



ENABLING YOUNG CARERS to pursue their goals in life and reach their full potential

Converting research findings into policy actions



**Policy
brief:
SWEDEN**





Psychosocial support for promoting mental health and wellbeing among adolescent young carers in Europe

The Me-We project (2018-2021) brings together prominent universities, research institutes and civil society organisations from six different European countries – including Eurocarers, the European network representing informal carers. The project aims to improve the mental health and wellbeing of adolescent young carers, by strengthening their resilience (the process of positive adaptation within the context of significant adversity).

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#youngcarers

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Summary

Childhood is commonly seen as a protected and responsibility-free stage of life where adults are “in charge” and provide care, while children are primarily beneficiaries of care. Yet, for a number of children and adolescents across Europe, this is far from being true as they find themselves providing – sometimes very intensive levels of – care to a family member/friend in need of support (because of illness, disability, addiction, etc.) and have to assume responsibilities that would be more fitting for an adult.

NUMBER OF YOUNG CARERS ACROSS EUROPE

Although there is currently very limited data regarding the number of young (adult) carers across Europe, some national statistics and pilot projects have helped to unveil a substantial – and yet largely unknown – population group.

The **2011 census for the UK (England and Wales)** revealed that there are some **177.918 young carers under the age of 18**. The number of young carers is increasing over time: 27.976 more than in 2001 (an increase of 19% over 10 years).

In **Ireland**, the 2016 Census showed that **3.800 children under 15 years** engaged in providing care to others, accounting for **1,9 % of all carers**. Half of these children (1.901) providing unpaid care were aged 10 and under. In Italy, according to the most recent national statistics, there are 391.000 young and young adult carers (15-24 years), corresponding to 6,6 % of the whole population.

Census and official statistics are very important. Yet, they often **overlook young carers or underestimate** their number (the adult who fills in the census may not be aware/want to reveal that in his family there is a young carer). As confirmation of this, an unofficial data from a 2018 BBC survey revealed there are **800.000 young carers in England** (opposed to the 166.000 identified via the Census).

For other countries, research projects or unofficial sources give us the following estimated numbers: in the Netherlands, young carers form the 6% of the population aged 13-17. In Switzerland, 7,9% of children aged 10-15 years are young carers. **In Sweden 7% of children aged 14-16 years carry out substantial amounts of caring.**

While the phenomenon of informal care – the provision of care, usually unpaid, by a family member/friend outside of a professional framework is gaining momentum across Europe, little is known on the situation of those carers who are under 18. Young carers are indeed still largely invisible to public authorities and service providers and this failure to identify and support them can negatively affect their (mental) health, educational experience, employability and social inclusion. The negative impact at individual level can entail long-lasting negative consequences for society as a whole.

Oftentimes, policy-makers and service providers are unaware of the challenges faced by young carers and the possible measures to prevent or overcome them – rather than unwilling to address the situation.

This brief precisely aims to raise awareness on the topic and fill the knowledge gap, by sharing the findings of a European research and innovation project, funded through the EU's Horizon 2020 Programme and called Me-We - Psychological Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe. While this document directly draws on research and evidence, its objective is to reflect and ponder on the policy impact of Me-We's findings. As such, it should not be approached as a scientific report.

The Me-We project (2018-2021) brings together prominent universities, research institutes and civil society organisations from six different European countries – including Eurocarers, the European network representing informal carers. The project aims to improve the mental health and well-being of adolescent young carers, by strengthening their resilience (the process of positive adaptation within the context of significant adversity).

Whose responsibility is it to care?

The first year of the project was dedicated to systematising the existing knowledge about young carers.

The aim was to gain insight into:

- ▶ the profiles, needs and preferences of adolescent young carers in six European countries (Italy, Netherlands, Slovenia, Sweden, Switzerland and UK);
- ▶ the legislation, policy and service frameworks that exist to support adolescent young carers in the six countries (with a focus on how they work in practice, the drivers of their development, their strengths and limitations); and
- ▶ successful strategies to support young carers.

An online survey, literature review and a series of interviews with key experts were carried out to that end. As a result, and for the first time ever, our research has made cross comparisons on the topic of young carers possible between six European countries. It also shed light on the differences in the contexts that exist between these countries.

The collated knowledge is currently being used to co-design an innovative framework of primary prevention interventions, with adolescent young carers themselves as well as with other relevant stakeholders. These interventions will be implemented and evaluated in the six project countries.

The Me-We project is part of a bigger picture and it is framed in the context of ongoing debates regarding the future of European care systems – in the face of ageing societies - and the implementation of the Europe 2020 Strategy's goals in the fields of education and employment. The Introduction to the brief also builds on pre-existing research and data to shed light on the impact of informal care on young carers themselves and on urgent need to act.

Chapters 1, 2 and 3 focus on the initial findings of the Me-We project, arising from the first year of activity, which have consisted in an online survey, an analysis of the legislative/policy frameworks as well as a review of existing practices. The full results will be published in peer reviewed journals in 2019 and 2020.

Chapter 4 theorises on the basis of the Me-We findings, the knowledge deriving from previous research and the current policy environment, in order to identify policy priorities as well as possible courses of action.

Our research study has clearly highlighted that no “one size fits all” solution exists. The countries explored in this project are indeed at different stages of awareness and action as regards young carers’ needs; they are equipped with very different welfare systems, and have highly divergent philosophical approaches to the topic of care and caring, starting with “Whose responsibility is it to care?”. Bearing in mind these cultural differences, the objective of this brief is to present a comprehensive set of easily adaptable recommendations to all stakeholders and policy-makers who are willing to address the needs of young carers at their level. Each of these recommendations is driven by our core vision: young carers should be able to pursue their life projects as they desire and achieve their full potential, without being negatively impacted by their caring responsibilities.

Introduction

THE CHALLENGES OF BEING A YOUNG CARER

Who are young carers?

Young carers are children and young people under 18 who provide or intend to provide care, assistance, or support to a family member or a friend, who has a chronic illness, disability, frailty or addiction. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult.

Young carers aged 15-17 are called “**adolescent young carers**”. They deserve special attention, as they are in a key, transitional phase of their development: moving from childhood into adulthood. This transitional stage is critical not only for biological and psychosocial considerations; but will also affect the positioning of potentially vulnerable adolescents with regards to the law, policy, as well as health and social care.

The reasons why children become carers are manifold and include (among others) the cultural background, a sense of duty, the lack of alternative options, love and empathy for the care recipient, the lack of financial and practical resources within families.

There is a continuum of children providing care, which starts with **caring about** (low levels of care responsibility, routine levels of caregiving and little evidence of negative outcomes) moving to **taking care of** (increasing care tasks and responsibilities) to **caring for** (high levels of care responsibility, substantial regular and significant caregiving, evidence of significant negative outcomes).

The impact of caring

Mental health and wellbeing

There are some positive impacts related to caring, for example young carers can gain satisfaction from caring and experience self-esteem, empathy, maturity. Yet, having to reconcile the challenges that life throws at them with caring responsibilities can be overwhelming. The pressure associated with caring is considered as a risk factor for mental ill-health.

Education

Young carers may face particular barriers in relation to school and further education: they may have frequent lateness, absences and ultimately, they may be forced to drop out. Similarly, it can be challenging to combine paid employment with caring responsibilities.

Social life

Young carers may have less time for personal development and leisure and be isolated. They can also become victims of social stigma and bullying and may be more frequently subject to social exclusion throughout their life course.

Despite these negative impacts, young carers are still too often invisible to policy makers and service providers.

What do young carers do?

- ▶ Practical tasks (e.g. cooking, housework and shopping);
- ▶ Physical care (e.g. helping someone out of bed);
 - ▶ Emotional support (e.g. talking to someone who is distressed);
- ▶ Personal care (e.g. helping someone dress);
- ▶ Managing the family budget and collecting prescriptions;
 - ▶ Helping to give medicine;
 - ▶ Helping someone communicate;
 - ▶ Looking after brothers and sisters

**“We ignore
young carers at our
peril and at the peril of
these children’s future.”**

**Prof Saul Becker,
University of Sussex**

Why are young carers invisible?

- ▶ Young carers do not recognise themselves as young carers
- ▶ They are afraid of being taken away from their home by social services/child protection.
- ▶ They are afraid of being judged or misunderstood by their peers, teachers or service providers
- ▶ There is stigma (especially when cared for person has mental illness or substance dependency)
- ▶ They are uncertain about who to talk to
- ▶ They believe that nothing will change if they disclose their caring responsibilities
- ▶ Service providers tend to focus on the cared for person
- ▶ Wider community is not aware of specific services for young carers (if any exist)



**Young carers remain unidentified
and their needs are not met.**

WHY DO WE NEED TO ADDRESS THE ISSUE?

Young carers are unable to fully enjoy their human rights

The UN Convention on the Rights of the Child states that **“Every child has the right to...”**- among others- rest and leisure (Article 31), education (Articles 28 & 29), adequate standard of living (Article 27), express their views (Article 12), enjoy the highest attainable standard of health (Article 24).

Young carers, just like all children, should be able to enjoy the rights to which they are entitled. Too often though, the challenges they face directly hinders that process and so the level playing field may no longer be sufficient to guarantee equal opportunities for young carers. Young carers are a particularly vulnerable group of children and should be recognised as such. They should not only benefit from the universal implementation of their rights but be subject to additional and tailored policy and support measures with a scale and intensity that is proportionate to their level of disadvantage. This is in line with the international human rights law which requires States to adopt **affirmative actions** in fulfilling their obligations to respect the equality principle. It can be argued that the lack of positive actions from States to support young carers is a failure to protect and promote their rights.

Supporting young carers makes economic sense

Early school leaving creates high individual, social and economic costs

Young people with only lower secondary education or less are more often affected by unemployment, are more likely to depend on social benefits and have a higher risk of social exclusion. Their lifetime earnings, well-being and health are negatively impacted, as well as their participation in democratic processes.

In addition to the individual costs, early school leaving hampers economic and social development and is a serious obstacle to the European Union’s goal of smart, sustainable and inclusive growth. That is explicitly recognised by the Europe 2020 strategy, which includes the target of reducing the EU average rate of early school leavers to under 10%.

Poor mental health is a cost for societies

At international level, there is growing recognition of the importance of early intervention and **prevention** to avoid poor health outcomes. As stressed by the World Health Organisation, promoting and protecting children and adolescents’ health brings benefits not just to their health, both in the short and the long term, it also contributes to economies and society, with healthy (young) adults able to make greater contributions to the workforce, their families, communities and society as a whole.

Investing in young people is a social investment. As recognised by the EU in the Social investment Package, through early intervention, socio-economic inequalities can be tackled at the roots, the cycle of disadvantages can be broken and equality of opportunity can thus be promoted.

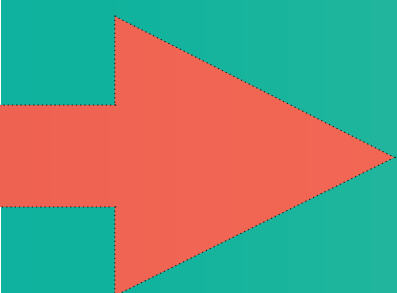
Between support and emancipation - the Young carers’ Dilemma

Before proceeding, it is worthwhile to look into a common ethical conundrum regarding the situation of young carers: “it actually does not pertain to children and young people to assume caregiving responsibilities and so, consequently, supporting young carers is intrinsically detrimental to their best interest”. Let us see the different arguments brought about by those who endorse these conflicting approaches.

Young carers should not exist and policy attention should be put elsewhere	Young carers should be identified and supported
<p>By supporting young carers and teaching them how to cope, some may argue that we effectively accept the transfer of care responsibilities from the public to the private sphere, thereby harming both the principles of universal access to care and the rights of young carers.</p>	<p>The principle that children should be exempt from caring responsibilities makes absolute sense. Yet, it is unrealistic to ensure that children have no caring roles anymore and we should therefore rather provide interventions, support programmes and methods to prevent or lower the care burden among young carers.</p> <p>Young carers exist and they will be there for many years to come, so we should focus on how to support them and follow up on their needs.</p>
<p>“If appropriate services are delivered to the cared for person, the child or young adult could get on with the ordinary business of growing up. Hence, it is important to direct resources and strategies at reducing the need for children to care in the first place (by providing services to the person in need of care).”*</p>	<p>“We recognize that in an ideal world where the voluntary and statutory support services are willing and able to provide extensive or unlimited support, the role of young carers would be greatly reduced. But we also recognize unpalatable current political and economic realities and that in an increasingly pressurised and residual welfare system, in the context of economic recession, uncertainty and charges for social care, family carers are going to be expected to continue their support. In such a context, it is important that the role of (adult and) young carers is fully appreciated and valued.”**</p> <p>If we have zero tolerance – pretending that young carers do not exist- then we will not see them until it is too late, when their needs for support have escalated.</p>
<p>From a human rights perspective, children have the right to be children and not to be carers. A system of support would have the effect of entrapping them into a caring role from which they should be free, in so doing violating their rights.</p>	<p>Young carers’ right to self-determination includes the right to care, if they wish to do so, provided that their best interest is safeguarded. Measures should therefore seek to preserve young carers from inappropriate caring, i.e. caring responsibilities which have a negative impact on the child’s health, wellbeing or education, or which can be considered unsuitable in light of the child’s circumstances.</p>

The vision of the Me-We consortium

*Richard Olsen & Gillian Parker, Critical Social Policy, Issue 50 ** Jo Aldridge and Saul Becker, Critical Social Policy, issue 16.3



Choice

should be the backbone of every decision about carers. People should have the right to choose freely whether they want to be – and remain - a carer, and to what extent they want to be involved in caring. However, choice is unlikely when no professional or informal care alternative is available. The universal provision of affordable and good quality long-term care services is therefore a prerequisite for the self-determination of carers. At the same time, we recognize that the availability of alternative options – while being imperative – may sometimes not be sufficient to allow for a genuine choice. Indeed, other factors (such as the feeling of guilt or of familial duty) may play a role and influence personal perception on offered alternative options. Having said that, when caring responsibilities result from a well-informed and unaffected choice by both the carer and care recipient, society's mission should be to prevent and minimise the negative impact that caring responsibilities can have on young carers, in order to ensure that they can pursue their life goals and reach their full potential.

The care recipient can be a friend. Of those 731 respondents who indicated that they have a close friend with a health condition, 62% (N=453) reported that they provide care for their close friend. This is the first instance in our research study in which more respondents indicate that they care for a friend than those who do not. As to the health condition of the friend, in the majority of cases it is mental ill-health. How much care do young carers provide?

In Sweden, 23% of the total adolescent young carers in the sample perform high amount of caring activities (domestic tasks, household management, personal care, emotional care, sibling carer and financial/practical care); for 9.5%, the amount of caring activity is very high. When compared to their non-caring peers, adolescent young carers perform greater amounts of caring activities in the home, and the differences are highly statistically significant. Hence, they have different experiences of daily life than their non-caring peers. Overall, girls perform a greater amount of care activities compared to boys.

IMPACT ON EDUCATIONAL ATTAINMENT

8.8% of the adolescent young carers report that they experience difficulties in school due to caring. 12.8% report that their school performance has been negatively impacted due to caring. 9.7% report that they have been bullied, teased, or made fun of due to their caring role.

OVERALL WELLBEING

Adolescent young carers were found to be more likely to report a lower state of well-being in comparison to their non-caring peers (on a scale where 50 indicates extremely high wellbeing and 10 indicates low wellbeing, non-carers have a mean value of 34.96, whereas adolescent young carers have a mean value of 27.67).

HEALTH IMPACT OF THE CARING ROLE

12% of adolescent young carers report physical health problems due to their caring role; 28% report mental health problems. This is a different result compared with the other surveyed countries (except UK); there, the impact of caring is stronger on physical than on mental health.

SEVERE MENTAL HEALTH IMPACTS DUE TO CARING: SELF-HARM AND HARM TO OTHERS

10.7% of adolescent young carers have thought about hurting themselves due to their caring role, and 4.7% have thought about hurting others due to their caring role. Of those adolescent young carers, the majority (72.4%) have thought of hurting someone other than their care recipient. This is in contrast to the findings from the other surveyed countries, as typically thoughts of harm are directed towards the care recipient.

ACCESS TO FORMAL AND INFORMAL SUPPORT

In Sweden, the proportion of adolescent young carers receiving personal support in connection to their caring role is higher than in the other surveyed countries: 42.1% of adolescent young carers personally receive support, compared with 13-18% in all the other countries (except UK). This finding reflects the presence of the welfare state model and its availability of formal support for more vulnerable families. The formal support services available in Sweden are not direct, dedicated services for young carers, but rather more general formal health and social services targeted towards vulnerable families.

Adolescent young carers can receive informal support by the network around them. 51.1% of adolescent young carers report that they have a friend who is aware of their caring role and who gives them support. 4.7% report that their employer is aware of their caring role. 31.4% report that someone at school is aware of their caring role. It is worth noting that this is the highest proportion of school awareness across all the surveyed countries.

Chapter 2:

Recognition, protection, support: what does the law say on young carers?

The aim here was to examine the legislation, policy and service frameworks that exist to support adolescent young carers in 6 European countries, with a focus on how they work in practice, the drivers of their development, their strengths and limitations. To this end, we conducted a literature review as well as a series of interviews with experts (four in the case of Sweden).

The term 'young carers' is not used in Sweden. Barn som anhöriga (Children as next of kin or close relatives) is the term

used: children with parents who have a mental disorder or disability, a serious physical illness, injury or disability, or are addicted to alcohol or other addictive agents or unexpectedly die.

In Sweden, **the focus - of legislation and support- is not on the caring roles of children but more about children as next of kin.** In the table below, we underline the differences in the definitions as well as the philosophical rationale and the practical implications.

	Children as next of kin	Young carers
Definitions	Children with parents - or any other adults they permanently live with- who have a mental disorder or disability, a serious physical illness or injury, or are addicted to alcohol or other addictive agents or unexpectedly die.	Children who provide or intend to provide care, assistance, or support to a family member or a friend, who has a chronic illness, disability, frailty or addiction.
Differences	Children as next of kin is a broad group. Among these, some children may have caring responsibilities. Yet, children caring for a friend or for a family member other than a parent (e.g. a sibling) are not included in the definition of children as next of kin.	
	One of the experts interviewed underlines another difference: "(Children as next of kin) is a view of children as victims, children as exposed, children as vulnerable. That's the focus, while young carers is more focused on children who actually do something, who are an actor [...] We have to combine these two, I think. It's not one or the other, it's both together".	
Rationale	The rationale behind the focus on children as next of kin and not as young carers lies on two premises	
	<ul style="list-style-type: none"> ▶ The Swedish welfare system is supposed to take full responsibility for care. Thus, no children should have to assume a caring role. ▶ The Swedish system is very individualistic. The focus is on person in need of care, not on his/her relatives. 	
	In the words of one expert: " <i>This thinking, that children should have the possibility to be just next of kin, and not caregivers, I think it's quite special for Sweden. We have come so far in this as well as in the individualistic thinking. In many other countries, it's obvious that there is the family first, and if the family have needs, they take care of these needs by themselves</i> ".	
implications	The idea according to which children/adolescents are not supposed to have caring responsibilities contributes to the invisibility of (adolescent) young carers.	
	In the words of one interviewed expert: "In some way, it's like we don't want to... see them, since there is an idea that, in the welfare system we have built... it's the society's responsibility to take care of adults, and children shouldn't be caregivers. And from that point of view, I believe they have become invisible".	

LEGISLATION, POLICY AND SERVICE FRAMEWORK

Specific legislation

In Swedish legislation, there is no specific reference or provision for children with caring responsibilities. However, the [Health-care Act](#) explicitly recognise the so called 'children as next of kin' as being a group of children who should be particularly taken into account. As some within this group of children are likely to have caring responsibilities, Sweden – while not recognizing the caring role of adolescent young carers – can be considered as equipped with **partial specific legislation**.

In details, the **Healthcare Act** (as emended in 2010) recognise the **child's need for information, advice and support** if the child's parent or any other adult the child lives permanently with has a mental disorder, disability or a serious physical illness, alternatively an injury or is addicted to alcohol or any other addictive agent, who has died unexpectedly. The provision is unique in Swedish legislation, because the **responsibility for the children's needs is placed on the staff that treats adult patients**.

This important change in the legislation – definitely a positive development in the protection of vulnerable children – has been possible thanks to the work of the organisation [Allmänna Barnhuset](#).

Non-specific legislation

While health and medical care are primarily the responsibility of the 21 Swedish counties and regions, social services are competence of the 290 municipalities.

The [Social Services Act](#) (2001) requires municipalities to provide support for daily living to inhabitants who are unable to secure this through other means. This legislation places a clear responsibility on municipal social services to:

- ▶ Promote children and young people to **grow up under safe and good conditions**;
- ▶ Carry out outreach activity and other **preventive** work in order to prevent that children and young get poorly;
- ▶ Pay attention to children and young people in environments that are **harmful** to them.

Authorities and professionals are also obliged to notify social services if they suspect that a child can be at risk.

The assistance from the social services can consist in having a contact person or contact family as support mechanism, or financial support in case of insufficient income.

It is important to note that children over 15 can ask for support for themselves, while for younger children the **parent's consent is needed**.

Other legislations that can indirectly protect young carers are the following:

- ▶ The [Care of Young Persons \(Special Provisions\) Act](#) (1990) regulate the situation of children who do not get the support they need from their parents or who live a destructive life.
- ▶ The [Patient Safety Act](#) (2010) states that healthcare professionals should pay particular attention to a child's need for information, counselling and support (for children who are next of kin).
- ▶ The [Law on Support and Services for Certain Disabled People](#) contains provisions on the best interest of the child and the right of children to speak.
- ▶ The [Education Act](#), that places on schools an obligation to ensure that all children receive the support that they need in order to acquire and complete their education.

FROM LEGAL PROVISION TO ACTUAL IMPLEMENTATION: A GAP TO BE FILLED

The provision in the Healthcare act is a very innovative one for the Swedish system. Yet, its actual, proper implementation will require time. One of the main obstacles is the lack of competence of adult care professionals in implementing the provision for children.

It takes time before health and social care services have the routines and competence to be able to fully take on the responsibility put on them by the legislation. Indeed, changing views about children having their own rights and about their participation is a lengthy process. This is even more valid considering that the development within public health and social care has gone towards increased individualization and specialization since the 1970s. Therefore, the family perspective has been lost a lot: there are sometimes local guidelines that directly prohibit those who provide this support to include children and families.

In order to overcome this obstacle in the implementation of the legislation that support children as next of kin, the National Board of Health and Welfare - together with The Swedish Family Care competence centre (Nka) and those responsible for health and medical care in the various regions- is working so that legislation is known and applied. Among other things, they promote a family-oriented approach, especially in social services, but also in psychiatry.

STRENGTHS AND LIMITATIONS OF LEGISLATION, POLICY AND SERVICE FRAMEWORKS

Strengths

- ▶ There is a **well-developed welfare system** in Sweden.
- ▶ Swedish legislation has a **strong focus on the rights of the child**. This has been further strengthened by the ratification of the Children's Convention (which is going to be incorporated into Swedish law, from January 1, 2020.) There is a shift in the direction of seeing the children as a partner.
- ▶ The **regulations and framework are open**. This feature, unique in comparison to the other surveyed countries, is a strength, as there are no limitations to providing support and intervening with young carers. At the same time, it can also be a weakness, as the protection of the child ultimately lies on individual social secretaries and child protection professionals.

Limitations

- ▶ The Swedish legislative and policy framework features provisions that can be used to support young people with caring responsibilities. Yet, it is a **patchwork of provisions** and there is no clear regulation among the different laws.
- ▶ The Swedish authorities are unwilling to accept that the health care sector and social welfare are not taking care of the problems. As a result, **children have not been thought about as young carers**. This makes identification – and support- of young carers challenging.
- ▶ As legislation doesn't refer explicitly to young carers, there is **no definition of when caring roles are 'over the limit'** and what is acceptable.
- ▶ Very open regulations and frameworks put a lot of **emphasis on individual** social secretaries and child protection professionals.
- ▶ The legislation does not specifically include **siblings or parents with developmental difficulties** (learning disabilities).
- ▶ **Resources have been reduced** over the years. This makes difficult for social services to work with a preventative approach, as required by the Social Services Act.
- ▶ One regulation of the Healthcare Act relates to thinking about whether there are children involved, but this is not the case automatically with the Law on Support and Services for Certain Disabled People (LSS) or the Social Services Act.
- ▶ There is a **lack of clarity** with the Healthcare Act. For example, no guidance on what should be done if parents refuse that information is given to their children and how it relates to the obligation to report to social services.
- ▶ There is a conflict between **family privacy** and the interests of children, which can result in children with caring roles remaining unseen.

Chapter 3:

Successful strategies to improve young carers' mental health and well-being

VISIBILITY AND AWARENESS OF YOUNG CARERS

In Sweden, the concept of "children as next of kin" has begun to receive attention in the latest decade and it is becoming more and more used. On the contrary, the term young carers is not established at all, as children are not thought as carers.

Among professionals, the attention to children as next of kin has increased in recent years, and still is increasing. However, there are regional and local divergences. Children as next of kin usually get attention in specialist care. Similarly, social workers are aware that children of parents with substance abuse often take great responsibilities. In addition, as a result of their experience, family counsellors have become alert to children being 'next of kin'.

In the majority of cases, all depends on the people who work in the caring fields and the attention is often due to **individual professionals with a burning interest** of the issue of children as next of kin and/or (adolescent) young carers.

In schools, the awareness of (adolescent) young carers' situation is low. School staff may notice that some children take great responsibilities at home, but it is not sure that the staff realize what this means for the individual child/adolescent. The lack of understanding by educational staff entails a lack of support in case of problems at school due to caring.

Among the general public, the awareness is limited. A lot of people may see what is going on, but do not reflect on the consequences for the children. In the words of one of the interviewed experts: "*Seeing and being aware is not the same thing*".

CURRENT STRATEGIES, INTERVENTIONS AND/OR PROGRAMMES TO IDENTIFY & SUPPORT YOUNG CARERS

Support available in Sweden

The support available in Sweden is highly influenced by the assumption that children should not be carers. Therefore, the support for them is not regulated as it is for adult carers. The focus is on children as next of kin and it is often the case that a situation is not regarded as one related to caring, but it is rather related to parenting.

Parenting support: For instance, parents with neuropsychiatric disabilities in some contexts can get support in their parenting through text messages reminders about times to keep, daily tasks to be performed, etc. They can also get practical support at certain times of the day, for example, someone can come home to them every weekday morning and help get the kids to pre-school and school. Through a questionnaire, developed by Karolinska Institutet, one can investigate which parental skills are not fully functioning, and parents are given the opportunity and assistance to train these skills.

Whole family support: There are also a range of support initiatives targeted to the whole family with the aim to release the child from caring responsibilities. In some regions, child rehabilitation centres offer support for children and adults who have a family member with disabilities. There is a collaboration between five municipalities who, together with the Swedish municipalities and county councils, investigate which family-oriented innovative efforts may be needed in families where there is abuse problems. Municipal efforts for families where abuse occurs often also includes support for close relatives.

Respite: The summer camp organised by Maskrosbarn (Dandelion Children) is described as an appreciated form of relaxation for children whose parents suffer from mental illness or substance abuse problems. In a Northern Swedish

region, relaxing weekend breaks are organized for children whose parents suffer from cancer. The Swedish Alzheimer association is financing summer camps for children to parents suffering from dementia.

Multi-stakeholders support: In a few projects, school and social care services have collaborated to increase opportunities to support children and young people in vulnerable situations.

Evaluation of available support

- ▶ One big obstacle in the provision of support for young carers is the **rigidity and the individual approach of the Swedish welfare system**. According to the established practices – despite the changes in legislation- the decisions on assistance or support only concern the individual and not the rest of the family. The focus is on the family member who has a disease / disability and there is an uncertainty in talking with children about their situation.

In the words of one of the interviewed experts: *“Our systems are built around individuals and not around families and relatives, which makes it more complicated to bring a family perspective in many contexts. So we have to find systems for bridging this”*.

- ▶ The **lack of cooperation** between different regional and local organizations is described as an obstacle in various contexts. Caused by a lack of resources, it entails unequal opportunities across the country. For example, the existing support phone lines, which are valuable to children and adolescents in vulnerable situations, are driven primarily by NGOs with limited resources. They are not able to answer every call and there is no coordinating function that can forward unanswered calls.
- ▶ The current support system may work but it relies on **capabilities and empathy of individual professionals**.
- ▶ Many of the support measures are **targeted to children as next of kin and not as carers**. For instance, in the case of peer support groups, one may wonder whether the issue of caring responsibility (focused on the active role they play in the family) is given space in the group conversations.
- ▶ Several of the Swedish experts emphasized the **lack of practical help and support**: services are considered good at providing psychosocial and psychoeducational support, but, in the experts’ opinion, these forms of support need to be supplemented with practical support and help to the family, which currently is performed to a quite limited extent. Reasons behind this lack of practical help may include scarcity of resources, lack of knowledge about available resources, or the parents’ unwillingness to receive practical support.

Possible strategies to support young carers

The Me-We research study – with its cross-national comparison – allows us to provide an overview of the (adolescent) young carers’ needs and possible support strategies.

→ Ensure that legislation works in practice or adopt specific legislation

Young carers need to be acknowledged and protected by legislation.

According to some among the interviewed experts, legislation that can protect young carers is already there and, rather than changing it, it’s a matter of **using it**.

“We have had discussions with our lawyers earlier that we would like the Social Care Act to indicate clearly the group of children as next of kin, but the more groups that are pointed out the greater risk there is of some group falling outside protection [...] Our current legislation covers young carers, because it speaks about children’s safe childhood and environment, health and development, and that social care services should work preventively. So I believe it’s more about using it, in order to highlight this group, instead of requiring some specific legislation”.

“It is more on an organizational level... it is... We have legislations that are sufficient, but then you perhaps have some municipalities organized in a way that doesn’t... that makes young carers be left out. But through political and organizational changes, you can deal with that [...] This responsibility is already extremely clear”.

Other experts call for changes in legislation. For them, the concept of (adolescent) young carers need a definition and a place in legislation.

“Somewhere in the law you need [...] to state that you have to pay attention to children as next of kin and being young carers and then a definition [...] or something overarching from the National Board of Health and Welfare that says that this term should be related to that legislation”.

Whether to extend not specific legislation or to adopt specific legislation on young carers depends on the efficacy of existing legislative and policy frameworks and it needs to be based on an accurate understanding of the reality on the ground, rather than on assumptions. Indeed, our study shows that support and protection that adolescent young carers receive in practice does not always reflect the objectives of legislation and policy.

→ Raise awareness and reduce the stigma

Awareness on young carers and the challenges they face needs to be raised, among professionals and the general public. Indeed, awareness of new vulnerable groups takes time and in Sweden it still needs to be created.

The following measures can be implemented:

- ▶ Discuss the topic of informal caring, resilience and mental health or addiction at school, so that they become less a taboo.
- ▶ Ask all parents and children about the care situation at home continuously during the child's upbringing in a way that is not stigmatising.
- ▶ Awaken the debate in the media.
- ▶ Provide training to professionals on young carers and on the legislation that can protect them.

→ Identify young carers

Young carers are not likely to actively seek out help or support, because of lack of self-identification, or fear to be taken away from their families. Hence, health care professionals, school staff and social workers need to play an active role in identifying YCs.

Effective measures can include:

▶ **Screening at health settings**

Professionals can identify (adolescent) young carers whose parents are known within health care or social care. This can be done by asking patients/clients if they have children and follow-up questions about the children's situation, and by proposing a meeting between professionals and the child. Three methods are suggested by the Swedish experts: 'Föra barnen på tal', 'BRA-samtal' and Beardlee's family intervention.

Föra barnen på tal' (Talk about the children) is a manual based method in which the professional meets the parent(s) on two occasions and together with the parents talk about the children and their situation. During the meetings, they use a structured logbook as support.

BRA-samtal (Children's Rights as Next of kin) is a model for talking with children as next of kin, in order to ensure that the children gets opportunities to talk about their situation, be involved, and be aware of their rights.

Beardlee's family intervention is a family-based approach for the prevention of depressive symptoms among children at risk. It consists in meeting the children in their home and then having a conversation with the whole family, in order to gain knowledge about the children's situation in the family.

▶ **Screening at school**

Schools can play a vital role in early identification of young carers. When enrolling to kindergarten/school, social conditions of a child could be screened (adverse childhood experiences –ACE- screening could be used, or a box to tick "I have caring responsibilities").

→ Gather more data

More knowledge and data are still required to improve understanding of young carers and their needs.

In particular, more research is needed in the following areas:

- ▶ How well do authorities comply with the obligation to inform the children of patients in Swedish healthcare?
- ▶ How do people in general define the terms 'care' and 'carers'?
- ▶ The percentage distribution of (A)YCs among children and young people
- ▶ (Adolescent) young carers' needs
- ▶ Development, testing and revision of interventions in order to meet (adolescent) young carers'
- ▶ Systematic follow-ups of existing support programs.

→ Adopt a preventative approach

Support should be preventative; parents should be able to ask for it without fear and children should know they can receive support at an early stage. According to the experts, Swedes are not so good in implementing this approach.

In the words of one expert, "*We should not be so afraid of starting and offering something, because for the child it is about needing help now or support now [...]*".

→ Support young carers at school

The findings from the Me-We survey on adolescent young carers' negative experiences in school underline the need for the educational sector to identify and engage with young carers. Adolescent young carers who responded to the on-line survey call for increased flexibility and an extended student health care with a focus on preventing mental illness. In the words of one Swedish young carer: "*The help I would need is an improved student health care, with more and easier opportunities for students (and children) to get support and help at a professional level. All students are called to individual meetings with the school nurse. Similarly, I think everyone should be called to meetings with the school social worker*".

Overall, it is about **flexibility** (understanding from teachers in case of lateness, absences, no homework done...) and **extra, tailored support**. For example:

- ▶ Have counsellors that young carers can talk to one-to-one.
- ▶ Refer students to help services (e.g. sport club, youth club) and let them aware that these support services exist.
- ▶ Make school psychologist aware of young carers and let him reach out to them

- ▶ Attribute a special status to young carers, similar to the status of sportspersons.
- ▶ Adopt integrated actions in which educational, social and health services should be involved (e.g. multidisciplinary team in the school embedding psychologists).
- ▶ Release a Carers card so that young carers don't have to explain their situation every time.
- ▶ Assist them with the financial cost of participation in these activities.
- ▶ Provide respite care (i.e. someone who goes home and takes over the caring responsibility) while the young carer take part in these activities.

→ Support the mental health of young carers

The findings from the Me-We survey contribute to shedding light on the severe mental health condition of adolescent young carers who do not receive timely and adequate support. The substantial numbers of adolescent young carers reporting self-harming thoughts and thoughts of harm to their care recipients is an alarming finding. This calls for the engagement of health professionals, particularly mental health practitioners, in the identification and support of young carers.

In the words of Swedish young carers: *"I need someone to talk to, but, since everyone thinks that the best thing is to include my parents in the conversations, I put it down. I asked for help for a reason, and it was not about talking to the parents. I want to talk to a completely outside person"*.

"I think it's difficult to keep the mask all the time, and just pretend that everything is fine. I feel that I have a pressure to look strong before my little sister. I also find it difficult to talk about this with someone in the family [...] I have friends I can talk to, but it doesn't feel right to burden them with this. I'd rather go to a social worker, or someone similar, to vent this. However, I don't have the information on how to do this, how to 'book' this, or even what to talk about. Well, that's probably what I need support for. Someone to talk to, just talk, not to get commands on what to do and how" "I need help to be reminded that I have to do stuff that I think is fun, and not to feel forced to be with the person I support".

Measures that can be implemented to respond to these needs are indicated below:

Peer/group support/Information

- ▶ Set up young carers' groups, peer support groups, in order to provide children with the insight that they are not alone (this can also empower them).
- ▶ Provide young carers with examples of people who used to be young carers and succeeded in their goal (via Mentoring).
- ▶ Make easier to get information on the available support (e.g. Inform teachers and GPs and social workers about led local activities to support young carers).

Provide respite breaks for young carers

- ▶ Organise summer camps, cinema, café, sport activities
- ▶ Give young carers a break from caring, let them have fun and get in contact with peers.

Increase resilience

- ▶ Allow young carers access to tools and support to find useful coping strategies. Building young carers' resilience also has the advantage of lessening the dependency of young carers onto formal support services, particularly in times of budget cuts and reduced services available.
- ▶ Psychoeducation may be a useful tool to increase resilience.

→ Consider young carers as participating actors and rights holders

Policy makers need to **recognize young carers as an important target group, in all policies**. Increase participation of adolescent young carers themselves and a view of children as partners, with regards to their situation and policymaking in general.

Young carers need to be involved in all decisions that affect them. In order to actively participate in decision processes, they have to be informed. Their rights have to be taken seriously and their opinion listened to.

The following strategies can be implemented:

- ▶ Provide adolescent young carers with information, e.g. about the parent's illness, as well as what support they can get and how to access it. Many professionals are not aware that children have the **right to be informed**.
- ▶ Ensure that care assistance staff, health care staff, social workers, teachers, and parents are respectful towards children.
- ▶ Co-design the support with young carers, to ensure that it fit their needs. The support should be tailored to the individual. A tailor made support can make families and children better off here and now – and prevent the problems from being passed on to the next generation.

→ Adopt a whole family approach

Many municipalities have now concluded that a family perspective is needed. The whole family should be supported and young carers should be seen and involved in a care plan where their opinions need to be sought.

With social services more available, children and adolescents might be more likely to ask for help and support and parents may feel they can receive support. A really long assessment is not needed but help should be readily available.

→ Adopt a collaborative approach

All experts agree that **cooperation** is an important key to a functioning support system. This means cooperation over municipal and county borders, and cooperation among different authorities, organizations, services and professions.

There are no legal obstacles to working in a more coordinated way; it is down to how things are organized. Yet, the division of responsibilities is unclear and there is uncertainty on where to get information and support. Given this context, envisaging **care coordinators** would be a huge help for young people and their families.

→ Provide financial support

Supporting efforts for adolescent young carers and their families should be financed by state and municipal funds. According to some of the interviewed experts, the costs pay for themselves in the long run, considering that the interventions would lead to fewer young people being affected by mental illness. An economic analysis shows that the cost for society could be reduced by 35 billion SEK per year if a child dealing with abuse or serious mental illness in the family does not develop himself in adulthood.

→ Ensure consistency within the State

Even though the well-being of young carers should be a collective responsibility of all members of the community, the primary responsibility to acknowledge young carers and to address the issue lies with the State. An involvement on a national level show political acknowledgement of the issue and ensure consistency in the protection and support for all young carers. According to some of the interviewed experts, an increased awareness at national level has increased the financial opportunities for the regions to meet adolescent young carers' needs.

→ Provide good quality, accessible long-term care

Adolescent young carers who responded to the Me-We survey emphasize needs for more/extended/improved professional support from social and health care, for the care recipient; more/extended/improved paid care assistance in the home; and financial assistance for the care recipient.

In their words: *"I take care of my dad, because there is not enough care assistance in the municipality"*

"Financial support is what would be needed to get rid of the crisis".

→ Give special attention to adolescent young carers and carers with migrant background

There is the need to pay special attention to protect adolescent young carers as they are developing their own identity and they are in a vulnerable transition period. Services need to be developed at the transition period from children's services to adult services and quicker interventions to assess needs should take into account the transition between school and work.

Young carers with migrant background also deserve special attention, because inequality exists among different groups regarding their health as well as in their use of care services.

Chapter 4:

Translating research findings into policy

RECOMMENDATIONS TAILORED TO THE SWEDISH CONTEXT

*“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. Yet, 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. We should instead see children as **participating actors in care tasks within the family**” (Nordenfors & Melander, 2017).*



RECOMMENDATION FOR SWEDEN

- ▶ We call on officials and politicians at national, regional and local level to acknowledge the reality: despite the strong welfare state, young carers exist – and will continue to exist- in Sweden, as in the other European countries. It is the State’s responsibility to make them visible, to take their needs into account and to ensure that their needs are met via adequate support.
- ▶ We recommend that the concept of (adolescent) young carers find a place – and a definition- in Swedish legislation. This may entail the adoption of specific legislation targeting young carers or an extension of the current legislation. For example, the regulations and the handbook in the Young Person’s Act could be updated to include **young carers** as an example of **children at risk**.
- ▶ Once young carers are recognised and defined in legislation and policies, we recommend to develop – and to clearly include in legislation and policy – an understanding about what **level of caring is inappropriate**.
- ▶ We call on the Swedish policy-makers to bring about a broader, family support perspective (**whole family approach**). For instance, the ‘family perspective’ could be included in the review of the Social Services Act.
- ▶ The **review of the Social Services Act** could also be an opportunity to make the support that young carers get from social services more accessible, in line with a **preventative approach**.
- ▶ The Social Services Act could be amended to **allow children and young people to receive support from social services without the consent of parents or guardians**.
- ▶ We recommend using the Patient Safety Act in relation to children’s needs not being met.
- ▶ We call on Swedish policy makers at all levels to adopt the child’s perspective in all contexts, as envisaged by the Convention of the Rights of the Child.



RECOMMENDATION AT EUROPEAN LEVEL

It is evident by now that we need to take action to support and empower young carers. This is increasingly recognised at international and European level.

The European Network of Ombudspersons for Children - in their [statement on child mental health](#) adopted on 21 September 2018- has stressed the importance of support programmes to better enhance and protect the mental health of young carers.

The European Parliament, in the [Report on Care services in the EU for improved gender equality](#) - approved on 15 November 2018 – calls on the Commission and the Member States to **undertake research on the numbers of young carers and on the impact of this role on their well-being and livelihoods** and, on the basis of this research, to **provide support** and address the specific needs of young carers, in cooperation with NGOs and educational establishments.

The actions recommended to the Swedish policy-makers can be complemented by actions taken at European level.

- ▶ Support **further research** on the profile and needs of young (adult) carers; Gather an insight into actual numbers.
- ▶ Ensure existing **good practices are disseminated** and made visible across Europe; Comparison with what is happening in other countries to support developing practices and legislation.
- ▶ **Include young carers** in the European Youth Strategy or EU agenda on higher education and other relevant policy dossiers.
- ▶ **Listen to young carers.** Along the lines of the Europe kids want, envisage platforms/ opportunities to have meaningful participation of young carers.
- ▶ **Make use of instruments at hand** – i.e. European Semester, European Pillar of Social Rights, European Structural and Investments Funds, European Youth Strategy, EU agenda on higher education European Platform for Investing in Children, Youth Guarantee and Open Method of Coordination – to promote the development of integrated approaches for the identification, support and social integration of young (adult) carers across Europe.



Figure 2 - The European Pillar of Social Rights and its relevance for young carers

The Principles	The relevance for young carers
Principle n. 1 Education, training and life-long learning	Caring responsibilities can have a negative impact on young carers' education (underachievement, absence and drop-outs)
Principle n. 4 Active support to employment	Young carers are more likely to be NEET (Not in education, employment or training) than their peers. A report by the Audit Commission in the UK found out that the likelihood of young adult carers being NEET for six months or more was twice that of their peers (audit commission, 2010). Source: Carers Trust
Principle n. 11 Childcare and support to children	Young carers need to be considered as children from disadvantaged backgrounds -> have the right to extra, tailored support so that they can have equal opportunities in enjoying social rights.
Principle n.18 Long-term care	By providing good quality formal LTC services to the person they care for, inappropriate caring can be avoided.

It is the role of policymakers to prevent and minimise the (potential) negative impacts of growing up while being a carer (restricted education, reduced life chances, affected well-being, isolation) and to enable young carers to thrive and flourish as human beings.

The life chances of thousands of children
across Europe are at stake.

THERE IS NO TIME TO LOSE.



#youngcarers

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