



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



## Enabling young carers to pursue their goals in life and reach their full potential – Converting research findings into policy actions

### Country Focus: Slovenia

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## Summary

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

### Number of young carers across Europe

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

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

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

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

For other countries, research projects or unofficial sources give us the following estimated numbers: in Slovenia, young carers form the 6% of the population aged 13-17. In Slovenia, 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 - Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe. While this document directly draws on research and evidence, its objective is to reflect and ponder on the policy impact of Me-We's findings. As such, it should not be approached as a scientific report.

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

The first year of the project was dedicated to gaining insight into:

- a) the profiles, needs and preferences of adolescent young carers in six European countries ((Italy, Netherlands, Slovenia, Sweden, Switzerland and UK);
- b) 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
- c) 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 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.

The Introduction is general, whereas the following sections focus specifically on Slovenia. To have an overview of the main findings across all the project countries, please refer to the European brief (available [here](#)).

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 support measures.

The full results will 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.

Each of these recommendations is driven by our core vision: young carers should be able to pursue their goals in life and achieve their full potential, without being negatively impacted by their caring responsibilities.

# Introduction

## The challenges of being a young carer

### Who are young carers?

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

### 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

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, 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.

## Why are young carers invisible?

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

- 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 exists)

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

\* Prof Saul Becker, University of Sussex

## 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 interventions, 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 worth to look into the common ethical conundrum regarding the situation of young carers according to which: "it actually does not pertain to children and young people to assume caregiving responsibilities and consequently, supporting young carers is by essence detrimental to their best interests".

Here are the various arguments brought about by those endorsing these contradictory approaches.

Vision 1: "Young carers should not exist and policy attention should be put elsewhere"	Vision 2: "Young carers should be identified and supported"
By supporting young carers and teaching them how to cope, we effectively accept the <u>transfer of care responsibilities from the public to the private sphere</u> , thereby harming both the principles of universal access to care and the rights of young carers.	The idea that children should be free from having a caring role makes absolute sense. Yet, it is <u>unrealistic</u> 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.  <u>Young carers exist</u> 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 <u>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)</u> ."*	"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, <u>family carers are going to be expected to continue their support</u> . In such a context, <u>it is important that the role of (adult and) young carers is fully appreciated and valued</u> ."** If we have zero tolerances – 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.	<u>Young carers' right to self-determination includes the right to care</u> , if they wish to do so, provided that their best interests is safeguarded. Measures should therefore seek to preserve young carers from <u>inappropriate caring</u> , 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.
<b>The vision of the Me-We consortium:</b> <b><u>Choice</u> 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.</b>	

\*Richard Olsen & Gillian Parker, Critical Social Policy, Issue 50

\*\* Jo Aldridge and Saul Becker, Critical Social Policy, issue 16.3



## 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 and education) for adolescent young carers.

In Slovenia, out of the 1.246 respondents to the survey, 392 were carers (people who provide - usually 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. The total number of **adolescent young carers (15-17 age)** in the Slovenian sample is **287** (caring for either a family member or a friend, including those who care for both, i.e. overlaps). 44% report that they have been providing care to someone for as long as they can remember.

The majority of adolescent young carers in the Slovenian sample (89%) are women, which is in line with the existing literature on the gendered nature of care, and the cultural, social and familial expectations of care.

90% of respondents (non-carers included) indicated that they are Slovenian citizens. 48,8% reported that they reside in rural environment.

The majority of respondents (non-carers included) reported that they live in dual parent households (87%). 50% of respondents live with a brother and 48% live with a sister. Multigenerational households are also a part of family life for many respondents: 28.7% live with a grandmother and 18.4% live with a grandfather.

### Who do adolescent young carers care for?

Of the 301 respondents who indicated that they have a family member with a health condition, 211 (74.8%) reported that they provide care, look after, or help their family member with a health condition. Thus, in the Slovenian sample, **there are 211 adolescent young carers looking after a family member with a health condition**. Of these adolescent young carers, 126 (70%) provide care for only one family member. There are a number of AYCs who provide care for multiple family members: 32 AYCs (17.8%) provide care for two people, 11 AYCs (6.1%) provide care for three people, 7 AYCs (3.9%) provide care for four people, and 4 AYCs (2.2%) provide care for five people.

The “typical” profile of adolescent young carer in Slovenia is a girl providing care for parents (31.9% mothers; 33.3% fathers) **with a physical disability**.

The care recipient can also be a friend. Of those 270 respondents who indicated that they have a close friend with a health condition, **137 adolescent young carers** reported that they **provide care for their close friend**. As to the health condition of the care recipient, in the majority of cases it is mental illness.

57 AYCs provide care for only one person (54.8%). There are a number of AYCs that provide care for multiple people: 28 AYCs provide care for two people (26.9%), 12 AYCs provide care for 3 people (11.5%), 5 AYCs provide care for four people (4.8%), and 2 AYCs provide care for five people (1.9%).

### How much care do young carers provide?

Caring activities can include domestic tasks, household management, personal care, emotional care, sibling care and financial/practical care. When compared to their non-caring peers, adolescent young carers perform greater amounts of caring activities. Hence, they have different experiences of daily life than their non-caring peers. In details, 51% of the total adolescent young carers in the sample perform high amount of caring activities (on a Multi-Dimensional Activities of Caring Checklist (MACA) score above 14), compared



to 14% non-carers. 26% adolescent young carers perform a very high caring activity (MACA score above 18), compared to 6% non-carers.

The amount of caring activities undertaken by adolescent young carers in the Slovenian sample is substantially higher in comparison to the other European countries in this study (except the UK). In the other surveyed countries – except the UK – the percentage of adolescent young carers with high and very high amount of caring activities are 23-35% (high), and 10-18% (very high).

More research is needed to explain this difference. Most likely, the finding can be attributed to the lack of formal long-term care services, which results into Slovenian adolescent young carers being pushed into caring roles and providing substantial amounts of caring.

Overall, girls perform a greater amount of care activities compared to boys (however, the differences are not statistically significant).

### Impact on educational attainment

256 AYCs (96.2%) reported that they were currently in education.

13% reported that they experience difficulties in school because of caring for someone. 10% reported that their school performance has been negatively impacted due to caring. 5% reported that they have been bullied, teased, or made fun of due to their caring role.

These percentages are much lower than for the other surveyed countries (except Italy). The difference could reveal specific regional or local approaches and sentiments towards family disability or illness and young persons caring. It could also be attributed to the sampling strategy and reflect specific school practices and culture. For example, a school district selected for participation in this research may have a strong anti-bullying policy, which could explain lower incidents of bullying within a particular country's sample. Also, the schools sampled in Slovenia in majority cover topics like care, health etc. and therefore these topics are not foreign to their students and in that sense might not represent something to be bullied about.

### Overall wellbeing

Adolescent young carers were found to be more likely to report a lower state of well-being in comparison to their non-caring peers. On a scale where 50 indicates extremely high wellbeing and 10 indicates low wellbeing, non-carers have a mean value of 32.2. Adolescent young carers have a mean value of 30. This disparity is highly statistically significant.

### Health impact of the caring role

24% of adolescent young carers report physical health problems due to their caring role. 15.6% report mental health problems.

### Severe mental health impacts due to caring: self-harm and harm to others

Due to their caring role, 8.2% of adolescent young carers have thought about hurting themselves and 5% have thought about hurting others (of these, 75% have thought of hurting their care recipient).

This finding indicates that adolescent young carers are at significant risk of mental distress and underlines the need to engage health professionals, particularly mental health practitioners, to identify and support young carers.

### Access to formal and informal support

In Slovenia, 14% of adolescent young carers personally receive formal support.

Whereas adolescent young carers may not have the opportunity to access dedicated formal support services for their caring role, many (46%) reported the presence of a friend who is aware of their caring role

and offers them support. 35 AYC's report that someone at their school is aware of their caring role and 10 AYC's reported that their employer is aware of their caring role.

This finding is important to consider in light of the resilience and protective factors encountered in young caring: adolescent young carers may find informal support valuable in the absence of formal dedicated services.

## Chapter 2: Recognition, protection, support: what does the law say on young carers?

The aim here was to examine the legislation, policy and service frameworks that exist to support adolescent young carers in 6 European countries, with a focus on how they work in practice, 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 experts working either in a legal academic position, in the government or on the topic of young carers (four in the case of Slovenia).

### Legislation

In Slovenia, no specific legislation protecting and supporting young carers and their families exists.

The current system offers just an indirect support to young carers, mainly from the following legislation:

- ✓ [Social Security Act](#): it is the basis for all the services within and for the family. The centres of social work have to intervene when there are difficult family situations. If the assessment is that a child is endangered, then a foster care placement is sought for the child.
- ✓ Long-term care legislation (still a draft): the focus is on integrated care, as the promotion of care should be a mutual responsibility between education, social and health care systems.
- ✓ [Domestic Violence Prevention Act](#): it includes measures to protect children.
- ✓ [Law on Marriage and Family Relations](#): This law regulates marriage, relations between parents and children and among other relatives, adoption, fostering and the protection of the rights of children.
- ✓ [Family Code](#) (come into force in May 2019). It includes provisions on assessing whether the child is endangered and steps to be taken to protect the child. The best interest of the child must be sought.
- ✓ [Volunteering Act](#): Some measures from the Volunteering Act could make the situation more bearable for young carers. Only certain provisions are applicable to young people.
- ✓ Education Law: It includes regulations that relate to how schools should communicate with the centres of social work, if they notice that a child needs special attentions.

### Key drivers for changes in legislation

The Family Code has recently introduced an important change in the field of child protection. In the past, the social workers had a double role: they worked with the family and they also decided if the child should be taken out of the family. The family code puts the decision making into the hands of the courts. Social workers will continue to work with the families and propose child protection measures to the courts, who will then decide if they should be adopted or not.

The high workload of social workers was a driver for these changes. An analysis of other European legislations (especially the German one) was undertaken in the process of introducing the new legislation.

As to the Long-Term Care legislation, in 2002 a special group was formed from the representatives of the Ministry of Labour, Ministry of Health, the Health Insurance Institute and some other experts with the aim to prepare a report for the government. A draft act on LTC was prepared at the end of 2017 and opened to public debate. One of the greatest differences between the new proposal of the long-term care legislation and the old one is that the old one was holistic and the proposal integrated all the support needed during the life span, while the new legislation will deal only with adults. The draft has been criticized by different stakeholders for being vague on many points.

## Policy and service frameworks

There are no policy and service frameworks, specifically addressing young carers. Yet, the experts mentioned non-specific policy or service frameworks that can indirectly support young carers and their families:

- ✓ [National Programme for Youth](#). It deals with different policies related to young people, with the aim to empower them. It does not include young carers as a specific target group.
- ✓ Strategic Documents by the Ministry of Labour, Family and Social Affairs. In the field of social protection and social care, the Ministry is adopting strategic documents on a national and local level and the focus of those documents is on long-term care. But so far there is no mention of the protection of young carers and their families.
- ✓ Policy for young people with special needs. Slovenia provides very strong institutional care for young people with special needs (referring mainly to people who have a cognitive or physical impairment).
- ✓ Education policies. They include measures focusing on [inclusion](#). Within higher education, students who fall under a broad category of 'special status' are entitled to certain [additional rights](#).
- ✓ At local level, [Youth Policy](#) is strong in including [young people with fewer opportunities](#).

### Key drivers for changes in policy

The EU process promoting young people as a target group for different policies supported the policy development in Slovenia as well, proving that sometimes external pressure is beneficial. A key role was also played by the youth sector - who had become stronger in identifying different policies needed by young people- and by youth wings of political parties, who had the necessary political weight to support the introduction of the National Programme for Youth.

### **Focus: Determining the “best interests of the child”**

The Convention on the Rights of the Child (CRC) states that the best interests of the child shall be a primary consideration in all actions affecting children.

The term “best interests” broadly describes the well-being of a child. Such well-being is determined by a variety of individual circumstances, such as the age, the level of maturity of the child, the presence or absence of parents, the child’s environment and experiences.

The judiciary system often tends to apply the concept of “best interests of the child” to growing up in a healthy environment by considering safer to remove her/him from the compromised household instead of providing supports to allow her/him to stay in the family. A support intervention to keep him/her in the household, which sometimes could be a solution, is often not pursued as it is considered more risky and less predictable in terms of human and economic resources to be applied.

It is important that the interpretation and application of the principle is in compliance with the CRC and other international legal norms. Moreover, there is the need for situation specific solutions, addressing the issue case by case, as **the best interests of a child can be different for every child!** Hence, we call for the increased participation of young carers themselves (and their families), in regard to decisions that concern them.

## Strengths and limitations of legislation, policy and service frameworks

The experts were asked to assess any key strengths or limitations in legislation, policy and service frameworks.

### Key strengths

- Slovenia has a **tradition of good care of children** (via child protection and families policies).
- **Presence of key stakeholders:** social workers (with expertise and authority) and youth centres (offering information and counselling).

- Active role played by youth centres in including young people and supporting those **youth with fewer opportunities**.

#### Key limitations

- **Lack of awareness** on the topic of **young carers**; hence, they are **not** identified as a **target group in legislation or policies**.
- The concept of young carers is very distant to state bureaucrats, responsible to design the legislation, but often disconnected from the real issues.
- **Lack of an entrepreneurial mind-set and political willingness**: there is a reluctance to implement new initiatives, to design new measures for a new target group.
- National ministries are vertically-oriented, and as a consequence there is **no cross-sectorial collaboration** (e.g. between schools and centres of social work).
- **Lack of cooperation and commitment** from some ministries, which explains, for example, why the implementation of the National Youth Programme is not as effective as it could have been.
- The **Long-Term Care legislation** deals only with adults in need of long-term care and it **does not include young carers**.
- At local level, the increase of responsibilities upon municipalities - not matched by adequate financial resources- has caused a strong **opposition by municipalities**.

#### Future needs and recommended changes to legislation and policies

Once the strengths and limitations of the current system were identified, the experts were asked whether they would suggest any changes to the legislation, policy and/or service frameworks.

A first issue to solve was whether a new legislation or policy framework would be most effective, or whether existing measures can be applied to the case of young carers. It is the dilemma between adopting a specific legislation targeting young carers (as it is the case in the UK) and extending non-specific legislation to include young carers as a target group.

#### **Dilemma: Do we need specific legislation and policy on young carers or a better direction would be maintaining non-specific legislation/policies?**

The answer depends on aspects that are specific to individual countries, such as 'how effective is the current non-specific legislation/policy at recognising, identifying, protecting and supporting AYCs?'. The answer has to be based on an understanding of the reality on the ground. Indeed, our study shows that support and protection that AYCs receive in practice does not always reflect the objectives of legislation and policy that is in place. Without an accurate understanding of the realities on the ground, assumptions regarding the efficacy of existing legislative and policy frameworks may be unknowingly leaving AYCs to fend for themselves without even the recognition of their existence.

The experts empathised the risks of overregulation and agreed that there is no need to create a special law or legislation for young carers, as they can be included in already existing legislation.

*"I do not agree that there is no policy regulation connected to ... carers, because if we put it in context, we can apply the legislation and regulations connected with the protection of child's rights and interests and in this sense it would be harmful to discuss it as a completely separate matter".*

#### Recommended changes to legislation and policies

Some experts thought the best way forward is to **mention young carers within long-term care legislation**. Some experts recommended changing the legislation related to the **educational system** and **improving services that can support young carers in schools**.

In terms of policies, young carers could be included as target group in the **youth policy** (among young people with fewer opportunities) or in the strategic documents by the Ministry of Labour, Family and Social Affairs in the field of social protection and social care.

The experts stressed the need for more synergies between different policies and for these to be framed to correspond to the existing structures of the ministries (in order to ensure a clear leadership). Guidelines and agreements to support communication between institutions are also required.

The experts emphasized that legislation and policies need to be accompanied by a **clear budget**, otherwise they won't be effective.

They called for an active engagement of young carers in decision-making processes, because, in the words of one expert ***“we are seeking the solutions for them, therefore they need to be involved.”***

## Chapter 3: Successful strategies to improve the mental health and well-being of young carers

The project partners interviewed 10 Slovenian 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 visibility of young carers and support provided to them.

### Visibility of young carers and available support

Young carers are an overlooked subject in Slovenia.

According to the experts, one reason for the low visibility could be that in Slovenian society caring is not regarded as a problem, but as a part of normal family functioning. Yet, the experts stressed the need to *“draw a line between what is wanted or normal [...] and where the negative aspects of informal care start showing up”*.

They emphasized the need to ensure that caring is the result of a free choice and that it does not go to detriment of the child's development.

### Future needs

Experts agreed on the need for young carers to be recognized, identified and supported. In their opinion, the system to do so is already in place and is made of schools, health and social care professionals. Therefore, the support to young carers can be reached by building on what is already there.

- ✓ **There is no need to develop a new system, what is needed is a cooperation between existing systems.**

The experts stressed the need for an integral approach, with cooperation between different ministries (Ministry of labour, family, social affairs and equal opportunities and Ministry of health), schools and other institutions connected with children and their wellbeing. A network of different actors, well connected and committed to address the issue.

*“Basically this network of different actors should be well connected – if we imagine a young person with troubles at school, caused by his absence as a consequence of him caring for example for his parents - the professional at school should know who to notify in the Centre for social work and then this professional at the Centre for social work should have his/her own protocol who to call and how to act, how to communicate with such person (YC).”*

Continuity and exchange of information among the experts was emphasized, so that a child does not need to tell a story from a scratch.

- ✓ **The State is responsible to address the issue of young carers and to allocate funding**

Majority of experts agreed that the primary responsibility to acknowledge young carers lies on the State.

Mixed feelings were expressed about the level of government better placed to address the issue. If some experts emphasized the importance of bottom up approach (and related role played by local authorities), other expressed concerns, by stressing that the local level is too low for this problem. Similarly, majority of the experts stated that funding – of activities to support young carers- should be the responsibility of the state and not municipalities, to avoid significant differences among the larger and smaller as well as from the richer and the poorer municipalities.

*“It is important that we work on a local level, but on the other hand, we need to be careful that the state would not leave everything to the local communities. Meaning that if it is a local level, things should not have been done in a way that the state would “wash its hands”.*

Some of the experts emphasized that in order to get funding, something must be perceived as a social problem and if it is not relevant enough, it is hard to obtain funding.

*“And as long as something is not recognized as a social problem, it would not get any funding. Maybe it would be reasonable to emphasize the prevention of the problem, so the strategy for Slovenia would not be that it is a big social problem and we should address it through public tenders and financing, but that it should not become a big social problem, therefore we have to act preventative and in order to do it, we need some funding”.*

✓ **A definition of young carers is needed, to ensure they can be recognized**

In order for a phenomenon to be acknowledged, it has to be defined, first. According to the experts, the definition needs to be limited to long-term care responsibilities, but broad and flexible to acknowledge a number of situations in which young carers can find themselves. Some experts even proposed not to limit the definition of young carer to those who are under 18, but rather focus on their student/dependent status.

✓ **Raise awareness**

More awareness of young carers among the general public, education institution, companies and policy makers is needed.

✓ **Ensure early identification and support**

Experts stressed the importance of early recognition and the key role that can be played by schools in this regard. Indeed, it is the only contact point where all adolescents are present.

Yet, they recognized that one can not expect schools solving all the problems of young carers. Other actors have to play a role in this regard (e.g. centres for social work, who can intervene into family issues, while schools cannot).

*“I think the school is an important institution regarding the identification or a place, where young people struggling can find help. But school as a coordinator of everything else and not school as an institution solving their situation, because they (schools) do not have professional staff nor is their purpose to solve their (YC) problems.”*

The experts recommended developing protocols about how to act when various actors detect negative aspects of informal care with a young person.

They also suggested the possibility to have a case manager (i.e. somebody responsible to coordinate among different services).

Hesitations were expressed about the role of youth organisations, since in Slovenia they are politically focused.

✓ **Actively engage with young carers**

The experts stressed the need to provide young carers with information, e.g. about the parent's illness, as well as what support they can get and how to access it.

The support needs to be co-designed with young carers, so that it can be tailored to their needs.

✓ **Adopt a whole family approach**

*"The support of individual without supporting his family is like watering the sand in the desert".*

The experts stressed that the crucial goal is the support for all individuals involved in the caring process: the young carer, person in need of care and the rest of the family. They called for home help and other services, which would help the person in need of care, hence reducing the "burden" on young carers.

## Successful strategies

Once identified the need to identify and support young carers, the experience of other countries could be helpful to know what strategies to implement. A warning came from the interviewed experts, though: the practices from other countries can act as inspiration for Slovenian policymakers and service providers. Yet, they cannot simply be copied; they have to be adapted to the specific Slovenian context.

## 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 social/health settings

- Schools can play a vital role in early identification of young carers. Tool such as MACA-YC18 could be used. Social conditions of a child should be screened when enrolling to kindergarten/school.
- Health care professionals/social workers – when coming into contact with an adult- could routinely ask whether the network around the adult in need of care includes children and whether they have any needs. They should follow up on a regular basis (as the disease evolves and so does caring).

### Training for professionals

- Professionals (from the educational, health and social sectors) could receive training on young carers (on the challenges they face, measures to identify and support them, as well as effective ways to listen to them). Such education for professionals could be included in the professionals' basic education programs.

*"We do not need to find completely new approaches, but to train the professionals in this field, to empower them with the information about young carers' existence."*

### Raising awareness among professionals and general public

- The topic of informal caring, resilience and mental health or addiction could be discussed at school, so that they become less a taboo.
- The positive effects of caring activities could be promoted (providing care is an element leading to build skills, to develop the ability to face situations and conflicts and to build relationships with others).
- Awareness weeks in schools, sharing individual stories in lectures, television programs, social network campaigns are good ways for improving awareness and reducing stigma.

Slovenian experts proposed the creation of a body of pressure (e.g. a strong NGO), which could act on already existing systems and push them into solving young carers' issues.

## Successful strategies to support young carers with education

To ensure that young carers can complete educational programs and have good achievements, the main support measures is flexibility, which can take different forms:



- understanding from teachers in case of lateness, absences, no homework done
- educational plan and learning activities more focused on (A)YCs needs

In addition to flexibility, schools can put in place extra, tailored support, to prevent drop-outs and to ensure a smooth transition to further education or work.

For example:

- Have counsellors that young carers can talk to one-to-one.
- Refer students to help services (e.g. sport club, youth club) and let them aware that these support services exist.
- 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.
- Envisage a psychological supervision in school, in order to support (adolescent) young carers in managing frustration, anger and all the feelings raising from caregiving activities.
- Release a Carers card so that young carers don't have to explain their situation every time.
- Tutor
- Provide support in orientating young carers in relation to the choice on the next school order.
- Create an evaluation (and certification) system in order to enhance the soft skills gained by young carers, which can prove very useful on the labour market.
- Envisage flexible working conditions for young carers, e.g. by providing incentive for employers who hire teleworking caregivers with part-time working hours.

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

Measures that can be implemented to support the mental health of young carers are exemplified below:

### Peer/group support/Information

- Set up young carers' groups, peer support groups, in order to provide children with the insight that they are not alone (this can also empower them).
- Provide young carers with the opportunities to take advantage from the experience of former young carers (via mentoring or coaching).
- Improve access to information on the available support (e.g. Inform teachers and GPs and social workers about local activities to support young carers).
- Give young carers enough space to share their emotions and frustrations, also when they do not necessarily seek practical support to 'fix' their situation. Such space and recognition may be important in a professional context, for example within their school, but even more so within their personal environment.

### Provide respite breaks for young carers

- Organise summer camps, school camps, cinema, café, sport activities to remove the person sometimes from the "pressure cooker" in which it is located
- 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.

Slovenian experts expressed skepticism as to coping strategies being an appropriate solution, since the goal should be not to have young carers and not to teach them how to cope.

*“If we are talking about young people, for them coping is definitely not the right thing, because it mainly speaks about burden and stress, and burn outs are not prevented with coping, but with withdrawing from the situation.”*

#### **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, Malmö, 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.

## **Chapter 4: Translating research findings into policy**

### **Recommendations tailored to the Slovenian context**

*“There are young informal carers and probably there is always some degree of care work in the family, but when this ‘certain degree’ starts to interfere with the normal development of a child, then it becomes a problem and only then it is also a societal problem.”*

In Slovenia, the family plays an important role in the architecture of the welfare system, acting as one of the main providers of care besides the state. Caring is considered as a family obligation. Most Slovenes (60%) consider that it is the children’s responsibility to care for their parents, when they get old; this figure is higher than the EU average (48%). (Source: ESPN, Thematic Report on Challenges in Long-term care).

Even though informal care among young people is somehow accepted in the Slovenian society, the experts interviewed for our study emphasized the need to ensure that caring stems from free choice and that it does not take place at the expense of the child’s development. *“We need to draw a line between what is wanted or normal [...] and where the negative aspects of informal care start showing up”.*

It is the responsibility of the State to ensure that this line is not crossed. According to experts, the State has an obligation to intervene, under the legislation derived from the UN Convention on the Rights of the Child. Under this Convention, States have indeed committed to doing everything in their power to protect and

promote children's rights to survive and thrive, to learn and grow, to make their voices heard and to reach their full potential. The lack of positive action from States to support and especially protect young carers from a harmful burden can therefore be considered as a failure to protect and promote the rights of this particular group of children.

In the light of these considerations, we would like to make the following recommendations to policy-makers and service providers in Slovenia:

**1) Address the need to recognize and support informal care in the legislation on Long-term care (still under discussion)**

It is increasingly acknowledged that the traditional care model – where a large part of the care responsibilities lies on the family - is not only unfair, but also unsustainable. Demographic ageing – combined with the push towards home-based care, in a context of limited public resources - indeed puts more and more pressure on informal carers, including young carers.

*"It is true, if we extrapolate a bit, that this problem could intensify in the future. I think it might happen, because some of the survival strategies in Slovenia are going in the direction that, if a family or a household cannot provide certain services on the market to meet the care recipient's needs, then they rely on informal care. And we see it with "usual" informal carers, and will probably also see it with the young ones, therefore we should not underestimate the problem."*

If the Slovenian government wants to successfully address the challenges related to long-term care (in terms of quality, accessibility and financial sustainability), informal carers need to be recognised and supported. In this way, they can continue to provide care (if they wish to do so), while at the same time being socially included and active on the paid labour market. Supporting informal carers is a winning strategy for all: carers, care recipients and society as a whole (as well as for the economy).

**2) Include young carers in the Long-Term Care legislation**

Our study has shown that adolescent young carers in Slovenia provide substantial amounts of care, higher than the ones found in the other countries surveyed. Young carers are likely to play an increasingly bigger role to respond to the growing long-term care needs of an ageing population. Failing to acknowledge their role and the need to support and especially protect them from the increasing burden in the legislation on long-term care would be a serious missed opportunity.

**3) Provide (good quality, affordable) formal long-term care**

The first way to support young carers – and to ensure that their responsibilities are the result of a genuine choice and that the burden is not harmful for their well-being - is through the provision of accessible, affordable long-term care to the person in need. Yet, in Slovenia, the affordability of long-term care has been worsening since 2007 (ESPN, 2018). Addressing this challenge must be at the top of policy priorities.

**4) Adopt a multi-disciplinary approach to address the issue of (young) carers**

The success of initiatives aiming to address the needs and preferences of (young) carers largely depends on the interplay between a broad set of policies (e.g. long-term care, education, youth policies). All experts suggested that integrated actions involving educational, social and health services are essential to overcome siloed actions and to effectively address the challenges faced by young carers.

**5) Set clear goals and new indicators tailored to the target group**

For young carers to become a target group in legislation and policies, clear goals and indicators have to be created and a monitoring mechanism has to be put in place. This will require efforts in overcoming the lack of an entrepreneurial mindset lamented by the experts, which currently causes reluctance to implement new initiatives, to design new measures for a new target group.

**6) Include young carers among the target groups of support services**

As highlighted by the experts, for the support to be effective, the following elements have to be satisfied:

- A joined-up approach is needed, with different stakeholders (from educational, social, health care, NGOs, policy) working together.
- Emphasis should be on prevention.
- A Whole Family Approach should be applied.
- The support needs to be tailored to the specific needs of each individual
- Young carers need to be actively engaged in designing and implementing their support.
- A rights-based approach should inform every decision by service providers (including the determination of the best interests of the child).

The experience of other European countries shows that country-specific research and a large-scale awareness raising exercise are key drivers to bring about change in policies and practice on young carers. Consequently,

- 7) We recommend to conduct further **research on young carers** and their needs for support and to ensure that the research findings are translated into policy actions.
- 8) We call for a **large-scale awareness raising** campaign on young carers targeted at professionals and society as a whole.

Following these recommendations will allow Slovenia to move forward in the classification of country awareness and support on young carers (Leu, Becker, 2016), where it currently stands at the bottom. More importantly, it will allow Slovenia to move towards the vision – enshrined in many existing national policies (e.g. youth or education policies) - of a society where every child and young person is included and can fully enjoy the human rights s/he is entitled to.

### Recommendations at European level

At European level, the need to take action to support and empower young carers is increasingly recognised.

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

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

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

- Support **further research** on the profile and needs of young (adult) carers; Gather an insight into actual numbers.
- Ensure existing **good practices are disseminated** and made visible across Europe; Make comparisons 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.

The Principles	The relevance for young carers
Principle n. 1 – Education, training and life-long learning	Caring responsibilities can have a negative impact on young carers' education (under-achievement, absence and drop-outs)
Principle n. 4 – Active support to employment	Young carers are more likely to be NEET (not in education, employment or training) than their peers.
Principle n. 11 – Childcare and support to children	Young carers need to be considered as children from disadvantaged backgrounds —→ have the right to extra, tailored support so that they can have equal opportunities in enjoying social rights.
Principle n. 18 – Long-term care	By providing good quality formal LTC services to the person they care for, inappropriate caring can be avoided.

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

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.