

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











**Vilans** 



**Country Focus: The Netherlands** 

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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 <u>2011 census for the UK (England and Wales)</u> 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 <u>unaware</u> 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);
- 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 the need to act.

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

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

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

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

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

# Introduction

# The challenges of being a young carer

# Who are young carers?

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

# What do young carers do?

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

Young carers aged 15-17 are called "adolescent young carers". They deserve special attention, as they are in a key, transitional phase of their development: moving from childhood into adulthood. This transitional stage is critical not only for biological and psychosocial considerations; but will also affect the positioning of potentially vulnerable adolescents with regards to the law, policy, as well as health and social care.

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

There is a continuum of children providing care, which ranging from <u>caring about</u> (low levels of care responsibility and routine levels of caregiving) moving to <u>taking care of (increasing care tasks and responsibilities)</u> to <u>caring for (high levels of care responsibility, substantial regular and significant caregiving.</u> For the latter there is broad evidence of significant negative outcomes, but for The Netherlands research also shows negative outcomes of growing up with a sick family member without having caring tasks.

## 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.

# 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 more positive actions from States to support young carers are needed 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.

<sup>\*</sup> Prof Saul Becker, University of Sussex

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 transfer of care responsibilities from the public to the private sphere, 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.  Young carers exist 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 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)."*	"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, family carers are going to be expected to continue their support. In such a context, it is important that the role of (adult and) young carers is fully appreciated and valued."**  If we have zero tolerances – pretending that young carers do not exist- then we will not see them until it is too late, when their needs for support have escalated.
From a human rights perspective, children have the right to be children and not to be carers.  A system of support would have the effect of entrapping them into a caring role from which they should be free, in so doing violating their rights.  The vision of the Me-We consortium:	Young carers' right to self-determination includes the right to care, if they wish to do so, provided that their best interest is safeguarded. Measures should therefore seek to preserve young carers from inappropriate caring, i.e. caring responsibilities which have a negative impact on the child's health, wellbeing or education, or which can be considered unsuitable in light of the child's circumstances.

#### The vision of the Me-We consortium:

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

# 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 Netherlands, out of the 645 respondents to the survey, 190 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 respondents within the age range 15-17 was 533. The total number of adolescent young carers (15-17 age) in the Dutch sample is 154 (caring for either a family member or a friend, including those who care for both, i.e. overlaps). 38% report that they have been providing care to someone for as long as they can remember.

The majority of adolescent young carers in the Dutch sample (72%) 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.

56% reported that they live in towns and smaller cities.

The majority of respondents (non-carers included) reported that they live in dual parent households (87%). In comparison to other European countries in this research study, a smaller proportion of respondents live in multigenerational households; only 2% live with a grandmother and 1% with a grandfather.

# Who do adolescent young carers care for?

The "typical" profile of adolescent young carer in The Netherlands is a girl providing care for her mother with a physical disability.

Of the 234 respondents (aged 15 to 17 years) who indicated that they have a family member with a health condition, 130 (59%) report that they provide care, look after, or help their family member with a health condition. Thus, in the Dutch sample, there are 130 adolescent young carers looking after a family member with a health condition. Of these adolescent young carers, 71 (72%) provide care for only one family member. There are a number of AYCs who care for multiple family members: 20 AYCs provide care for two people (20%), 6 AYCs provide care for 3 family members (6%), and 2 AYCs provide care for 4 family members (2%).

The care recipient can also be a friend. Of those 127 respondents who indicated that they have a close friend with a health condition, 50 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.

In some cases – even though just for a small number of adolescent young carers- young people provide support to several close individuals in their lives.

#### 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. In details, 35% of the total adolescent young carers in the sample perform high amount of caring activities (On a Multi-Dimensional Activities of Caring Checklist (MACA) score above 14), compared to 14% non-carers. 17%

adolescent young carers perform a very high caring activity (MACA score above 18), compared to 6% non-carers. Overall, girls perform a greater amount of care activities compared to boys (however, the only subscales in which differences between boys and girls are statistically significant are the sibling care and domestic activity).

## Impact on educational attainment

The majority of adolescent young carers were currently engaged in education at the time of the survey. 13% report that their school performance has been negatively impacted due to caring. 15% report that they have been bullied, teased, or made fun of due to their caring role.

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 in the Me-We project, indicating a good overall wellbeing. Adolescent young carers have a mean value of 36. The difference is not as large as in the other countries, but still significant.

# Health impact of the caring role

20% of adolescent young carers report physical health problems due to their caring role. 11% report mental health problems.

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

Due to their caring role, 11% of adolescent young carers have thought about hurting themselves and 4% have thought about hurting others (of these, 33% have thought of hurting their care recipient). This finding indicates that adolescent young carers are at significant risk of mental distress and underlines the need to engage health professionals, particularly mental health practitioners, to identify and support young carers.

#### Access to formal and informal support

In The Netherlands, 19% of adolescent young carers personally receive any form of formal support.

Many (61%) reported the presence of a friend who is aware of their caring role and offers them support.

When considering external awareness of their caring role, more AYCs in this survey indicated that they have a friend who is aware of their caring role (61%), rather than someone at school (31%) or an employer (11%).

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

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

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

# Legislation, policy and service frameworks

In the Netherlands, no specific legislation protecting and supporting young carers ('jonge mantelzorgers') and their families exists.

The current system offers an indirect support to young carers, mainly from legislations related to health and social care, general legislation for children and families, education, child protection. In details:

- ✓ Jeugdwet 2015 / The Child and Youth Act (2015): local municipalities are responsible to protect and support children through early identification and early intervention as well as by promoting parenting skills and strengthening the problem solving capacity of the young person, his parents and the persons belonging to their social environment.
- ✓ Wet Maatschappelijke Ondersteuning 2015 / The <u>Social Support Act</u> (2015): local municipalities support people who have difficulty participating in society or who cannot take care of themselves. Municipalities are responsible for the appreciation and recognition of informal caregivers by providing financial rewards of in-kind support. Where the recipients of support are parents, siblings or families in general, this helps to lessen the need for a child to take on a caring role.
- ✓ **Leerplichtwet 2007** Compulsory education Act (2007): students have to attend school until they are 18 or have obtained a basic qualification. The Compulsory Education Act is implemented by municipal authorities. Parents are responsible under the law to ensure their children attend school and sanctions can be imposed under criminal law.
- ✓ <u>Child protection legislation</u>. In some circumstances, being a young carer might necessitate initiating child protection measures.
- ✓ Wet Meldcode huiselijk geweld en kindermishandeling /The Mandatory Protocol (Domestic violence and Child abuse) Act: organisations from certain sectors (health care; education; child care; social support; youth care; the criminal justice system) are required by law to have a domestic violence and child abuse protocol in place. This includes a Child check: professionals check whether a family has children and, if so, whether these children are safe.

## A paradigm shift

The changes in legislation introduced in 2015 (with the Child and Youth Act and the Social Support Act) have been accompanied by a paradigm shift. They have brought about a huge decentralization and transformation of the Dutch (youth) care system. Responsibilities have not only been decentralised to the municipalities, but there has been a transformation of approach with a focus now on: the role of the family and social networks in the care process, prevention and a better coordination and integration of services.

#### **Service frameworks**

In addition to legislation, there are multiple protocols and guidelines being used in different areas of support:

✓ The Dutch Ministry of Health, Welfare and Sports launched three programs in 2018, with the aim that all people with disabilities and their significant others/relatives should be able to participate in society in line with their preferences. In particular, the program Volwaardig Leven ('A fulfilling life')

- states that the family of a disabled child (including brother and sisters) need to be visible within the healthcare sector and society at large and that the need of the family members should be addressed. The importance of information is also mentioned.
- The Ministry of Education, Culture and Science initiated a framework targeted at universities (following up on a Parliament's motion on the accessibility of psychological aid to students). A student welfare working group has been set up, focused on different groups of students, including those with informal caring responsibilities. A joint ambition between the ministry, universities, student organisations and the Expertise Center for Disability and Education has resulted from this work.
- ✓ Richtlijn Kinderen van Ouders met Psychische Problemen (KOPP) / <u>Guidelines Children of Parents</u> with Mental Problems (KOPP): guidelines for professionals in the field of for youth care and youth protection.
- ✓ <u>Toolkit Mantelzorg</u>: an advice of the Association for Dutch General Practitioners for general practitioners to pay attention to informal carers, including young carers.
- ✓ Het Verdrag inzake de rechten van het kind / The United Nations Convention on the Rights of the Child (UNCRC) is viewed as very important because it sums up all the rights for the children and because there is no other treaty worldwide that is ratified by nearly all countries.

## **Enactment of legislation**

The extent to which young carers are receiving support through existing legislation is not clear. The interviewed experts reported dissatisfaction about how effective the new system is. This may be due to the fact that the legislative changes are recent and legislation may not have embedded smoothly everywhere. Some initiatives following legislation exist, but the local legal frameworks and policies do not. Despite the significant focus on youth support, young carers could remain largely unnoticed in the current local legislative and policy system.

Some municipalities have been developing and promoting support programmes for adolescent young carers (see for instance the <u>support provided by the municipality of Amsterdam</u>) or the project Young and Caring initiated by four municipalities in the Province of North Holland - and provided by care support organisation Mantelzorg & Meer - aimed to provide support to adolescent young carers. Yet, current support for young carers is likely to be very inconsistent between municipalities and is dependent upon municipalities and the viewpoints and actions of individuals: children, parents and professionals.

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

- The new Child and Youth Act 2015 has brought new clarity and goals for supporting children, youth and families and the extent to which these goals are being met.
- The responsibility to support young people and carers has been devolved to the municipalities. They have more insight into what the problems are and hence they can respond better.
- In some cases, the support under the Child and Youth Act 2015 can continue until the young is aged 23.

#### Limitations

Young carers are not explicitly mentioned in the Child and Youth Act. According to some experts, the reason why legislation or policy do not specifically address the issue of young carers may be due to the perception of children and young people. That young people are seen as being children for perhaps longer than in some countries and there is therefore a focus on their protection as children, which may not accommodate the possibility that as they become older and independent they may require support as informal carers. One expert pointed to the importance of finding a

balance between taking the burden off young carers, while also recognizing their own desire to care for their family member.

- "...you try to take the burden off children and youth as much as possible [...] while at the same time [...] for the kids it can be important to be able to do something. And then I think: it is also important to respect that."
- \* As consequence of the decentralization process, the municipalities can decide for themselves what constitutes basic care provision. They must also shape their informal care policy and purchasing and arranging a supportive supply of services. On one hand, this ensures a better response to real needs. On the other hand, this has led to inconsistent support with substantial differences between municipalities.
- There have been budget cuts for youth support.
- Monitoring of goals and outcomes are not yet in order.
- There are <u>challenges around the transition period</u> (in all areas of youth rights), for example in a smooth connection of support when children legally become adults.
- <u>Care is segmented</u>: there are multiple protocols and guidelines being used in different areas of support such as in health, mental health care as well as in youth care. An integrated approach is lacking.

#### Future needs

The experts expressed some considerations as to future needs and ways forward on legislation, policy and service frameworks in the Netherlands. Here are some of their comments which were supported by one or multiple experts:

- Legislation and policy is important for laying the foundations and is necessary to bring about uniformity, as well as clarity about goals and how to reach them. Legislation should then be enacted in different ways to accommodate the needs of such a diverse group.
- Discussions about young carers should be integrated with discussions about adult informal carers.
   In relation to that, it is likely that approaches to supporting young carers will in the future come through family care under the Social Support Act. At the same time, young carers under 18 should be viewed differently from adult carers over 18 years old since they have different legal positions.
- The needs of young carers need to be assessed and support provided to meet those needs.
- Comparisons could be made with what is being done in other countries.
   For example, research could be undertaken as to how the 'Care Act' in England -legislation explicitly recognizing and defining young carers- came about. (Please refer to the box "Focus on the English model").
- Current social care legislation could be amended to include the assessment of the needs of young
  carers as in the UK. The <u>International Cooperation Agency of the Association of Netherlands</u>
  <u>Municipalities</u> could be involved to draw up legislation along the lines of the Care Act in England.
- The Child and Youth Act could be changed to a more prescriptive entitlement of provision of care.
- Since the Netherlands is moving increasingly towards a preventative model of support, it is hoped
  that children should also be part of discussion. A preventative approach should be taken to lessen
  negative impacts and need for specialist support. Schools should also play a key role as part of
  a preventative approach by identifying and assessing the needs of young carers.
- **More** recognition and **understanding** is needed about this group of children and young people, including the number of young carers, the impact of caring roles, their needs and their rights and the support available to them.
- A **broad awareness** is needed among all those working with young people. Professionals need training about who young carers are and the impacts of caring. Students also need to be made aware of the issue through the education curriculum.
- Identification of young carers needs to improve and new approaches need to be employed.

•	Young carers need to be consulted when taking decisions that have an impact on them.

### Focus on the English model.

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

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

Right to assessment of needs and support. The new legislative framework defines young carers, 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 <u>2015 report</u> 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 <u>briefing</u> 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.childrenssociety.org.uk/sites/default/files/tcs/nycc key points briefing on young carers the care bill.pdf

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

## Focus on the Netherlands

The project partners interviewed 10 Dutch 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 of young carers

The interviewed experts confirmed that in the Netherlands visibility and awareness on young carers are increasing. This mainly concerns children caring for someone with mental ill-health (and the focus is on the prevention of psychological issues as a consequence of their parents' condition, rather than as a consequence of their caring roles). For young carers in general, the **awareness** remains **low** and much more improvement is needed.

Experts also mentioned a **lack of recognition and knowledge among professionals** working with young people. In the health sector, still too often the link is not made between a parent being ill or disabled and a child being a young carer. In the educational system, there is no consistent approach to identify young carers: they could be identified and supported if school attendance is disrupted, however this does not appear to be structurally happening in a preventative manner.

To make the situation even more complicated, young carers often do not self-identify as carers, with the result that municipalities are unable to know who the young carers are in their area.

# Available support

Different initiatives are implemented – mainly at local level- to raise awareness, identify and support young carers. Some of them are indicated in the table below:

Who Cares?!	"Who cares?!" is a programme roll out in different high schools in the Haaglanden region. The goals are: recognition by teachers and mentors, recognition for young carers themselves, and better support for young carers.
<u>Ervaringsmaatjes</u>	Ervaringsmaatjes is a project where a volunteer or student who has experience of being a young carer provides individual support for young carers, acting as a buddy. Given his personal experience, the buddy knows better than anyone what that is like to be a young carer and he is there for the child without restriction, offering a listening ear, opportunities for socialization, as well as support on practical matters. He or she also helps to gain insight into the personal wishes and needs of young carers.  Ervaringsmaatjes is an initiative of Stichting Informele Zorg (SIZ) Twente and is being carried out in various municipalities in the Netherlands.
Week of the young informal carer	The week of the young informal carer is since 2019 an annual awareness raising event held in many municipalities across the Netherlands. The ultimate goal is to enlarge and enhance the support provision for young carers.
Vanzelfsprekend?!	"Vanzelfsprekend?!" is a platform for recognizing and acknowledging young carers where they can ask questions and be listened to. Together the young carer and Vanzelfsprekend?! look at the (A)YC's situation to see what he/she needs and to refer to formal care where needed. Vanzelfsprekend?! organizes activities like 'chill-

	evenings', and other events, for young carers to relax and have the space to share experiences with fellow young carers.	
Online Young Carer test (MantelzorgNL/Mez zo) SIZ Twente	This online test is a tool for the recognition of young carers. How do you know if you, or someone you know, is a young carer? This test raises questions to identify young carers. After you completed the test, the website provides tips and tricks for young carers and people who know young carers.  SIZ Twente organizes activities and courses for young carers in different municipalities in the east of the Netherlands. SIZ offers activities, courses, individual support and experienced buddies. The goal is to strengthen the resilience of young carers, also via an enhanced role played by the social network around him/her.	
Training for professionals	One expert particularly discussed the trainings that are offered to various professionals, including social workers, youth workers, family coaches, (child) psychologists, nurses and medical specialists. Another expert also mentioned doing presentations for these professionals, i.e., often those working at Centres for Youth and Family. These courses and presentations aim to stimulate professionals' awareness and to equip them with the skills to recognize young carers within their work field, to understand how their care tasks may affect their development, and to know how this group can be addresses (including referrals to third parties). Despite professionals' positive response, this expert lamented the limited reach of these courses, portraying their impact as 'a drop in the ocean'.	
Kind check/'Child check' in mental health sector	Several experts also referred to interventions that are developed within the mental healthcare sector. Within this domain, there seems to be a considerable amount of attention for 'Children of Parents with Psychiatric Problems'. For example, doing a 'Kind check / child check' (asking the question "Do you have children and how are they doing and who is taking care of them now and how is that going?) is reported to be mandatory for mental healthcare professionals. Programs and interventions developed for this particular group may also be helpful for young carers more broadly.  In some municipalities, a standard question is asked during regular youth checkups about possible caregiving to a family member. This, however, is not the standard procedure everywhere.	

As to initiatives at national level, the interviewed experts mentioned a number of actors that address the subject of young carers, including the Ministry of Health, MantelzorgNL (National organization for informal (family) care), Movisie (a national knowledge institute on the social domain) and the Dutch Youth Institute. Some of these national actors jointly developed a platform ('JMZ Pro') among professionals working in education, youth healthcare, healthcare and social care. Meetings have been organized, in order to raise awareness, as well as to stimulate a more integral approach across domains to support young carers.

#### Evaluation of available support

## 1) Considerable local variations in support and limited learning between municipalities

In the Netherlands, as described earlier, policies and regulation around (support for) informal carers fall under the individual municipalities' jurisdiction, as they execute the Wet Maatschappelijke Ondersteuning / Social Support Act at the local level. This decentralisation has the potential of creating space for local actors to jointly address the issue. Yet, it has allowed for considerable local variation in the extent to which young carers are addressed as a specific target group. Support is not consistent across the country: only a few municipalities have informal care policies and interventions for young carers; learning between municipalities is still limited.

In the words of one of the interviewed experts: "Well I think it differs very much per municipality to what extent this is on the agenda and that is worrying. There are some progressive municipalities that are very active on this, but there are also enough that say: Oh, that is not a problem for us."

Also in other countries differences in awareness and support to young carers are observed as well (Leu & Becker, 2017).

#### Lack of implementation of integrated approach across domains

Another challenge mentioned by the experts is to not only address the issue of young carers from the domain of social care, but also align with, for example, (preventive youth) healthcare, public health, and education.

Experts pointed out that - within the municipalities providing support to young carers- welfare organizations are generally the actors who take the initiative. Welfare professionals sometimes reach out to and align with other organizations in different domains (e.g. local centers for youth and family care or schools) but these other stakeholders do not show any leadership. This can be problematic, because, in the words of one expert:

"...before they [young carers] have reached a welfare organization that offers something, a lot of time has passed and the problems have gotten worse."

Lack of time or resource can be the underlying causes for the still-limited involvement of schools and healthcare professionals, as well as their not perceiving the issue of young carers as part of their (main) responsibilities. For example, healthcare professionals are still very focused on the person in need of care, not on the family around him/her.

The experts were unanimous in stressing the important (potential) role of schools and healthcare professionals (starting from GPs) in identifying young carers, as well as the lack of awareness that may keep these stakeholders from taking up this role.

### 2) <u>Limitations of current interventions from welfare</u>

The experts identified further limitations in the current interventions:

- They do not necessarily match the needs of young carers
- There are good interventions that remain underused because people are not familiar with them
- Lack of research to substantiate the effectiveness of interventions in the welfare domain

#### Future needs

In the light of the challenges identified above, the experts have expressed considerations on future needs and possible ways forward.

#### 1. Make sure that young carers are on the local agendas of the municipalities

Experts discussed the role of both local governments (municipalities) and the national government in future developments around support for young carers. Municipalities can play a role in ensuring that local approaches move beyond a single domain and contribute to an integral approach, and to make sure that young carers receive attention in the first place. National governments may play a role in stimulating such local processes by facilitating mutual learning and (according to some experts, forcefully) urging municipalities to address the subject of young carers and to make sure that resources (including earmarked funding) are available.

In the words of one expert: "The Dutch national government should make sure that [....] there is a national way [to do this]. At least some kind of collaboration or some uniformity is needed to know which steps to take."

There was a degree of divergence in experts' perspectives on the role of regulations. Some experts advocated for stricter regulation, mentioning the need to force both municipalities, care professionals and schools to take action in involving and supporting young carers.

"The ministry can only stimulate municipalities. But if municipalities say 'sorry, but we don't have time for that now, we don't see it as a problem', then nothing happens. So policies and regulation, and the international convention [on the Rights of the Child], that can be highlighted a bit more. That it is not optional, in that sense, but that it is actually mandatory."

"If municipalities say to schools that these awareness-campaigns have to be done by us and that it becomes kind of mandatory for schools to do it, then that would really help. [...] Because now it is all voluntary, for the schools. And if they don't want to join, than they don't join."

Yet, several experts were critical of calls for stricter regulation, stressing the importance of focusing on actual implementation instead.

"And that is the tension ... about interaction between, on the one hand, laws and regulation and, on the other hand, what professionals can do and what society is doing itself. So these are no isolated issues, but they interact."

#### 2. Adopt a collaborative approach and improved integrated working

Experts stressed the importance of developing integral approaches that move across education, welfare and (youth) healthcare. On the one hand, such collaboration can especially be developed at the local level, with municipalities in a coordinating role. On the other hand, experts point to the importance of not reinventing the wheel in every location, but to learn from one another at a regional or even national level. Yet, they also mention that regional collaboration may be challenging because funding is often arranged locally.

According to the experts, a pre-condition before even talking about collaboration between different stakeholders is for them to recognise their own roles and responsibilities. As explained above, this is not yet the case, for instance for healthcare and school professionals. Hence, it is important to raise awareness and train them.

In relation to the need for an integrated working with young carers, several experts mentioned the importance of looking beyond formal and professional support to young carers. 'Society', which may entail civil society organizations but also people's informal social networks (e.g. sports club), has an important role to play in supporting young carers.

"As a care professional, you are leaving at some point. You have to realize that. You have to make sure you are not needed anymore".

One experts also connects this importance of informal support to policy developments in the direction of government downsizing and citizen participation.

"We, as a society, are choosing for a smaller role for the government. So then I think, well, if society says it's no public responsibility, than society will have to show responsibilities."

#### 3. Adopt a Family focused approach

The interviewed experts stressed that engaging with young carers requires a shift in perspective: from focusing on the person that is suffering from illness or impairment to focusing on the broader (family) system that they are part of. They highlighted the importance of increasingly paying attention to the (emotional) dynamics within a family. They stressed the merits of staying in touch with several family members when delivering care.

While stressing the importance of taking a family-oriented perspective in the support of young carers, the experts also pointed out the need to look beyond the family and include the broader social network around the person.

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

One of the challenges of the current welfare interventions is that they often do not match the needs of young carers. Hence, the experts stressed the importance to assess the needs of young carers and provide support on the basis of these needs (different for each young carer). Experts recognised that tailoring support to an individual young carer's needs requires professionals to be flexible and to have sufficient room to maneuver.

Experts emphasized that deciding whether and how to provide support to young carers should always happen in a conversation with young carers themselves. Failing to do so often means that activities are offered that later turn out to be irrelevant.

#### 5. Focus on (A)YCs own strength and do not 'problematize' the group

The interviewed experts highlighted the risk of overly problematizing the group of young carers, stressing that when professionals problematize young carers too much (portraying them as people you should feel sorry for), there is a risk of not reaching this group at all. Experts recommended drawing attention to the positive qualities of young carers. For instance, school programs should take care not to treat young carers as a tragic or pathetic group, but rather focus on their strength, resilience and opportunities,.

#### 6. Give special attention to adolescent young carers

Experts stressed the need to pay special attention to protect adolescent young carers as they are developing their own identity and they are in a vulnerable transition period. Services need to be developed at the transition period from children's services to adult services and quicker interventions to assess needs should take into account the transition between school and work.

# The experience of other countries

The interviews with the Dutch experts allowed us to identify aspects of the current system that may require improvement. The experience of other countries can be helpful to understand how to move forward.

The Me-We research study – with its cross-national comparison – allows us to provide an overview of possible strategies to identify and support young carers

# Promising 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 youngsters 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.

# Promising strategies to support young carers with education

To ensure that young carers can complete educational programs and have good achievements, the main support measure 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 <u>extra, tailored support</u>, 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, such as tutors.
- Services (e.g. sport club, youth club) may be more aware that support services for young carers
  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.
- 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.

# Promising strategies to support the mental health of young carers

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

#### Peer/group support/Information

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

"I would prefer to have a kind of 'peer support group', because you could then meet other people who kind of understand your situation. If I talk with friends, I often have the feeling that they do not understand me", says a young carer from The Netherlands.

# Provide respite breaks for young carers

- Organize summer camps, school camps, cinema, café, sport activities to remove the person sometimes from the "pressure cooker" in which the young carer is located
- Give young carers a break from caring, let them have fun and get in contact with peers.
- Assist them with the financial cost of participation in these activities

#### Increase resilience

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

# Promising strategies to engage with young carers

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

The following strategies can be implemented:

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

#### Nothing about us without us!

The Me-We project applies the **co-design approach** we advocate for, by encouraging direct participation by end users (adolescent young carers, education/care professionals and policy makers) and by fostering collaboration amongst stakeholders.

In line with the co-design approach, all project partners have set up Blended Learning Networks, i.e. heterogeneous 'communities of practice' involving adolescent young carers and relevant stakeholders. These actors, sitting together at one table, have to find the best solutions (e.g. they are actively engaged in all the project activities, in particular in planning the interventions and in the development of an app for adolescent young carers).

<u>Here</u> you can access a video presenting the Dutch experience of active engaging young carers in their Blended Learning Network.

Another channel that has ensured the active involvement of young cares 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, Malmo, 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 Dutch context

The Dutch system has undergone a major reform over the recent years. The new pieces of legislation in 2015 have brought about a paradigm shift, characterized by a **decentralization** and a **stronger focus on the role of families and social networks in the provision of care**.

The rationale behind the devolution of care responsibilities from governments to municipalities was to better respond to the real needs, because the municipalities operate on a local level and, it is assumed, they have more insight into what is needed. Yet, this has allowed considerable variations between municipalities as to the visibility and support for young carers. Therefore, the interviewed experts called for more consistency in the country, via a better monitoring of goals and a strengthened exchange of experiences at regional and national level.

"Local authorities they need to be willing to work together with one another and share knowledge, because otherwise they will have [...] separate activities that run parallel from each other. And that's a waste of money."

As to the other key element of the recent reforms, the Dutch government aims for a more effective use of informal care, **encouraging people to involve their own social network in the provision of some care tasks.** This approach has to be read in the light of the trend – common to other European countries- of deinstitutionalization: people are encouraged to receive care at home for longer.

At the same time, budget cuts in the healthcare sector have decreased the availability of formal care.

The interviewed experts expressed concerns that the changes in the Dutch welfare state could result in an increased pressure on informal carers. They stressed the risk that 'cutting costs' in the welfare state will eventually result in rising costs when **carers get overburdened**.

"And then you're cutting costs, but of course that is not really true. Because the costs will always come. If people get overburdened, there will be costs. If people can't go to work because they are caring all the time, those are also costs."

Therefore, they stressed the importance of focusing on and answering to support needs of carers.

This is in line with what was recommended by the European Social Policy Network, in its 2018 Thematic Report on Challenges in long-term care, focused on the Netherlands: it is important that the Dutch government (at the national and local level) should accept the limitations of informal care and seek ways both to support informal care better and to provide good-quality professional care, where necessary, within the budgetary limits.

The project findings, framed into the above broader considerations, allow us to address the following recommendations:

- 1. Policymakers and service provides should be aware of young carers and potential negative impacts of caring, and then to provide carers with **adequate support**.
- 2. The discussions about carers should be integrated with discussions about young carers. At the same time, we recommend to recognise the differences in the specific needs of young carers compared to those of adult carers.
- 3. We call for support tailored to the needs of young carers.
- 4. We recommend to adopt a **preventative approach**, ensuring that the needs of young carers are addressed before they escalate into a crisis. This entails active engagement and **collaboration between different stakeholders** (education, youth, social, healthcare).
- **5.** A pre-requisite of collaboration is acknowledgment of responsibility. Hence, we encourage to **raise awareness** on the topic among professionals and general public.
- **6.** We recommend undertaking **further research** on the topic (in particular, to link interventions and research, in order to evaluate what works).
- 7. We ask to consider young carers not just as a target group but as active participants in the society. Hence, we recommend to **involve them** in the development of interventions and policy.

In line with the division of competences across levels of government, the above recommendations mainly target policymakers at local level. Yet, we believe that the national level can play the following important role:

1. To **stimulate local processes** on young carers and to **facilitate mutual learning** at regional and national level.

#### 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 <u>statement on child mental health</u> 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 Dutch policy-makers can be complemented by actions taken at European level.

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

The Principles	The relevance for young carers
Principle n. 1 – Education, training and life-long learning	Caring responsibilities can have a negative impact on young carers' education (under-achievement, absence and dropouts)
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 <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.
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.