



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: Switzerland

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This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 754702

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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. We call them young carers\*.

### 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 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.\*

In Switzerland, 7,9% of children aged 10-15 years are young carers (Leu et al. (2019); Leu & Becker, 2019).

In the Netherlands, research projects give us the following estimated numbers: young carers form the 6% of the population aged 13-17.

In Sweden, according to a survey, 7% of children aged 14-16 years carry out substantial amounts of caring.

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.

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).

\*Istat, Rapporto sulle condizioni di salute e ricorso ai servizi sanitari in Italia e nell'Unione Europea, dati 2015.

\* Please refer to page 4 for the exact definition.

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 of any age. 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 gain 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 the caring role of young carers themselves and on urgent need to act.

The Introduction is general, whereas the following sections focus specifically on Switzerland. 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 complete study results will be published in peer reviewed journals in 2020 and 2021.

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. (Becker, 2000)

#### 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 (Leu & Becker, 2019).

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) (Joseph et al. (2019).

### 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 (Banks et al., 2001; Cass et al., 2009; Cassidy et al., 2014; Heyman & Heyman, 2013; Joseph et al., 2009; Robson et al., 2006). 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 (Aldridge & Becker, 2003; Ali et al, 2015; De Roos et al., 2017; Greene et al., 2016).

#### 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 (Becker & Sempik, 2018; Kaiser & Schulze, 2014; Moore et al., 2009). 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 (Barry, 2011).

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, it is important that the role of (adult and) young carers is fully appreciated and valued."** 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.
The vision of the Me-We consortium:	



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

\*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?



What is it like 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 Switzerland, out of the 2.057 respondents to the survey, 485 were carers aged 13-27 years (born between 1991 and 2005). The total number of **our target group (adolescent young carers aged 15-17 years)** in the Swiss sample was **85** (caring for either a family member or a friend, including those who care for both, i.e. overlaps). 19% report that they have been providing care to someone for as long as they can remember.

Figure 1- The Me-We online survey

The majority of adolescent young carers in the Swiss sample (78%) are women, which is different from previous Swiss data so far (Leu et al. (2019), but is in line with the existing literature on the gendered nature of care, and the cultural, social and familial expectations of care.

62 adolescent young carers indicated that they are Swiss citizens. 56% reported that they reside in villages.

The majority of respondents (non-carers included) reported that they live in dual parent households (85%). 29.5% live with a brother and 24% live with a sister, indicating that a large number of respondents may be the only dependent living with a family. Multigenerational households are a very small feature of family life for the respondents in this survey: 5.5% live with a grandmother and 4.5% live with a grandfather.

### Who do adolescent young carers care for?

Of the 116 respondents who indicated that they have a family member with a health condition, 57 (50%\*) reported that they provide care, look after, or help their family member with a health condition. Thus, in the Swiss sample, **there are 57 adolescent young carers looking after a family member with a health condition**. Of these adolescent young carers, 26 (57,8%) provide care for only one family member. There are a number of AYCs who care for multiple family members: 9 AYCs (20%) provide care for 2 people, 4 AYCs (8.9%) provide care for three people, 3 AYCs (6.7%) provide care for 4 people, and 2 AYCs (4.4%) provide care for 5 people, and 1 AYC (2.2%) reported caring for 9 individuals.

\* Note, the calculated percentages – in this chapter - exclude missing values.



The “typical” profile of adolescent young carer in Switzerland is a **girl** providing care for her **mother with a physical disability**. Grandmothers and grandfathers are respectively the second and the third type of care recipient.

The care recipient can also be a friend. Of those 99 respondents who indicated that they have a close friend with a health condition, **46 adolescent young carers** reported that they **provide care for their close friend**. In the majority of cases the health condition is mental illness.

18 AYCs provide care for only one friend (62%). There are a very small number of AYCs who provide care for multiple close friends.

### How much care do young carers provide?

Caring activities can include domestic tasks, household management, personal care, emotional care, sibling carer 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. 24% of the total adolescent young carers in the sample perform high amounts of caring activity (on a Multi-Dimensional Activities of Caring Checklist (MACA) score above 14), compared to 20% non-carers. 17% adolescent young carers perform very high amounts of caring activity (MACA score above 18), compared to 12% non-carers.

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

### Impact on educational attainment

52 AYCs (64%) reported that they were currently enrolled in an apprenticeship within vocational secondary school. This reflects the Swiss sampling strategy that featured three vocational schools. Further schools were included later on in the next recruitment phase in order to achieve the target number of 200 adolescent young carers aged 15-17.

15% reported that they experience difficulties in school because of caring for someone. Similarly, 14% reported that their school performance has been negatively impacted due to caring. 15% reported that they have been bullied, teased, or made fun of due to their caring role.

These findings underline the need to engage the educational sector in identifying and supporting young carers.

### Overall wellbeing

Adolescent young carers were found to be more likely to report a lower state of wellbeing in comparison to their non-caring peers. On a scale where 50 indicates extremely high wellbeing and 10 indicates low wellbeing, non-carers have a mean value of 34.9. Adolescent young carers have a mean value of 30.5. This disparity of 4.4 is highly statistically significant and can also be considered as a potential for concern.

### Health impact of the caring role

Adolescent young carers in Switzerland generally reported higher amounts of health difficulties because of caring in comparison to the other European countries (except the UK): 40% of adolescent young carers reported physical health problems due to their caring role. 33% reported mental health problems.

Further research is needed to explain the reasons for this particularly significant finding.

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

Due to their caring role, 21% of adolescent young carers have thought about hurting themselves and 5% have thought about hurting others (of these, 50% have thought of hurting their care recipient).

The proportion of adolescent young carers who have thought of hurting themselves is higher than that found in the other surveyed countries, except the UK (8-11%). Again, further research is needed to investigate the reasons behind this difference.

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 Switzerland, 15% of adolescent young carers personally receive formal support. Fewer families of AYCs receive monetary assistance in Switzerland in comparison to the other countries sampled in this research study. One might surmise therefore that the socioeconomic position of AYC families in Switzerland may be higher than those in other countries, however additional research is needed to examine the true cause of this difference.

Whereas adolescent young carers may not have the opportunity to access dedicated formal support services for their caring role, many (61%) reported the presence of a friend who is aware of their caring role and offers them support. This finding is important to consider in light of the resilience and protective factors associated with being a young carer: adolescent young carers may find informal support valuable in the absence of formal dedicated services.

When considering external awareness of their caring role, the AYCs in this survey indicated that it is more likely that they have a friend aware of their caring role, rather than someone at school or an employer. This follows the findings of other countries in this research study.

## 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 six European countries, with a focus on how they work in practice, their strengths and limitations and the drivers in their development. To this end, a literature review was conducted as well as a series of interviews with experts (working either in a legal, academic or government position) on the topic of young carers (four interviews were carried out in Switzerland).

### Legislation, policy and service frameworks

In Switzerland, no specific legislation protecting and supporting young carers and their families exists. Young carers are not specifically defined in the law.

The current system delivers (only) indirect support to young carers, mainly from legislation related to child protection and social care::

- ✓ [Federal Constitution of the Swiss Confederation](#), which states that children and young people have the right to the special protection of their integrity and to the encouragement of their development. They may also personally exercise their rights to the extent that their power of judgement allows;
- ✓ [Swiss Civil Code](#), Child and adult protection law;
- ✓ Convention on jurisdiction, applicable law, recognition, enforcement and cooperation in respect of parental responsibility and measures for the protection of children ([Hague Convention on the Protection of Children](#));

- ✓ [Social Security Law](#), in particular Art. 29 septies Federal Law on Old Age and Survivors' Insurance: it provides financial funding for families (care credits), thus indirectly relieves the burden on young carers as well.

Regarding the changes in legislation, there has been **paradigm shift** from a welfare approach to a rights-based approach. This has also led to children now being better informed about their rights.

There are policy and service frameworks, specifically addressing young carers:

- ✓ [Action plan for support and respite of relatives providing care](#)

On December 5<sup>th</sup> 2014, the Federal Council published the "Report on supporting people looking after and caring for relatives". This has emerged from a political push from the Swiss Parliament and of the Federal Council as part of the [agenda Health 2020](#) and it shows a growing momentum around carers in the Swiss political landscape. The measures indicated in the plan which include better information, respite, reconciliation of work and family care – are to be implemented in cooperation with the cantons, communes and private organisations.

In 2014, young carers were not included in the action plan. However, a petition from the Parliament addressed their exclusion and they are now explicitly mentioned.

- ✓ Federal Research Programme "[Support and Relief Offers for Carers 2017-2020](#)". The Research targets carers of any age. Young carers are explicitly included. The programme will provide stakeholders in the cantons, communities, companies and other organisations with evidence-based knowledge bases and models of good practice, so that they can develop or promote their own programmes or introduce appropriate new offers themselves.

The experts also mentioned non-specific policy or service frameworks that can indirectly support young carers and their families:

- ✓ [Children and youth policy](#).
- ✓ [Health Promotion Switzerland](#) is a foundation supported by cantons and insurers. With a legal mandate it initiates, coordinates and evaluates measures implemented by the cantons in the field of health prevention and promotion. Four modules and eight principles can be used by the cantons as a basis for their cantonal action programmes.
- ✓ In the Canton of Vaud, the organisation [Espace Proches](#) offers respite and counselling services to carers.
- ✓ In almost every canton, there are likely to be public services for young people and their families.

### 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

- Legislation is very clear.
- There is a solid legal system with a lot of protection for children.
- The child protection system is very well established and working well in an interdisciplinary manner in Switzerland.
- Legislation and services are regionally flexible, enabling solutions that fit with the regional contexts (flexibility). The plurality of solutions makes innovations easier.
- The Federalist system allows a "Me-too-effect": where one canton has good practice, then other cantons will adopt this sooner or later.
- Terminology within the Swiss Civil Code such as "best interests of the child" is very open to interpretation. This can be a limit, but it also is an opportunity, because it allows acting and reacting to individual situations and individual circumstances.

### Key limitations

- Young carers do not exist as a specific social group in Switzerland and therefore they are not addressed by support programmes.
- Laws, policy frameworks, and even some associations working with carers do not use an age-appropriate language for young people, so the information may not be accessible to young carers, who do not have an adequate level of literacy.
- Lack of coordination between the different legal systems (e.g. social security system, family law, medical law, child protection, etc.).
- The policy provisions for carers are not as relevant for young carers, since they relate to supporting a balance between work and informal care, without taking into account young carers who are studying or who are doing an apprenticeship.
- There are differences between how cantons implement the UN Convention on the Rights of the Child, despite the recommendations made by the Federation about how to enact it.

In relation to child protection services, the following limitations were identified:

- **Identifying young carers is challenging**

The child protection authority only becomes involved if a young carer's problems are evident. As young carers do not reach out themselves, professionals (from education, social and healthcare) should notify the authorities (e.g. child protection services). However, since professionals are not aware of young carer, they remain invisible.

- **Focusing on protection rather than prevention or empowerment.**

Child protection measures can only be taken if the child's best interest is threatened. It is not sufficient that the child's best interests are not being fully achieved. A threshold needs to be reached before child protection services can intervene. Hence, the focus is on protecting children once problems have already escalated, rather than on preventing them from arising in the first place.

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).

- **Families do not reach out for help from child protection services**

Child protection services can be frightening for families as their role is to intervene to safeguard children. It seems like there is no middle ground between "invisibility" of young carers and "mistreatment" (and consequently the intervention of child protection services).

The marred history with respect to child protection in Switzerland (see focus on determining the best interest of the child) has created a situation where young carers and their families do not ask for help from social services, for fear of being separated.

- **No evaluation of the outcomes of child protection interventions**

The outcomes of the interventions taken by child protection authorities are not actually evaluated. It is therefore unclear whether these interventions are appropriate for young carers and their families.

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

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

The term “best interest” 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.

In Switzerland, there is a debate on child protection authorities: some think that children are not “property” of their parents and the State has an obligation to intervene, while others think that child protection authorities have too much power. This is due to different interpretations of the “best interest of the child” principle.

The concept has often been applied to justify intervention from child protection services in removing from their family, considering this a safer option. Child protection services have forced children out of their families in the name of child protection under circumstances that would be seen from today’s perspective as grave violations of the rights of these children and their families.

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

#### **Future needs**

After the experts had identified the strengths and limitations of the current system, they were asked about changes in legislation, policy and/or service frameworks.

A first dilemma to solve was the opportunity to adopt a specific legislation on young carers, following the example of the UK (see box Focus on the English model).

The experts agreed that the UK model is not likely to suit the Swiss context, for different reasons:

- 1) A specific legislation would be a lengthy and complicated project, because of the federal structure. Young carers do not have time to wait. Hence, it makes more sense to include young carers within strategies and programmes that already exist or are in development.
- 2) It is not necessary to have specific legislation for young carers, because specific laws do not exist for every group of people in need.
- 3) In Switzerland, there are already many existing legal provisions that can form a basis for new frameworks or services addressing young carers, such as child protection legislation and the UN Convention on the Rights of the Child. Introducing legislation that specifically targets young carers would mean over-regulating.
- 4) Having a specific legislation is not sufficient to ensure that young carers are supported in practice (it can be seen in the UK for example that the support and protection that young carers receive in practice does not necessarily reflect the objectives of legislation).

Given the aforementioned considerations, the experts agreed that, rather than introducing a specific legislation for young carers, it is more advisable to integrate young carers into existing legislation/policy.

This needs to be extended and amended, so that young carers can be recognised and adequately supported.

Among others, the experts recommended:

- The issue of young carers must be systematically addressed. More data is needed in order to find solutions to make these children visible, understand how child protection measures are working and to inform decision making and legislation in regard to future support for young carers.
- Strong political commitment and support from for example, non-profit, or non-government organisations
- Changing the law with regard to the legal duties for child protection, to ensure that a preventative approach is working in practice.
- Integrating the topic of (A)YCs into the national care policy of the Federal Office of Public Health in Switzerland. Besides changes in the Federal programme, there should also be changes on cantonal level
- Further legislation and policy frameworks to address the structures and conditions allowing professionals to work well together (taking into consideration the right to privacy).
- Include a definition of young carers.

**Dilemma: Do we need specific legislation and policy for young carers? Or would a better approach 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 should be based on an understanding of the local reality. Indeed, our study shows that the 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 local realities, assumptions regarding the efficacy of existing legislative and policy frameworks may be unwittingly leaving AYCs to fend for themselves without even recognising their existence.

**Dilemma: Do we need legislation or are soft laws and the commitment of different stakeholders enough?**

For there to be commitment, it is necessary for different stakeholders (professionals, families, carers, organisations, the State) to be aware of and recognise that children and young people do take on caring roles and that this can result in negative impacts.

For their commitment to be effective, the stakeholders must know how to effectively support AYCs.

For commitment to be actioned, stakeholders require adequate capacity and the necessary resources.

Where one or more of these factors are missing, then that is perhaps the role that legislation and policy should play.

### Focus on the English model.

Only the UK has **specific legislation on the topic** that explicitly recognises or defines young people with caring responsibilities. Hence, it may be worth investigating this system more closely.

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

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

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

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

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

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

### Paradigm shift: a whole family approach

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

### The drivers of the change of legislation

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

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



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

### Focus on Switzerland

The project partners interviewed 10 Swiss experts from the fields of academia, policy, health and/or social care on the topic of adolescent young carers and related topics. Interviews focussed on the visibility of young carers within Switzerland and the support provided to them.

### Visibility and awareness of young carers

According to the experts, in Switzerland the visibility, awareness and understanding of young carers is low or invisible, at the local, regional and national level. Therefore, increasing recognition and awareness of young carers and their needs with professionals and families is required.

The term young carer is generally not known. Only people specialized in the field use it (interestingly, they tend to use the English term).

The idea that a child takes over care for their parents, siblings, grandparents etc. is practically not recognised. Few people talk about this topic and stigma remains.

Young carers often do not self-identify as carers, or, even if they do, they do not speak about it, they keep it private, for fear to be stigmatized and for fear that the authorities will find it out and take them away from the family.

Some experts mentioned that children with migrant backgrounds are more open to talk about their caring experience, as in their culture caring for family members is a common phenomenon. One expert was in partial disagreement and pointed out that – if the term young carer is viewed in a negative light in society – even children from migrant families will no longer be open to speak about their caring tasks.

The interviewed experts agreed about **the lack of awareness among professionals** from different backgrounds (healthcare, education, social service). The only exception is for children caring for someone with a mental illness, as for this specific case there is a little bit visibility.

There is little significant media coverage of young carers. Where there is, the focus is on younger children.

Things are likely going to change. Indeed, the Young Carers Research Group is developing a body of research evidence and this will hopefully result in increased visibility of AYC's. Thanks to these developments, it is likely that Switzerland will emerge higher in the next iteration of the classification proposed by Leu and Becker of in-country awareness and policy responses to 'young carers' (currently, it is at level 5 – emerging).

### Available support

Young carers do not exist as a specific social group in Switzerland, hence there are no dedicated interventions for them. Support for (A)YC's comes through child protection routes and some more general interventions (for children and young people in general).

There are many platforms for young people, for example, [Pro Juventute](#), which is a charitable foundation dedicated to supporting the rights and needs of Swiss children and youth.

There are a few new, – mainly local – programs, aimed specifically at supporting (A)YC's, such as awareness raising activities in schools, where professionals discuss the issue of young carers with students.

Special programmes are well established for young carers who care for parents with mental health conditions. For instance, the foundation [Kinderseele Schweiz](#) is committed to ensuring that children of mentally ill parents can develop as well as unaffected children. They advise those affected, their social environment and professionals and provide help.

In the mental health field, the Open Dialogue Approach – where professionals work directly with the entire family (Family Approach) – could have the advantage of identifying young carers and reduce the care “burden” on them. Yet, this approach is underdeveloped and not yet accepted enough in Switzerland.

## Evaluation of available support and future needs

The experts evaluated the current support system for young carers and, based on this analysis, identified key needs.

### ✓ **Caring role as an everyday phenomenon**

A huge challenge relates to the perception of **caring as something to be kept private**, hidden, for fear of being stigmatized or separated from the family.

Hence, it's important to make the issue visible and to remove any stigma attached to being a young carer. The focus should be 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).

### ✓ **Empower professionals**

It is important to **empower professionals** from all sectors (education, social and health care), so that they can better identify and support young carers. Practical tools (e.g. guidelines, checklists) have to be provided to them.

### ✓ **Integrated work**

Currently, there are gaps between the healthcare system, the schools, the educational system and the social system, those are all very different entities with little inter-connections.

The experts called for better integrated work, for inviting all the relevant stakeholders from one region to meet and discuss the topic and find solutions together (along the lines of what has been done with the topic of children of parents with a mental health problem).

### ✓ **Whole family approach**

Services working with adult in need of care focus only on the adult, not on the network gravitating around him/her. As a result, young carers are invisible.

The experts called for a family approach, that could reduce the burden on (A)YCs.

### ✓ **Personalised support**

The experts stressed the need to accept the diversity of families. Young carers are not an homogenous group. Every child has his/her own story. Therefore, instead of creating one concept that fits all, it is better to provide personalised support, based on individual needs.

*“But there are more and more children where one has to say that this is a very great diversity and one cannot meet this diversity by standardizing programs. And also not by doing an awareness raising campaign for every single life situation, but telling the people who work with them for example, hey, if you have a class, there are certainly 4,5,6 children, some are poor, others have a migrant background, the third have a parent at home they have to care for, the fourth have a disabled sibling, the fifth have an escape behind them, look at these children and look at what they need individually.”*

### ✓ **Include young carers in existing interventions and programmes**

Rather than creating programmes specifically targeted at young carers, the experts recommended including them in the general offer of services. There was disagreement on the level of support currently provided: for

one expert, adolescents are not very well supported by Swiss society. On the contrary, another expert stressed that the “the variety of services that offer help for adolescents is quite respectable and the numbers too.”

✓ **Improving communication, promotion and access to support programmes**

The experts expressed concerns about how well known support programmes are within the general population.

*“I really do think we are in a very good, very favourable situation in Switzerland or Central Europe in general. There are many offers, but what I notice, or what I feel is that communication or sometimes the accessibility of the one of the stakeholder group is often the biggest problem, so that it doesn't do much good if we have insanely good programs, if you don't bring them to the target group. I really think the big focus must be on communication work.”*

✓ **Make special efforts to identify and support adolescent young carers**

The experts recognised that the difficulty in identifying young carers is even bigger in the case of adolescent young carers, because they are in transition from child to adult services. They typically don't see paediatricians anymore and they do not communicate their situation to their GPs. They have finished the regular nine school years and then typically start an apprenticeship or further schooling.

✓ **More funding for preventative services**

Foundations and organisations that could provide support to young carers are partly private and partly state-funded, but they are small and underfunded. According to the experts, more could be done if the law was changed to allow more funding for preventative services. Interventions should be funded by different sources (foundations, government, donors, health insurances...) to keep them independent. They can be financed from the welfare budget, but it should be a general financing, not a case financing.

✓ **Co-design the support with the young carers**

The support needs to be co-designed with young carers, to ensure that it fits their needs. In order to actively participate, young carers have to be properly informed.

## The experience of other countries

The Me-We research study – with its cross-national comparison – allows us to provide an overview of possible strategies to identify and support young carers. The experience of other countries can be a great inspiration for Swiss policymakers and service providers (with due recognition of the specificities of the Swiss context underlined in the previous section).

## 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. In order to facilitate identification, tools such as MACA-YC18 could be used.
- Health care professionals/social workers – when coming into contact with an adult in need of care – could routinely ask whether the network around the adult 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.

#### Raising awareness among professionals and general public

- The topic of unpaid 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.

#### Successful strategies to support young carers with education

To ensure that young carers can complete educational programs and perform well, the main support measure is flexibility, which can have different values:

- 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 know 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 favoured 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 the feelings raising from caregiving activities.
- Release a carers card so that young carers don't have to explain their situation every time.
- Offer tutoring
- To support young carers to enable them to make informed choices about which type of school to attend. 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 carers 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, 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 young person from the "pressure cooker"
- Give young carers a break from caring, let them have fun and get in contact with peers.
- Assist them with the financial cost so they can participate in these activities

#### Increase resilience

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

### Successful strategies to engage with young carers

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

The following strategies can be implemented:

- Provide adolescent young carers with information, e.g. about the parent's illness, as well as what support they can get and how to access it.
- Ensure that care assistance staff, health care staff, social workers, teachers and parents know how to communicate with children in a child/youth friendly and respectful way.
- Co-design the support with young carers, to ensure that it fits their needs. A tailor made support can make families and children better off here and now – and prevent the problems from being passed on to the next generation.

### 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 countries. 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.

Four members of the Young Carers Working Group are part of 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 Swiss context

Many of the experts interviewed in our study stressed that caring is seen as a private issue by Swiss families. It is important to break this taboo: caring, rather than being **a hidden, 'private' issue, has to become the focus for public policy and intervention (the personal is political)**.

In Switzerland, there is a growing political interest towards informal carers. The "Report on supporting people looking after and caring for relatives" – published by the Federal Council in 2014 – is evidence of this trend. The Federal Council recognises the important role in society played by informal (unpaid) carers. With an ageing population and a lack of resources, this is a role that will become even more important in the future in meeting the increasing demand of long-term care. Initial and nonetheless important steps on the path towards recognition and support of unpaid carers have been taken.

- 1) We call on policymakers to be innovative and implement a **strategy to support carers of any age**. Such a strategy will **adopt a life-course perspective** to caring, because in every life-phase one can be a carer.
- 2) We recommend to **extend/amend existing non-specific legislation/policy** so that young carers can be identified, recognized and supported. In particular, we recommend strengthening **the focus on prevention**, which is currently lacking.
- 3) **We call for service providers to include young carers among the target groups of their activities.** 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.
  - A whole family approach should be adopted.

- 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 decisions by service providers (including the determination of the best interest of the child).

The experience of other European countries tells us that country specific research and the presence of championing NGOs are key drivers to bring about change in policies and practice on young carers (Becker & Leu, 2016). Therefore,

- 4) We call for **further research on young carers**, which will allow to make better decisions on the type of support needed by young carers and in this way make evidence-based changes to the legislation/policy.
- 5) We stress the urgent need of a **large-scale awareness-raising** exercise among health, education, social care practitioners, policy makers and society as a whole. NGOs could play a key role, if adequately supported by state funding.

A joint effort by each member of our society will ensure that we **move forward** in our vision: one where young carers can fully enjoy the human rights they are 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 Swiss 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 practice is disseminated** and made visible across Europe; Make comparisons with what is happening in other countries to support developing practice 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 policy makers 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.