





## 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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(lead partner)**

Sweden



**Eurocarers**

Belgium



**University of Sussex**

United Kingdom



**Carers Trust**

United Kingdom



**Kalaidos University of Applied Sciences**

Switzerland



**The Netherlands Institute for Social Research**

The Netherlands



**The national Centre of Expertise for Long-term Care in the Netherlands (Vilans)**

The Netherlands



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Italy



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Italy



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

#youngcarers

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# The Me-We project



Me-We, an abbreviation for “Psychosocial Support for Promoting **M**ental health and **W**ellbeing among adolescent young carers in Europe” (January 2018 – March 2021), is an ambitious research and innovation project, funded by the European Union under the Horizon 2020 Programme. It brings together prominent universities, research institutes and civil society organisations from six different European countries – including Eurocarers, the European network representing informal carers.

The overall goal of the project is to strengthen the resilience of Adolescent Young Carers in transition to adulthood (15-17 years old) in order to impact positively on their mental health and well-being and to mitigate the negative influence of psychosocial and environmental factors in their lives.

## **Me-We aims to:**

- ▶ Systematise knowledge on adolescent young carers in six European countries (Sweden, Slovenia, Italy, Netherlands, Switzerland and UK) by (a) identifying their profiles, needs and preferences; b) analysing national policy, legal and service frameworks and (c) reviewing good practice, social innovations and evidence;
- ▶ Co-design, develop and evaluate together with adolescent young carers a framework of psychosocial interventions focused on improving their mental health and well-being and tailored to each national context;
- ▶ Carry out wide knowledge translation actions for dissemination, awareness raising and advocacy, by spreading results among relevant stakeholders at national, European and international level.

## **The innovative aspects of the Me-We project include:**

- ▶ Its co-design approach whereby researchers engage directly with adolescent and young adult carers, together with carer organisations and major stakeholders through all the stages of the project;
- ▶ A framework of primary prevention interventions tested and adapted in 6 European countries (Italy, Netherlands, Slovenia, Sweden, Switzerland, United Kingdom) at different stages of awareness and development of services for adolescent young carers; and
- ▶ Its Blended Learning Networks, i.e. heterogeneous ‘communities of practice’ - set up by each project partner- involving adolescent young carers and relevant stakeholders for discussing and finding best solutions.

The knowledge arisen from the research activities of the first year (an online survey targeting young carers, literature review, a series of interviews with key experts and a ranking of good practices to identify and support young carers), as well as the structured discussions that have taken place throughout the whole duration of the project in the Blended Learning Networks informed the content of this Manual and ensured its co-creation with the target audience.

For more information about the Me-We project, please visit <https://me-we.eu/>  
Details about the project partners are available at <https://me-we.eu/partners/>

## **Acknowledgements**

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This Manual also benefited from the expert input of Mieke Schuurman (Senior Policy Advisor at Eurochild), who acted as an external reviewer.

Finally, the production of the publication would not have been possible without the financial support of the European Union, under the Horizon 2020 programme for which we are most grateful.

## **Disclaimer**

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# Foreword

## Dear readers,

In recent months and years, I have been pleased to see the phenomenon of informal care – the provision of long-term care, usually unpaid, by a family member outside of a professional framework – gaining ground on policy agendas across Europe.

While there is a growing recognition of the contribution made by informal carers to our welfare systems and to our economies, much remains to be done to address the risk of a negative impact of care on carers and to provide them with the **choice to be involved in caregiving or not**. This is why we need a European Carers Programme.

This is particularly true in the case of **young carers**: children and young people providing care to a family member with a long-term care need (due to disability, chronic disease, frailty, addiction or other condition).

A few years ago, a meeting of the **European Parliament Informal Carers Interest Group** – which I have the pleasure to co-chair since 2009 – opened my eyes with respect to this **hidden army of carers**.

I was taken by surprise by the numbers of children and young people across Europe who have to **juggle growing up with caring responsibilities**: it is estimated that about 7-8% of children in Europe are young carers. While listening to the testimonies of those young people, I was touched by their maturity, their **resilience** and unconditioned dedication. At the same time, their personal stories made me realise that, despite the differences in the situation of these young people, there was a **common cry for recognition and support**. Yet, in most of the cases, **nobody was there to listen to them**.

**It is striking that young carers are still largely invisible**. This invisibility directly results in a lack of support, with a negative impact on the development of young carers and a heavy toll on their education, mental health and social inclusion.

In many cases, young carers are invisible as the people around them (friends, school professionals, health and social care professionals) are simply not aware of the phenomenon.

That is why initiatives like the EU's Horizon 2020 funded ME-WE Project (Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe) are highly relevant for **increased awareness**. By providing **research-based evidence**, the ME-WE project sheds light on the needs of young carers, as well as on the concrete actions that can be taken to **strengthen their mental health and wellbeing and to empower young carers to pursue their goals in life**. The ME-WE project also gives a voice to young carers, stressing the importance of **co-creating** solutions with and for them.

It is now up to us all – policymakers, service providers, the general public – to transform the **knowledge produced by the ME-WE Project into concrete policies and practices**.

In my position as Member of the European Parliament, I am committed to investigate how – current instruments and those undergoing development can present a framework within which the EU institutions will undertake action for young carers. The **European Pillar of Social Rights** (with the principles on “Education”, “Equal opportunities”, “Child-care and support to children” and “Long-term care”), as well as the **new EU Strategy on the Rights of the Child and a Child Guarantee** (planned to be adopted by the European Commission in Spring 2021) provide useful points of entry for policy change.

We all have a role to play to ensure that young carers can move from a position of vulnerability to one of growth enabling them to flourish as human beings.

Tools like the ME-WE Manual provide us with the knowledge we need to take action. If no measures are implemented, then the reason is not to be found in lack of awareness; rather in lack of political will.

**We must ensure that the needs of young carers are not disregarded and their human rights – as stated in the UN Convention on the Rights of the Child – are fully enjoyed.**

**Ms. Pietikäinen**  
**Member of the European Parliament**

# Executive summary

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Across Europe, a substantial number of children and young people provide care to a family member or a friend who has a disability, chronic disease, frailty, addiction or other condition related to a **long-term care need**. Whilst these children and young people (**young carers**) can gain satisfaction from caring and experience an enhanced self-esteem, empathy and maturity, caring can also negatively impact on the development of young carers, compromising their education, mental health and social inclusion. **Human rights considerations** call for the need to address this issue, so that young carers can enjoy the rights to which they are entitled, just like all children. These considerations are strengthened by **economic arguments**, as poor mental health, early school dropout and low employability levels are increasingly recognized as a cost not only for young carers themselves but also for our societies.

Despite the relevance of the phenomenon, many of the key stakeholders whose work has a bearing on the daily life of young carers are often unaware of the existence of young carers and of the challenges faced by them. As a result, **young carers remain invisible** and their needs for support are not met.

This manual precisely aims to fill the knowledge gap and to inform multidisciplinary action aiming to address the needs of young carers. It targets stakeholders from different fields (e.g. policy makers, health and social care providers, school professionals, youth, care workers, the media and the general public), as all of them have a role to play to enable young carers to flourish as human beings.

In detail, the **Introduction** sheds light on the phenomenon of young caring, stressing the positive and negative impact of caring responsibilities on the development of young carers and underlining the different reasons why action is needed.

The section **Identifying, Listening to and supporting young carers - Resources** presents concrete actions that can be carried out to identify, support and successfully engage with young carers, ranging from policy planning to service provision. The practical measures are grouped by category of stakeholders, in order to stress the role that each of them can play to support young carers. Yet, the success of the different initiatives presented in this Manual lies on the interplay among the different actors.

The information provided in this document was informed by the knowledge arising from the research activities carried out in the first year of the Me-We project (an online survey targeting young carers, literature review, a series of interviews with key experts and a ranking of good practices to identify and support young carers). The Manual also benefitted from the valuable inputs by young carers and professionals, whose advice is constantly sought after in the framework of the Me-We activities, in the spirit of co-designing solutions with the target audience. Quotes from young carers and professionals are included and case studies displayed, to strengthen the messages and hopefully inspire the readers.

**Overall, this Manual aims to contribute to the development of an environment in which young carers are able to pursue their goals and thrive, in line with the principles described in the UN Convention on the Rights of the Child (1989).**




# Introduction

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Childhood is commonly seen as a sheltered and responsibility-free stage of life where adults are “in charge” and provide care, while children are the subjects of attention and care. However, for a number of children and adolescents across Europe, this is far from being the case. Many indeed find themselves providing – sometimes very intensive levels of – care to a relative in need of long-lasting support due to a chronic disease, a disability, a mental health illness or an addiction. As such, these children often assume duties that would be more fitting for an adult.

While the phenomenon of informal care – the provision of long-term care, usually unpaid, by a family member, friend or neighbour outside of a professional framework - is slowly gaining momentum on policy agendas across Europe, the situation and needs of young carers remain by and large invisible to the public eye. Yet, the failure to identify and support these children and young adults comes at a cost and the impact of caring on carers’ (mental) health, educational experience, employability and social inclusion is well documented. In turn, the negative outcomes at individual level entail adverse consequences for society as a whole.

This is nonetheless avoidable. Caring roles can be reduced when families receive adequate support and when young carers benefit from personalised interventions, especially in the transition years. The success of these initiatives very much depends on the interaction between a broad set of stakeholders, policies and practices in the youth, social, health, education and employment sectors.



**IF YOU SEE ME LESS,  
IT'S BECAUSE I'M  
DOING MORE**



## WHO ARE YOUNG CARERS?

Young carers are “children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grand-parent or another relative with a disability, chronic illness, mental health problem or other condition requiring long-lasting care, support or supervision”<sup>1</sup>.

Young carers aged 15-17 belong to the group of “adolescent young carers” - (A)YCs. 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.

Research has shown that young carers in different countries and circumstances carry out broadly similar tasks including support with basic activities of daily living (personal/intimate care) and/or instrumental activities of daily living (e.g. shopping, cooking, financial management);<sup>2</sup> emotional support and supervision; managing the family budget and collecting prescriptions; helping to give medicine; or helping someone communicate.<sup>3</sup>

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 and a lack of financial and practical resources within families.<sup>4</sup> **Although prevalence data are incomplete, it is estimated that about 7-8% of children in Europe – i.e. about 7 million children<sup>5</sup> - will have caregiving responsibilities**

## WHAT DO YOUNG CARERS DO?

- ▶ **Personal Care** (e.g. helping the person dress and undress, wash and use the bathroom, administering medicine or changing dressings etc.)
- ▶ **Emotional Care** (e.g. keeping an eye on the care recipient, providing supervision and taking him/her out.)
- ▶ **Sibling Care** - looking after siblings either alone or with a parent present.
- ▶ **Domestic Activities** (e.g. cleaning, cooking, washing dishes or clothes etc.)
- ▶ **Household Management** (e.g. shopping, household repairs and lifting heavy objects etc.)
- ▶ **Financial and Practical Management** (e.g. helping to pay the bills, working part-time etc.)

Multidimensional Assessment of Caring Activities (MACA-YC18), Copyright © 2012 (Becker, Becker, Joseph & Regel, 2012).

## IS CARING A GIFT OR A CURSE FOR YOUNG CARERS?

The impact of caring on young carers themselves is well documented. Having to reconcile the everyday challenges that life throws at them as children and teenagers with extraordinary caring responsibilities can be overwhelming. Without adequate support, young carers may face negative outcomes as regards their health, their social as well as their behavioural, psychosocial, and academic adjustment and self-confidence.

“AS A YOUNG CARER I OFTEN FEEL LIKE AN OUTSIDER.”

Young carers have been identified as a population group at higher risk of becoming “NEET” (Not in Education, Employment or Training), often as a result of challenges in obtaining relevant qualifications. They often face barriers in relation to school and further education: they may have punctuality issues, experience absenteeism and ultimately, be forced to drop out of education. Similarly, they may struggle to combine paid employment with their caring responsibilities. Young carers may also have less time for personal development and leisure and, as a result, may suffer from isolation. Many also report social stigma and bullying. They may therefore be particularly prone to social exclusion throughout their life course.

As to the impact of caring on the physical and mental health of young carers, the results of the research carried out in the framework of the Me-We project shows that while many adolescent young carers report physical health problems due to their caring role, over 45% of them experience mental health issues. In addition, many confess thoughts of harming themselves or others<sup>6</sup>. The project findings also seem to indicate that the lack of sufficient and sustainable resources in care services may act as economic and societal stressors and influence the psychosocial health experience of adolescent young carers.

Having said that, research has also demonstrated that – provided adequate support is available – young carers may develop a greater repertoire of coping strategies as well as enhanced self-esteem. This, in turn, makes them more resilient, empathetic and mature than their peers. Living with and making allowance for a sick family member on a daily basis can help young people learn to be more understanding and tolerant of (feelings of) others.

In other words, caring responsibilities are not problematic in themselves, but only when they are not the result of a genuine choice and when they become inappropriate (i.e. when they have a negative impact on the child’s health, wellbeing or education, or when they can be considered unsuitable in light of the child’s circumstances). Some young carers would stop if they had the choice. In this case, their desire needs to be respected and alternatives need to be provided (either by providing professional care to the person in need or by relying on other informal carers).

“I MISS THE CAREGIVER IN ME. IT WAS MY BEST SIDE. I FEEL STRONGER. I KNOW I CAN COPE WITH ANYTHING AND THAT I CAN SEE BEAUTY WHERE MOST PEOPLE CANNOT SEE IT.”

FORMER YOUNG CARER FROM ITALY

“...You try to take the burden off children and youth as much as possible [...] while at the same time [...] for the kids it can be important to be able to do something. And then I think: it is also important to respect that.”

One expert from the Netherlands interviewed in the framework of the Me-We project.

On the contrary, some young carers do not wish to stop care provision completely; rather they wish to be supported in their caring role. Their right to self-determination includes the right to care, if they wish to do so. In this case, society's mission should be to prevent and minimise the negative impact that caring responsibilities can have on young carers, while maximising its gains. Recognition, support, protection from inappropriate caring are key elements to enable young carers to pursue their life goals and lead a thriving life.

## So, how can we reduce the adverse impact of caring on young carers while maximising its gains?

I WOULD  
JUST LOVE IF  
SOMEONE COULD  
SUPPORT MY FAMILY SO  
THAT I DON'T HAVE TO  
DO IT.

The answer to this question lies in the exploration of the variety of children involved in the provision of care. This continuum starts with caring about (low levels of care responsibility, routine levels of caregiving and little evidence of negative outcomes), moves on to taking care of (increasing care tasks and responsibilities) and culminates with caring for (high levels of care responsibility, regular and intense caregiving, evidence of significant negative outcomes). Ensuring that the responsibilities of young carers remain in the realm of "caring about" rather than "caring for" is a central condition to prevent the negative impact of caring.

In order to ensure low levels of care by children and young adults and to reduce the negative impact of caring responsibilities on their wellbeing, the provision of affordable and good quality formal care services for the care recipient is essential<sup>7</sup>. Indeed, it enables respite and better time management of the young carer. It is also a prerequisite for the self-determination of carers: choice is unlikely when no professional or informal care alternative is available.

In addition to boosting the formal care for the care recipient, individual support to those young carers who want to remain 'reasonably' involved in the care provision needs to be provided, via personalised and flexible approaches.

In other words, successful strategies to support young carers (as for carers of all ages) consist in the interplay between better provision of formal care services to the care recipient, combined with individualised support to young carers to enable them to pursue their goals in life.

**"I didn't realise I was a young carer until I was nineteen. I thought you needed to do a certain number of hours of work to qualify as a carer but now I realise that I was caring all the time even when I wasn't doing something practical."**

Former young carer from UK

**Full testimonials  
available in  
the [Me-We booklet](#)**

# WHY ADDRESSING THE CHALLENGES OF YOUNG CARERS IS ESSENTIAL

Firstly, the challenges facing young carers mean that many of them are not always able to enjoy the rights to which they are entitled, just like any other children. From a rights-based perspective, it may therefore be argued that the level playing field is no longer 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.

Secondly, as highlighted above, being a young carer with no or limited access to support often leads to negative impacts. Many young carers face tremendous challenges as a result of their caring tasks as regards their health and wellbeing, education and professional attainment and capacity to live a fulfilling social life. Addressing their needs should therefore be approached as a preventative measure and as an investment.

In spite of this very clear rationale for attention and support, policy makers and service providers still tend to disregard young carers as a group potentially at risk. Often times though, this results from a lack of awareness and knowledge rather than from a reluctance to address the situation.

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.

The absence of a clear, comprehensive and consistent definition of young carers across Europe is one of the root causes behind young carers' apparent invisibility in the public discourse. A definition of young carers would indeed not only allow to map out and engage with relevant stakeholders, it would also help young carers identify themselves as such. Many indeed often do not know that they are carers but simply see their caring tasks as part and parcel of family life. Consequently, they may not understand the impact this has and will continue to have on their lives and well-being. The definition should not become a label though as young carers are more than their caring responsibilities.

# Identifying, listening to and supporting young carers

## Resources

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**The Me-We study has allowed us to identify broad policy priorities that are valid for all countries: young carers need to be identified, supported and actively engaged in – policy and support - decisions that affect them.**



It's important for young carers to be noticed, rather than having to reach out themselves. Here the education and youth sectors as well as health and social care professionals, employers and families all have a leading role to play.



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!



Finally, no policy or practice that concerns and impacts on young carers should be developed without them. Young carers should be invited to co-produce all initiatives that concern them.

# POLICY PLANNING AND IMPLEMENTATION

**A  
simple  
action can  
change the life  
of young  
carers**

All children, regardless of their circumstances, should see their human rights respected; in accordance with the UN Convention on the Rights of the Child (1989). They should not to be separated from their parents against their will (Article 9); be safeguarded from violence, neglect and abuse (Article 19); be protected from economic exploitation and from performing any work likely to interfere with their education, health or physical, mental, spiritual, moral or social development (Article 32). They should have access to education (Article 28), rest and leisure (Article 31), an adequate standard of living (Article 27), as well as the highest attainable standard of health (Article 24). They should also be able to express their views (Article 12).<sup>8</sup> **When it comes to young carers as a particular group at risk, it is clear that more could be done to lead and monitor initiatives that promote their rights.**

Policy responses (when they exist) tend to differ greatly between and within EU countries and regions. Whilst some have sophisticated services and legal recognition in place, others are only beginning to acknowledge the issue or are still reluctant to do so<sup>9</sup>.

Addressing the needs of young carers does not necessarily require the introduction of new legislation<sup>10</sup>. Among the Me-We project countries, only the UK has **specific legislation on the topic** that explicitly recognises or defines young people with caring responsibilities. In the other countries, the protection and support of children with caring responsibilities can be ensured by including them in broader, already existing, legislation, such as: health and social care legislation, general legislation for families and children, education legislation, child protection legislation or carers legislation.

## Supporting young carers – THE ENGLISH POLICY 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 **preventive and whole-family approach** to identification, needs' assessment and support.

The new legislative framework defines young carers, places on local authorities a **universal duty to identify young carers and assess their needs**. The needs assessment must include an evaluation of whether it is appropriate for the young carer to provide, or continue to provide, care for the cared-for person. **Inappropriate caring** should be considered as anything likely to impact on the child's health, wellbeing or education, or which can be considered unsuitable in light of the child's circumstances.

**Read  
more**

The legislation builds on the idea that **Investing in carers' wellbeing and in the prevention of the adverse effects of caring is worthwhile and ultimately reduces public expenditure.**

The Me-We study clearly indicates that the existence of legislation and policies is not sufficient to ensure that young carers are supported in practice. For instance, in the UK, despite the undeniable positive aspects of the legal provision, there is some distance between the legal foundation and the actual implementation of the law.

**“WE’VE  
DONE THE LEGISLATION.  
THAT ISN’T THE HARD WORK.  
THE IMPLEMENTATION IS THE HARD  
WORK, AND I DON’T THINK WE’RE THERE  
YET (...) THERE’S THIS REALLY GOOD PIECE  
OF LEGISLATION, BUT ON THE PRACTICAL  
LEVEL, IT’S NOT HAPPENING FOR YOUNG  
CARERS”**

A UK EXPERT INTERVIEWED IN THE FRAMEWORK  
OF THE ME-WE PROJECT

### **Supporting young carers by referring to non-specific legislation AN EXAMPLE FROM ITALY**

**With law 517/77, Italy declared the rights of all children and teenagers to satisfy all their diverse needs of learning. According to this law, schools must be flexible to meet the needs of each student, and they must provide individualised assistance.**

**The law allows a personalized didactical plan (e.g. more flexibility concerning attendance, planned oral exams, tutoring) for those students who have special educational needs.**

**It can be applied in the case of disability and learning disorders such as dyslexia, but also in the case of “other situations of social disadvantage”. A vocational high school in the North of Italy used the opportunities offered by this broad category to include the case of young carers. It developed and piloted a template of Individual Education Plan suitable for this target group.**



# THE EU POLICY CONTEXT

At EU level, a number of broader EU initiatives offer great potential to address the needs of carers. For instance, the European Pillar of Social Rights includes many entry points for the enhancement of their recognition and support. The principles that concern the right to education, training and lifelong learning, equal opportunities, work-life balance, healthcare and access to long-term care are of particular relevance to young carers. Yet, implementation gaps continue to exist and policy-makers' understanding of the needs of young carers remains limited. There is nevertheless good hope that the upcoming Action plan on the European Pillar of Social Rights will pave the way for progress in that regard.

Other instruments such as the new EU Strategy on the Rights of the Child and a Child Guarantee – planned to be adopted by the European Commission in the Spring 2021- can similarly be used for the development of comprehensive measures supporting this potentially vulnerable group of children.

Overall, the EU can play a vital role in facilitating further research on the profiles and needs of young carers and in ensuring that existing good practices are widely disseminated.

## Delivering effective support services – Main recommendations and promising practices

During the first year of Me-We, the project partners interviewed experts on adolescent young carers or related topics, from the fields of academia, policy, health and/or social care, in order to reflect on the situation in their country as to the visibility of young carers and support provided to them. Building on their comments, the following key recommendations can be outlined, to ensure that the support is effective.

### Adopt a collaborative, multi-stakeholders approach

Currently, there are gaps between the healthcare system, schools, the educational system and social system, as they are all different entities with little inter-connections. Experts called for improved referrals and collaboration between professionals from different services. A precondition for an integrated work is for each stakeholder to recognise their own roles and responsibilities.

### Adopt a Whole Family approach

Young carers' needs and preferences should be assessed together with the ones of other family members (whole family approach)<sup>21</sup>. The added value of this approach lies in the possibility to identify the health and social needs of all parties involved - care recipients, carers and other family members - as a unit. In doing so, a 'virtuous circle of collaboration among services' is created which then contributes to positive outcomes for young carers.

### Focus on prevention and empowerment, rather than protection

Experts stressed the importance of addressing young carers' needs before they escalate into a crisis (by acting when the child's best interests are not being fully achieved, rather than when the child's best interests are threatened).


Similarly, according to some experts, the focus on protection is in contrast to the need to empower young carers and recognising that caring responsibilities can also bring positive outcomes (not just something to be protected from).

### Provide support based on the needs of each young carer and co-design it with young carers

One of the challenges of the current welfare interventions is that they often do not match the needs of young carers. Hence, experts stressed the importance to assess the needs of young carers and provide support on the basis of these needs (different for each young carer).

Experts recognised that tailoring support to an individual young carer's needs requires professionals to be flexible and to have sufficient room to manoeuvre.

Experts emphasized that deciding whether and how to provide support to young carers should always happen in a conversation with young carers themselves. Failing to do so often means that activities are offered that later turn out to be irrelevant. This approach also has the merit of recognising that young carers have specific needs at specific times. In so doing, it allows for the different needs of young carers and young adult carers to be taken into account.



“WE SHOULD NOT BE SO AFRAID OF STARTING AND OFFERING SOMETHING, BECAUSE FOR THE CHILD IT IS ABOUT NEEDING HELP NOW OR SUPPORT NOW [...]”  
AN EXPERT FROM SWEDEN INTERVIEWED IN THE FRAMEWORK OF THE ME-WE PROJECT.



# THE ROLE OF HEALTH AND SOCIAL CARE PROVIDERS

Schools and education settings are a privileged social environment where young (adult) carers are in direct contact with a series of well-trained professionals. They play a vital role in both early identification and in the provision of support for young carers and their families. Empowering them to identify and support young (adult) carers in their educational career holds great potential to avoid the negative consequences of caring and to allow young carers to engage fully with the educational and social opportunities available to them, to integrate with other pupils, maintain a good level of participation and attendance in classes, reach learning goals, finalise formal education of high school and maintain their potential for a fulfilling professional career. An innovative assessment tool developed as part of the Erasmus+ funded project EdyCare (<https://eurocarers.org/current-projects/edycare/>) allows teachers and school staff to determine the amount of activities a young person does for his/her family, the reasons behind this involvement, as well as the (perceived) impact of these tasks on the educational experience of the young person.

“SCHOOL WAS A CHALLENGE; I’D OFTEN HAVE A SHIFT DONE BEFORE GETTING THERE, EXHAUSTED. HOMEWORK WAS DIFFICULT, FINDING TIME FOR DOING ANYTHING JUST FOR ME WAS IMPOSSIBLE.”

## TOWARDS A PROACTIVE YOUNG CARER STRATEGY AT SCHOOL<sup>12</sup>

Below you will find examples of steps and practical measures that can be implemented in education settings to address the needs of young carers.

### **Understand and address young carers’ needs by:**

- ▶ Designating a staff member as responsible for young carers.
- ▶ Promoting the initiative to families, students and staff.
- ▶ Publishing a school young carer policy (separate or integrated in other policies) recognising young carers as a distinct group of vulnerable students.

### **Raise awareness about young carers at school by:**

- ▶ Ensuring that information on disability, chronic conditions and (young) carers (and the support available to them) is available to students and school staff.
- ▶ Using assembly or PSHE (personal social health education) lessons to raise awareness of young carer issues and incorporate positive images of disability/ illness (including mental illness, substance misuse and HIV).
- ▶ Using drama/arts to raise awareness of young carer issues.
- ▶ Including articles on young carers on school magazine/Young Carers Newsletter.

### **Ensure that young carers are identified at school by:**

- ▶ Organising training for staff on identification of young carers, including those who may be hidden.
- ▶ Making sure admission forms include a statement to help identify families where someone has a long-term illness or care needs.
- ▶ Including information regarding identified Young Carers in feeder school’s transitions plans.
- ▶ Including a question regarding potential need for extra support or presence of illness/disability in the family (which may impact on the child/parents) in home-school agreement.
- ▶ Presenting the topic in PSHE sessions and assemblies.
- ▶ Disseminating questionnaires among all students, following assembly talks, inviting self-identification.
- ▶ Checking School Census data on pupils with disabilities, to identify sibling young carers.

### **Listen to young carers by:**

- ▶ Ensuring they feed into the work of the school council via a suggestion box.
- ▶ Giving them access to drop- in sessions.
- ▶ Taking their views into consideration in school policies (e.g. use of mobile phones).
- ▶ Consulting disabled parents on the support required to promote their inclusion and that of their children.

# THE ROLE OF CAREER ADVICE AND EMPLOYMENT SERVICES

Career advice and employment services can play an important role in ensuring that young carers reach their ambitions despite their caring responsibilities.

Below we list examples of practical measures that can be implemented:

- ▶ ensure that career advice services adequately address and take account of caring responsibilities;
- ▶ provide clear information about the financial support that exists for young adult carers going to college and university;
- ▶ empower young carers to recognize and value the **soft skills gained from their caring role**.

This measure –which could prove very useful for young carers as they enter the labour market – could be strengthened by the existence of an **evaluation (and certification) system of the soft skills gained by caring**.

Another measure that could facilitate the access of young carers in the labour market is the possibility of flexible working conditions for young carers (e.g. teleworking with part-time working hours). Local or national authorities could offer incentives to employers who adopt this measure.

“DURING ALL THOSE YEARS, I FELT LIKE I HAD TO STAY AT HOME, LIVE ACCORDING TO MY FATHER’S ILLNESS AND PUT MY LIFE ON HOLD. I HAD FORGOTTEN THAT I EVEN HAD DREAMS”

FORMER YOUNG CARER FROM SLOVENIA,  
FULL TESTIMONIAL AVAILABLE IN THE ME-WE  
BOOKLET

# THE ROLE OF YOUNG CARERS/ YOUTH SERVICES, CARERS AND CIVIL SOCIETY ORGANISATIONS

Several experts mentioned the importance of looking beyond formal and professional support to young carers. ‘Society’, which may entail civil society organizations but also people’s informal social networks (e.g. sports club), has an important role to play in supporting young carers.

Examples of practical measures include:

- ▶ Help young people access services and information, facilitate contacts with local authorities and service providers;
- ▶ Enable young carers to access relevant training to help them in their caring roles;
- ▶ Offer non-formal education, personal development opportunities (to build young carers’ confidence) and be a place of welcome where young carers are valued and supported;
- ▶ Encourage **peer support group** and **mentoring by lived experience experts**. This provides young carers with the insight that they are not alone and can help to empower them.
- ▶ Provide **respite breaks for young carers**, by organising summer camps, cinema, café, sport activities (and assisting young carers with the financial cost of participation in these activities)

## A BUDDY PROJECT FOR AND BY YOUNG CARERS

### Case study from The Netherlands

ERVARINGSMAATJES is a project whereby a volunteer or student with past experience as a young carer provides individual support to young carers, acting as a “buddy”. Given her/his personal experience, the buddy knows better than anyone else what a young carer may be experiencing and is there for the child/young person without any restriction, offering an open ear, opportunities for socialisation, as well as support on practical matters. S/he also helps to gain insights into the personal wishes and needs of young carers.

ERVARING-SMAATJES - <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 as effective in supporting the social life of (A)YCs, in increasing social connectedness among (A)YCs, as well as in building resilience.

## RESPITE BREAKS FOR YOUNG CARERS

### examples from Sweden

The summer camp organised by MASKROSBARN (Dandelion Children Association) 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 also finances summer camps for children to parents suffering from dementia.

Experience shows that engaging young carers in positive activities has beneficiary effects on their social isolation. Young carers themselves say that having the opportunity to socialise and share with other young people in a similar situation to their own helps them work off their stress and anxiety.

# THE ROLE OF THE MEDIA

Oftentimes young people consider their caring responsibilities as something to be kept private, hidden, because they are afraid of being stigmatized or separated from their family.

Hence, it's important to remove the taboo, to make the issue visible and remove the stigma. Media can contribute by focusing on the fact that caring is part of the human experience and that there are positive aspects associated with it (providing care helps to build skills, to develop the ability to face situations and conflicts and to build relationships with others).

Television programs, social network campaigns are good ways for improving awareness and reducing stigma around the phenomenon of young care. It is thanks to these media initiatives that the visibility of young carers is slightly increasing in some of the project countries.

Media can also help to promote the rights of young carers (as carers and as children). When children know their rights, they are more likely to express their needs.

## References

1. Becker, 2000; Leu & Becker, 2019 – for a broader use of the word see Wepf et al (2017)
2. ADLs: Activities of Daily Living are self-care activities that a person must perform every day such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions. IADLs: Instrumental activities of daily living are activities related to independent living and include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.
3. Joseph, et al. 2020, op cit
4. Joseph, S., Sempik, J., Leu, A. and Becker, S. 2020. Young Carers Research, Practice and Policy: An Overview and Critical Perspective on Possible Future Directions, *Adolescent Research Review* 5, 77–89.
5. Combating child poverty: an issue of fundamental rights, Fundamental Rights Agency, 2018
6. 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. Me-We project - <https://me-we.eu/wp-content/uploads/2019/05/Me-We-European-brief.pdf>
7. The findings arising from the Me-We project clearly show that the lack of formal long-term care services impacts on the extent and nature of caring amongst adolescent young carers, as well as on their health and wellbeing.
8. <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>
9. For details, please refer to the Me-We Policy briefs, available here: <https://me-we.eu/launch-of-policy-briefs-enabling-young-carers-to-pursue-their-goals-in-life-and-reach-their-full-potential-converting-research-findings-into-policy-actions/>
10. Leu et al. (2020) Transnational Analysis of Legislation, Policy and Service Frameworks for Adolescent Young Carers in Europe. *Journal of Youth Studies* (submitted).
11. The Whole Family Approach is a family-led strategy that provides adults and children with the tools they need to set goals together, create plans, and to achieve those goals. While families are made up of individuals, their challenges and successes are interdependent. By using the Whole Family Approach, family members work together to support each other's goals and achieve long-term change and stability.
12. EDY-CARE: Innovative school education methodologies and tools for guaranteeing social inclusion of young carers <https://eurocarers.org/current-projects/edycare/>



# Conclusions:

Young carers often have to resolve a particularly acute tension between their right to self-determination and their roles and responsibilities in their family. Ensuring that they are identified, their needs are addressed and the needs of their whole family are assessed is critical for ensuring that their caring role does not prevent them from enjoying their rights as children. Policies and practices should therefore aim to allow them to move from a situation of vulnerability to one of growth, where they can flourish as human beings. Experience shows that the involvement of young carers themselves in the creation of measures aiming to address their needs is often highly beneficial. Only the combination of personalised support (i.e. training, counselling, psychological and emotional support) and more adequate and intensive formal care services can achieve that goal and yield a brighter future for millions of children and young people across Europe.

**WE ALL HAVE A ROLE TO PLAY TO ENSURE THAT YOUNG CARERS CAN PURSUE THEIR GOALS IN LIFE AND THRIVE!**

