



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: United Kingdom

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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, unofficial data from a [2018 BBC survey](#) revealed there are 800.000 young carers under the age of 18 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 UK, 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.

Policy-makers and service providers are still either unaware of the challenges faced by young carers and the possible measures to prevent or overcome them, or 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, the United Kingdom, Switzerland and Sweden);
- 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 the UK. To have an overview of the main findings across all the project countries, please refer to the European brief (available [here](#)).

Chapters 1, 2 and 3 focus on the initial findings of the Me-We project, arising from the first year of activity, which have consisted in an online survey, an analysis of the legislative/policy frameworks as well as a review of existing support measures.

The full results will published in peer reviewed journals in 2019 and 2020.

Chapter 4 theorises on the basis of the Me-We findings, the knowledge deriving from previous research and the current policy environment, in order to identify policy priorities as well as possible courses of action.

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

Introduction

The challenges of being a young carer

Who are young carers?

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

What do young carers do?

- Practical tasks (e.g. cooking, housework and shopping);
- Physical care (e.g. helping someone out of bed);
- Emotional support (e.g. talking to someone who is distressed);
- Personal care (e.g. helping someone dress);
- Managing the family budget and collecting prescriptions;
- Helping to give medicine;
- Helping someone communicate;
- Looking after brothers and sisters
- Financial assistance (e.g., working a paid job to support the family finances)

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, and a deficit in formal support and services from the State and/or community.

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

The impact of caring

Mental health and wellbeing

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

Education

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

Social life

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

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

Why are young carers invisible?

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

- Young carers do not recognise themselves as young carers
- They are afraid of being taken away from their home by social services/child protection.
- They are afraid of being judged or misunderstood by their peers, teachers or service providers
- There is stigma (especially when cared for person has mental illness or substance dependency)
- They are uncertain about who to talk to
- They believe that nothing will change if they disclose their caring responsibilities
- Service providers tend to focus on the cared for person
- Wider community is not aware of specific services for young carers (if any exists)

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

* Prof Saul Becker, University of Sussex

Why do we need to address the issue?

Young carers are unable to fully enjoy their human rights

The UN Convention on the Rights of the Child states that **“Every child has the right to...”**- among others- rest and leisure (Article 31), education (Articles 28 & 29), adequate standard of living (Article 27), express their views (Article 12), enjoy the highest attainable standard of health (Article 24).

Young carers, just like all children, should be able to enjoy the rights to which they are entitled. Too often though, the challenges they face directly hinders that process and so the level playing field may no longer be sufficient to guarantee equal opportunities for young carers. Young carers are a particularly vulnerable group of children and should be recognised as such. They should not only benefit from the universal implementation of their rights but be subject to additional and tailored policy and support measures with a scale and intensity that is proportionate to their level of disadvantage. This is in line with the international human rights law which requires States to adopt **affirmative actions** in fulfilling their obligations to respect the equality principle. It can be argued that the lack of positive actions from States to support young carers is a failure to protect and promote their rights.

Supporting young carers makes economic sense

- **Early school leaving creates high individual, social and economic costs.**

Young people with only lower secondary education or less are more often affected by unemployment, are more likely to depend on social benefits and have a higher risk of social exclusion. Their lifetime earnings, well-being and health are negatively impacted, as well as their participation in democratic processes.

In addition to the individual costs, early school leaving hampers economic and social development and is a serious obstacle to the European Union's goal of smart, sustainable and inclusive growth. That is explicitly recognised by the Europe 2020 strategy, which includes the target of reducing the EU average rate of early school leavers to under 10%.

- **Poor mental health is a cost for societies.**

At international level, there is growing recognition of the importance of early intervention and **prevention** to avoid poor health outcomes. As stressed by the World Health Organisation, promoting and protecting

children and adolescents' health brings benefits not just to their health, both in the short and the long term, it also contributes to economies and society, with healthy (young) adults able to make greater contributions to the workforce, their families, communities and society as a whole.

Investing in young people is a social investment. As recognised by the EU in the Social investment Package, through early interventions, socio-economic inequalities can be tackled at the roots, the cycle of disadvantages can be broken and equality of opportunity can thus be promoted.

Between support and emancipation - the Young carers' Dilemma

Before proceeding, it is worth to look into the common ethical conundrum regarding the situation of young carers according to which: "it actually does not pertain to children and young people to assume caregiving responsibilities and consequently, supporting young carers is by essence detrimental to their best interest". Here are the various arguments brought about by those endorsing these contradictory approaches.

Vision 1: "Young carers should not exist and policy attention should be put elsewhere"	Vision 2: "Young carers should be identified and supported"
By supporting young carers and teaching them how to cope, we effectively accept the <u>transfer of care responsibilities from the public to the private sphere</u> , thereby harming both the principles of universal access to care and the rights of young carers.	The idea that children should be free from having a caring role makes absolute sense. Yet, it is <u>unrealistic</u> to ensure that children have no caring roles anymore and we should therefore rather provide interventions, support programmes and methods to prevent or lower the care burden among young carers. <u>Young carers exist</u> and they will be there for many years to come, so we should focus on how to support them and follow up on their needs.
"If appropriate services are delivered to the cared for person, the child or young adult could get on with the ordinary business of growing up. Hence, it is important to <u>direct resources and strategies at reducing the need for children to care in the first place (by providing services to the person in need of care)</u> ."*	"We recognize that in an ideal world where the voluntary and statutory support services are willing and able to provide extensive or unlimited support, the role of young carers would be greatly reduced. But we also recognize unpalatable current political and economic realities and that in an increasingly pressurised and residual welfare system, in the context of economic recession, uncertainty and charges for social care, <u>family carers are going to be expected to continue their support</u> . In such a context, <u>it is important that the role of (adult and) young carers is fully appreciated and valued</u> ."** If we have zero tolerances – pretending that young carers do not exist- then we will not see them until it is too late, when their needs for support have escalated.
From a human rights perspective, children have the right to be children and not to be carers. A system of support would have the effect of entrapping them into a caring role from which they should be free, in so doing violating their rights.	<u>Young carers' right to self-determination includes the right to care</u> , if they wish to do so, provided that their best 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.
The vision of the Me-We consortium: <u>Choice</u> should be the backbone of every decision about carers. People should have the right to choose freely whether they want to be – and remain - a carer, and to what extent they want to be involved in caring. However, choice is unlikely when no professional or informal care alternative is available. The universal provision of affordable and good quality long-term care services is therefore a prerequisite for the self-determination of carers. At the same time, we recognize that the availability of alternative options – while being imperative – may sometimes not be sufficient to allow for a genuine choice. Indeed, other factors (such as the feeling of guilt or of familial duty) may play a role and influence personal perception on offered alternative options. Because of the feelings of love and duty, some young people do not wish to stop care provision completely; rather they wish to be supported in their caring role. In these cases, society's mission should be to provide them with recognition and support and to protect them from inappropriate caring responsibilities (those which are 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). Recognition, support, protection from inappropriate caring are key elements to enable young carers to pursue their life goals and lead a thriving life.

*Richard Olsen & Gillian Parker, Critical Social Policy, Issue 50; ** Jo Aldridge and Saul Becker, Critical Social Policy, issue 16.3

Chapter 1: What is it like being an adolescent *and* a carer?



Figure 1- The Me-We online survey

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

The aim was to assess the extent of caring and its effects (impact on general wellbeing and education) for adolescent young carers.

In the UK, out of the 963 respondents to the survey, 353 were carers (people who provide 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 UK sample is **276** (caring for either a family member or a friend, including those who care for both, i.e. overlaps). 37% report that they have been providing care to someone for as long as they can remember.

The majority of adolescent young carers in the UK sample (73.6%) are girls and young women, which is in line with the existing literature on the gendered nature of care, and the cultural, social and familial expectations of care. 23% are boys, 2.2% transgender and 1% identified as other.

The total number of AYCs sampled in *England* is 244 (88.4%). The total number of AYCs sampled in *Scotland* is 31 (11.2%). There was only 1 AYC in this sample who reported living in *Wales*, and no AYCs reported that they lived in Northern Ireland. This discrepancy reflects the sampling strategy and difficulty in accessing gatekeepers and participants in Northern Ireland and Wales. 252 AYCs indicated that they are British citizens, and 23 AYCs reported that they do not possess British citizenship. Of those who indicated that they possessed British citizenship, there are 218 AYCs (87%) who identify as English, 29 AYCs (11.6%) who identify as Scottish, and 3 AYCs who identify as Welsh (1.2%). It is important to note that there were respondents who did not affirmatively answer that they possessed British citizenship, yet they affirmatively answered that they identify as Scottish or Welsh. This corresponds with the societal understanding of identity in the United Kingdom between the inhabitants of the four nations.

The majority of the AYCs in the UK sample (N=163; 59%) reported that they live in a town or small city.

Whilst most of the respondents (non-carers included) live in dual parent households, it is observed that there are more households with lone mothers than in the other European countries in this research study. Findings also indicate that the multi-generational households in the United Kingdom occur less often than in the other European countries in this survey: 3% live with a grandmother and 1% live with a grandfather.

Who do adolescent young carers care for?

Of the 309 respondents who indicated that they have a family member with a health condition, 231 (77.5%) report that they provide care, look after, or help their family member with a health condition. Thus, in the UK sample, **there are 231 adolescent young carers looking after a family member with a health condition.**

The “typical” profile of adolescent young carer in the UK is a girl providing care for her **mother with a mental illness**. This is a difference compared with the other surveyed countries – except Sweden- as there the main condition of the family recipient is physical disability.

Even though mothers are the primary care recipient in the UK sample, there is a strong presence of sibling care (the same is valid in the case of Sweden). More research is needed to explain why there is a strong feature of sibling caring within the United Kingdom sample. A possible explanation could be the decrease of formal services for siblings with disabilities or illnesses. As a result, more adolescents have taken on caring roles in their families for their siblings to circumvent the lack of formal support. The finding could also be attributed to the composition of the family, e.g. when there is only the mother and she does work, siblings are taking up more caring roles.

145 AYC's (72.5%) provide care for only one family member. 44 AYC's provide care for two people (22%).

Care can be provided also to non-family members. 223 respondents (46.8%) indicated that they have a friend or another person close to them with a health condition. **118 adolescent young carers** reported that they **provide care for their close friend**. As to the health condition of the caree, in the majority of cases it is mental illness.

39 AYC's (44%) provide care for only one close friend. 29 AYC's (33%) provide care for two 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, and the differences are highly statistically significant. Hence, they have different experiences of daily life than their non-caring peers. In details, 51% of the total adolescent young carers in the sample perform high amount of caring activities (MACA score above 14), compared to 32% non-carers. 29% adolescent young carers (78) perform a very high caring activity (MACA score above 18), compared to 18% non-carers.

The amount of caring activities undertaken by adolescent young carers in the UK sample is substantially higher in comparison to the other European countries in this study (except Slovenia). In the other surveyed countries – except Slovenia- the percentage of adolescent young carers with high and very high amount of caring activities are 23-35% (high), and 10-18% (very high). This finding can be explained with the fact that nearly all of the adolescent young carers who took part in this research survey would have participated through their young carers project - due to the selected sampling strategy. Because of the severe budget cuts in formal services during the time of British austerity, young carers projects are seeing more young people at "crisis level", and because of projects' limited capacity and resources, they often prioritize referrals of young carers with particularly significant levels of caring responsibilities.

Overall, girls perform a greater amount of care activities compared to boys (however, on the household management and financial and practical subscales the differences are not statistical significant).

Impact on educational attainment

The majority of adolescent young carers (97%, N 246) were currently engaged in education at the time of the survey. 103 AYC's (41%) reported that they have experienced difficulties in school due to their caring responsibilities. 94 AYC's (22%) reported that they have experienced negative school performance due to caring. 92 AYC's (36.9%) reported that they have been bullied, teased, or made fun of, due to caring.

These percentages are higher than in the other surveyed countries.

This finding corresponds with previous young carers research in the UK: negative school performance and bullying are strong features of the educational experience of young carers in the UK.

This finding underlines 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 well-being in comparison to their non-caring peers. On a scale where 50 indicates extremely high wellbeing and 10 indicates low

wellbeing, non-carers have a mean value of 38.2 – the highest among all surveyed countries, indicating a good overall wellbeing. Adolescent young carers have a mean value of 35.9. The difference is not as large as in the other countries, but still significant.

Health impact of the caring role

As to the impact of caring on the physical and mental health of young carers, the results from the UK sample stand out: the sample shows higher percentages compared with the other countries (except Switzerland): 30% of adolescent young carers report physical health problems due to their caring role. 60% report mental health problems.

This finding can be attributed to economic and societal stressors the economic effects on families with disability and illness during the period of government-sanctioned austerity could influence the psychosocial health experience of adolescent young carers. This may help explain why adolescent young carers in the United Kingdom continue to report greater health difficulties due to caring despite the formal support services in place within their specific country context.

Another difference in comparison with the other countries (except Sweden) is that in the case of UK adolescent young carers the impact of caring is stronger on mental than on physical health.

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

Due to their caring role, 30% of adolescent young carers have thought about hurting themselves and 12% have thought about hurting others (of these, 43% have thought of hurting the person they care for).

Once again, adolescent young carers in the UK have reported more negative impacts in comparison to the other countries. This can be attributed to the sampling strategy: the majority of recruitment efforts focused on AYC's in young carers projects. Those projects may engage with a higher proportion of AYC's with already existing health problems and severe emotional distress.

The negative mental health impacts may be related to the societal disparities caused by the British austerity period, but future research is needed to determine any correlation. It is also worth adding that young people generally in the UK have a difficult time accessing mental health services (see for instance [here](#)). This means that mental health condition of young people, including AYC's continues to worsen as they are denied services and treatment.

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. It also provides insights for better understanding the phenomenon of neglecting and abuse against (older) people with disability, in order to plan intervention for preventing aggressive behaviors and limit domestic violence episodes.

Access to formal support

In the UK, 47% of adolescent young carers surveyed personally receive formal support (from statutory agencies, such as social service). This is a higher percentage in comparison to all the other surveyed countries (except Sweden).

This finding can be attributed to the sampling strategy of the research in the United Kingdom (participants were largely recruited from young carers projects and therefore accessing a level of support in regard to their caring role), as well as the actual presence of dedicated young carers support services in the United Kingdom.

When considering external awareness of their caring role, the AYC's in this survey indicated that it is more likely that they have a friend aware of their caring role (68.6 % report that they have at least one friend who is aware of their caring role and gives them support), than someone at school (59%) or their employer (9%).

However, the proportion of school awareness of their role is the highest in comparison to the other European countries in this survey.

These findings indicate that the AYCs in the United Kingdom in this research study appear to have more external awareness of their caring role, particularly amongst their friends or at school. This may be due to their engagement in formal support services, such as young carers projects, which often liaison with school administrators on their behalf.

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

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

Legislation

In the UK, young carers are protected as children (via non-specific legislation) and as young carers (via specific legislation). The four countries of the United Kingdom are the only ones among the countries of this study to have specific legislation on young carers. An overview is provided below.

England	
Specific legislation	<p>In England, provisions for young carers fall within Children and Families Act 2014 and The Care Act 2014, which work together in order to bring about a preventative and whole family approach to identification, assessment and support.</p> <p>The Children and Families Act 2014:</p> <ul style="list-style-type: none"> - Defines young carers: a person under 18 who provides or <u>intend to provide</u> care for another person - Places a duty on local authorities in England to <u>assess young carers' needs on the appearance of need</u> of whether they receive a request from the young carer or the parent. - Places a duty on local authorities to <u>take reasonable steps to identify</u> the extent to which there are young carers within their area who have needs for support <p>The Care Act 2014 reforms the law relating to care and support for adults and the law relating to support for carers. It refers to adult carers but it contains some provisions for young carers in <u>transition between childhood and adulthood</u> (no set age for this transition). It places a duty on local authorities to assess whether a young carer is likely to have needs for support after becoming 18 and, if so, what those needs are likely to be.</p> <p>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.</p> <p>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.</p>
The rationale of the new legislation	<p>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.</p> <p>There was evidence showing the very low percentage of young carers who were receiving an assessment of their needs. Human rights considerations – reinforced by economic</p>

	arguments- were used to advocate for a change in the policy. 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 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.”
<u>Paradigm shift: a whole family approach</u>	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 (see this briefing). 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 ' (holistic view of the person's needs, including identification of how the adult's needs for care and support impact on family members or others in their support network).
<u>Key drivers for changes</u>	Non-Governmental Organisations (NGOs) 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.
Wales	
<u>Specific legislation</u>	In Wales, the Social Services and wellbeing Act 2014 provides the legal framework for improving the wellbeing of people who need care and support. Children with caring responsibilities are included within the general definition for a carer (a person who provides or intend to provide care for an adult or disabled child). The Act gives carers a right to an assessment on appearance of need.
Scotland	
<u>Specific legislation</u>	In Scotland, legislation for young carers sits within legislation that is specific to carers: the Carers (Scotland) Act 2016 . Within this legislation, there is a duty to prepare a 'young carer statement' for young carers which sets out their identified personal outcomes, any needs they may have and the support for them (if any) to be provided by the local authority. Definition of young carers: “young carer” means a carer who (a) is under 18 years old, or (b) has attained the age of 18 years while a pupil at a school, and has since attaining that age remained a pupil at that or another school. Local authorities have the duty to identify young carers and to offer them a young carers statement. If the professional who is working with the young carer feels that the young person is in need, they can refer back to the Children and Young People's Act * and, under that legislation, they will have a child's plan put in place. * The Children and Young People's Act (Scotland) 2014 is a non-specific legislation. It ensures a single planning framework – a Child's Plan – will be available for children who require extra support that is not generally available to address a child or young person's needs and improve their wellbeing.
<u>Key drivers for changes</u>	The Carers Parliament, funded by the Scottish Government, was a key element for the introduction of a legislation for carers in Scotland, because it raised the awareness toward this topic. It was kind of a natural progression, starting from a national strategy and then making it stronger, and then introducing a new legislation. In the first proposal of the Carers Act, there was nothing about young carers, because it was assumed that they are covered by the provisions within the Children and Young People's Act. However, through

	consultation and the involvement of young carers, the Act was amended and now it explicitly includes young carers. Young Carer Statements were legislated for giving young carers their own provision to help ensure that they would be identified.
Northern Ireland	
<u>Specific legislation</u>	The Children (Northern Ireland) Order 1995 places a duty to carry out an assessment where 'a child ("the carer") provides or intends to provide a substantial amount of care on a regular basis for a person aged 18 or over' or upon request of the child. The assessment determines whether the child is to be taken to be "in need". If they are a child in need they can receive support.

Policy and service frameworks

Policy and service frameworks in England, Scotland and Northern Ireland address the identification of young carers, their needs for support (especially in education), as well as the improvement of their outcomes. No policy document is available in Wales and this is considered a limitation by the experts.

Policy and service frameworks	
England	
<p>Carers Action Plan 2018 – 2020 Supporting carers today prepared by the Department of Health and Social Care. This policy paper sets out how the government will improve support for carers in England between 2018 and 2020. It specifically addresses young carers and their identification, improving their educational opportunities and outcomes and access to support services and the transition for young adult carers. This will hopefully be a helpful instrument to embed the legislation.</p> <p>Working Together to Safeguard Children - A guide to inter-agency working to safeguard and promote the welfare of children (2018). This statutory guidance has a number of references to young carers.</p> <p>The Care Act and Whole-Family Approaches. This document aims to provide practical guidance for practitioners working in adult social care in relation to carrying out assessments and developing plans which consider the needs of the whole family.</p> <p>No wrong doors: working together to support young carers and their families. This template helps to promote the cooperation between adult's and children's social services and enhances the partnership with health and third sector partners.</p>	
Scotland	
<p>Getting it Right for Young Carers - The Young Carers Strategy for Scotland</p> <p>The aim is to help improve outcomes for young carers, e.g. through the identification of their needs and priorities; measures to help professionals in education, health and social care to identify young carers; etc.</p> <p>Although it refers to 2010-2015, there are still action points that the Government is keen to see fully implemented.</p>	
Northern Ireland	
<p>The Children and Young People's Strategic Partnership Young Carers Group identifies children acting as carers' as a priority group. It brings together the voluntary sector of providers working with young carers with representatives from health and social care and education to look at the needs of young carers. They have produced a booklet called "Supporting Young Carers in School" which is a co-production with the education authority.</p>	

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

The experts interviewed for our study unanimously recognised that the changes in legislation considerably improved the rights of young carers, by putting in place the infrastructure to protect children from being negatively and unduly impacted by caring for family members.

In relation to the Care Act and the Children and Families Act, the experts identified the following key strengths:

- Young carers are now recognised within legislation and local authorities have a duty to actively look for them and identify them
- The legislation triggers a whole family approach
- Comprehensive, explicit and detailed regulation for young carers
- The words “or intend to provide care” in the definition of young carer highlight that prevention is also important.
- Engagement of young carers in shaping the development of policy and legislative changes

Similarly, in relation to legislation, policy and service framework in Scotland, the experts welcomed the introduction of a legal definition of the term “young carer” and praised the active engagement with young carers and the voluntary sector in shaping and implementing the legislation.

Despite the undeniable positive aspects of the legal provision, the experts pointed out that **there is some distance between the legal foundation and the actual implementation of the law**: identification and assessment of the needs of young carers and families has not happened in the way it should have done; many young carers and their families still aren’t receiving the support they need.

According to the experts, the gap between legal provision and practice can be attributed to different reasons. Some of them are country-specific. For instance, experts in Northern Ireland indicated that the lack of government since 2017 has contributed to the de-prioritization (and generally, complete lack of focus) of young carers in governmental discourse.

Other reasons are common to all the countries of the UK:

✓ **Legislation is good but guidance is needed**

In relation to England, it was stressed that:

- Local authorities may have different approaches on how to enact the legislation. Some local areas will have fixed up local working groups to address the duties and how to implement them with a multi-agency approach. Others still have gaps between children’s services and adult services in terms of understanding what their responsibilities are under the Care Act towards young carers. The most successful areas tend to be those whose work on policies and working for young carers was pretty strong before the legislation came into place and were therefore already in a strong position to be able to implement the duties.
- There is no template for the assessment and this creates confusion among local authorities. This results in some areas producing their own young carer’s assessment and in using different assessment tools.
- Central government legislation is hard to enact in practice because it is so detailed

Similarly, in relation to Scotland, the experts pointed out that:

- There is the potential to have a wide variation of the type of statement offered, because the statements were not prescribed and different local authorities have different approaches. There are 32 local authorities so there is the potential to have 32 different types of statement.
- The Carers Act is complicated and some local authorities are quite confused about aspects of it such as who is responsible

- ✓ **The law is seen as useful but only if people assert their rights.**

Young carers tend not to use the law and their parents do not know about it.

- ✓ **(Self)identification is still problematic**

In order to receive a young carer's assessment young carers firstly need to be identified. Some children and families however do not identify with the term "young carer", or they are frightened of having a child labelled as a young carer because that might lead to family separations.

- ✓ **The implementation of a whole family approach does not work effectively because of the gaps between children's services and adult services.**

The adult service professionals still focus on the adult with needs and not on the child.

- ✓ **The legislation is vague about the support to be provided following the assessment,** including the need for support from young carer groups.

It is thought this makes the groups feel quite vulnerable and sometime vulnerable with budget cuts. According to the experts, the actual support that families and young carers should receive following their assessment should be strengthened within legislation and policies.

- ✓ **The existing policy in place is difficult to deliver without the proper amount of funding**

- The resources of local authorities for implementing the legislation, policy or service frameworks are tight.
- The health and social care services are confused about how to deal with the legislation without enough resources.
- Social services are very stretched with limited resources and therefore having an assessment may not be seen as worthwhile by families.
- Some local authorities have massive waiting lists for assessments

As a result of the above, despite the good potential of the legislation, which is taken as example from other countries across Europe, in reality young carers are still being left alone to provide support for family members, leaving their own futures at risk.

"I think some of the legislation that was introduced a few years ago potentially offered a really effective system of support and identification but unfortunately without the resourcing at a local level to back it up, many of the intentions of the policy probably haven't played out in practice."

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

The project partners interviewed 10 UK experts on adolescent young carers or related topics, from the fields of academia, policy, health and/or social care, in order to reflect on the situation in their country as to visibility of young carers and support provided to them.

Visibility and awareness

According to the classification of in-country awareness and policy responses to young carers (Becker, Leu) the UK can be characterized as advanced. The awareness and recognition of young carers amongst public, policy makers and professionals is widespread. Young carers in the UK have specific legal rights (as carers and as children) as well as access to a national network of dedicated services.

The interviewed experts recognised the important role played by NGOs such as Carers Trust and The Children's Society in raising awareness, leading to the changes in legislation. Since then, the visibility of young carers has been increasing, also thanks to celebrities/politicians speaking up about their own caring

experiences, or the appearance of young carers in media (e.g. popular Hollywood movies such as the *Hunger Games*).

One of the interviewed experts stressed that there is a sentiment that all has been accomplished for young carers and nothing further must be done. This expert alluded to the dissolution of the National Young Carers Coalition and their view that national NGOs do not appear to be leading on work for young carers as strongly as they had in the past.

Yet, the interviews with the experts allowed to identify few gaps in visibility and awareness.

✓ **Some young carers remain hidden**

Overall, it was thought that certain young carers still remain quite hidden in UK society: those out of contact with a formal support service; those living in rural areas; those from Black and Minority Ethnic communities; LGBT young carers; migrant AYC's; those with their own health issues; those caring for someone with a mental illness or substance misuse condition; those caring for those with HIV/AIDS; those in Roma, Gypsy, and traveller communities; those out of education. Similarly, experts agreed that adolescent young carers and young adult carers are particularly hidden in comparison to young carers.

The experts also pointed out some shortcomings in the ways currently used to identify young carers. For instance, some colleges have a tick box question in their admission forms. According to the experts, if the question is "are you a young adult carer?" young carers may not understand that concept themselves, so they may not tick the box. If the question is phrased as 'do you care for someone at home who might have a long term...?' then it may be easier to self-identify.

The same applies in the case of Census: it is important to ask the right question in the right way, otherwise the numbers won't correspond to the reality.

Always in relation to self-identification, the experts stressed that there is an overemphasis on what housework the person does versus the emotional support that they are offering and this needs to be improved, otherwise the child may not recognise himself as a carer.

✓ **Need for improvement in awareness among professionals**

It was overwhelming agreed that professionals in a variety of sectors need to receive more training on how to identify and support young carers.

School professionals are the ones who usually refer young carers to the services (together with the voluntary sector). Yet, on an individual level there could still be some resistance, meaning that some teachers may feel that identifying and supporting young carers is not their responsibility, rather, it is the responsibility of social welfare.

More importantly, the experts pointed out that much more could be done by health professionals and professionals from the adult services.

It was suggested that GPs and GP attached nurses should play a more significant role in the identification of young carers. Yet, they do not, for different reasons, such as:

- Historically, carers were not a central focus in health training, and therefore even the concept of "carers" was absent from health professional language.
- Health care professionals are frightened to ask more questions leading to the identification of young carers because they feel incompetent in regards to how to direct young carers to services.
- It was also thought that the lack of a "solid" duty (in reference to the Care Act and Children and Families Act, health professionals have a "duty of cooperation") for health professionals to engage with carers was one reason for the disengagement with young carers.

Child and adolescent psychiatrists also should play a role in identifying young carers. However, they currently work in Child and Adolescent Mental Health Service teams (CAMHS) which are “grossly underfunded and grossly understaffed” and at a “state of crisis in the child and adolescent mental health”. This explains, according to one expert, why they are not active in identifying young carers. The issues of understaffing and underfunding continue in adult mental health services and therefore the transition period for young carers aging into adulthood is also fraught with troubles. Adult mental health services are “very threadbare, understaffed, and over-pressed”, and further complicating matters, adult mental health services do not typically think of the social context of the family and often claim that they do not know how to talk to children.

“This isn’t just an issue for GPs. This is an issue for every professional that’s working with the adult in the family and that issue is that the child is invisible. The GP might see a patient or it could be a counsellor from a substance misuse service or it could be any number of professionals and they’re just seeing a parent. They might see them during office hours when all the children are at school. My personal feeling is that there is often out of sight out of mind. Even if they know that there are children in the home, they won’t really go out of their way to explore how they are affected by that adult’s condition.”

Evaluation of available support

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

The experts recognised the positive aspects of such services: young carers projects are useful because of the way they can offer family support and consider the needs of the entire family; they provide the opportunity to talk amongst other young caring peers and talk to adults who are knowledgeable about their family situation; they can also direct a young person to other avenues of support, respite care, or help facilitate communication between social care and schools.

The experts reflected that formal support offered in the UK has transitioned from offering only respite activities to model of building resilience. This is to lessen the dependency of young carers onto formal support services, especially in times of budget cuts and reduced services available.

“We have moved to much more of a resilience based model, where young carers do not stay in the project for the rest of their lives, but they move through levels.”

When asked to evaluate the available support, the experts identified the following limitations of the support system available in the UK.

✓ **Supporting programmes are piecemeal**

Experts felt that it was critical to remember that supportive programmes and policy were varied across the four nations within the United Kingdom. The diverse political contexts (e.g., devolved governments) mean that what formal interventions are in one place, may not be in another. Experts felt that a unified system is needed.

“That was an awful lot of [young carers] project work that’s fantastic and has brilliant elements to it, but actually is still so piecemeal across the country and across the UK that we’re not actually delivering anything sustainable for those young people. And that really worries me.”

✓ **Continuity of support is often problematic (from an age perspective, from a funding perspective and from an integration of services perspective)**

Young carers services are often delivered by NGOs and enforced by commissioning arrangements with the local authority, who is in charge of deciding the remit of support, as well as the funding.

In relation to the continuity of support from an age perspective, the experts identified a huge challenge, consisting in the fact that when the commissioning arrangements put particular age barriers in place that means a young person can no longer access support even though they may need it.

“Aside from the basic struggle with identification in the first place, we’re then making it so much harder for ourselves by knocking them off another cliff once we’ve recognised these young people. So we can have young people in huge need, have acknowledged that, have started some great services for them, but all of a sudden, “Well you’re 18 so actually sorry, you’re off again.” And adolescence is hard enough where we’re identifying people and giving them a bit of hope, actually we’re not then actually giving them the continuity of support and the confidence that actually what we’ve offered to them is going to continue”.

In relation to the continuity of support from a funding perspective, it was widely agreed that austerity has had a big impact upon support. Some experts stressed the need to be realistic and practical about what formal support is present and its sustainability in a time of post austerity.

“We are in ten plus years of austerity, we’ve seen some really great programmes disappearing because there are just not the funds to sustain them, what I feel that we need to do now is take stock of what we know works, what we can sustain, how we sustain it in a practical way and so that we’re not letting down children and young people because that’s just happening right, left and centre and is unforgivable. And then build from there, because hopefully the austerity doesn’t last forever but what we’ve got to do is plan as if it does and I don’t think we’re doing that yet.”

In relation to the continuity of support from an integration of services perspective, the experts highlighted that the gap in transitional services remains a problem for (A)YCs; once identified, if there is no available supportive service for them once they hit the legal age of 18, this can cause more stress for (A)YCs.

✓ **The support should be more tailored to the specific needs**

The experts pointed out the importance to provide a support tailored to the specific needs. In the case of adolescent young carers, they need support with particular challenges that they might be facing that are different to young carers and to older carers. The support sought by adolescent young carers may be more holistic i.e., guidance on career choices, nutrition, and life management skills.

“They’re interested in healthy eating, and career advice. They were interested in learning more, going to university and adapt to things like that. Also, life skills, and they wanted to know about more mortgages and tax, because they’re taking on some of that responsibility at home, they actually want to get advice on.”

✓ **There are barriers across different government departments and different services**

“The 21-hour rule in the benefit system which prevents young adult carers from studying and claiming carer’s allowance if they are studying for 21 hours or more per week. I think that is just a real example of how government policy effectively works against each other really because not many people would disagree that young adult carers deserve the right to study and also receive small amount of benefits for supporting their families, but actually, the policy is not joined up across departments, so it is effectively education and welfare policy working against each other.”

Successful strategies to identify and support young carers

In this section we exemplify some strategies and good practices (from UK) to identify and support young carers.

Identifying young carers

It is 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, colleges, and universities can play a vital role in early identification of young carers. Tool such as MACA-YC18 could be used or tick box question in admission forms.
- 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 programmes.

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 programmes, social network campaigns are good ways for improving awareness and reducing stigma.

Supporting young carers with education and transition to employment

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

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

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

For example:

- Have counsellors that young carers can talk to one-to-one.
- Refer students to help services (e.g. sport club, youth club) and let them aware that these support services exist.
- Apply to young carers special measures already existing for other groups (e.g. in some schools, children performing top sports have a special status, consisting in getting extra time for their exams and other preferential treatments). These measures could be extended to children/young people who have caring responsibilities.
- Envisage a psychological supervision in school, in order to support (adolescent) young carers in managing frustration, anger and all the feelings raising from caregiving activities.
- Release a Carers card so that young carers don't have to explain their situation every time.
- Tutor
- Provide guidance to move to further education or employment
- 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.
- Ensure that young carers can access apprenticeships
- Envisage flexible working conditions for young carers, e.g. by providing incentive for employers who hire teleworking caregivers with part-time working hours.
- Raise awareness among employers

Good practice: the [Young Carers in Schools Programme](#)

Carers Trust and The Children's Society are leading the Young Carers in Schools initiative which makes it as easy as possible for schools to support young carers, and awards good practice. More than 700 schools are engaged in the programme and 69 have been given a Young Carers in Schools Award). The Young Carers in Schools Programme provides a step by step guide on how to implement a whole school approach to identification and support for young carers as well as a bronze, silver and gold standard.

Supporting the mental health of young carers

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

Peer/group support/Information

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

Good practice: Kidstime project

The organization Kidstime (a formal support service for children of parents with mental illness) helps the parents and children to communicate with each other and discover a joint understanding of mental illness, which they both accept and understand. It uses drama, awareness work in schools, separate parent and child groups, and joint groups on a monthly basis with up to 10 to 20 families. One expert emphasized that such dedicated groups are critically important for children with parents affected by mental illness as a "typical" young carers group may not fully address their unique needs and experiences.

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 recreational activities (e.g. by covering the transportation costs)

Good practice: [Young Carers Festivals](#)

Often run throughout the country, the longest running young carers festival takes place in Southern England through The Children's Society. The festival provides the young people with the opportunity to have fun, relax, socialize and have their voices heard about issues that affect them. The outcomes from participatory consultations inform future work and are communicated to the government.

Increase resilience

- Allow young carers access to tools and support to find useful coping strategies.
- Psychoeducation may be a useful tool to increase resilience.

Reducing the care burden

- Adopt a whole family approach in long-term care service provision.

- Improve the quality of long-term care services in order to reduce inappropriate caring
- 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.

Good practice: [Barnardo's action with young carers project](#)

This project focusses on young carers up to the age of 25 and provides assessments, specialist one-to-one support for each child, out-of-school and out-of-home activities, counselling and group work. The project also emphasizes indirect work with local agencies that include strategy planning, development, training and promotional work to ensure that local services were joined up. The project acts as a signpost to other services.

Engaging with young carers

Young carers needs should be considered in wider areas than just health and social care policy.

Young carers should actively been engaged in all decisions that affect them, as well as in policymaking in general. For their participation to be meaningful, they have to receive appropriate information, at the right time. 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 young carers know their rights
- Actively engage young carers in evaluation of policies and services

Good practice: [NHS England Young Carer Health Champion Programme](#)

Established in 2015 to support improved health literacy, promote health and well-being and develop the capacity of young carers to participate in planning and the development of young carer friendly services, it aims to support service change through young carer voices. It does so by means of group sessions and one-to-ones with support workers.

Good practice: [Edinburgh Young Carers Project Forum](#)

The forum is the main way that Edinburgh Young Carers Project consults young people about their views and encourages them to become involved with the project. The service of need is to encourage leadership and self-advocacy skills for young carers, providing an opportunity for young carers to influence the practices of their young carers project by means of face to face group meetings

Young carers led the forum with city commissioners and project workers present, providing an opportunity for them to share their views. The young carers forum demonstrates the success of empowerment and skills building for adolescent young carers, as they have listed their participation in the forum on their CV and for college admission.

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 the project activities, in particular in considering how to make the interventions successful and in the development of an app for adolescent young carers).

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

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

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

Chapter 4: Translating research findings into policy

Recommendations tailored to the UK context

1) Ensure that legislation is implemented

"We've done the legislation. That isn't the hard work. The implementation is the hard work, and I don't think we're there yet (...) there's this really good piece of legislation, but on the practical level, it's not happening for young carers."

The experts pointed out that there is a danger that the 'journey' with regards to legislation has 'come to an end' but there is still the need to ensure that legislation is implemented.

→More guidance

- Guidance about how to translate the legislation and policies into practice needs to be more effectively embedded and it needs to be reviewed and ensured that it is still workable for the local area
- More guidance for local authorities around what an assessment should actually look like

→More monitoring and evaluation

- More national monitoring around how local authorities' duties are being implemented, ensuring that young carers have been identified and that they received a young carer's assessment
- More evaluation on how the implementation of legislation and policy frameworks is working

→More resources for funding support services

The resources available to professionals to implement the law are often insufficient to do the job properly, especially in an economic climate of 'austerity'. Despite good legal intentions, most AYC's e.g. in the UK have not had their legal right to an assessment met and most AYC's receive no dedicated support at all. The interviewed experts admitted that there is no value in assessment without having a follow-up and money, time and people are needed to provide follow-up. Current cut backs in services across Europe, Brexit, and the increasing welfare, care, and health costs are barriers for effective follow-up and interventions.

2) Ensure early identification and intervention across all sectors

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. Similarly, the findings from our study 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.

→ More efforts in identifying young carers who are still hidden (e.g. children from parents with mental health problems or substance misuse)

→ Mandatory trainings to professionals from different sectors (includes GPs, school nurses and mental health practitioners)

→ More detailed definition of young carer in screenings tools and in Census

3) Enable positive transition into adulthood

→ Invest adequate resources to ensure continuity of support in terms of transition from children's services to adult services for young carers

→ Provide adolescent young carers/young adult carers with support tailored to their specific needs

4) 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.

→ Break down barriers across different government departments and different services

5) Protect young carers from inappropriate caring

State should be more responsive in improving the lives of the person needing care and, in turn, in improving the lives of young carers.

→ Health and social care needs to be adequately funded so that children and young people do not take on inappropriate caring roles which put their lives at risk.

6) Maintain consultations of young carers to keep their voice strong

7) Make sure that young carers stay as a recognised subgroup of vulnerable children and do not slip off the agenda

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 policy-makers in the UK can be complemented by actions taken at European level.

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

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

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

It is the role of policymakers to prevent and minimise the (potential) negative impacts of growing up while being a carer (restricted education, reduced life chances, affected well-being, isolation) and to enable young carers to thrive and flourish as human beings.

The life chances of thousands of children across Europe are at stake. There is no time to lose.