



# ENABLING YOUNG CARERS

to pursue their goals in life and  
reach their full potential

## Converting research findings into policy actions



# European policy brief



## 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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# TABLE OF CONTENTS

<b>Summary</b>	<b>4</b>
<b>Introduction</b>	<b>6</b>
The challenges of being a young carer	6
Who are young carers?	6
What do young carers do?	6
The impact of caring	6
Why do we need to address the issue?	7
Young carers are unable to fully enjoy their human rights	7
Supporting young carers makes economic sense	7
Between support and emancipation - the Young carers' Dilemma	8
<b>Chapter 1:</b>	
<b>What is it like being an adolescent and a carer?</b>	<b>10</b>
Who do adolescent young carers care for?	10
How much care do young carers provide?	11
Impact on educational attainment	11
Overall wellbeing	11
Health impact of the caring role	11
Severe mental health impacts due to caring: self-harm and harm to others	12
Access to formal and informal support	12
<b>Chapter 2:</b>	
<b>Recognition, protection, support: what does the law say on young carers?</b>	<b>13</b>
Specific vs. non-specific legislation	13
From legal provision to actual implementation: a gap to be filled	15
Strengths and limitations of legislation, policy and service frameworks	15
<b>Chapter 3:</b>	
<b>Successful strategies to improve young carers' mental health and well-being</b>	<b>16</b>
Visibility and awareness of young carers	16
Current strategies, interventions and/or programmes to identify & support young carers	16
<b>Chapter 4:</b>	
<b>Translating research findings into policy</b>	<b>18</b>
Policy implications	18
Policy recommendations	20
Recommendations at European level	21
Recommendation to States	22

# Summary

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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 per cent 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 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 - Psycho-

social 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.

## 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

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## 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 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

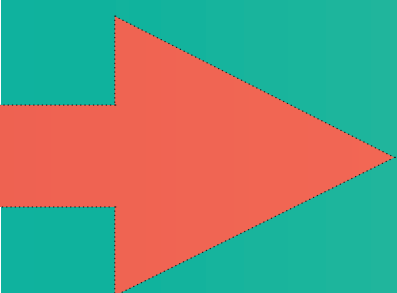
Before proceeding, it is worthwhile to look into a common ethical conundrum regarding the situation of young carers: "it actually does not pertain to children and young people to assume caregiving responsibilities and so, consequently, supporting young carers is intrinsically detrimental to their best 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
By supporting young carers and teaching them how to cope, some may argue that we effectively accept the <b>transfer of care responsibilities from the public to the private sphere</b> , thereby harming both the principles of universal access to care and the rights of young carers.	The principle that children should be exempt from caring responsibilities makes absolute sense. Yet, it is <b>unrealistic</b> 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. <b>Young carers exist</b> 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.
"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 <b>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)</b> ." <sup>*</sup>	"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, <b>family carers are going to be expected to continue their support</b> . In such a context, <b>it is important that the role of (adult and) young carers is fully appreciated and valued</b> ." <sup>***</sup> 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.
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.	<b>Young carers' right to self-determination includes the right to care</b> , if they wish to do so, provided that their best interest is safeguarded. Measures should therefore seek to preserve young carers from <b>inappropriate caring</b> , 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.

## The vision of the Me-We consortium

<sup>\*</sup>Richard Olsen & Gillian Parker, Critical Social Policy, Issue 50 <sup>\*\*</sup> 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.

# Chapter 1:

## **What is it like being an adolescent and a carer?**

### Figure 1- The Me-We online survey



How is it to navigate a changing world - the transitional period from childhood to adulthood - while implementing caring tasks? To gain insight into this, the Me-We consortium ran an online survey in six European countries from April to mid-November 2018.

The aim was to assess the extent of caring and its effects (impact on general wellbeing, work and education) for adolescent young carers. Out of the 9,298 respondents, 2,418 were carers (person who usually provides unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework), of all ages. A total of 1,684 adolescent young carers (15-17 age) were identified in the process.

The majority of them across the six project countries identified as women, which is in line with the existing literature on the gendered nature of care, and the cultural, social, and familial expectations of care.

## WHO DO ADOLESCENT YOUNG CARERS CARE FOR?

The “typical” profile of a European adolescent young carer is a girl providing care for her mother with a physical disability (in the case of Sweden, a mother with mental illness).

Having said that, grandparents - specifically grandmothers - formed a large part of the care recipients among Italian respondents. This finding can be attributed to the lack of appropriate formal, long-term care services for older people in Italy (despite an ageing population), with the result of more adolescents taking up caring responsibilities.

In Sweden and the UK, the survey showed a high prevalence of care provision among siblings. In the case of Sweden, this finding is likely reflective of the presence of strong community care policies, ensuring that substantial care is more likely to take place in the home rather than in long-term care facilities. Therefore, siblings living at home are more likely to undertake caring activities.

In the case of the UK, the findings can be attributed to the recent period of austerity in British social policy, which has led to decreased formal services for siblings with disabilities or illnesses, with the result of more adolescents having to take on caring roles in their families for their siblings.

It is also important to note that some adolescent young carers in the study indicated that they provided care to individuals who are close to them but are not family members (i.e. typically a close friend). The majority of respondents in this situation indicated that they provide care to a friend with a mental illness, except for in Italy where the care responsibility was because of a physical disability.

## HOW MUCH CARE DO YOUNG CARERS PROVIDE?

When compared to their non-caring peers, adolescent young carers perform greater amounts of caring activities in the home (domestic tasks, household management, personal care, emotional care, sibling carer and financial/practical care), and the differences are statistically highly 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, however the statistical significance varies between countries.

Adolescent young carers in Italy, the Netherlands, Sweden, and Switzerland generally perform a similar amount of caring activities. In Slovenia and the United Kingdom, adolescent young carers report substantially higher levels of care compared to the other four European countries explored in this study.

In the case of Slovenia, the finding can be attributed to a lack of formal support services for both the ill or disabled family member and adolescent young carers.

In the case of the UK, it can be attributed to the recruitment methodology of the project; nearly all of the adolescent young carers who took part in this research survey were identified through their young carers' project. Because of the severe budget cuts in formal services during the time of British austerity, young carers' projects are seeing more young people at "crisis level", and because of projects' limited capacity and resources, they often prioritize referrals of young carers with particularly significant levels of caring responsibilities.

## IMPACT ON EDUCATIONAL ATTAINMENT

The majority of adolescent young carers (over 90%) were currently engaged in education at the time of the survey.

Adolescent young carers in Slovenia and Italy reported the lowest percentage of negative school performance and of being bullied due to caring, whereas the adolescent young carers in the Netherlands, Switzerland, and Sweden reported a greater percentage of negative educational impacts due to caring. In stark contrast, the adolescent young carers in the United Kingdom reported the most considerable amount of negative experiences in education due to caring. Whilst this finding is supported by previous research in the UK, the observed cross-country difference may be due to region-specific school cultures or practices.

## OVERALL WELLBEING

Adolescent young carers in the 6 surveyed countries surveyed experience both positive and negative outcomes related to caring. They were found to be more likely to report a lower state of well-being in comparison to their non-caring peers.

## HEALTH IMPACT OF THE CARING ROLE

Adolescent young carers in Switzerland and the United Kingdom generally reported higher amounts of caring-related health difficulties compared with the other European countries.

**Figure 2 - Health difficulties in connection to caring role**

### ITALY

- 26% of AYC's report physical health problems (N=45)
- 17% of AYC's report mental health problems (N=30)

### THE NETHERLANDS

- 20% of AYC's report physical health problems
- 11% of AYC's report mental health problems

### SLOVENIA

- 24% of AYC's report physical health problems
- 16% of AYC's report mental health problems

### SWEDEN

- 12% of AYC's report physical health problems
- 26% of AYC's report mental health problems

### SWITZERLAND

- 40% of AYC's report physical health problems
- 33% of AYC's report mental health problems

### UNITED KINGDOM

- 30% of AYC's report physical health problems
- 60% of AYC's report mental health problems

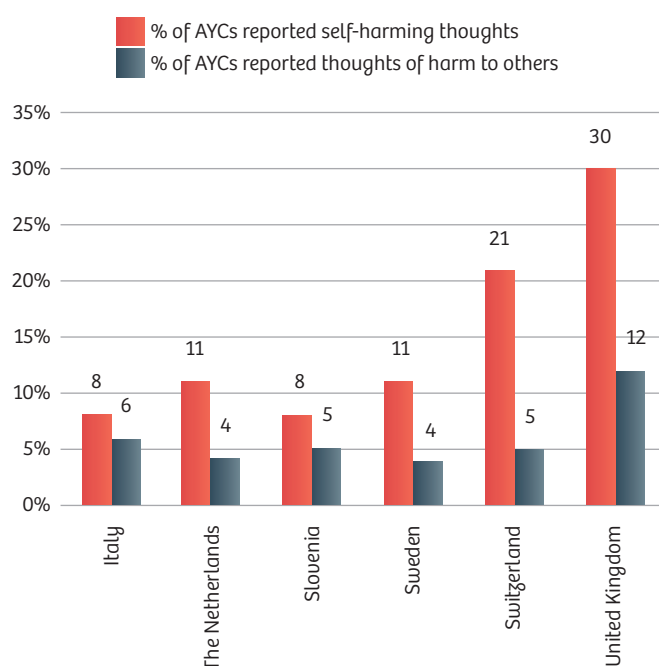
The observed differences may be attributable to the nature of the care recipient and/or economic and societal stressors (e.g., British austerity).

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

Generally, 8-11% of adolescent young carers reported that they have thought about hurting themselves because of their caring role.

Exception: in Switzerland and the UK, adolescent young carers reported a more substantial experience of self-harming thoughts and thoughts of harm to others because of caring, in comparison to the other European countries.

**Figure 3- Severe mental health impacts due to caring: self-harm and harm to others**



The differences observed may be attributable to the sampling strategy in the UK, as well as an influence from economic and societal stressors (e.g., British austerity).

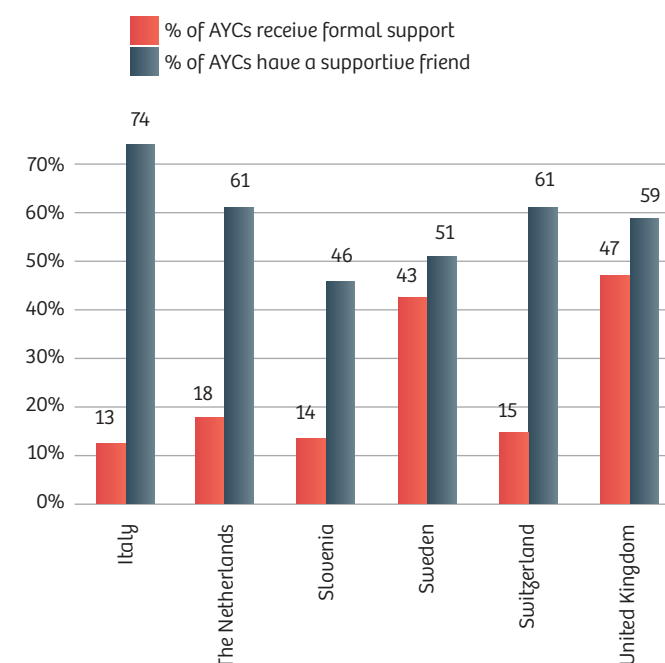
## ACCESS TO FORMAL AND INFORMAL SUPPORT

Relatively low numbers of European adolescent young carers receive, or have the opportunity to access, formal support services.

Exception: in Sweden and the UK, adolescent young carers reported a higher percentage of formal support received in connection to their caring role in comparison to the other four European countries in this research.

In the case of the UK, this can be attributed to the sampling strategy, as well as to the actual presence of dedicated young carers support services. In the case of Sweden, this finding might potentially reflect a greater availability of welfare support compared to the other European countries.

**Figure 4- Access to formal and informal support**



It is important to emphasize that whereas adolescent young carers may not have the opportunity to access dedicated formal support services for their caring role, many reported the presence of a friend who is aware of their caring role and who offers them support. This finding is important to consider in light of the resilience and protective factors encountered in young carers: **adolescent young carers may find informal support valuable in the absence of formal dedicated services** from governmental or social care agencies.

# Chapter 2:

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

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The aim here was to examine the legislation, policy and service frameworks that exist to support AYCs in 6 countries, with a focus on how they work in practice, their strengths and limitations and the drivers in their development. To this end, we conducted a literature review as well as a series of interviews with 25 experts.

### SPECIFIC VS. NON-SPECIFIC LEGISLATION

Only the UK has **specific legislation on the topic** that explicitly recognises or defines young people with caring responsibilities. Hence, it may be worth investigating what the rationale and the drivers of the legislation were (please refer to the box: “Focus on the English model”).

Sweden – while not recognizing the caring role of adolescent young carers - does legally recognise the needs of children with parent/s who have a mental disorder, disability or a serious physical illness, alternatively an injury or who has died unexpectedly. As such, it can be considered as equipped with specific and yet ‘partial’ legislation in place.

In the other countries, the legislation can be defined as non-specific, i.e. it lacks any recognition or definition of young carers but can still be used to protect and support children with caring responsibilities. Examples of non-specific legislation include:

- ▶ **Health and social care legislation:** Prevent or reduce the necessity for children to take up caring roles by ensuring that the needs of those with care needs are met.
- ▶ **General legislation for children and families.** Each country has general legislation in place to protect all children and families. This legislation has the potential to safeguard children from being negatively impacted by caring responsibilities at various levels, such as (a) by recognising these children as a specific group in need, (b) by supporting their identification, (c) through child protection measures and (d) by ensuring that they are attending school and being educated.
- ▶ **Education legislation.** The child’s right to education could offer protection to young carers in ensuring their attendance at school. Education legislation can also be relevant in relation to the identification of adolescent young carers by schools and the support offered to them.
- ▶ **Safeguarding and child protection legislation.** Young carers at risk can be protected under these laws.
- ▶ **Carers legislation** (supporting carers of all ages).



In some countries, the legislation lacks any recognition or definition of young carers but can still be used to protect and support children with caring responsibilities

# FOCUS ON THE ENGLISH MODEL

In England, provisions for young carers fall within The Care Act 2014 and the Children Act 1989 (amended by the Children and Families Act, 2014) which work together in order to bring about a **preventative and whole family approach** to identification, assessment and support.

## Right to assessment of needs and support.

The new legislative framework defines young carers, place on local authorities a **universal duty to assess young carers' needs**, as well as the duty to take **reasonable steps to identify** the extent to which there are young carers within their area who have need for support (i.e. actively look for them). The Children and Families Act 2014 gives young carers and young adult carers in England a right to a carer's assessment and to have their needs met (if the assessment shows this is necessary). A young carer's needs assessment must include an assessment of whether it is appropriate for the young carer to provide, or continue to provide, care for the person in question. **Inappropriate caring** responsibilities should be considered as anything which is likely to have an impact on the child's health, wellbeing or education, or which can be considered unsuitable in light of the child's circumstances.

Both acts specifically mention young carers for the first time. In the previous legislation young carers were mentioned as a vulnerable group but the right to assessment was dependent on two pre-requisites: the care provided had to be substantial and regular. What equated to regular and substantial care was open to local interpretation, which meant that in one area someone might qualify for an assessment, whereas they wouldn't in another area.

With the new legislation, there is clear accountability and responsibility for identifying young carers and for providing support to the whole family through joined up working across adult and children's services, health and social care.

## The rationale of the new legislation: Investing in carers wellbeing and prevention is a worthwhile investment!

The main reason why the English legislator decided to change the legislation –for carers in general - is the understanding that **investing in carers wellbeing and prevention** work was a **worthwhile investment** ultimately reducing the cost to the state. A 2015 report by Carers UK and Sheffield University revealed that carers save the UK £132 billion a year. The failure in early identification and support led to escalation of needs, with negative consequences not only on individual carers - negative and costly impacts on carers' health and wellbeing, their education and employment outcomes- but also on the finances of the State. In the case of young carers, there was evidence showing the very low percentage of young carers who were receiving an assessment of their needs. As stated by the National Young Carers Coalition in a briefing in 2013: "We strongly believe that reforming the law for young carers would not only improve identification and support for young carers which would have a positive impact on their longterm outcomes, but legal reform would also reduce burdens on local authorities by preventing the risk of inappropriate caring and providing a clear framework for whole family support, at an ultimately lower cost to the state."

## Paradigm shift: a whole family approach

Moreover, the government had received evidence that adult and children's law didn't join up, preventing whole family working. Young carers were supported in isolation, without their families receiving the right support. Very few young carers were identified and referred for support by adult's social care and health services, only 4-10% of referrals to young carers services were from adult social care\*. This was not effective. Hence, a paradigm shift occurred: the approach to supporting young carers moved from supporting them separately from their family to supporting them through a 'whole family approach'.

## The drivers of the change of legislation

**Non-Governmental Organisations** have played a key role in **raising awareness and campaigning for change**. They have also played a strategic role in steering and shaping public discourse and policy developments through engaging with policy-makers, politicians and young carers themselves. In order for them to be able to carry out this role, they have drawn upon **research findings** that are specific to their countries.

\* [https://www.childrensociety.org.uk/sites/default/files/tcs/nycc\\_key\\_points\\_briefing\\_on\\_young\\_carers\\_the\\_care\\_bill.pdf](https://www.childrensociety.org.uk/sites/default/files/tcs/nycc_key_points_briefing_on_young_carers_the_care_bill.pdf)



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

How legislation is translated into practice was found to be variable and relates to the existence of implementation guidelines, regulations, collaboration between services, the culture of local authorities and on the type of support offered by legislation. Consequently, in many countries this has led to a **wide variation of how legislation and policy is translated into practice within different regions**. Countries are not homogeneous with regards to their support of young carers.

In the countries within the UK despite their unique provisions from young carer-specific legislation, legislation is not enacted in practice as it should. The implementation of a whole family approach does not work effectively because of the gaps between children's services and adult services. Moreover, austerity measures have impacted the capacity of local authorities: social services are stretched with limited resources and some local authorities have massive waiting lists for assessments. Furthermore, the actual support that families and young carers receive following their assessments is a bit vague.

The reality is that although governments across the six European countries have responsibilities, and even with a well-developed legal structure in some of the countries, adolescent young carers still fall through the gaps in policy and legal safety nets, and between adult and children's services. **There is some distance between the legal foundation and the actual implementation of the law.**

## STRENGTHS AND LIMITATIONS OF LEGISLATION, POLICY AND SERVICE FRAMEWORKS

The Me-We project has offered us for the first time the unique opportunity to make a transnational analysis of legal structures, policies and service frameworks for adolescent young carers and the 'gap' between legal provision and actual implementation. This research has enabled us to identify strengths and limitations of the different systems, from which we can

deduct evidence-based policy recommendations. This will be particularly helpful for those countries where legislation, policy and service frameworks are only just emerging.

### Strengths

- ▶ Legal provisions bring about clarity, especially when they define young carers and their rights.
- ▶ A **decentralised approach** provides the opportunity of finding solutions that fit with regional contexts and is a positive influence on innovation because of a plurality of solutions. Local authorities are closer to those with needs; hence, their role is crucial.
- ▶ Good **relationships between the voluntary sector and the government**, as well as the inclusion of regional stakeholders are very important.
- ▶ The **participation and inclusion of young carers** themselves in helping shape the development of policy and legislative changes was highlighted by experts as a key strength in the UK countries.
- ▶ The **whole family approach**, which looks at the needs and views of all individuals within the family- offers the added value of identifying health and social needs of care recipients, carers and the family as a unit. This contributes to a virtuous circle among services.
- ▶ **Prevention and early intervention** are important in order to limit the negative impacts on young carers.

### Limitations

- ▶ The law is useful but only if people assert their rights. Young carers tend not to use the law and their parents do not know about it.
- ▶ The law is useful but only if it is properly enacted. Shortages of resources may impact the enactment of legislation.
- ▶ The vital role played by local authorities, if not accompanied by an involvement at the national level, risks to entail variations in local practices and lack of consistency in support.
- ▶ Identification is still an issue across all the countries, including those (UK) where young carers are explicitly recognized by law. This is due to problems in self-identification by young carers and families and a lack of awareness by authorities and professionals and society in general.
- ▶ The implementation of a whole family approach does not work effectively because of the gaps between children's services and adult services.

### DILEMMA: Does the "best interests of the child" consist in removing young carers from their family or in supporting them by preserving the family?

The "best interests of the child" has often been applied (i.e. in Italy or Switzerland) to justify intervention from the State (mainly child protection services) in removing young carers from their family, considering this a safer option. Child protection services have forced children out of their families in the name of child protection under circumstances that would be seen from the perspective of today as grave violations of the rights of these children and their families. The fear to be separated is one of the reasons why often young carers don't ask for help to social services.

Child protection measures can only be taken if the child's best interests is threatened, it is not sufficient that a child's best interests is not being fully achieved. Young carers and their needs should be recognized by applying the UN Convention on the Rights of the Child. However, the **best interests of a child can be different for every child!** Hence, there is the need for situation specific solutions, addressing the issue case by case (depending on the kind of care activity that is provided, for whom, for how long, etc.). We call for the increased participation of young carers themselves and a view of **children as partners**, with regard to decisions that affect them.



# Chapter 3:

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

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### VISIBILITY AND AWARENESS OF YOUNG CARERS

With the exception of the UK and Sweden, there is a lack of visibility and awareness about young carers at all levels in all the project countries, in particular Slovenia and Italy. There are also differences within countries between regions. Low visibility and awareness are mainly on a national level, so when visibility and awareness is raised then this mainly takes place on a local level. Despite a lack of visibility, awareness has slowly been increasing in recent years. This has been supported by attention in the media (television/newspapers) on the topic of young carers.

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

Many interventions to support young carers are running in the various EU countries, mostly at a local level. Access to interventions and programmes **vary between and within countries, states, municipalities and even schools.**

The UK stands out, thanks to the huge amount of nationally dispersed charity and voluntary projects for young carers that remains unmatched by any other country, with more than 350 dedicated young carer projects serving approximately 30,000 young carers and employing hundreds of workers and volunteers.

#### Successful strategies to identify young carers

It's important for young carers to be noticed, rather than having to reach out themselves. Hence, the following measures can be applied:

#### Screening at schools and at health settings

- ▶ 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").
- ▶ The screening can also take place in primary health care settings. Health care professionals could routinely ask about children and whether they have any needs when a parent is ill. They should follow up on a regular basis (as the disease evolves and so does caring).

#### Trainings for professionals

- ▶ Professionals need to be educated/trained about young carers, about effective ways to listen to them and to meet their support needs. Such education for professionals could be included in the professionals' basic education programs.

#### Raising awareness among professionals and general public

- ▶ Awareness weeks in schools, sharing individual stories in lectures, television programs, social network campaigns are good ways for improving awareness and reducing stigma.

Once young carers have been identified, there has to be a system of support in place. Otherwise, **without proper services in place, the identification can feel meaningless at best, and harmful at worse!**

#### Successful strategies to support young carers at school

Flexibility (understanding from teachers in case of lateness, absences, no homework done...)

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 be aware that these support services exist.
- ▶ Make school psychologists aware of young carers and let him/her reach out to them
- ▶ Apply to young carers special measures already existing for other groups (e.g. in some schools, children performing top sports have a special status, consisting in getting extra time for their exams and other preferential treatments). These measures could be extended to children/young people who have caring responsibilities.
- ▶ Adopt integrated actions in which educational, social and health services should be involved (e.g. multidisciplinary team in the school embedding psychologists).
- ▶ Initiate a Carers card so that young carers don't have to explain their situation every time.

## Successful strategies to support the mental health of young carers

### Peer/group support/Information

- ▶ Setting up young carers' groups, peer support groups provide children with the insight that they are not alone, which can also empower them.
- ▶ Providing young carers with examples of people who used to be young carers and succeeded in their goal (via mentoring) can be particularly helpful.
- ▶ Improve access to information on the available support (e.g. Inform teachers and GPs and social workers about 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.
- ▶ Assist them with the financial cost of participation in these activities.

### Increase resilience

- ▶ Allow young carers access to tools and support to find useful coping strategies. Building young carers' resilience also has the advantage of reducing 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.

## Successful strategies to reduce the care burden

- ▶ Adopt a **whole family approach** in long-term care service provision. Next to a family-oriented perspective, it is important to look beyond the family and include the broader social network, such as friends and neighbours.
- ▶ **Improve the quality** of long-term care services
- ▶ **Strengthen collaboration** between different **professionals and agencies** and make clear to users who is responsible for what
- ▶ Have **care coordinators** responsible for communication and building relationship

## CASE STUDY: An innovative resilience-building camp for young carers AUSTRALIA

In Australia, young carers recruited from Carers Queensland attended a 3-day resilience-building camp, which combined training and psycho education activities – based on the Resourceful Adolescent Program (RAP-A) - with recreational activities (i.e. circus workshops, campfires and sports).

The Resourceful Adolescent Program (RAP-A) is a universal resilience-building programme that aims to promote positive mental health and prevent adolescent depression. It is positively focused, with the emphasis on building and recognizing strengths, rather than focusing on remediating 'deficits'. The overall aim of RAP-A was to assist young carers to identify their individual strengths and existing resources, for them to be more resilient and better equipped to cope with the challenges of caring.

The camp format for this RAP-A programme – typically delivered in a school setting – had the advantage of offering respite and social engagement, in addition to the benefit of increased resilience.

## CASE STUDY: A buddy project for and by young carers THE NETHERLANDS

Ervaringsmaatjes is a project where a volunteer or student who has experience of being a young carer provide individual support for young carers, acting as a buddy. Given his personal experience, the buddy knows better than anyone what that is like to be a young carer and he is there for the child without restriction, offering a listening ear, opportunities for socialization, as well as support on practical matters. He or she also helps to gain insight into the personal wishes and needs of young carers.

Ervaringsmaatjes - <http://ervaringsmaatjes.nl/> - is an initiative of Stichting Informele Zorg Twente and is being carried out in various places in the Netherlands.

This project has been rated very effective in supporting the social life of (A)YC, in increasing social connectedness among (A)YCs, as well as in building resilience.

# Chapter 4:

## Translating research findings into policy

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### POLICY IMPLICATIONS

- ▶ The findings on the negative experiences of adolescent young carers in school underline the **need for the educational sector to identify and engage with young carers**.
- ▶ 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.
- ▶ The findings from the Me-We survey also contribute to shedding light on **the severe mental health conditions of adolescent young carers who do not receive timely and adequate support** and provide insight into the potential risk of **neglect and abuse against (older) people with disability**, which highlights the need to plan preventative interventions against aggressive behaviours and domestic violence episodes.
- ▶ The survey findings are also concerning with regard to the **lack of formal long-term care services** and programmes in some European countries and **the impact on the extent and nature of caring amongst adolescent young carers** as well as their health and wellbeing. This is especially worrying in the context of demographic ageing and the shift toward home care.

#### Adopt a rights based approach

- ▶ The rights of young carers need to be known and taken seriously by society in general and by children themselves. When children know their rights, they are more likely to express their needs. Collaboration with Children's ombudspersons could be envisaged.
- ▶ We need to ensure that legislation protects children from (inappropriate) caring.

#### Ensure that legislation works in practice

- ▶ Legislation is not enough. It needs to be enacted and therefore resources are needed.

- ▶ Is it better to extend non-specific legislation or to adopt specific legislation for young carers? The answer to this question 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 the support and protection that adolescent young carers receive in practice does not always reflect the objectives of legislation and policy.

#### Ensure consistency within the State

- ▶ A key question that has emerged from our study is on what level of government the responsibility to address the challenges faced by young carers lies. The regional/local level is often considered the most appropriate to address the issue, as it is closer to the needs. Yet, it is advisable for it to be strengthened by a political acknowledgement of the topic at national level, in order to ensure consistency in the protection and support for all young carers, without inequalities between regions.

#### Listen to young carers and involve them

- ▶ Hearing the views and experiences of young carers is important. Young carers should be recognised as an important target group for policy makers and relevant stakeholders.

#### Raise awareness

- ▶ We need improved recognition and increased awareness by the general public, professionals and by policy makers of the situation of young carers, the difficulties they experience and the (positive and negative) impacts on their own lives and on their families.
- ▶ There should be more support and awareness raising in schools, where topics such as informal caring, resilience and mental health should be taught and discussed.
- ▶ We need to increase awareness about the positive aspects of caring. Providing care helps to build skills, to

develop the ability to face situations and conflicts and to build relationships with others.

- ▶ A definition of young carers is needed, so that young carers can identify themselves. The definition however should not become a label.

## Gather more data

- ▶ More knowledge and data are still required to improve understanding of young carers, their issues related to caring and their needs. Research should play a role by explicitly including policymakers and young carers.

## Support young carers

- ▶ A **multi-faceted approach** involving different stakeholders is needed, e.g. different ministries, the health and education sectors, NGOs and children themselves. Better collaboration, communication and a clear division of responsibilities between different support services 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.

- ▶ Young carers should be provided with **information**, including information at different points in their life, about what support they can receive and how to access it.
- ▶ There is a 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.
- ▶ The experience of the United Kingdom, where countless initiatives that exist to support young carers are mostly based on temporary funding – with the result that actual help and follow-up strongly depend on the financial context in a given moment- teaches us that young carers' support should rather be an **integral part of (social) care or welfare**.
- ▶ The support for young carers needs to be **flexible and personalised**, tailored to different young carers' needs, which could differ for social, financial and individual conditions.
- ▶ The support needs to be **co-designed with young carers**, to ensure that it fit their needs.

# NOTHING ABOUT US WITHOUT US!

The Me-We project applies the co-design approach we advocate for, by encouraging direct participation by end users (adolescent young carers, education/care professionals and policy makers) and by fostering collaboration amongst stakeholders.

In line with the co-design approach, all project partners have set up Blended Learning Networks, i.e. heterogeneous 'communities of practice' involving adolescent young carers and relevant stakeholders. These actors, sitting together at one table, have to find the best solutions (e.g. they are actively engaged in all the project activities, in particular in planning the interventions and in the development of an app for adolescent young carers).

Another channel that has ensured the active involvement of young carers in the Me-We project activities has been the establishment of links with the Eurocarers Young Carers Working Group.

The Eurocarers Young Carers Working Group is a platform bringing together young/adult carers and former young carers from different States. It was established in 2017, building on the incredible energies shared during the International Young Carers Conference (May 2017, Malmo, Sweden). Currently, there are 27 members from 10 European States and one from Australia. The aim is to combine efforts and resources, so that young carers' voices are heard and policies and practice are put in place all across Europe to empower and support them.

4 members of the Young Carers Working Group sit in the International Advisory and Ethics Board, on an equal footing with the other experts. Furthermore, the members of the Eurocarers Young Carers Working Group have regularly had the opportunity to give their perspective and feedback on the project activities.

## POLICY RECOMMENDATIONS

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.

Figure 5 - The European Pillar of Social Rights and its relevance for young carers

The Principles	The relevance for young carers
Principle n. 1 <b>Education, training and life-long learning</b>	Caring responsibilities can have a negative impact on young carers' education (underachievement, absence and drop-outs)
Principle n. 4 <b>Active support to employment</b>	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 <b>Childcare and support to children</b>	Young carers needs 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 <b>Long-term care</b>	By providing good quality formal LTC services to the person they care for, inappropriate caring can be avoided.



# RECOMMENDATION 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.





# RECOMMENDATION TO STATES

- ▶ **Identify** young carers
- ▶ **Assess their needs**, for example by adopting the **whole family approach**
- ▶ **Provide support** based on the needs (of young carer and the family), by adopting a **collaborative approach**
- ▶ **Act early, in a preventative way**, with a lifelong approach
- ▶ **Listen to young carers** and involve them in decisions which affect them and in general in policy making

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.**



More information: [www.me-we.eu](http://www.me-we.eu)  
#youngcarers



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