



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: Italy

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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 the Netherlands, young carers form the 6% of the population aged 13-17. In Switzerland, 7,9% of children aged 10-15 years are young carers. In Sweden 7% of children aged 14-16 years carry out substantial amounts of caring.

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

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

This brief precisely aims to raise awareness on the topic and fill the knowledge gap, by sharing the findings of a European research and innovation project, funded through the EU's Horizon 2020 Programme and called Me-We - 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 Italy. 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 practices. 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 the recommendations at the end of this brief is driven by our core vision: young carers should be able to pursue their life projects as they desire and achieve their full potential, without being negatively impacted by their caring responsibilities.

## Introduction

### The challenges of being a young carer

#### Who are young carers?

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

Young carers aged 15-17 are called “**adolescent young carers**”. They deserve special attention, as they are in a key, transitional phase of their development: moving from childhood into adulthood. This transitional

stage is critical not only for biological and psychosocial considerations; but will also affect the positioning of potentially vulnerable adolescents with regards to the law, policy, as well as health and social care.

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

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

### 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
- 

## The impact of caring

### Mental health and wellbeing

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

### Education

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

### Social life

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

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

## 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 exist)

→ 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 intervention, socio-economic inequalities can be tackled at the roots, the cycle of disadvantages can be broken and equality of opportunity can thus be promoted.

### Between support and emancipation - the Young carers' Dilemma

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

Young carers should not exist and policy attention should be put elsewhere	Young carers should be identified and supported
<p>By supporting young carers and teaching them how to cope, some may argue that we effectively accept the <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.</p>	<p>The principle that children should be exempt from caring responsibilities 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.</p>
<p>"If appropriate services are delivered to the cared for person, the child or young adult could get on with the ordinary business of growing up. Hence, it is important to <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>"*</p>	<p>"We recognize that in an ideal world where the voluntary and statutory support services are willing and able to provide extensive or unlimited support, the role of young carers would be greatly reduced. But we also recognize unpalatable current political and economic realities and that in an increasingly pressurised and residual welfare system, in the context of economic recession, uncertainty and charges for social care, <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 tolerance – pretending that young carers do not exist- then we will not see them until it is too late, when their needs for support have escalated.</p>
<p>From a human rights perspective, children have the right to be children and not to be carers. A system of support would have the effect of entrapping them into a caring role from which they should be free, in so doing violating their rights.</p>	<p><u>Young carers' right to self-determination includes the right to care</u>, if they wish to do so, provided that their best interest 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.</p>
<p><b>The vision of the Me-We consortium:</b> <b>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.</b></p>	

\*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 2- The Me-We online survey

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 Italy, out of the 1.004 respondents to the survey, 243 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 Italian sample is **206**. 38.3% of AYC's reported that they have been caring for a family member for as long as they can remember.

The majority of adolescent young carers (66,8%) 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.

90,8 % of adolescent young carers are Italian citizens. 48% report that they live in towns and smaller cities. This reflects the sampling strategy, consisting in recruiting participants in the survey from small towns in Marche and Emilia Romagna Regions.

The majority of respondents (non-carers included) reported that they live in dual parent households (89%). Multigenerational households are also a part of family life for some respondents: 9% live with a grandmother and 4,7% live with a grandfather.

### Who do adolescent young carers care for?

In the Italian sample, out of 221 respondents who have a family member with a health condition, there are 138 adolescent young carers (looking after a family member). Some of them care for multiple family members: 20,3% provide care for two people, 2,5% provide care for 3 people.

The most common health condition amongst family members is a physical disability, followed by cognitive impairments, mental illness and addictions.

Grandparents, especially grandmothers, are the most commonly identified family member with a health condition.

Hence, the "typical" profile of adolescent young carer in Italy is a **girl providing care for her grandmother**. This is a unique finding, as in the other surveyed countries the person cared for is usually a mother. The finding can be attributed to an aging population at home (resulting in more adolescents taking up caring responsibilities), as well as to the lack of appropriate formal, long-term care services and programmes for older people in Italy. **In the context of an absent formal eldercare system, Italian adolescents are being pushed into caring roles and serve as the reinforcement for their aging population's care needs.**

Italian teenagers also provide care for people who are not family members. 97 adolescent young carers reported that they provide care for a close friend (out of 200 who have a friend with a health condition). In the majority of cases the friend's condition is physical disability, followed by cognitive impairment and addiction. This is a difference compared with the other countries, where the main condition is mental illness.

## How much care do young carers provide?

In Italy, 32% of the total adolescent young carers in the sample perform high amount of caring activities (domestic tasks, household management, personal care, emotional care, sibling carer and financial/practical care); for 10%, the amount of caring activity is very high. When compared to their non-caring peers, adolescent young carers perform greater amounts of caring activities in the home, and the differences are highly statistically significant. Hence, they have different experiences of daily life than their non-caring peers. Overall, girls perform a greater amount of care activities compared to boys.

## Impact on educational attainment

8% of the adolescent young carers report that they experience difficulties in school due to caring. 8,4% report that their school performance has been negatively impacted due to caring. 6% report that they have been bullied, teased, or made fun of due to their caring role. These percentages are lower than those found in the other surveyed countries. The differences could reveal specific regional or local approaches and sentiments towards family disability or illness and young caring. The differences could also be attributed to the recruitment 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.

## Health impact of the caring role

26% of adolescent young carers report physical health problems due to their caring role; 17% report mental health problems.

This finding call for the **engagement of health professionals, particularly mental health practitioners**, in the identification and support of young carers.

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

8% of adolescent young carers have thought about hurting themselves due to their caring role, and 6% have thought about hurting others due to their caring role. Of those adolescent young carers, the majority have thought of hurting their care recipient.

This finding sheds light on the severe mental health conditions of adolescent young carers who do not receive timely and adequate support and provide insight into the phenomenon of neglect and **abuse against (older) people with disability**, which highlights the need to plan preventative interventions against aggressive behaviours and domestic violence episodes.

## Access to formal and informal support

Only 23% of adolescent young carers personally receive formal support.

It is important to emphasize that whereas adolescent young carers may not have the opportunity to access dedicated formal support services for their caring role, many (46%) reported the presence of a friend who is aware of their caring role and who offers them support. This finding is important to consider in light of the resilience and protective factors encountered in young carers: **adolescent young carers may find informal support valuable in the absence of formal dedicated services** from governmental or social care agencies.

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

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

## Legislation, policy and service framework

### National level

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

Actually, Italy is one of the European countries without an ad hoc legislation on carers (of all ages). The national legislator is currently working to address this issue. The Senate Commission for Labour and Social Security has started the process of examination of 5 Law proposals concerning informal care. It is noteworthy that all of them recognise the existence of student young carers and that the care activity they perform is socially relevant (hence envisaging the possibility to grant them credits to facilitate their educational experience).

An important step forward in the direction of recognising Italian carers has been the establishment – with the Budget Law for 2018 (Law 27 December 2017, n. 205)- of a **Fund to support the caring role of informal carers**. For the first time, a definition of informal carers appears in national legislation. € 20 million are allocated for each of the years 2018, 2019 and 2020. The institution of the Fund and the definition of carer included in it represent a total innovation in the Italian legal framework. This important result has been possible thanks to the active commitment of family associations. Yet, for the Fund to be operational, implementation laws are needed and they have not been enacted yet.

Waiting for the adoption of a legislation on carers of all ages, the current system offers just an indirect support to young carers, mainly from the following legislations:

- ✓ [Law 23 December 1997, n. 451](#), Establishment of the Parliamentary Committee on Children and the National Observatory for Children, with the aim to control the implementation of international conventions and legislation on the rights of the child.
- ✓ [Law 28 August 1997, n. 285](#), Provisions for the promotion of rights and opportunities for childhood and adolescence.
- ✓ [Law 5 February 1992, n. 104](#), Provision for the assistance, social integration and rights of people with disabilities. This law envisages psychological support service from the Local Health Authority for the family member of a person with physical or mental illness or disability. The law also sets a right to a paid leave: any family member within the third degree has the right to a series of benefits, which take the form of the possibility to have 3 days of paid leave per month.
- ✓ [Law 28 May 2017, n. 71](#) Provisions for the protection of minors and for the prevention of cyberbullying. The aim is to counter cyberbullying in all its forms, with preventive actions and with a strategy of protection and education towards the children involved.

At policy level, an important success has been the signature of a Memorandum of Understanding between Italian organisations ([Anziani e non Solo](#), [CAR.ER.](#) and [COMIP](#)) supported by Eurocarers and the Italian Ministry of Education, University and Research. The MoU is a first, important step, as it acknowledges for the first time the topic of young carers and the impact that caring responsibilities can have on educational attainment. In this document – signed in September 2018- the different actors have underlined the challenges faced by young carers in the educational field and have committed to raise awareness on the issue. From his side, the Ministry of Education commits to take all necessary actions to protect students who are at educational risk or who are experiencing a situation of psychosocial distress (broader definition including the case of young carers).

### Regional level

Moving to regional level, there are some realities that stand out as good practices.

Emilia Romagna has been the first Italian region to legislate on the topic of carers ([Emilia-Romagna Regional Law 28 March 2014, n. 2](#), Norms for the recognition and support of the family caregiver).

Family caregiver is defined, for the first time in legal terms, as: the person who on a voluntary basis, in a free and responsible way, provides care of a person in conditions of non self-sufficiency or whose disability or health condition necessitates long-term assistance.

In the implementation guidelines, the general concept of carers has been extended, and specific areas and clarifications concerning young carers have been included.

This law has been taken up by other regions: Abruzzo in 2016 (law available [here](#)) and Campania in 2017 (law available [here](#)). In a further six regions a legal text was filed, taking as reference that of Emilia-Romagna.

Another relevant piece of legislation is the [Emilia-Romagna Regional Law 30 July 2015, n. 14](#) Provision to support the job integration and social inclusion of people in conditions of fragility and vulnerability through the integration of public services in the labour, health and social sectors.

In addition to legislation, at regional level there are also policy and service frameworks that can indirectly support young carers, such as:

- Extended offer of online course of study by universities in Emilia-Romagna
- In relation to the job market, the "[Patto regionale per il lavoro](#)" in Emilia-Romagna, which has a specific reference to the importance of caring work.

At local level, we find a specific policy targeted to young carers: a technical school in Cesena has included students with caring responsibilities among the beneficiaries of the Special Educational Needs. This tool allows a personalized didactical plan (e.g. more flexibility concerning attendance, planned oral exams, tutoring).

## From legal provision to actual implementation: a gap to be filled

### At national level

The Law establishing the Fund to support informal carers only sets the general-strategic aim: the recognition of the role and function of carers. For the Regions to be able to use the resources of the Fund, it is necessary to wait for specific regulations, which are not available yet. Moreover, according to the national experts interviewed, the resources allocated to the Fund are not high enough, considering that it is for the financial coverage of interventions aimed at recognizing the social and economic value of family carers and the number of potential beneficiaries is high compared to the available resources. Therefore, there is the risk that Regions simply reinforce policies they already have (e.g. mainly refinance care allowances) rather than implement targeted and innovative interventions (based on provision of services for carers).

In relation to the Law 5 February 1992, n. 104, the 3 days of paid leave can theoretically be requested by anyone, even by the minor who is working. But, in reality, due to the fact that there are not so many working minors, the application of this provision is not used by children.

Therefore, according to the current legislation, in the activities targeting youth (and not specifically young carers, who at the moment are not recognised by law) the only available support is the psychological counselling offered by Local Health Authorities according to the law 5 February 1992 n. 104.

### At regional level

In Emilia-Romagna the "[Deliberazione della giunta regionale](#)" 16 June, n. 858 defines the implementation methods of the Regional Law 28 March 2014, n. 2, concerning the recognition and enhancement of family carers. In the implementation guidelines the general concept of caregivers has been extended, and specific areas and clarifications concerning young carers have been included. The carer's skills are recognised. Moreover, it is emphasized that educational institutions can enhance the status of carers in accordance with current legislation on training credits. The decision of including a broader age range was based on the high

percentage of young people who reported to be NEETs (Not in Education, Employment or Training) because of caring activities in their family.

In Abruzzo and Campania no implementation guidelines have been issued.

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

### Strengths

- The Italian system is characterised by a strong engagement of family associations and an active involvement of regional stakeholders. These actors have been the main drivers of the changes in legislation at national and regional level.
- There are virtuous realities (best practices) where families are under control and social services intervene, if needed, acting on prevention and support.

### Limitations

#### At national level

- Italy is one of the EU countries without an ad hoc legislation on carers. Based on current legislation, the only support carers can receive is the paid leave (Law 5 February 1992, n. 104). Yet, only working carers can profit from this support (hence, it is not very relevant for young carers).
- The financial support without other strategies is not enough (vision 'no cash for care, but services for care'). Carers also need services and all the activities with the Fund for dependent people (Law 27 December 2006, n. 296) were aimed exactly at encouraging the creation of a system of services that would help families to manage this kind of situation.
- Lack of awareness on the topic of young carers, among policymakers, service providers and the general public.
- Lack of a definition: the young person providing care is not identified by social and health services as a carer, but as a minor experiencing personal and family difficulties.
- Social services often do not act in a preventive way and intervene only once something striking happens.
- 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.

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

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

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

#### At regional level

- Lack of a formalized national coordination. There are regions which are well-organized, while others do not function well. The disparity in the different territorial areas of the country with regard to welfare systems, social services and primary care system impacts differently on the possibility of giving help and support to both young carers and carers in general.
- Unequal allocation of resources between North and South.

#### Local level

- Lack of resources in some municipalities.
- Lack of clarity regarding the procedures of the social services, which often are complicated and not child-friendly. As a result, when a young carer tries to navigate the system to support his/her family might s/he might find it too complicated and decide to give up.

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

In Italy, there is a lack of visibility and awareness on (adolescent) young carers at all levels (local, regional, national) which is accompanied by a lack of systematic studies and official statistical survey. As a result, (adolescent) young carers are an “invisible crowd”.

There are no widespread strategies or programs to support young carers. When support takes place, this is due to individual/organisation initiative (e.g. the interventions carried out by Anziani e non solo in the area of Carpi or one support action in a school in the same geographical area).

The Me-We research study – with its cross-national comparison – allows us to provide an overview of the (adolescent) young carers' needs and possible support strategies. This section is the result of analysis of needs of Italian system (according to the experts and the young carers interviewed), as well as good practices from all across Europe (and beyond).

### **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.
  - 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.
- 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.

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

### Successful strategies to support young carers

#### ✓ Support young carers with education and transition to employment

The findings from the Me-We survey on the negative experiences of adolescent young carers in school underline the need for the educational sector to identify and engage with young carers. In Italy, this is crucial, as the negative impact of caring responsibilities on education and employment opportunities is very strong. According to the Report published by the programme Youth Guarantee, caring responsibilities are the first reason why Italian young people – from 15 and 29 years- are NEET (not in employment, education or training).

“In my opinion, all youth organizations and groups should have a particular sensitivity to discover and support these children. The **school** does not have only sensitivity, it has a **moral and professional duty** and there must be a specific training to support these children. So as organizations I would say all organizations, all educating communities should be sensitized on this issue. But the school in particular.” One of the Italian experts interviewed.

Too often caring responsibilities force young people to think in the short term, with consequences for life, such as the choice of school.

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.

“Have less homework and less to study so to have more time to take care of someone, because otherwise there is no time to take care of others and time for oneself”. Italian adolescent young carer who responded to the Me-We survey.

“I would like some form of empathy from teachers.” Italian adolescent young carer who responded to the Me-We survey.

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.

Opportunities for funding are identified in funding for schools to prevent drop-out, the National Operational Programme for Education (European Funds through the ESF), resources that schools dedicate to the training of teachers.

#### ✓ **Support the mental health of young carers**

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

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

#### Peer/group support/Information

- Set up young carers' groups, peer support groups, in order to provide children with the insight that they are not alone (this can also empower them).
- Provide young carers with 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).

#### 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.

"I often take care of my little brother who has a psycho-physical disability, and being the only daughter left at my parents' house, I am always with him, sometimes too much because at 5 pm I would sometimes prefer to go out and concentrate more about the study, but I don't have the possibility. It is absolutely not a burden because I do it willingly and with a great desire, but I would like a little more time for me." Italian adolescent young carer

### Increase resilience

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

### Successful strategies to reduce the care burden

- Adopt a whole family approach in long-term care service provision. Next to a family-oriented perspective, it is important to look beyond the family and include the broader social network, such as friends and neighbours.
- Improve the quality of long-term care services.
- Strengthen collaboration between different professionals and agencies and make clear to users who is responsible for what. A contact person (e.g. a teacher in a school, a social worker in social services) with deep knowledge on the problems affecting young carers and the necessary tools. Such professionals should be available in schools and social services, where actions aimed at supporting and helping both the young carer and the person in need of help should be implemented.

### Successful strategies to engage with young carers

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

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

The following strategies can be implemented:

- Provide adolescent young carers with information, e.g. about the parent's illness, as well as what support they can get and how to access it. Many professionals are not aware that children have the right to be informed.



"I need more collaboration, support and advice from experts, since I am not specialised in certain areas, I would need advice." Italian adolescent young carers

- Ensure that care assistance staff, health care staff, social workers, teachers, and parents are respectful towards children.
- Co-design the support with young carers, to ensure that it fit their needs.

## Chapter 4: The need for a young carers' agenda at European and national level

### Recommendations tailored to the Italian context

The Italian welfare system is characterised by a familistic approach: the family indeed plays a central role in the architecture of the welfare system, acting as the main provider of care. The intervention from the State – to meet the long-term care needs of its population – has traditionally been limited to the provision of financial support, rather than services.

The findings arising from the Me-We project clearly show that the lack of formal long-term care services impacts on the extent and nature of caring amongst adolescent young carers, as well as on their health and wellbeing. The unique finding related to Italy concerns the prevalence of young people providing care to their grandparents, which - while being a laudable example of intergenerational solidarity - also seems to indicate that adolescent young carers are instrumental in meeting the care needs of an ageing population.

It is more and more recognised that the traditional care model – where all the care responsibilities lie on the family - is unsustainable and unfair. Demographic ageing is putting more and more pressure on informal carers. Informal carers need to be recognised and supported, so that they can continue to provide care – provided it is their choice, while at the same time being able to pursue their life project and reach their full potential.

The Italian legislator has taken initial and nonetheless important steps on the path towards the recognition and support of all informal carers, with a series of law projects currently under examination by the Parliament. The experience of other countries – which have faced (and addressed) the same challenges as Italy - can be of inspiration to Italian policymakers. See for instance the English model and the rationale for changes in legislation in that country (Box at page 19).

The following recommendations build on the knowledge derived from these experiences, while taking into account the specificities of the Italian context. In most cases, the considerations indicated regards young carers are also valid for all informal carers in general.

#### **1. Adopt a national legislation which recognises and support all carers**

The Italian legislator should seek to adopt a national legislation which recognises and support carers (of all ages), on the basis of a broad and inclusive definition of carers (independently from the condition of the caree or from the intensity of the care provided).

This legislation should also pay specific attention to the problems and needs of young carers.

The involvement and leadership of the national legislator is vital to demonstrate a political recognition of the issue and to ensure consistency in the protection and support of all young carers. The implementation of this overarching legal framework can then be adapted to the regions specificities, if required.

The law should not be too rigid, but rather allow for personalised solutions, addressing the issue case by case (depending on the kind of care activity that is provided, for whom, for how long, etc.).

#### **2. Cash for care is good, services for care are better**

Support to (young) carers should not be limited to financial transfers but should consist in services.

The provision of financial support can be useful for (young) carers but is not sufficient as it does not help the young person to handle the caring responsibilities and the consequences of this on his/her own life.

Other types of actions and support (such as psychological, educational, relational) should be provided in order to promote an harmonious development of (young) carers and to let them express their own abilities. The successful strategies adopted in other countries and indicated in the previous section can be of inspiration.

### **3. Provide support to (young) carers tailored to their needs, focusing on a preventative, whole-of-family approach**

Rather than providing standard services, it is important to tailor the support to the individual needs of (young) carer, which may differ as a result of social, economic and individual conditions.

To do so, the definition of the support to be provided should stem from an assessment of the needs of (young) carers.

This approach should be preventative and take place before the needs convert into a real crisis.

The **whole family** should be supported and young carers should be seen and involved in a care plan through which their opinion is sought.

### **4. Ensure consistency of support across the national territory**

The local level is closest to the needs of carers and it therefore makes sense to organise the provision of support at that level. It is nevertheless important for the national authorities to monitor the situation and ensure equity within and between regions and municipalities. The disparity in some areas of the country with regard to access to the welfare system, social services and primary care is among the reasons why equitable support to all carers is currently difficult in Italy.

### **5. Adopt a multi-disciplinary approach in addressing 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 health and social policies. All experts suggest 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. For example, coordination platforms between the Department for Family Policies, the Ministry of Labour, the MIUR (Ministry of Education, University and Research) could be envisaged.

We recommend the inclusion institutional stakeholders from different levels of government, as well as the voluntary sector, in this process. Both regional stakeholders and the third sector have indeed proven to be very valuable resources in the Italian context, acting as the main drivers of changes in legislation.

### **6. Adopt a co-design approach by engaging with young carers**

Young carers should be actively engaged in every process that affects them and in decision making, in general. Their rights have to be taken seriously and their opinion listened to. In order to actively participate in decision processes, they have to be properly informed.

The support needs to be co-designed with/by young carers, to ensure that it fit their needs.

### **7. Raise awareness on young carers**

The level of awareness is still very low and active efforts needs to be made to improve that, among professionals and among the general public.

### **8. Collect more data**

More knowledge and data is still needed to improve the understanding of the young carers needs and number.

**The current knowledge gives us reasons to believe that, if the Italian State takes action to recognise all carers, to promote their wellbeing in a preventative manner and to provide flexible support based on their needs, this will reveal a winning strategy for all: carers, care recipients and society as a whole (as well as for the economy).**

## Focus on the English model.

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

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

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

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

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

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

Paradigm shift: a whole family approach

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

The drivers of the change of legislation

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

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

## 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 Italian policy-makers can be complemented by actions taken at European level.

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

The Principles	The relevance for <u>young carers</u>
<b>Principle n. 1 – Education, training and life-long learning</b>	Caring responsibilities can have a negative impact on <u>young carers'</u> education (under-achievement, absence and drop-outs)
<b>Principle n. 4 – Active support to employment</b>	Young carers are more likely to be NEET (not in education, employment or training) than their peers.
<b>Principle n 11 – Childcare and support to children</b>	Young <u>carers</u> 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.
<b>Principle n. 18 – Long-term care</b>	By providing good quality formal LTC services to the person they care for, inappropriate caring can be avoided.

Figure 3 - 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.