports provide the foundation for this work. The references to the original reports are found at the end of the overview. The overview builds on results from the studies:

- a survey to 15-year-olds in Sweden to explore if they perform care tasks and if so what types
- an online survey about how young carers are affected by providing care
- in-depth interviews with children and youths who have taken care of a family member.

The reports are produced by researchers at the University of Gothenburg. The work was commissioned by the Swedish Family Care Competence Centre (Nka)/Linnaeus University (LNU) who in turn had a remit from the National Board of Health & Welfare to build up a knowledge base and to disseminate the knowledge and enable knowledge exchange and learning networks to take place.

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Young Carers in Sweden – Short Version

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## Summary

In certain cases when a parent is suffering from serious difficulties, the family's living situation requires the children to take responsibility and provide care, thereby becoming so-called young carers. Providing extensive and regular care duties can lead to limitations in the children's development, participation, and opportunities. This study began in 2014 with a survey of the extent to which 15-year-olds in Sweden perform care tasks and if so what types (2424 pupils in Grade 9 answered a survey). In addition ten young people responded to an online survey about how they are affected by providing care. The third and final part of the study is based on in-depth interviews with four children and youths who, for different reasons and in different ways, have taken care of a family member.

The survey study shows that many children help with various types of housework and over half watch siblings. Twelve percent work in order to earn money for the household at least once a month, and half contribute to the family's finances by not asking for money for themselves. Almost one-third help their parents interpret or translate at least once a month. A small percentage of the youths (2.5 percent) help a parent to wash at least once a month. Many perform emotional care, where they pay attention and act in response to how their parents feel.

Seven percent of the youths who responded to the survey take on extensive care duties, in terms of the number of activities or how often they carry out the care tasks. Similar to previous research, this study shows complex relationships where such aspects as the parents' problems, finances, family structure, family culture, relationships, and available choices shape the youths' provision of care. Three percent of those who answered the school survey reveal that they stay home from school at least once a week in order to take care of a parent, sibling, or other relative.

The online survey discloses varying degrees of negative and positive consequences of giving support, care and assistance to a family member. Six of the youths answer that sometimes or often life does not feel worth living because they regularly provide support, care, and assistance. Several say that they often feel that they are doing something good by helping.

In previous research and in our study, young carers and youths who grow up with a parent with mental health and /or a substance-abuse issues describe that they sometimes live under difficult conditions without talking about this to someone outside the family.

"Young carers" challenge our way of looking at (a "normal") childhood as an innocent and responsibility-free stage in life where adults take responsibility and provide care, and children only receive. Our studies show that we should instead see children as participating actors in care tasks within the family. In situations where parents and other adult carers for different reasons are not able to give children adequate care, we can expect that children take on extensive care responsibility for themselves and their immediate family members.

# Introduction

When a parent is physically or mentally ill, has a disability, suffers from substance-abuse or another difficulty, the children in the family are also affected. In some cases, the family's living situation requires the children to take responsibility and provide care. The concept of young carers originates from the UK, and involves children and youths under 18 years old (in some circumstances up to 25 years) who provide support, care and assistance to a person in the family. The person receiving care is often a parent, but can also be a sibling, a grandparent or another relative who needs support, care and assistance because of a physical or mental illness, disability, substance-abuse problem or for some other reason (Becker, 2007).

That children carry out some degree of care is considered to be healthy for their psycho-social development in many societies, and in certain contexts it is necessary for the family's survival. It is now known that there are children who have extensive, regular care duties, which can lead to limitations in their development, participation, and opportunities. This is true even in situations where the care can be associated with positive effects such as increased coping strategies, social skills, maturity, a sense of meaningfulness, and "closer" relationships (Aldridge et al., 2003).

Since the late 1990s, there is a growing interest amongst researchers, policy makers, welfare institutions and professionals within healthcare, social services, and medical care regarding the conditions of young carers. In the UK and Australia, young carers have received increased recognition as a social category within research, policy, and the welfare sector. Becker (2007) states there is a need for the young carers' situation to be recognised, identified, and analysed as a distinct group of "at-risk children" and that they need to receive support. In Sweden there is little knowledge about children and youth as carers.

This study began in 2014 (Nordenfors, Melander & Daneback, 2014) with a survey of the extent to which fifteen-year-olds in Sweden provide care, what kinds of care, and how the youths who take the responsibility for care, experience they are affected by performing care. Pupils in Grade 9 in Swedish compulsory schools participated in this part of the study: 7542 surveys were sent to 300 schools selected through a random sample. Many schools chose not to participate. 2424 pupils answered the survey, which makes up 77 percent of those who actually received the survey. The aim was also to investigate how youths, aged 15 to 18 years, who define themselves as persons providing support, care or assistance to a person who is a close relative, perceive that they are affected by providing care. In total only ten youths answered all the questions on the online survey used in this part of the study. The final part of the study is based on in-depth interviews with four children and young adults who, for different reasons and in different ways, have taken care of a parent and/or a sibling.

## Earlier Research

Research studies about young carers are increasing in number, which indicates that the interest in this group is growing worldwide. In the UK and Australia, young carers have received increased recognition as a social category within research, policy and the welfare sector. Despite there are few countries that have reliable data on how many young carers there are (Becker and Leu, 2014) it is reasonable to assume that children and youths all over the world, regardless of the country's welfare system, perform care for persons they are closely related to. Previous studies include surveys of how many carers there are in a country (Becker and Becker, 2008; Nagl-Cupal et al., 2014; Nordenfors, Melander and Daneback, 2014), the reasons for the care, experiences and consequences of the care (Pakenham et al., 2006; Rose and Cohen, 2010; Earley et al., 2007; Nordenfors, Melander and Daneback, 2014) and the composition of young carers (O'Dell et al., 2010). Hamilton and Adamson (2013) have studied the agency of young carers and young adult carers including how it is exercised within a framework of certain constraints. Smyth et al. (2011) have investigated "self-identification" among young carers in Australia.

According to Becker and Leu (2014) few countries have reliable data on how large the number of young carers is. Becker and Becker (2008) show that between two and three percent of all children in the UK and about five percent of young adults between the ages of 18 and 24 years have a caring role. These figures, however, are based on parents' statements about their children's care tasks, presenting the suspicion that numbers can be underreported. The British Broadcasting Corporation (BBC, 2010) conducted a survey where they asked nearly 4000 pupils in secondary school about their care duties. The results showed that eight percent of the pupils performed intimate and personal care and that an even higher percentage carried out other types of care tasks in the family. According to Becker and Leu (2014) it is difficult to estimate the number of young carers. The percentage is nonetheless important, since it has implications for decision-makers and for the development of service functions. Nagl-Cupal, Daniel, Koller and Mayer (2014) have studied the prevalence of young carers in Austria. 7403 children, aged 10 to 14 years, responded to a survey. Of the respondents, 4.5 percent of the youths were identified as carers.

In light of a study by Dearden and Becker (1995), Becker et al. (1998) suggest that children's caring roles can be classified as domestic, nursing, intimate and personal care, emotional care, household management and child care. Research in Australia shows that young carers take on care duties and think about the person receiving care to a greater extent than other children and youths, and that they often carry out these tasks without support or supervision (Gays 2000; Moore 2005).

The reasons that children become carers are multi-faceted and complex. Becker and his colleagues propose a framework for understanding the "the push and pulls" in care based

on their own and others' research results. In British studies (both qualitative and quantitative) such factors as the nature of the parents' illness or disability, love and attachment, co-habitation, family structure, gender, socialisation, low income, and lack of available choices and alternatives, make up the "push and pulls" for children providing care.

Research also shows that the interaction between financial resources and available choices is particularly important. In the majority of families, young carers are drawn into care because there are no other alternatives (Becker et al., 2007). They provide care as a result of the interplay between the demand and the availability of informal care in the family or community; the lack of available healthcare and social services, particularly home-based care for persons with these needs, and the lack of recognition of and available support to accommodate "parenting needs" for sick or disabled parents. In the research from the UK, Australia and Africa, there are often spoken references to the fact that low income characterises and distinguishes many families where it is known that children are carers. These families lack the financial and other resources to be able to make use of care alternatives that can work against children taking on care responsibilities and can reduce the extent to which the children provide care.

Children as next of kin grow up in a family where adults have a serious health problem or injury, mental ill-health or disability, substance-abuse or dependency, or where a parent has died, or violence occurs in the family. Children as next of kin are a heterogeneous group with different needs, and their livelihoods are affected in shifting ways by the situation in the family. Several studies, from Sweden and other countries, show that some children provide care and take responsibility in the home for those who grow up with parents who have a substance-abuse problem (Backet-Milburn et al., 2008) or with a parent who has a mental illness (Aldridge et al., 2003, Skerfving, 2014). In Johansson, Höjer and Hill's (2011) study, several children who were placed in social care describe experiences indicating they have taken responsibility for their parents and / or their siblings. There are also studies showing other groups of children, such as children growing up with foster siblings (Nordenfors 2006, Höjer and Nordenfors 2006, Nordenfors 2015) who in certain situations take on increased responsibility in the family. The results show that there are positive and negative consequences of this. Another group who take the care responsibility for their parents and siblings, are unaccompanied immigrant children. The results from a study by Stretmo and Melander (2013) where both children and professionals in the Gothenburg area were interviewed, show that children took on a care responsibility by sending money and by helping with applying for the family's reunification. Some of the children also revealed that they refrained from asking their parents for help with their own problems in regard for their parents' health. The consequences of feeling a care responsibility that they could not live up to, were that the unaccompanied immigrant children were worried, had guilty feelings and felt personal failure.

Saul Becker and Agnes Leu (2014) reviewed earlier research on young carers and show that the care can have both positive and negative consequences for the children's well-being and development as well as for their transition from childhood to adulthood. They

emphasise in particular the negative consequences. These are reduced opportunities to develop social networks and to participate in recreational activities, problems in transitioning from childhood to adulthood because of the difficulty in leaving home and being able to seek work and education elsewhere, problems keeping up with schooling, high absenteeism from school, and experiences of being bullied. Haugland's (2006) research review provides more thorough insight into the consequences and further implications. Reduced opportunities to develop social networks and leisure activities hinder children from developing socially and from building a support network outside their families. Haugland's research review also reports the consequences for identity development. Children who become known for what they do instead of who they are, can develop an understanding of self based upon their parents' wishes and on vulnerability, rather than upon the children's own feelings, needs and characteristics. This type of self-understanding can make separation and becoming independent from the family in their adult years difficult, when this can be perceived as disloyalty and selfishness. Haugland takes up several studies that show that children who have taken on large parental responsibility are at higher risk of acquiring mental ill-health problems such as depression, anxiety, low self-esteem, suicidal tendencies, psychosomatic disorders as well as associated problems with drug and alcohol abuse. Other consequences are that children who have been carers can transfer this parentification model to their own children, or also become overly focused on care and provide care that need not be requested by the recipient.

Even though the positive aspects go together with the negative ones, it is important to present the abilities and resilience that care can bring.

In their compiled research, Becker and Leu (2014) highlight that care can develop the children's ability to feel responsible, as well as their social and care capabilities. Care can also strengthen the relationship between parents and children in a positive and loving way. Participating in care duties in relation to a parent in need of care, can also give a sense of control and empowerment in a situation that the child actually has little influence over. According to several studies in the Saul Becker and Agnes Leu review, the surrounding social network and its support appear as the most significant factor for the caring role to be manageable for the children. Other factors that have positive impact on the children's well-being and sense of manageability are if they reach their goals, have positive relationships, do well in school and have a feeling of hope.

# Theory

## Children and care

The present study is about children's and youths' experiences of providing support, care and assistance to their families. Within childhood sociology, children are considered as participatory in forming the relationships in their everyday life. By asking them about their experiences and their understanding of their daily life, the children's participation in daily life has received attention. The study premise is that children actively, in interaction with others, form relationships, and they are not merely passive recipients of care, but they are also carers in particular situations.

According to childhood sociology, children and childhood are relational concepts whose meanings are determined in relation to other age categories (Alanen, 2001). Ideas about what is adequate care vary among different cultures and groups in society, and these ideas depend on such aspects as group affiliation, class, gender, function, and age. In the western world, adult definitions of children are strongly associated with a developmental view, which links emotional and cognitive maturity with chronological age. Based on this perspective, children are considered to be too immature to understand adult morals and are thus regarded to be morally incompetent (Such & Walker, 2003). At the same time we look at childhood as a time of innocence, when the child should be free from responsibility. Seen from this perspective, we can say that there are opposite expectations on parents and children regarding care. Parents are expected to take responsibility and provide care, both at home and at work, and children are expected to receive care. When we look at this on an individual level, we see another situation where individual children in specific situations are expected to take responsibility and provide care by caring about and involving oneself with younger siblings.

Ideas about children and care become critical for how we acknowledge and understand that children provide care and what we think about that.

The study highlights the tension between the children's agency and the limitations imposed, such as through the overall age hierarchy in society.

Care is a cognitive and moral activity (Sevenhuijsen, 1993) and ideas about relationships, affinity and a will to create a sense of well-being for others are central for the concept (Brannen et al., 2000). Care is the engine of a family, and one family context particularly refers to the parents caring for their children (ibid).

Ideas about what is adequate care vary among different cultures and groups in society, and these ideas depend on such things as group affiliation, class, gender and age. Ideas about children and care become critical for how we acknowledge and understand that children provide care and what we think about that. Through her research across national



borders, the Turkish family researcher Cigdem Kagitcibasi (2002) has determined three different types of family models where the upbringing of and expectations on children differ. These family models are more or less prominent depending on whether the family lives in an urban environment or in a rural area, and on the family's and the society's economic prosperity. In the family model referred to as the interdependent family model, the family culture is collective, the children are expected to contribute to the parents' and family's livelihood, both during childhood and as adults, and socialisation is characterised by values in the form of loyalty and mutual dependence between generations. This model exists primarily in rural and less economically prosperous areas, where the children are seen as a resource for the family's continued survival. The second family model that Kagitcibasi highlights is the independent family model, which is characterised by care and welfare provided by the parents to the children, and not the reverse. Socialisation is based on fostering independence and becoming independent of the family and relatives. Here the family's survival is not threatened by the child developing into an independent person. This model is usually described as that of the western world, found in urban and industrialised middle-class environments with good economic conditions. In her research, Kagitcibasi has found a third family model which she states has developed in Turkey with the coming of urbanisation and improved living standards. Her research shows that development toward a better economic standard in Turkey does not go against the independent family model, but instead towards a mutual emotional-dependency family model. This model combines the values of autonomy and interdependence in the socialisation of the children. Adult children and parents are expected to be independent of each other on the financial plane, but not on the emotional plane.

These family models and results are valuable to keep in mind also during the discussion about the expectations on children living in Sweden and their degree of care.

### Caring about/caring for

According to Jennifer Mason (1996) who has studied the concepts of care and responsibility for others in the context of the family and relatives, there is comprehensive research in this area since the 1970s. A large part focuses on the distinction between ideas of "caring about" which involves feelings of a non-active nature and "caring for" which involves care of a more active sort. Mason argues that there is a way of caring about, providing care in family and relative relationships, which takes a lot of time and energy for those who do this and which does not fit into one of the categories, "caring about" and "caring for." Mason proposes a way to go beyond this distinction, and she approaches this by focusing on aspects of care that conventionally have been defined as belonging to the category of caring about.

Mason (1996) suggests two ways to understand care and responsibility for other family members and relatives. She uses these terms:

- Sentient activity (sympathetic activity) – refers to thinking and feeling as activities.
- Active sensibility (active susceptibility/ sensitivity) – is the activity of feeling responsible for someone else or being dedicated / committed to someone else.

Examples of sentient activity in relation to care and responsibility for family and relatives can be to pay attention to / listen to/ interpret others' needs/ moods / well-being or to organise and plan interactions between oneself and others.

These concepts form a good basis for analysis of young carers. A concept of care that is only based on active caring, or alternatively that is only focused on feelings, becomes narrow. Previous research shows that care is a complex and multi-dimensional activity, which Mason's theory describes in a good way. This is a suitable model for discussing children's and youths' care, since the two stated categories of work and emotion seldom cover the full range of their engagement and commitment for others. Finch and Mason's (1993) study helps us also to regard children as actors, and not only as victims of the circumstances they are in. The theory describes the emotional care that many children and youths engage in, and seldom receive recognition for. This care is about paying attention to another's needs and taking responsibility for how to act according to the other's needs.

## Parentification

Parentification is a concept that has been used since the 1960s to describe family interactions where children and youths are dealt roles and responsibilities within a specific context normally performed by adults (2006). Haugland describes parentification as including various role patterns. The first involves the child having a parent role in relation to his or her own parents. The child has responsibility and control, and one or both parents receive care to a large degree. In the second role pattern, the child has a partner role in relation to his or her parents. The child has taken on an adult position, and the parent relates to the child as if he or she were of the same generation. The third role pattern is about the child having an adult role in relation to other family members without a role exchange taking place between the child and the parents. In the latter role pattern, the family hierarchy can thus remain intact.

There are a number of different family constellations that present a risk for the child to develop a parentification family pattern, and one indication is imbalance in the care system. The reason for this can be a parent's physical or mental illness, separation, parent's substance-abuse and parents with high career ambitions, in combination with difficulties

in managing these. The risk of parentification also goes together with other factors, such as the family's finances, access to support and assistance from a network or the public (Haugland, 2006).

Haugland describes the circumstances under which care leads to a destructive versus a more adaptive situation for the child and his or her health and development. The circumstances associated with an adaptive parentification can be likened to those factors that influence the children's ability to develop resilience in vulnerable situations. Resilience is a developed resistance that makes a difficult living situation more manageable. Knowledge about what contributes to children who live in risky living situations, developing the resistance that enables them to handle their situation and develop in a positive direction, is important in prevention efforts and for being able to give adequate support to those already identified as young carers.

Conditions that characterise an adaptive parentification are similar to those raised by Becker and Leu (2014) in their research review on factors relevant for how children who are carers will be able to manage their situation and safeguard their well-being. Adaptive parentification is described as care performed in a context where there are simultaneously a number of protective factors that reduce the risk for destructive consequences. According to Haugland (2006) there are specific circumstances for adaptive parentification, where the child has support from others and the care duties have a limited duration. In an adaptive parentification, the care tasks are more appropriate in relation to the child's physical strength and mental maturity. An additional factor contributing to adaptive parentification is if the child receives positive recognition for the care he or she performs and if the surroundings acknowledge these efforts. Furthermore, what influences a less destructive parentification is if, despite they need the child's care, the parents at the same time have an understanding for their child's needs and for how the child experiences providing care, and they can support the child.

The type of care task and clarity in the duties assigned to the child (or taken upon oneself) play a role for whether the development becomes adaptive or destructive. Instrumental or more practical care tasks are described as less damaging than emotional care tasks, which are more diffuse in their character. The child's age and maturity play a role for whether the child perceives that he or she can handle the needs that one attempts to fulfil for the other family members. If the child experiences the inability to meet the needs, he or she can feel ashamed.

The positive consequences highlighted in Haugland's (2006) research review are, in addition to the ones mentioned above, the development of competence in leadership and in mediating and solving conflicts. Care in and of itself can contribute to resilience, where a sense of taking responsibility, having control and being useful strengthens one's self-esteem and leads to various skills development. Haugland's research highlights that while care can be destructive for an individual child, it can be adaptive for the family as a whole, because the child's care input enables the family to adapt better to a new family situation.

# Results

## The survey studies

The present study shows that many youths who responded to the school survey help with various forms of housework to varying degrees, such as cleaning their own room, tidying other rooms, shopping occasionally for groceries, preparing food and washing dishes. Just over half of the youths watch younger siblings. Sixteen percent take a parental responsibility for siblings at least once a week, and seventeen percent make sure that siblings get to school at least once a week. Twelve percent work to earn money for the household at least once a month, and half contribute to the family's finances by not asking for money for their leisure activities, clothing or food. Almost one-fifth get paid for providing care, support and assistance. Almost one-third of the youths help their parents to interpret/ translate at least once a month, and more than forty percent help their parents to understand information. Although we do not know the type of information and in which situations the interpreting and translating occur, it is likely that some of these occasions involve information to or from different authorities and community institutions. It is probable that some youths are compelled to handle important and sensitive decisions and that they act as a bridge between the society and their parents.

According to some researchers, helping one's parent or another close relative with intimate hygiene and activities in daily living, such as dressing or washing, is what distinguishes young carers from other children who help in the household. In our study there is a small percentage of youths (1.6 percent) who help parents get dressed or undressed at least once a month. 2.5 percent help a parent wash himself or herself at least once a month. Compared to a BBC study in the UK, where the proportion was eight percent (337 pupils) out of 4000 pupils in secondary school (Howard, 2010) there is a lower proportion of youths in our study who help parents with personal care tasks. Explanations for this difference can be that the pupils were somewhat older in the BBC study, that the BBC study asked about care given to more family members than only parents and siblings, and that the Swedish welfare system probably offers parents more extensive support in the home and home medical care.

Children often pay attention to how a parent feels, and they know when a parent does not feel well. Worrying about one's parent can consume a lot of time and energy. One-fifth of the youths revealed that several times a week they keep an eye on a parent to make sure that the parent feels alright. More than a quarter try as often in various ways to get the parent to feel better, or be company for the parent by visiting, reading or talking to him or her.

Relieving a parent by "taking a step back" can be another way to exercise care. Twelve percent respond that they relieve a parent by not asking for support when they have

problems, and fifteen percent by not asking for help with schoolwork and homework several times a week. The results show that many of the youths exercise these kinds of emotional care for their parents. This is a reflexive work where the youths pay attention to how their parents feel and act based on their judgement of this.

Seven percent of the youths who responded to the survey are involved in extensive care duties, either in terms of the number of activities or how often they perform the care tasks. A slightly larger proportion of them are foreign-born, have a foreign-born parent, are an older sibling, live in a rental flat and live only with the mother. A rather large proportion say the household income is not always enough for the rent, food and clothing, and they also usually have parents who are employed to a somewhat lesser degree compared to the parents of youths who administer a lower level of care. Similar to previous research, these results point to how the complex relationships among factors such as the nature of the parents' problems, finances, family structure, family culture, relationships and available choices, shape the youths' care.

Previous research shows that girls provide care to a greater extent than boys. Our study does not show any significant differences between the genders overall. There are, however, differences in some care tasks. A group that consistently stands out in the study does not fit in the gender category girl or boy. They report a higher degree of care. The results are interesting to reflect upon, and they are important to consider in future studies, and not only valid for young carers.

In the online survey, some of the twelve respondents have mentioned support, care and assistance not only for parents and siblings, but also for grandparents and friends. In the school survey and in part of the online survey asking about what youths do and how often, we only asked questions about the care of parents and siblings. It is a limitation of the study that we do not know the extent of care directed to other persons in the youths' surroundings. What we can say is that the number of youths who perform a high degree of care probably would have been greater if we had included a question about care given to persons other than parents and siblings.

What are the consequences of the care? Both international and Swedish research show that one consequence of the care duties that young carers provide, can be school problems; they miss school or have learning difficulties. The CHES report (Hjern et al., 2013) shows that parents' substance-abuse, illness and death often affect youths' school performance in a negative way. Our study shows that three percent of the youths who responded to the school survey, say they stay home from school at least once a week to take care of a parent, sibling or other relative. School is a protective factor that influences the manageability and well-being of youths who are in vulnerable situations, and being absent presents a risk factor.

The twelve youths who answered the online survey and identified themselves as persons who provide support, care and assistance to someone in their family, report different degrees of positive and negative consequences. Six of the respondents answer that

sometimes or often life does not feel worth living because they regularly give support, care and assistance. Many feel stressed, and some want to move away from home sometimes because they regularly provide support, care and assistance. A couple of respondents who report a very high level of care, also write comments that indicate they are suffering from mental ill-health. Haugland's (2006) research review about parentification and its consequences, shows that children who get or take upon themselves extensive care responsibilities run a greater risk of developing various forms of mental ill-health. The youths also think that the care brings some positive consequences. Several responded that because they regularly provide care, support and assistance, they often feel they are doing something good/ worthwhile, that they are helping, and that it gives them positive self-esteem. Half say that they often feel good providing care, support, and assistance. Most say that because of the care, they sometimes feel that they learn useful/ worthwhile things, they feel better equipped to deal with problems, and they like who they are.

Young carers is a concept that is defined in different ways by different researchers. The results from the online survey (despite the low response rate) are important background for problematizing this concept. The responses show, for example, that negative consequences/ experiences of care are not uniquely associated with how often and how many care tasks the youths perform, but also because of other factors. We know that the frequency and extent are important, but also a lower level of care can lead to negative consequences and experiences, depending on the circumstances. A high degree of care can just as well have positive consequences. The context the youth is in and various circumstances influence the experience of providing care. The problems of the care-recipient, types of care tasks, perception of affirmation, access to support, and the age-appropriateness and manageability of the tasks, are important for the experience and consequences of the care.

## The interview study

The children and youths in this study describe how they provide support, care and assistance to a parent, sibling and themselves in different ways. They have in common the motive that they care about and concern themselves for their family members. This can be seen as a natural part of being a family and the expectation of mutual giving and receiving that exists in close relationships. Our interview respondents' provision of care distinguishes itself and is of another scope. Two of the respondents have experienced taking on full responsibility for the care of a family member, themselves and the household during certain periods while growing up. This was not the case for the other two respondents who took on responsibility to a much lesser extent and for a limited period of time. That which we perceive to be the dividing line regarding children's care in our interview study, is not only the scope of the care duties over time, but also the extent to which the respondents perceived the responsibility for the care tasks rested upon them.

The emotional care could be seen as the basis for all other care. In this case one figures out how the parent feels and then acts in a way that can make the parent feel better. Ac-

According to the youths we interviewed, because of having a parent who does not feel well for long periods of time, they have developed an increased ability to know the telltale signs and sense the mood of how their parent feels, and then act accordingly. There are examples of how our informants figure out how the parent feels, and on this basis, they console, make sure they are home, keep the parent company, talk with the parent or accompany the parent to visit friends. All four informants said they provided emotional care.

The youths describe various consequences of their care. All four have felt worried about their parents. They worry about the parent dying or that something might happen to the family. Three of the youths have had sleeping problems. The two who have provided a high level of care, describe how occasionally they have stayed home from school in order to take care of their parents. Three youths have stayed home from school to be able to check on a parent, and these youths say also that they sometimes have stayed home because they did not have the energy to cope with school.

Three of our informants have not felt well mentally. A young woman says that up to twenty years old, she had “gone the whole time wanting to die,” and another describes that she tried to take her own life.

The two who carried out a high degree of care, describe that they have felt alone and abandoned. Today they think that despite everything, there is also a positive side, namely, that they have learned a lot from their experience.

In previous research and in our study, young carers and youths who grow up with a parent who has mental ill-health and / or a substance-abuse problem, describe that they sometimes live under difficult conditions, without talking about this to someone outside the family. One reason can be fear of what would happen if the family situation became known to others. One factor that plays a role for the youths’ possibilities to make their voices heard, is the stigmatisation that often accompanies mental illness and / or alcohol and drug abuse. How the surroundings view this problem can lead to the family system being closed, and the transparency and possibility to allow a support system in for the family are effectively absent. The adults’ stories are those that govern, and the adults’ rights are those that often prevail, which results in the youths’ stories being invalidated, their voices not being heard and their needs landing outside access to the community support resources. Similar to what earlier research has shown, the youths in our interview study have described how the presence or absence of a protective social network had a critical importance for how they managed their own care, and the consequences of their parents’ illness and reduced ability to care.

In our informants’ stories, we can distinguish both positive and negative turning points linked to how their social networks of supportive relationships became either reduced or reinforced. It becomes especially clear how the children’s vulnerability increases when previously supportive adult relationships disappear at the same time as a parent’s or both parents’ problems worsen. The support which has had the most significance for managing the lack of care and the responsibility for the parent’s problem, is foremost the other pa-

rent's presence in the daily care duties and the relationship to grandmothers and grandfathers, and also to siblings. The degree of the vulnerability is influenced by the overall care capacity of the entire social network of family members and close relatives. Based on our informants' experiences, it is essential to monitor how the care of the social networks looks and changes over time for children and youths with parents who are mentally or physically ill, have a substance-abuse problem or for some other reason have a reduced care capacity.



## Conclusions

In Sweden the group of young carers can be described as a hidden population. That children and youths provide support, care and assistance is not something we have spoken about in Sweden. We know that an individual child does this; we know that children as next of kin do this; but the discussion about children's care and taking responsibility has not existed as its own item on the agenda in the public debate. This is reflected in the legislation, where adult family-carers have a right to support according to the Social Services Act 5 § chapter 10, but not explicitly those under 18 years old. A strong welfare state (from which the children's and the youths' parents and their next of kin should get support, care and assistance) together with ideas about children not having to perform care and take responsibility at too high a level, have contributed to the notion that children do not need to become carers in this country. This means paradoxically that individual children are left alone without support, sometimes with a very high level of care as a result. Officials and politicians at the local, regional and national levels must take into account children's care and responsibility in policy decisions and in developing support measures directed to parents, and also to children and youths.

"Young carers" challenge our way of looking at (a "normal") childhood as an innocent and responsibility-free stage where adults take responsibility and provide care, and the children only receive. Our studies show that instead we ought to see children as participatory actors in the care duties in the family. In situations where the parents and other adult care-persons for various reasons cannot provide children adequate care, we can expect that the children take on an extensive care responsibility for themselves and their closest family members. In order to capture the children and parents in need of care, we must monitor the families' need for care support continuously in the contexts where there are children and parents. The school and the family health clinic are places where there are children and parents, and where they could be called for regular health visits that also include questions about care. If all parents and children get asked about the care situation at home continuously during the child's upbringing in a way that is not stigmatising, problems that cause a care neglect can be detected early. When problems are discovered early, there must also be measures that can be implemented with a preventive purpose. This work needs to be developed and coordinated with the school, health care and social services.

The children and youths who have had the opportunity to be heard in our studies about the consequences of taking a large care responsibility, have expressed in several cases that they have suffered with mental ill-health and have had recurring thoughts about life not being worth living. If we want to improve children's emotional well-being, then we must take them seriously and listen to their stories.

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