

## D2.1

# Final report on case study analysis of policy, legal and service frameworks in six countries



ME-WE  
deliverable

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

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).

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#youngcarers

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



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## D2.1

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## Foreword and Overview of the ME-WE project

ME-WE is a 39 month project, funded by the European Union through the EU Framework Programme for Research and Innovation HORIZON 2020. The ME-WE project is funded by the Health program, Fighting Infectious Diseases and Advancing Public Health. It involves Italy, The Netherlands, Slovenia, Switzerland, UK and Sweden.

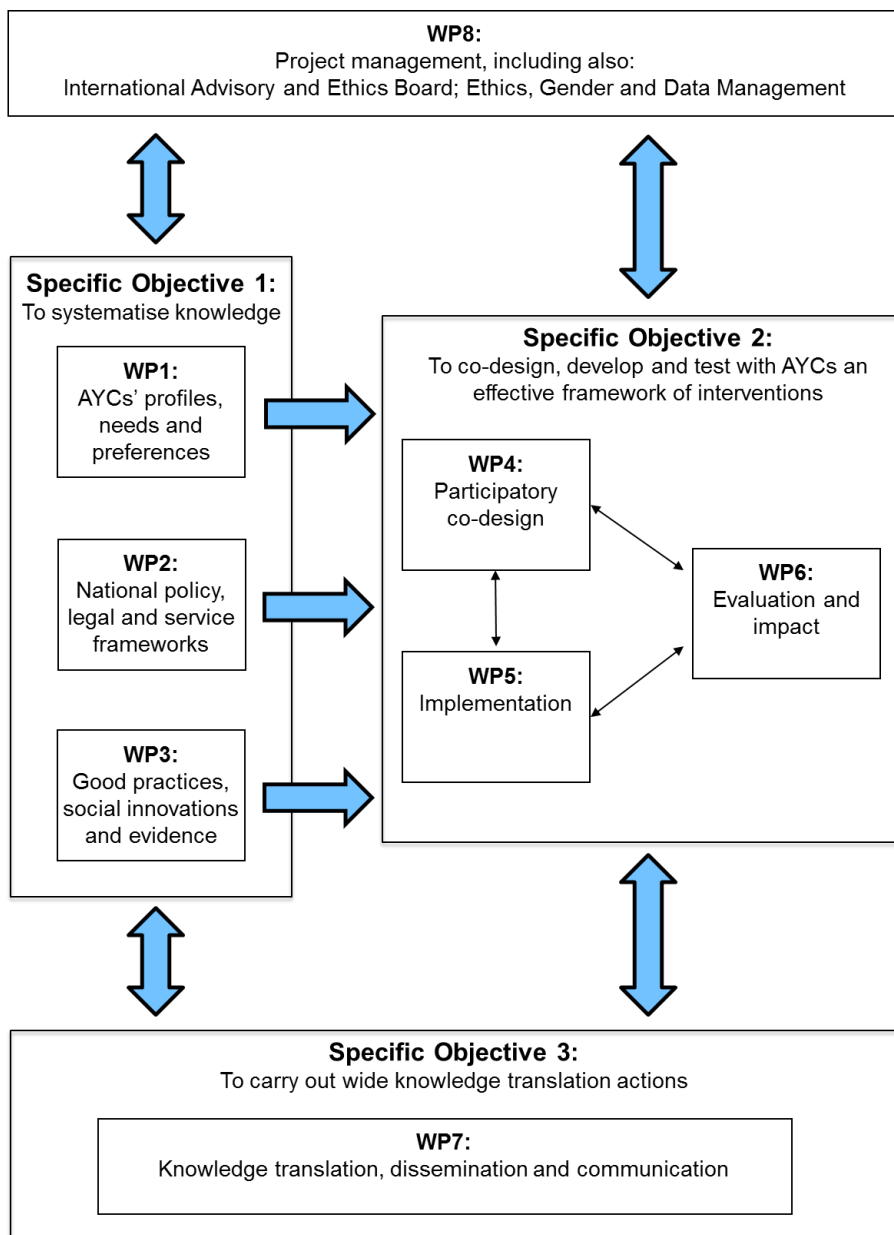
The overall goal of the ME-WE project is to strengthen the resilience of Adolescent Young Carers (AYCs) in transition to adulthood (15-17 years old) in order to impact positively on their mental health and well-being and to mitigate the negative influence of psychosocial and environmental factors in their lives. The ME-WE project will contribute to a fuller understanding of AYCs' needs and preferences in the six partner European countries and propose an innovative framework of primary prevention interventions, to be adapted according to country specifics, able to prevent the occurrence of mental disorders, co-morbidities and socio-economic disadvantages during the life-course, going beyond current state-of-the-art and exploiting international good practices in the field. Europe will have a demonstrable realistic programme for promoting mental health and wellbeing in AYCs through the development, implementation and evaluation of the project.

A proportion of young people across Europe carry out a significant role in caring for their ill and/or disabled family member and/or persons closely associated with them. These young people are defined in the literature as young carers (YCs), that is "children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out significant or substantial caring tasks, often on a regular basis, and assume a level of responsibility that would usually be associated with an adult" (Becker, 2000). Despite the lack of specific figures the phenomenon is raising attention in many countries, such as the UK (at advanced level, with systematic policies and responses) but also in Sweden, Netherlands and Switzerland (at different degrees of development level) and Italy and Slovenia (at an initial stage of awareness) (Leu & Becker, 2016). Being an adolescent young carer is a risk factor for impaired mental health, well-being and social exclusion. Research has highlighted that being an AYC exacerbates health inequalities during the life-course. AYCs often also experience the consequences of social exclusion, with higher absenteeism and drop-out rates from education and low employability. Further, failing to adequately support AYCs has long- term negative consequences for society as a whole.

A basic principle of the ME-WE project is to be user based, user friendly and user driven. This requires an understanding of AYCs' needs and preferences, national policy, legal and service frameworks and good practices, social innovations and evidence. The ME-WE project has three specific objectives, linked to eight work packages (WPs):

1. To systematise knowledge on AYCs by (a) identifying their profiles, needs and preferences (WP1), (b) analysing national policy, legal and service frameworks (WP2), and (c) reviewing good practices, social innovations and evidence (WP3);
2. To co-design, develop and test, together with AYCs, a framework of effective and multicomponent psychosocial interventions for primary prevention and focused on improving their mental health and well-being, to be tailored to each country context (WP4-6);

3. To carry out wide knowledge translation actions for dissemination, awareness promotion and advocacy (WP7), by spreading results among relevant stakeholders at national, European and international level.



**Figure 1 PERT chart of interrelations between work packages**

The three specific objectives listed above will be secured by a series of intermediate and final achievements that are planned during the duration of the ME-WE project (39 months).

The specific objectives are linked to concrete deliverables that will support the monitoring and evaluation of the project success. The information generated in WP1, WP2, WP3 and WP4, presented in four reports, provides the foundation for the subsequent phases and deliverables of the ME-WE project.

The WP1 deliverable is a report that describes 1,831 AYCs' profiles, needs and preferences in the six partner countries based on an online survey study. The survey includes demographic, social and personal characteristics and the validated MACA, PANOC and Kidscreen instruments.

The deliverable for WP2 is presented in this report and provides an analysis of the policy, legal and service frameworks in the six partner countries. The deliverable is presented as country case studies based on interviews with 25 experts in the partners' countries and validated by 6 AYCs, experts and country partners.

The WP3 deliverable is a consolidated strategy and theory report presenting good practices, social innovations & evidence. The report is based on a Delphi study and systematic literature reviews and social media analyses. Through a rating, ranking and consolidation task a ranked high impact list with national and international strategies and programmes has been provided.

The WP4 deliverable is a technical specifications report for the ME-WE app that forms part of the intervention for supporting AYCs. The views of both YCs and professionals as potential users form the basis for setting the technical specifications alongside relevant findings from WP1, WP2 and WP3.

All partners, whom are members of Eurocarers<sup>1</sup> contribute to the work of all work packages. This helps to ensure a wide range of knowledge, experience and expertise in the area. The participating partners are:

- Linnaeus University (LNU), Kalmar, Sweden, ("Coordinator") (LNU)
- Eurocarers - Association Européenne (EuCa), Brussels, Belgium
- Ministerie van Volksgezondheid (SCP), Den Haag, Netherlands
- Stichting Vilans (VIL), Utrecht, Netherlands
- Istituto Nazionale di Riposo e Cura per Anziani Inrca (INCRA), Ancona, Italy
- Anziani e non solo società cooperativa sociale (ANS), Carpi MO, Italy
- Univerza v Ljubljani (UL), Ljubljana, Slovenia
- The University of Sussex (UoS), Sussex, United Kingdom
- Carers Trust (CT), United Kingdom
- Stiftung Kalaidos Fachhochschule (SKF), Zürich, Switzerland

The ME-WE project has become a reality following support from the EU, in addition to support from different organisations and Young Carers organisations and professionals in Europe. The consortium gratefully acknowledge the support from and funding provided by the European Commission, Directorate-General Research & Innovation and schools, health and social care organisations, NGOs and communities in Italy, The Netherlands, Slovenia, Switzerland, UK and Sweden. The consortium would also like to acknowledge all those who have contributed to the work, particularly young carers and professionals who have provided invaluable advice.

Elizabeth Hanson  
Principal Investigator  
President Eurocarers  
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<sup>1</sup> Eurocarers is a European Association working for and with informal carers, consisting of 67 carer and research organisations in Europe

## Executive Summary

This report provides a first comprehensive transnational comparison of the different legislation, policy and service frameworks that exist to protect and support adolescent young carers (AYCs) in six European countries (Italy, Netherlands, Slovenia, Sweden, Switzerland and United Kingdom) and how these work in practice. Until now, research has primarily focused on estimating the numbers of AYCs and the impact that their caring tasks have on them. Work Package 2 (WP2: National policy, legal and service frameworks) is part of the overall project “Psychosocial support for promoting mental health and wellbeing among adolescent young carers in Europe” (ME-WE), funded by the European Union (Horizon 2020).

The main goal of Work Package 2 was to analyse the development and implementation of legislation, policy and service frameworks addressing AYCs in six European countries and how such policies are enacted in the ‘real’ world. Specific aims of the research were to examine what legal provisions and other policy frameworks exist in Italy, Netherlands, Slovenia, Sweden, Switzerland and United Kingdom that provide support and protection for AYCs. Such provisions may be laws and guidance that are specifically directed at AYCs, or they may be legislation and guidance that apply to all vulnerable children and which can be used to protect and support AYCs.

A case study approach was adopted for analysing the development and implementation of legislation, policy and service frameworks addressing AYCs. The methodological framework included (1) a preliminary examination through an internet search for different policy responses of AYCs in the six European countries (2) 25 (four for each country, five for the UK) interviews with experts with expertise in the field of AYCs and related legal provisions (3) a case study analysis which included the results of the preliminary examination and expert interviews.

The key finding is that with the exception of the United Kingdom where legislation specifically recognises children’s caring roles, none of the other five European countries have any specific legislation for AYCs. In Switzerland, Italy, the Netherlands and Slovenia the recognition of children and young people with caring responsibilities is reliant upon ‘non-specific legislation’ such as education, health and social care legislation. Even though in Sweden the caring role of AYCs is not recognised, Sweden does legally recognise the needs of children with parent/s who have a mental disorder, disability or a serious physical illness, alternatively an injury or who has died unexpectedly and thus can be said to have ‘partial’ specific legislation in place.

How legislation is translated into practice was found to be variable and relates to the existence of implementation guidelines, regulations, collaboration between services, the culture of local authorities and on the type of support offered by legislation. Consequently, in many countries this has led to a wide variation of how legislation and policy is translated

into practice within different regions. Recent changes are seen in the development of specific or non-specific policies and service frameworks, which although not specific for AYC's, have the potential to protect and support them and their families. Although governments across the six European countries have responsibilities, and there are well-developed legal structures in some of the countries, AYC's still fall through the gaps in policy and legal safety nets, and between adult and children's services.

The findings in this report highlight the potential to extend existing legislation, policy and service frameworks to include AYC's, as well as the importance of recognising and raising awareness about the role and challenges experienced by young people with caring responsibilities. Awareness should be raised at all levels of society for example with professionals in the health, social and education sectors and with the general public. A definition for young carers is needed, so that AYC's can identify themselves. AYC's should also be recognised as an important target group for policy makers. Therefore a multi-faceted approach involving different stakeholders is needed, e.g. different ministries, the health and education sectors and NGOs. AYC's should be involved as well, in order to improve understanding of their situation and to gather their ideas for improving support. Additionally, research should play a role by explicitly including policymakers and AYC's. Policymakers may prefer to have a home-grown research evidence base to inform their local and national decisions rather than drawing or relying on research from other countries, even when research findings are likely to be similar.

This transnational study highlights a range of different responses to the issue of AYC's across the six European countries that include the development of specific legislation and policy for AYC's and the extension of non-specific frameworks. The findings from Work Package 2 fill an important international research gap. For the first time there is a transnational analysis of legal structures, policies and service frameworks for AYC's and the 'gap' between legal provision and actual implementation. This enables us to develop evidence-based policy and practice responses to the needs of AYC's and their families, aimed specifically at promoting the development, education, health, well-being, future employability and life chances of AYC's in all European countries and worldwide.

The importance of cross-national studies cannot be overstated. Conducting transnational research on legislation, policy and service frameworks relating to AYC's enables us to identify benchmarks and the strengths (e.g. defining AYC's and their rights and collaboration of stakeholders) and limitations (e.g. the lack of an integrated approach or a family and preventative approach) of different countries' responses and systems. This will be particularly helpful in the future development of both legislation and policy, for those countries where the legal structures, policy and service frameworks for AYC's are only just emerging or are non-existent.

## List of acronyms

YC	Young Carer <sup>2</sup>
AYC	Adolescent Young Carer <sup>3</sup>
YAC	Young Adult Carer <sup>4</sup>
WP	Work Package
NGO	Non-Governmental Organization
GA	Grant Agreement
Par.	Paragraph
IT	Italy
NL	Netherlands
SI	Slovenia
SE	Sweden
CH	Switzerland
UK	United Kingdom
FAQs	Frequently Asked Questions
UNCRC	United Nations Convention on the Rights of the Child
YCRG	Young Carers Research Group
SKF	Stiftung Kalaidos Fachhochschule

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<sup>2</sup> Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member (p. 48 GA).

<sup>3</sup> Adolescent young carers (AYCs) are young people (15-17 years old) providing significant or substantial care, assistance or support to other family members (p. 3 GA).

<sup>4</sup> Although different definitions exist that use different age ranges, this report refers to 'young adult carers' as defined by (Becker & Becker, 2008): "people aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support or supervision".

## 1. Introduction

Research has primarily focused on estimating the numbers of (young) carers and exploring and documenting the outcomes and consequences of caring. Although there has also been some examination of policy in individual countries, there have been no studies that provide a comprehensive transnational comparison of the different legal and policy frameworks that apply to young carers (YCs) in six European countries, and how they work in practice. One study at least has explored how policies ‘formalise’ the role and status of informal carers in a subset of European countries, but this is in relation to adult carers (e.g. Zigante, 2018). This study addresses that gap in the research with respect to YCs. The legal situation of adolescent young carers (AYC) has not been researched. For the first time there will be a transnational analysis of legislation, policy and service frameworks for younger carers and the ‘gap’ between legal provision and actual implementation. In addition, this study which highlights a range of legislative and policy responses, their strengths and limitations and what has driven their development, will help us to develop evidence-based policy and practice responses to the needs of AYC and their families in six European countries. The importance of cross-national studies cannot be overstated. They have been used to good effect in many different areas of law and social policy. The arguments for conducting transnational research on law and policy frameworks relating to adolescent young carers is essentially the same as that for researching different child protection systems – it enables us to identify benchmarks and the strengths and weaknesses of different systems. This will be particularly helpful for those countries where legislation, policy and service frameworks are only just emerging.

## 2. Aim and objectives

The main goal of work package 2 (WP2) was to analyse the development and implementation of policies, legislation and services addressing AYC in six countries: Italy (IT), Netherlands (NL), Slovenia (SI), Sweden (SE), Switzerland (CH) and United Kingdom (UK). Such provisions may be laws, regulations and guidance that are directed specifically at AYC, or they may be legislation and guidance that apply to all vulnerable children and which can be used to protect and support young carers. Secondly, the research explored how such policies are enacted in the ‘real’ world and how procedures work in practice.

## 3. Method

A case study approach was adopted for analysing the development and implementation of legislation, policies and services addressing AYC in six countries (IT, NL, SI, SE, CH, UK). SKF coordinated all WP2 tasks, centralising main activities of preliminary examination (Task 2.1), interviews (Task 2.2) and case study analysis (Task 2.3). All partners were engaged in carrying out interviews and supporting data analysis for their respective country. A more detailed description of the methodological procedure can be found in the individual task sections in paragraphs 4-6 (Task 2.1, Task 2.2 and Task 2.3).

### 3.1. *Block Diagram of research steps*

A block diagram of all of the research steps is given in the figure below; each of these represents an important milestone reached in WP2.



Figure 2: Block diagram of research steps

## 4. Involvement of AYCs

For ethical reasons involving AYCs to a large degree in the first phase of the research (the development of the expert interviews) would have been problematic since this would have involved asking young carers to provide feedback on the topic of legislation which they are unlikely to have had much knowledge about. It was therefore agreed by the ME-WE consortium to primarily involve AYCs at the draft report stage. However, one former AYC was involved in developing the interview guidelines and one young adult carer (YAC) from the UK provided minor feedback on the interview questions.

Once the analysis for each country was completed, case studies from each country were compiled and presented to the experts from the six countries and country partners for their feedback and responses to questions regarding specific aspects of the case studies.

Selected sections from each country case study relating to (1) how legal provisions and policy frameworks work in practice and (2) the experts' goals and hopes for the future, were presented to AYC and YACs representing each country to review. This information was presented to them along with related questions about their own experience and hopes for the future (see Annex 5). AYC reviewed these sections and provided feedback based on their own experience. Their feedback has been included in this final report (see paragraph 11). The two sections were selected as AYC/YACs were likely to be able to provide feedback on these. Feedback was not sought on other sections for ethical reasons. For example it would likely have been problematic asking AYC and YACs to provide feedback on the topic of legislation which they were unlikely to have had much knowledge about.

## 5. Preliminary examination (Task 2.1)

A preliminary examination of the different policy responses to the issue of young carers within six country partners (CH, IT, NL, SI, SE, UK) was conducted by briefly examining the websites and publications of universities, government and non-governmental organisations (NGOs) (Grant Agreement, Annex 1 Part A, p. 11).

A secondary aim of the preliminary examination was to identify academics and professionals who are working in the field of young carers or related fields, who could be classed as experts and could take part in Task 2.2 Expert Interviews (see par. 6).

### 5.1. Development

The primary strategy for searching for legal provisions, policy responses and experts who could participate in the interviews was performing a Google search using a combination of search terms, translated into the national languages (where necessary).

The following 'inclusion' and 'exclusion' criteria were set before starting the search:

Inclusion criteria:

- Legal provisions on a national, regional and local (or equivalent) level and policy and/or service frameworks (both current and historical) that provide protection and support for YC and their families
- Specific and non-specific legal provisions and policy frameworks (both current and historical) that benefit YC aged 0-24

Exclusion criteria (to delineate from work package 3):

- Practice guidelines

- Advice and resources for supporting young carers
- Other literature focusing on topics such as impact of caring on health, wellbeing and education

Google searches from Switzerland were carried out for all of the country partners and therefore the limitations of a ‘semantic search’ using Google because of the ‘Google Filter Bubble’ were discussed by the team<sup>5</sup>. The country settings in Google were modified in order to simulate a research conducted in the targeted country.

A search log in Excel was developed for each country in order to systematically document all the relevant information found through the Google search. The following information was stored:

- Date accessed
- Search terms used
- Origin of website (e.g. Knowledge of researcher; Source of URL, or Google search...)
- Website
- Website type (e.g. Government website (National); NGO/Social care; Education; Health etc.)
- High level finding (data we were interested in)
- National; Regional or Cantonal
- Experts identified
- Notes on experts
- New website identified
- New website type
- Notes

Search logs were compared in the early stages to ensure procedural consistency across the different countries. Upon request, detailed search logs could be sent to country partners.

## 5.2. *Search Terms*

The search terms employed for the research related to the “legal world” (e.g. legislation, legal provisions, regulation provisions, etc.), young carers (e.g. children as next of kin, sibling carers, children in need, etc.), their families (e.g. parental chronic illness, family support, family health, etc.) and others (e.g. learn and care, etc.).

The following table presents search terms employed for the research.

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<sup>5</sup> <http://personalization.ccs.neu.edu/>.

**Table 1: Search terms employed in the research**

<b>Legal and Policy Terms</b>	<b>Young Carer and Children Terms</b>	<b>Family and Parents Terms</b>	<b>Caring and Other</b>
Legislation	Young carers	Chronic patients with children	Care and school
Policy	Adolescent young carers	Parental (mental) health	Learn and care
Legal provisions	Carers	Parental chronic illness	
Rights	Caring responsibilities	Parental substance misuse	
Regulation	Caring roles	Children disabled parents	
Guidelines	Young adult carers	Family support	
Provisions	Children / Adolescents as next of kin	Policy for families	
Protection	Sibling carers	Family health	
Support	Parent carers		
Children rights	Children and young people with care tasks		
Services	Children in need		
Interventions			
Guidance			
Identification			
Assessment			

### **5.3. Individual Country Approach**

The search strategy in each country was based primarily on using the search terms in Google. However the approach was flexible and was adapted for each country in response to its particular characteristics. For example, for the UK, where the status of legislation and policy frameworks for YC is advanced, a Google search with few search terms generated significant information, whereas for SI for example, where the legislation and policy frameworks for YC are at a starting point, a broader approach was necessary. To complement the strategy of using search terms in Google, more targeted internet searches were employed, including searching through the partner institutions and the law faculties in SI universities.

Complementary strategies that were employed included searching:

- Partner institutions
- Letters of intent in Grant Agreement
- The 2<sup>nd</sup> International Young Carers Conference, ‘Every Child has the Right to... ‘ Malmö, 29-31 May 2017 conference programme
- The law faculties in partner country universities

## 6. Expert Interviews (Task 2.2)

### 6.1. *Aim*

The aim of the expert interviews was to explore what legal provisions and other policy frameworks exist in the six partner European countries (IT, NL, SI, SE, CH, UK) that provide support and protection for young carers. A secondary aim was to explore how any legal provisions and policy frameworks that exist, are translated into practice. Interviews also aimed to explore how legislation defines and constructs young carers, the strengths and limitations of legislation and policy frameworks, how changes in legislation and policy were achieved, the attitudes of experts towards existing legislation and policy frameworks and their hopes and goals for the future.

### 6.2. *Method*

An expert interview approach was chosen as the research method because the interviewees were academics and specialists who needed to have sufficient legal knowledge (Bogner, Littig, & Menz, 2009; Meuser & Nagel, 2009). The preliminary research (Task 2.1) resulted in the creation of a list of potential interviewees.

Experts were identified on the basis of their experience of working in the field of young carers or related fields and having a knowledge of the current related legal provisions, policy and service frameworks. There was no intention that the experts interviewed would constitute a representative sample of varying standpoints and opinions about the current and future direction of policy with regards to young carers. Consequently, no attempt has been made to 'place a weight' on individual statements or to reflect a consensus of opinion among the experts. The case studies instead capture the range of opinions of the experts within each country. However, where there are opposing views on a specific issue, those alternative views are also reported.

### 6.3. *Recruitment of experts*

Based on the results of the preliminary research (Task 2.1) a priority list of legal experts was developed. As mentioned above, the search strategy generated a list of potential experts for each country. Since the recruitment of four experts in each country was expected to be a challenge (risk number 7, GA, p. 35), a reserve list of experts was created. In addition, in few countries, the method of 'snowballing' was used to identify additional experts where necessary. The expert list was then cross-referenced against a list of potential experts put forward by the country partners and following some further discussion, a priority list of experts for the interviews was agreed upon. Four experts for IT, NL, SI, SE, CH and five experts for the UK (to ensure coverage of England, Scotland, Wales and Northern Ireland) were prioritised in each country to take part in the subsequent expert interviews. A reserve list was compiled in the event of any 'drop outs'.

The sample (see Annex 1) included 27 experts (20 female and 7 male) who are working either in a legal academic position, in the government or are known as experts on the topic of YCs. The SKF team agreed that where possible two law professors should be included in the sample of experts for each country. The other two experts could also be experienced professionals who know the legal provisions. 25 expert interviews were conducted (four in each country, five in the UK), but in two cases the interviews were conducted with two interviewees at the same time (in CH and NL). For example, one professor answered the question together with her assistant. All participants had to sign a consent form.

#### **6.4. Development of the interview guidelines**

The questions for the interview guidelines were initially based on the classification of in-country awareness and policy responses to YCs (Leu & Becker, 2016), and then adjusted to the aims of WP2 (GA, p. 11). One former AYC was involved in developing the interview guidelines and one young adult carer (YAC) from the UK provided some minor feedback on the interview questions which was also considered before these were finalised. One interview was initially undertaken by each country using the developed interview guidelines. Some minor modifications and additions to the original questions were made in response to the learning and feedback from country partners following these initial interviews, resulting in a final set of seven main question blocks. Categories for the analysis (conceptual framework) were then developed, based on these seven question blocks:

**Table 2: Main Questions and Categories**

<b>Main Interview Questions</b>	<b>Categories for the Analysis (Conceptual Framework)</b>
1a. Is there any specific legislation to protect and support young carers and their families?	Specific legislation
1b. Are there any specific policy and/or service frameworks to protect and support young carers and their families?	Specific policy and service frameworks
1c. How does the legislation define and construct young carers?	Recognition of young carers
1d. How do the policy and/or service frameworks define and construct young carers?	Definitions
2a. Is there any other (non-specific) legislation that can or has been used in the context of young carers and their families?	Non-specific legislation
2b. Are there any other (non-specific) policies and/or service frameworks that can or have been used in the context of young carers and their families?	Non-specific policy and service framework

3. How do the legislation, policy and/or services frameworks translate into practice?	Enactment of legislation Enactment of policy and service frameworks
4. How would you evaluate the current situation regarding the legislation, policy and/or service frameworks? 4a. What are the key strengths of the legislation, policy and/or service frameworks? 4b. Are there any limitations of the legislation, policy and/or service frameworks? 4c. Are there any changes with the legislation, policy and/or service frameworks that you would suggest were made?	Evaluation of the current situation Attitudes to existing policy responses Key strengths Key limitations Suggested changes
5. How were any changes in legislation, policy or service frameworks brought about or achieved?	Changes in legislation Changes in policy and service frameworks
6. What are your goals or hopes for the future with regards to the development of legislation, policy and/or service frameworks for young carers? 6a. Are there any changes you would suggest?	Future goals and hopes

The interview guidelines were pre-tested with an expert from Belgium to check whether the questions were understandable, whether any questions were missed out and to see how long the interview took to administer. It was found from the pre-test that some flexibility with the order of the questions would likely be needed where there was little or no legislation or policy regarding YCs in place.

### **6.5. Conducting expert interviews**

WP-Leaders of each country were asked to contact the experts in their respective country. A 'Briefing Pack' was developed for the country partners that included all the information and templates required for them to communicate with the experts in their individual countries and to administer the expert interviews. This included an invitation letter that was sent to experts. The briefing pack included frequently asked questions (FAQs) on the process in general and about how to conduct the interview itself, as well as templates and checklists to support country partners throughout the process.

To ensure the interview guidelines were appropriate, each country conducted an initial interview which they transcribed and returned to the SKF team, before carrying out further interviews. The SKF team undertook a quick analysis of the initial data to extract learning from these first interviews in each of the six countries and to check that they had worked

consistently across the countries and as intended. Feedback on the interview guidelines was also collected from the country partners after the initial interviews. Both tasks led to some modification of the interview guidelines to ensure that the interview guidelines and process worked appropriately. The adapted guideline was then sent back to all country partners for them to undertake the remaining interviews.

Interviews could either be carried out by telephone, Skype or in person. Country partners were free to choose English or their native language for the expert interviews. If the interviews were conducted in their native language, country partners duly translated the transcripts into English. In total, 15 interviews were carried out in English and ten in other languages. To help experts prepare, the main interview questions were sent to experts in advance of the interview. Interviews were carried out between May and September 2018, lasted an average of one hour and with permission were recorded and transcribed.

## 7. Case Study Analysis (Task 2.3)

A Microsoft Access database was constructed based on the 16 categories from the conceptual framework in order to store and manage the collected data. Transcripts were first coded by hand using the 16 categories (following the brief definitions, see table 3). Either single or multiple category codes were assigned to text segments. New categories were developed inductively if a text passage could not be included within the existing categories. 20 categories were finally developed (see table 3 below).

Each text segment was also coded in relation to the level it related to (national, regional or local level) and its origin (country and interviewee number, or preliminary research, task 2.1, see table 4 below). It was decided to study the countries within the UK (i.e. England, Wales, Scotland and Northern Ireland) separately due to their different legislation, policy and service frameworks specifically addressing AYC's. The enactment of legislation and policies and the changes that occurred in the past were also different in the four UK countries.

Coded interview transcripts were then double checked by another SKF team member. Any discrepancies were discussed before final codes were decided upon and the text segments were added to the database.

**Table 3: Categories**

Category	Brief Description
01 Specific legislation	Any legislation specific to young carers or AYC's that provides protection and support for young carers/AYC's and their families <ul style="list-style-type: none"> <li>• on a national, regional and local level (or equivalent)</li> <li>• present and historical</li> <li>• includes specific recognition of and/or a definition of young people with caring responsibilities.</li> </ul>
011 Specific regulations	Regulations specific to young carers or AYC's

012 Specific guidelines	Guidelines specific to young carers or AYC's
02 Specific policy and service frameworks	Any policy and service frameworks specific to young carers or AYC's that provides protection and support for young carers/AYC's and their families <ul style="list-style-type: none"> <li>• on a national, regional and local level (or equivalent)</li> <li>• present and historical</li> <li>• includes specific recognition of and/or a definition of young people with caring responsibilities</li> </ul>
03 Recognition of young carers	How (if at all) does the country recognise young carers or AYC's (present and historical)
04 Definition	How young carers or AYC's are defined (present and historical)
05 Non-specific legislation	Any legislation not specific to young carers or AYC's that provides (or could provide) protection and support for young carers/AYC's and their families <ul style="list-style-type: none"> <li>• on a national, regional and local level (or equivalent)</li> </ul> present and historical
051 Non-specific regulations	Non-specific regulations
052 Non-specific guidelines	Non-specific guidelines
06 Non-specific policy and service frameworks	Any policy or service framework not specific to young carers or AYC's that provides (or could provide) protection and support for young carers/AYC's and their families <ul style="list-style-type: none"> <li>• on a national, regional and local level (or equivalent)</li> </ul> present and historical
07 Enactment of legislation	How the legislation is translated into practice
08 Enactment of policy and service frameworks	How policy and service frameworks are translated into practice
09 Key strengths	Any key strengths of the legislation, policy and/or service frameworks? In the opinion of Experts
10 Key limitations	Any limitations of the legislation, policy and/or service frameworks? (in the opinion of experts)
11 Changes in legislation	Specific changes that have taken place in legislation
12 Changes in policy and service frameworks	Specific changes that have taken place in policy and service frameworks
13 Evaluation of the	How experts view the current situation

current situation	
14 Suggested changes	Any changes that the experts suggest to improve the protection and support of AYC/young carers
15 Attitudes to existing policy responses	Attitudes of experts to policy responses
16 Future goals and hopes	Any future goals and hopes that experts have
17 Miscellaneous	This is a PARKING category for anything that does not fit into the other categories
18 Best practices	Examples of practice relating to existing legislation, policy and/or service frameworks
19 WP3(Work package 3: Good practices, social innovations & evidence)	Examples of practice found in countries not relating to existing legislation, policy and/or service frameworks
20 Country specific structures & approaches	Structures and approaches specific to a country

Text segments were then extracted systematically from the database by filtering the database, firstly by individual country and then by individual category codes. A summary was then undertaken for each country on the text segments relating to each category to form the case studies for each country. Case studies were then doubled checked by a second team member. Whilst developing the case studies, where there were specific details that required validation, those details were checked using the internet. This was used for example to verify the names of legislation or dates provided by experts. A cross-check with the original data from the preliminary examination was also used where necessary.

Once the first drafts of the case studies were completed, they were sent to the experts who had been interviewed from the six countries as well as to the country partners. Experts and country partners were asked for their feedback on the case studies and to answer specific questions where further validation of specific points was required. Experts and country partners were provided with a standardised form on which to write their feedback (see Annex 4). Feedback and supplementary information provided by the experts and country partners was then used to modify and finalise the case studies.

AYCs and YACs were also presented with the draft case studies and asked to provide feedback. Their feedback was compiled and forms part of this report (see par. 11).

**Table 4: Country, origin and level codes**

<b>Country</b>
Italy
Netherlands

Slovenia
Sweden
Switzerland
UK- England
UK – Wales
UK – Scotland
UK – Northern Ireland
United Kingdom

<b>Origin</b>
01 preliminary research
02 expert interview 1
03 expert interview 2
04 expert interview 3
05 expert interview 4
06 expert interview 5

<b>Level</b>
01 national level
02 regional level
03 local level

## 8. Strengths and challenges of the methodology

### *Strengths*

- The interview guidelines for the expert interviews was developed collaboratively with country partners ensuring it was appropriate for each individual country context and was pre-tested with an expert in Belgium.
- A former young carer was involved in the development of the interview guidelines and a young adult carer provided feedback on it.
- The identification and interviewing of experts provided direct access to their country specific knowledge about legislation and policy frameworks as well as how these are being enacted. As experts were from each of the countries under analysis, this also ensured this knowledge was contextualised appropriately.
- The engagement of all partners with interviews and their support with the data analysis for their respective country was important for improving quality.

- Providing experts, country partners and AYC/YACs the opportunity to feedback on the initial case study drafts, validate specific points, and to answer remaining questions, was extremely beneficial.
- The SKF team included native English, Swiss German and Italian speakers as well as having knowledge of Dutch, French and basic Swedish, which supported any language challenges.

### *Challenges*

- Experts sometimes focused on particular legislation and policies whilst omitting others. Omission of legislation, policy and service frameworks in some countries that is supportive of children with caring roles and their families does not mean that it does not exist.
- Experts were unable to be found who had knowledge of all of the four countries within the UK. Although five experts were interviewed, only individual experts were able to provide substantive information about both Scotland and Northern Ireland.
- Not all the experts who were initially prioritised were interviewed. This was due to not being able to contact them or their declining to take part in the interviews due to lack of time resources. As a consequence, the reserve list of experts was used, as well as ‘snowballing’, which may have resulted in interviewing some experts with less knowledge than those who had originally been prioritised.
- Not all the experts who were interviewed provided feedback on the draft country specific case studies due to workload and time restrictions.
- Language was sometimes a challenge. During the preliminary examination and the development of the case studies, the collaboration of country partners was sometimes required to translate the documents, where an English version did not exist. Some interviews were carried out in English, where neither the expert’s nor the interviewer’s native language was English. Sometimes interviews were conducted in the native language and then translated.
- There might have been differences between the definition of AYC in legislation and policy documents and definitions used by the experts themselves. A definition and notes about young carers were however sent to the experts before the interviews.

## **9. Ethical considerations**

A jurisdictional enquiry was submitted to the Cantonal Ethics Committee in Zurich and clarification was received from the Ethics Committee stating that the research project does not fall within the scope of the Human Research Act and as such authorisation was not required (BASEC Request-No. Req-2018-00270).

Informed consent (see Annex 3) was received from all the expert interviewees and the identity of participants was protected through the anonymity of the data collected. The identity of experts was kept separately from the interview transcripts and a code list was created and kept securely. By signing the consent forms for the interviews, experts also gave their permission to be recognised as an expert in the report.

Data transfer from the country partners to SKF took place via a specific online storage service 'Box' with log-in. Country partners uploaded data files (interview transcripts) which were subsequently downloaded by the SKF team and stored on a secure server before deleting the interviews from the Box.

Recruitment and access to AYC's and YAC's was through stakeholders (primarily the Eurocarers Young Carers Working Group). Comments made by AYC's and YAC's within the report were anonymised and consent obtained for recognising their contribution in the project report.

## **10. Country-specific case studies**

In chapter 9 and chapter 10 the main results from the expert interviews are reported. In chapter 9 the main results are summarised within country-specific case studies. Each case study is structured by category. In chapter 10, a synthesis is provided for each category and presents commonalities and differences between the countries.

### 10.1. Case Study Italy

Categories	Results
<b>Specific legislation</b>	In Italy, no specific legislation protecting and supporting young carers and their families exists.
<b>Non-specific legislation</b> National level	<p><b>Law 23 December 1997, n. 451</b>, <a href="http://www.camera.it/parlam/leggi/97451l.htm">http://www.camera.it/parlam/leggi/97451l.htm</a> (Istituzione della Commissione parlamentare per l'infanzia e dell'Osservatorio nazionale per l'infanzia, pubblicata nella Gazzetta Ufficiale n. 302 del 30 dicembre 1997)</p> <p>Establishment of the Parliamentary Committee on Children and the National Observatory for Children, with the aim to control the implementation of international conventions and legislation on the rights of the child.</p> <p>Targeted age group: children (age not specified)</p> <p><b>Law 28 August 1997, n. 285</b>, <a href="http://www.camera.it/parlam/leggi/97285l.htm">http://www.camera.it/parlam/leggi/97285l.htm</a> (Disposizioni per la promozione di diritti e di opportunità per l'infanzia e l'adolescenza, pubblicata nella Gazzetta Ufficiale n. 207 del 5 settembre 1997)</p> <p>Provisions for the promotion of rights and opportunities for childhood and adolescence.</p> <p>Targeted age group: children and adolescents (age not specified)</p> <p><b>Law 22 June 2016, n. 112</b>, <a href="http://www.gazzettaufficiale.it/eli/id/2016/06/24/16G00125/sg">http://www.gazzettaufficiale.it/eli/id/2016/06/24/16G00125/sg</a> (Disposizioni in materia di assistenza in favore delle persone con disabilità grave prive del sostegno familiare)</p> <p>Provisions supporting people with serious disability who do not have support from their parents. It aims to promote the well-being, social inclusion and autonomy of people with disabilities.</p> <p>Targeted age group: not specified</p> <p><b>Law 27 December 2017, n. 205, paragraphs 254-255</b>, <a href="http://www.gazzettaufficiale.it/eli/gu/2017/12/29/302/so/62/sg/pdf">http://www.gazzettaufficiale.it/eli/gu/2017/12/29/302/so/62/sg/pdf</a> (Bilancio di previsione dello Stato per</p>

	<p>l'anno finanziario 2018 e bilancio pluriennale per il triennio 2018-2020)</p> <p>State budget for year 2018 and for the three-year period 2018-2020.</p> <p>Definition of family caregiver: "The person who assists and takes care of the spouse, of the partner in a civil partnership (between persons of the same sex) or of the cohabiting partner, in accordance with the law of 20 May 2016, n. 76, or of a family member within the second degree, or in the cases indicated by article 33, paragraph 3 of Law 5 February 1992, n. 104, of a family member within the third degree, who, due to an illness, disability, chronic or degenerative disability is not self-sufficient and able to take care of himself/herself, and is recognised as disabled in need of global, continuous and long-term care on the basis of Article 3, paragraph 3, of the Law 5 February 1992, n. 104 194/1992, or according to Law 11 February 1980, n. 18, establishing the National Attendance Allowance." (Paragraph 255)</p> <p>Fund for non self-sufficiency: "It is established by the Ministry of Labour and Social Policies a Fund for supporting the role of caring and assistance provided by family caregivers, allocating the provision establishes the fund to support the caring and assistance role of family caregiver, allocating € 20 million for each of the years 2018, 2019 and 2020. The Fund is intended for the financing of legislative interventions aimed at recognising the social and economic value of the care activity of family caregivers." (Paragraph 254)</p> <p>Targeted age group: not specified</p> <p><b>Law 5 February 1992, n. 104</b>, <a href="http://www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/sg">http://www.gazzettaufficiale.it/eli/id/1992/02/17/092G0108/sg</a> (Legge-quadro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate)</p> <p>Provision for the assistance, social integration and rights of people with disabilities.</p> <p>Psychological support: in cases of physical or mental illness or disability, the family members can benefit from a psychological support service from the Local Health Authority (LHA). There is no age restriction.</p> <p>Paid leave: any cohabitants' family member within the third degree has the right to a series of benefits, which take the form of the possibility to have 3 days of paid leave per month. These paid leaves can be theoretically requested by anyone, even by minors. Paid leaves are regulated by Art. 33, comma 3, of law 5 February 1992, n. 104.</p> <p>Targeted age group: not specified</p> <p><b>Law 11 February 1980, n. 18</b>, <a href="http://www.gazzettaufficiale.it/eli/id/1980/02/14/080U0018/sg">http://www.gazzettaufficiale.it/eli/id/1980/02/14/080U0018/sg</a> (Indennità di</p>
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	<p>accompagnamento agli invalidi civili totalmente inabili)</p> <p>Allowances for people with severe disability who are not self-sufficient.</p> <p>Targeted age group: minors who have severe disability can benefit from this law too. However, family carers are not mentioned.</p> <p><b>Law 28 May 2017, n. 71</b>  <a href="http://www.gazzettaufficiale.it/atto/serie_generale/caricaDettaglioAtto/originario?atto.dataPubblicazioneGazzetta=2017-06-03&amp;atto.codiceRedazionale=17G00085&amp;elenco30giorni=false">http://www.gazzettaufficiale.it/atto/serie_generale/caricaDettaglioAtto/originario?atto.dataPubblicazioneGazzetta=2017-06-03&amp;atto.codiceRedazionale=17G00085&amp;elenco30giorni=false</a> (Disposizioni a tutela dei minori per la prevenzione ed il contrasto del fenomeno del cyberbullismo)</p> <p>Provisions for the protection of minors and for the prevention of cyberbullying. The aim is to counter cyberbullying in all its forms, with preventive actions and with a strategy of protection and education towards the children involved.</p> <p>Targeted age group: minors (&lt;18 years old)</p>
<p><b>Non-specific legislation</b> Regional level</p>	<p><b>Emilia-Romagna Regional Law 28 March 2014, n. 2</b>, <a href="http://demetra.regione.emilia-romagna.it/al/articolo?urn=er:assemblealegislativa:legge:2014;2">http://demetra.regione.emilia-romagna.it/al/articolo?urn=er:assemblealegislativa:legge:2014;2</a> (Norme per il riconoscimento ed il sostegno del caregiver familiare (persona che presta volontariamente cura e assistenza), pubblicata nel Bollettino Ufficiale n. 93 del 28 marzo 2014)</p> <p>Norms for the recognition and support of the family caregiver.</p> <p>Family caregiver is defined, for the first time in legal terms, as: the person who on a voluntary basis, in a free and responsible way, provides care of a person in conditions of non self-sufficiency or whose disability or health condition necessitates long-term assistance.</p> <p>This law was then taken up by other regions, Abruzzo in 2016 (<a href="http://www2.consiglio.regione.abruzzo.it/leggi_tv/abruzzo_lr/2016/lr16043/Articolato.asp">http://www2.consiglio.regione.abruzzo.it/leggi_tv/abruzzo_lr/2016/lr16043/Articolato.asp</a>) and Campania in 2017 (<a href="http://regione.campania.it/normativa/item.php?7b7fec2087f982d694b26f0cc9f850d6=621512db6f270ae41a780e1cce881b25&amp;pgCode=G19I231R1742&amp;id_doc_type=1&amp;id_tema=26&amp;refresh=on">http://regione.campania.it/normativa/item.php?7b7fec2087f982d694b26f0cc9f850d6=621512db6f270ae41a780e1cce881b25&amp;pgCode=G19I231R1742&amp;id_doc_type=1&amp;id_tema=26&amp;refresh=on</a>). In a further six regions a legal text was filed, taking as reference that of Emilia-Romagna.</p> <p>Targeted age group: not specified</p>

	<p><b>Emilia-Romagna Regional Law 30 July 2015, n. 14,</b> <a href="http://demetra.regione.emilia-romagna.it/al/articolo?urn=er:assemblealegislativa:legge:2015;14">http://demetra.regione.emilia-romagna.it/al/articolo?urn=er:assemblealegislativa:legge:2015;14</a> (Disciplina a sostegno dell'inserimento lavorativo e dell'inclusione sociale delle persone in condizione di fragilità e vulnerabilità, attraverso l'integrazione tra i servizi pubblici del lavoro, sociali e sanitari)</p> <p>Provision to support the job integration and social inclusion of people in conditions of fragility and vulnerability through the integration of public services in the labour, health and social sectors.</p> <p>Targeted age group: not specified</p>
<p><b>Enactment of legislation</b> National level</p>	<p><b>Law 27 December 2017, n. 205:</b></p> <p>At the moment there is no law establishing how to use the funding (art. 254 Law 205/2017) to support informal carers (as defined in art. 255 della Legge 205/2017). It might translate into a care allowance provided to the family, or to the non self-sufficient person, so it can support the family and the carer.</p> <p><b>Law 5 February 1992, n. 104:</b></p> <p>The 3 days of paid leave can be theoretically requested by anyone, even by the minor who is working. But, in its practical application, due to the fact that there are not so many working minors, the application of this tool is used especially from the 18th birthday onwards.</p> <p>According to the opinion of one expert, the young carer who lives in a healthy environment is basically ignored by the legal system, set aside the psychological support from the Local Health Authorities. If, on the contrary, she/he takes care of the entire household, the answer of the legal system is to evaluate if the subjects who should have parental responsibilities are doing their job. According to the current legislation, in the activities targeting youth (and not specifically young carers, who at the moment are not recognised by law) the only available support is the psychological counselling offered by LHA according to law 5 February 1992, n. 104.</p>
<p><b>Enactment of legislation</b> Regional level</p>	<p><b>Law 27 December 2017, n. 205, paragraphs 254-255</b></p> <p>According to the opinion of one expert, 20 million euros a year is not much and now the regions have the possibility to implement targeted and innovative interventions or to reinforce policies they already have. Many of them will probably refinance care allowances.</p>

	<p>A second expert underlines that, according to art. 254 and 255 of this law, it is only the general-strategic aim of the law that is established: the recognition of the role and function of carers. To be able to use the resources of the Fund (art. 254) to support carers (as defined from art. 255) it is necessary to wait for specific regulations which are not yet available.</p> <p><b>Emilia-Romagna Regional Law 28 March 2014, n. 2</b></p> <p>In Emilia-Romagna the "Deliberazione della giunta regionale" 16 June, n. 858 (<a href="http://bur.regione.emilia-romagna.it/dettaglio-inserzione?i=aba33f088caa45c781e2755504e89925">http://bur.regione.emilia-romagna.it/dettaglio-inserzione?i=aba33f088caa45c781e2755504e89925</a>) defines the implementation methods of the Regional Law 28 March 2014, n. 2, concerning the recognition and enhancement of family carers. In the implementation guidelines the general concept of caregivers has been extended, and specific areas and clarifications concerning young carers have been included. The decision of including a broader age range was based on the high percentage of young people who reported to be NEETs (Not in Education, Employment or Training) because of caring activities in their family.</p> <p>In Abruzzo and Campania no implementation guidelines have been issued.</p>
<b>Changes in legislation</b>	<p>The introduction of provisions like the Law 27 December 2017, n. 205 was supported by some family associations.</p> <p>In Italy carers are defined in legal terms starting from the law of the Emilia-Romagna Region of 2014. At the national level, the path started at the beginning of 2017, with the discussion at the Senate Labour Commission (i.e. Labour and Social Security Commission (11th) of the Italian Senate) of three draft laws. One of these was filed by Senator Angioni in the Senate and by Honorable Patriarca in the Chamber of Deputies, on the basis of the experience made in Emilia-Romagna.</p>
<b>Specific policy and service frameworks</b> (only available on local level)	<p>Possibility of personalisation of the study plan: derives from experiences made by a school in Cesena, which used the BES/SEN (Bisogni Educativi Speciali/Special Educational Needs, <a href="http://www.miur.gov.it/bisogni-educativi-speciali">http://www.miur.gov.it/bisogni-educativi-speciali</a>). This tool allows, for example, more flexibility concerning the school attendance plan or the expected attainments for young carers.</p>
<b>Non-specific policy and service frameworks</b> Regional level	<p>In Emilia-Romagna logistical facilitations for participation in university studies can be provided. The online course of study, which allows for study at home, has been greatly expanded.</p> <p>In relation to the job market, the "Patto regionale per il lavoro" (<a href="http://formazionelavoro.regione.emilia-romagna.it/">http://formazionelavoro.regione.emilia-</a></p>

	<a href="http://romagna.it/patto-per-il-lavoro">romagna.it/patto-per-il-lavoro</a> ) in Emilia-Romagna has a specific reference to the importance of caring work.
<b>Non-specific policy and service frameworks</b> Local level	None mentioned.
<b>Enactment of policy and service frameworks</b> Regional level	The funds are allocated to the regions and then they are autonomous in using them, but often there is no concrete return of information. When the funds are allocated to the regions, they are distributed on the basis of very general programmes, after which there is not always a detailed analysis on how these funds are used.
<b>Enactment of policy and service frameworks</b> Local level	The quality of social services provided in Italy (including those aimed to the protection of children at risk) can really vary from place to place, also between realities that are in fact geographically close. As a consequence, to the same case there can be a very inefficient response in one place and a good practice in another.
<b>Changes in policy and service frameworks</b> (only available on regional level)	In the regional Commission set up for developing the implementation guidelines of the Regional Law 28 March 2014, n. 2, were included representatives of the regional educational institution. For the university context, collaboration with the Regional Agency for the Right to Education has been active for two years.
<b>Recognition of young carers</b> (only available on regional level)	<p>The Regional Determination 16 June 2017, number 858 (<a href="http://bur.regione.emilia-romagna.it/dettaglio-inserzione?i=aba33f088caa45c781e2755504e89925">http://bur.regione.emilia-romagna.it/dettaglio-inserzione?i=aba33f088caa45c781e2755504e89925</a>) defines the implementation methods concerning the recognition and enhancement of family carers of the Emilia-Romagna Regional Law 28 March 2014, n. 2.</p> <p>In the implementation guidelines of the Emilia-Romagna Regional Law 28 March 2014, n. 2, the caregiver's skills are recognised. Moreover, it is emphasized that educational institutions can enhance the status of caregivers in accordance with current legislation on training credits (<a href="http://www.istruzione.it/urp/credito_scolastico_formativo.shtml">http://www.istruzione.it/urp/credito_scolastico_formativo.shtml</a>).</p>
<b>Key strengths</b>	<ul style="list-style-type: none"> <li>– Engagement of family associations, which resulted in provisions like the Law 27 December 2017, n. 205</li> <li>– There are virtuous realities (best practices) where families are under control and social services intervene, if needed, acting on the prevention and support</li> <li>– Involvement of regional stakeholders (i.e. representative of the Regional School Office) in developing the implementation guidelines of the Regional Law 28 March 2014, n. 2</li> <li>– Agreements between stakeholders for the recognition of young carers (i.e. protocol signed with the</li> </ul>

	Ministry of Education, University and Research)
<b>Key limitations</b> National level	<p><b>General limitations:</b></p> <ul style="list-style-type: none"> <li>– Italy is one of the EU countries without an ad hoc legislation on family caregivers</li> <li>– Lack of resources: there are barriers of staff and costs</li> <li>– Lack of awareness: this is a topic so far that has not received the attention of the ministerial structures, nor of professionals. There is not an adequate recognition of the impact that such situations have on a young carer.</li> <li>– Lack of a definition: the young person providing care is not defined as a caregiver, but as a minor in adversity</li> <li>– Social services often do not act in a preventive way and intervene only once something striking happens</li> <li>– The judiciary system often tends to apply the concept of “best interest of the child” to grow up in a healthy context by considering safer to remove her/him from the compromised household instead of providing supports to allow her/him to stay in the family.</li> </ul> <p><b>Limitations of the Law 5 February 1992, n. 104:</b></p> <ul style="list-style-type: none"> <li>– The three days of paid leave do not allow family carers to manage the situation; they do not provide “real” and “concrete” support</li> <li>– Only carers who are working can benefit from the paid leave</li> <li>– This law has been interpreted in a quite restrictive way</li> </ul> <p><b>Limitations of the Law 27 December 2017, n. 205:</b></p> <ul style="list-style-type: none"> <li>– The fund to support the caring and assistance role of family carers is not high, considering that it is for the financial coverage of interventions aimed at recognizing the social and economic value of family caregivers and the number of potential beneficiaries is high compared to the available resources.</li> </ul>
<b>Key limitations</b> Regional level	<ul style="list-style-type: none"> <li>– Lack of a formalized national coordination. There are regions which are well-organized, while others do not function well. The disparity in the different territorial areas of the country as regards welfare systems, social services and primary care system, impacts differently on the possibility of giving help and support to both young carers and caregivers in general.</li> <li>– Unequal allocation of resources between North and South.</li> <li>– According to one expert, some regions do not have the necessary skills to build innovative programmes</li> </ul>

	<p>and projects and therefore have the tendency to take experiences and regulations already elaborated and adopted in other regional contexts</p> <ul style="list-style-type: none"> <li>– Criticalities in the administration of some regions, which are back on the application of norms. This leads to a lack of investment in new programmes.</li> </ul>
<b>Key limitations</b> Local level	<ul style="list-style-type: none"> <li>– Lack of resources in some municipalities</li> <li>– Social services procedures are sometimes complicated and not child-friendly, so when a young carer tries to navigate the system to support his/her family might find it too complicated and decide to give up</li> </ul>
<b>Evaluation of the current situation</b> National level	<ul style="list-style-type: none"> <li>– The financial support, without other strategies is not enough (vision “no cash-for-care, but services for care”). Family carers also need services, and all the activities with the Fund for self-sufficiency were aimed exactly at encouraging the creation of a system of services that would help families to manage this kind of situation.</li> <li>– Lack of awareness: this is a topic that so far has not received enough attention. It would be necessary to reflect and discuss more the issue of young carers.</li> <li>– According to one expert, the tribunals are sometimes strict in interpreting the “best interest of the child” to growing up in a healthy environment as removing her/him from the household. A support intervention to keep him/her in the household, which sometimes could be a solution, is often not pursued as it is considered more risky and less predictable in terms of human and economic resources to be applied.</li> <li>– The effects that such situations have on young carers have not yet been evaluated</li> <li>– The society is aging and this means that caring activities are part of everyone’s life. The State has to establish support for family caregivers.</li> </ul>
<b>Evaluation of the current situation</b> Regional level	<ul style="list-style-type: none"> <li>– According to the opinion of one expert, due to criticalities in the administration some regions will probably use the funds to refinance care allowances and not to implement targeted and innovative interventions</li> </ul>
<b>Attitudes to existing policy responses</b>	<p>The important result achieved with the involvement of the MIUR (Ministry of Education, University and Research), which represents a first level of national involvement on the issue of young carers, was assessed very positively. This is because the Ministry recognises that “this problem exists” and that it is necessary to help young people who are attending schools and experiencing these issues.</p>
<b>Suggested changes</b>	<ul style="list-style-type: none"> <li>– On the 17th of October 2018 the Senate Commission for Labour and Social Security has started the</li> </ul>

	<p>examination of 5 Law Proposals (DDL) concerning informal care and it is in the process of auditing different stakeholders (i.e. carers organizations) to collect their opinions. It is important to note that all of them recognise the existence of students young carers in Italy who are performing a socially relevant care activity who should be recognise with a credit to facilitate their educational process.</p> <ul style="list-style-type: none"> <li>- A national law: the same legal framework in the whole country, which, if needed, is applied differently from region to region</li> <li>- Raise awareness through an awareness campaign in schools and then towards professionals working in social, health and education sectors</li> <li>- Collect more data on the percentage of young carers and families living in this kind of situation, in order to show that this is a relevant issue</li> <li>- A specific law with situation-specific solutions, addressing the issue case by case (depending on the kind of care activity that is provided, for whom, for how long, etc.). The legal provisions should establish who intervenes, how they intervene and which specific tools can be used. After that, the application of the legal provision should be carried out by specific units.</li> <li>- Create a place for discussion and involving the following stakeholders: the Department for Family Policies, the Ministry of Labour, the MIUR</li> <li>- Officially recognise the value of young carers, during the study period and also beyond that, e.g. one of the experts suggests that the time devoted to caring activities could be economically compensated, as it happens for instance for the civil service</li> <li>- Tax deductions in addition to care allowances</li> <li>- Strengthen local support services</li> <li>- Adapt existing legislation, e.g. by officially recognizing young carers within the Law 5 February 1992, n. 104</li> <li>- Caregiving should be recognised by the health sector as a form of distress for carers</li> </ul>
<b>Future goals and hopes</b> National level	<ul style="list-style-type: none"> <li>- A national legislation on caregivers with specific attention to the problems and needs of young carers, and to actions of support for them</li> <li>- Definition of the profile followed by targeted interventions: young carers should receive adequate support in cases where they live problems related to their care responsibility. The support should be adequate to their age and to the problems and situations they experience.</li> <li>- Incentives for employers, who hire teleworking caregivers with part-time working hours. These are part of a draft law (<a href="http://www.handylex.org/gun/caregiver_testo_unificato_senato.shtml#testo_unificato">http://www.handylex.org/gun/caregiver_testo_unificato_senato.shtml#testo_unificato</a>).</li> <li>- A contact person (e.g. a teacher in a school, a social worker in social services) with deep knowledge on the</li> </ul>

	<p>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.</p> <ul style="list-style-type: none"> <li>- A social service that monitors the family and reacts promptly</li> <li>- More interconnections between services (e.g. schools) and policy areas</li> <li>- Increase awareness about the positive effects of caring activities: “providing care is an element leading to build skills, to develop the ability to face situations and conflicts and to build relationships with others” [13]</li> <li>- It would be helpful to constantly monitor the situation of young carers in Italy</li> </ul>
<b>Future goals and hopes</b> Regional level	<ul style="list-style-type: none"> <li>- Fewer differences among regions in the distribution of funds: the hope is that the regions can improve their knowledge and competences and, in this way, create more innovative intervention for young carers and then continue also with regional resources.</li> <li>- The approval of Regional Laws to recognise and support informal carers, based on the good practices already existing in some Regions.</li> </ul>

## 10.2. Case Study Netherlands

Categories	Results
<b>Specific legislation</b>	In the Netherlands, no specific legislation protecting and supporting young carers ‘jonge mantelzorgers’ and their families exists.
<b>Non-specific legislation</b> National level	<p><b>Child protection</b></p> <p>Child protection orders are regulated in the Dutch Civil Code  Book 1 Law of Persons and Family Law  Section 1.14.4 Custodial control remedies for minors  Article 1:254 Grounds for ordering custodial control over minors to Article 1:278 Request for a restoration of parental authority; probationary period  <a href="http://www.dutchcivillaw.com/civilcodebook01.htm">http://www.dutchcivillaw.com/civilcodebook01.htm</a></p> <p>To initiate a child protection order the municipality (under the Child and Youth Act (Jeugdwet)) or Veilig Thuis* (under the Mandatory Reporting Code Act <a href="https://www.government.nl/documents/reports/2013/03/14/model-">https://www.government.nl/documents/reports/2013/03/14/model-</a></p>

[reporting-code-domestic-violence-and-child-abuse](#) and Wmo) has to request an investigation by the Child Care and Protection Board (Raad voor de Kinderbescherming) to investigate a child protection order and file a request at the children's court.

\*Veilig Thuis= a certified institution or a youth assistance provider appointed by the municipal authorities (see brochure Child Care and Protection Board; Raad voor de Kinderbescherming;  
<https://www.kinderbescherming.nl/documenten/brochures/2015/01/01/brochure-about-the-child-care-and-protection-board-2015>)

Targeted age group: minors (<18)

**The Social Support Act (Wet maatschappelijke ondersteuning, Wmo 2015), January 2015**

<https://wetten.overheid.nl/BWBR0035362/2018-08-01>

Under the Wmo, local authorities support people who have difficulty participating in society or who cannot take care of themselves or have a need for sheltered accommodation or support.

Municipalities are responsible for the appreciation and recognition of informal caregivers by providing financial rewards of in-kind support within their municipalities.

Targeted age group: 18 years and older (adults).

**The Child and Youth Act (Jeugdwet) January 2015, Article 2.1** <https://zoek.officielebekendmakingen.nl/stb-2014-105.html>

Local municipalities are responsible for decreasing the number of children in specialised care, increasing preventive and early intervention support, and promoting the use of social networks.

**Article 2.1**

The municipal policy on prevention, youth assistance, child protection measures and juvenile rehabilitation and the implementation of youth assistance, child protection measures and juvenile rehabilitation is aimed at (amongst other things):

- the prevention and early identification of and early intervention in growing and upbringing problems, psychological problems and disorders;

	<ul style="list-style-type: none"> <li>– promoting the parenting skills of the parents, so that they are able to bear their responsibility for the upbringing and growing up of young people;</li> <li>– engaging, restoring and strengthening the potential and the problem-solving capacity of the young person, his parents and the persons belonging to their social environment, using their own input where possible;</li> <li>– promoting the safety of the young person in the parenting situation in which he / she grows up;</li> <li>– integral help to the youngster and his parents, if there are multiple problems, and</li> <li>– the establishment and implementation of family group plans and the provision of help on the basis of family group plans</li> </ul> <p>Targeted age group: children (up to 18 , which may be extended in some circumstances to 23).</p> <p><b>The Mandatory Protocol (Domestic Violence and Child Abuse) Act</b> Organisations are required by law to have a domestic violence and child abuse protocol in place.</p> <p><b>Legal framework for the protocol</b> The mandatory use of the protocol is specified in the Act. Organisations in the following sectors are required by law to have a domestic violence and child abuse protocol in place: health care; education; child care; social support; youth care; the criminal justice system. This requirement does not apply to volunteer organisations. Volunteer organisations are, of course, allowed to develop their own step-by-step plan.”</p> <p>The law stipulates that a reporting code must include a ‘Child Check’ (Kind Check) in the case of certain adult clients.</p> <p><b>Compulsory Education Act 1969 (Leerplichtwet 1969)</b> <a href="https://wetten.overheid.nl/BWBR0002628/2018-07-28">https://wetten.overheid.nl/BWBR0002628/2018-07-28</a> and <b>The Compulsory Education Act 2007, Article 4a and 4b</b></p> <p>Targeted age group: Students have to attend school until they are 18 or they have obtained a basic qualification.</p>
<b>Non-specific legislation</b> Regional level	None mentioned
<b>Enactment of legislation</b>	<b>The Child and Youth Act (Jeugdwet) January 2015</b>

National level	<p>Whether young carers are receiving any support through existing legislation is not clear. Current support for young carers is likely to be very inconsistent and is dependent upon municipalities and the viewpoints and actions of individuals; children, parents and professionals.</p> <ul style="list-style-type: none"> <li>– Young carers currently could be supported through either the voluntary sector or under child protection measures.</li> <li>– Significant youth support exists, however there may not be sufficient attention given to supporting young carers.</li> <li>– Parenting support is available.</li> <li>– The first evaluation of the youth law has been published. <a href="https://publicaties.zonmw.nl/eerste-evaluatie-jeugdwet/">https://publicaties.zonmw.nl/eerste-evaluatie-jeugdwet/</a></li> </ul> <p><b>Social Support Act (Wet maatschappelijke ondersteuning, Wmo 2015)</b></p> <ul style="list-style-type: none"> <li>– Parents are able to get respite care whilst their child is being looked after.</li> </ul> <p><b>Compulsory Education Act 1969 (Leerplichtwet 1969) and The Compulsory Education Act 2007</b></p> <ul style="list-style-type: none"> <li>– The Compulsory Education Act is implemented by municipal authorities. The Act requires each municipality to have one sworn attendance officer.</li> <li>– Parents are responsible under the law to ensure their children attend school and sanctions can be imposed under criminal law</li> </ul> <p><b>Child protection measures</b></p> <ul style="list-style-type: none"> <li>– A supervision order with or without an out of-home placement, can be enforced by the juvenile court; the parents remain responsible for the care of their child, but they are obliged to follow the advice of the guardian.</li> <li>– Youth support for the child can be deployed which often includes parenting support.</li> </ul> <p><b>Increasing awareness</b></p> <p>Project Group National Implementation Impulse Child Check in mental health care <a href="https://kindcheck-ggz.nl/">https://kindcheck-ggz.nl/</a> A national project group works with mental health care providers. Its aim is to increase awareness of adolescent young carers in mental health care using the (Child Check) 'Kind Check GGZ'</p>
<b>Enactment of legislation</b>	The project Jong & Zorgend (Young and Caring) provided by care support organisation Mantelzorg & Meer

Regional level	(Informal care & More). The project provides support for AYC's and was initiated by four municipalities (Aalsmeer, Amstelveen, Haarlemmermeer en Uithoorn in the Province of North Holland). The project is financed by the Province of North Holland within the framework of the Regionale Sociale Agenda (Regional Social Agenda). Within this framework, the province implements policy within the social domain, partly on the basis of its statutory duty to support municipalities in the implementation of the Social Support Act (Wmo).
<b>Changes in legislation</b>	Many different ministries were involved in introducing the Child and Youth Act (Jeugdwet) January 2015 which has recently brought about a huge decentralization and transformation of the Dutch youth care system. Responsibilities have not only been decentralised to the 393 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. Further decentralisation has taken place at the same time, with the Social Support Act (Wmo, 2015), and the Participation Act (Participatiewet, 2015) being introduced in January 2015.
<b>Specific policy and service frameworks</b> national level	There are no specific policy and service frameworks for young or adolescent young carers.
<b>Specific policy and service frameworks</b> local level	None mentioned
<b>Non-specific policy and service frameworks</b> National level	<p><b>Wet meldcode huiselijk geweld en kindermishandeling (Domestic violence and child abuse protocol)</b>  <a href="https://www.government.nl/topics/domestic-violence/domestic-violence-and-child-abuse-protocol">https://www.government.nl/topics/domestic-violence/domestic-violence-and-child-abuse-protocol</a> and  <a href="https://wetten.overheid.nl/BWBR0033723/2018-07-28">https://wetten.overheid.nl/BWBR0033723/2018-07-28</a>  This is the legal basis of the Child Check (Kind Check)</p> <p><b>Child check instructions</b>  Organisations need to have instructions in place before a child check can be carried out. A child check is when professionals check whether a family has children and, if so, whether those children are safe. For instance, when a parent has a psychiatric disorder or addiction. The government is currently compiling basic guidelines for the child check.</p>

**Decision compulsory reporting code domestic violence and child abuse**

<https://wetten.overheid.nl/BWBR0033723/2018-07-28>

Laying down the minimum requirements for the compulsory reporting code for domestic violence and child abuse (Decision compulsory reporting code domestic violence and child abuse)

**Toolkit Mantelzorg**

<https://www.lhv.nl/service/toolkit-mantelzorg%20>

The Toolkit Mantelzorg is an advice of the Association for Dutch General Practitioners for general practitioners to pay attention to informal carers, including young carers (under 18 years old).

**NHG Guidelines**

<https://guidelines.nhg.org/>

The Dutch College of General Practitioners (the scientific society of Dutch general practitioners) publishes clinical practice guidelines, of which some specifically refer to informal care. For example, the clinical guideline Dementia states that GPs need to assess the needs of carers.

**The Dutch Ministry of Health, Welfare and Sports launched three programs (Spring to Autumn 2018), with the aim that all disabled people and their significant others/relatives should be able to participate in society in line with their preferences.**

Onbeperkt meedoen! 'Participating without limits' and Zorg voor de jeugd 'Care for the youth' focus primarily on adults or youth with disabilities.

The third program addresses both patients and their family. In the field of disabled care this program (Volwaardig Leven 'A full and fulfilling life') for patients using long-term care and their relatives was developed by the national government in the Netherlands (launched October 2018). Brothers and sisters of a disabled child are explicitly mentioned. It is stated specifically that the family (including children) need to be visible within the healthcare sector and society at large and that their needs should be addressed. The importance of information is mentioned.

<https://www.rijksoverheid.nl/documen-ten/rapporten/2018/09/30/programma-volwaardig-leven>

House of Representatives (2017) passed a motion on the accessibility of psychological aid to students. As a result,

	<p>Minister Ingrid van Engelshoven called together the VSNU (Universities) and VH (Universities of Applied Science), the student associations LSVb and ISO and the Expertise Center for Disability and Education to discuss a joint ambition for students who need extra support. The minister decided to set up a student welfare working group. Bottlenecks have been identified and 5 aims have been developed. Focus is not only on students with psychological complaints, but also on students with informal care tasks, young parents and pregnant students, students in gender transition and students with a disability.</p> <p>The results of a kick off meeting 17 September 2018 will be included in a joint ambition to be presented in October in a letter from the Minister to the House of Representatives</p> <p><a href="https://www.handicap-studie.nl/89_1482_Start_aanpak_studentenwelzijn.aspx">https://www.handicap-studie.nl/89_1482_Start_aanpak_studentenwelzijn.aspx</a></p> <p>Framework targeted at universities, (18+)</p> <p><b>Guidelines Children of Parents with Mental Problems (KOPP) for youth care and youth protection</b></p> <p><a href="http://richtlijnenjeugdhulp.nl/kopp/">http://richtlijnenjeugdhulp.nl/kopp/</a></p> <p>On the initiative of the Netherlands Institute of Psychologists (NIP), the Dutch association of pedagogues and educationalists (NVO) and the Professional Association of Professionals in Social Work (BPSW), the Program Guidelines youth aid and youth protection is developing and supporting the introduction of guidelines for youth professionals. There are currently 14 guidelines available.</p> <p><b>United Nations Convention on the Rights of the Child (UNCRC)</b></p> <p><a href="https://www.unicef.org.uk/what-we-do/un-convention-child-rights/">https://www.unicef.org.uk/what-we-do/un-convention-child-rights/</a></p> <p>The Netherlands has ratified the Convention on the Rights of the Child. The Children's Ombudsman (<a href="https://www.dekinderombudsman.nl/241/english/">https://www.dekinderombudsman.nl/241/english/</a>) checks whether the rights of the child are respected. One of the rights in the Convention on the Rights of the Child is the right to education. In the Netherlands, the right to education is enacted (in national law) through the Compulsory Education Act.</p> <p>Targeted age group: minors (&lt;18)</p>
<b>Non-specific policy and service frameworks</b> Local level	None mentioned
<b>Enactment of policy and service frameworks</b>	A national website for diverse groups (including professionals, children, parents, municipalities) on the topic of children with parents with psychological problems (KOPP) or addiction problems (KVO) with information on

National level	interventions and guidance on how to cooperate with other organisations in this field. <a href="https://www.koppkvo.nl/">https://www.koppkvo.nl/</a> and <a href="https://www.trimbos.nl/themas/kopp-kvo/landelijk-platform-kopp-kvo">https://www.trimbos.nl/themas/kopp-kvo/landelijk-platform-kopp-kvo</a>
<b>Enactment of policy and service frameworks</b> Regional level	Municipalities have been developing and promoting support programmes for AYC's: In Amsterdam for example, support for young carers is promoted by the municipality <a href="https://www.amsterdam.nl/zorg-ondersteuning/ondersteuning/mantelzorg-gewoon/jong-mantelzorgen/waar-terecht/">https://www.amsterdam.nl/zorg-ondersteuning/ondersteuning/mantelzorg-gewoon/jong-mantelzorgen/waar-terecht/</a>
<b>Enactment of policy and service frameworks</b> Local level	None mentioned
<b>Changes in policy and service frameworks</b>	None mentioned
<b>Recognition of young carers</b> (only available on regional level)	<ul style="list-style-type: none"> <li>– Young carers are not specifically defined in the law and young informal caregivers do not recognise themselves as 'young carers'.</li> <li>– There is a general lack of recognition and awareness of young carers that is children who have care responsibilities even amongst professionals. However, more attention is now being given to the subject with stories about young carers which are being highlighted in the media and voluntary agencies recognising when children have caring responsibilities.</li> <li>– There is awareness of the psychological impacts on children who have parents with psychological or addiction issues (children of parents with mental (KOPP) or addiction problems (KVO)) and a taskforce has been set up to address this.</li> </ul>
<b>Key strengths</b>	<p>The new Child and Youth Act (Jeugdwet) 2015 has brought new clarity and goals for supporting children, youth and families and the extent to which these goals are being met. Responsibility for delivering this has been devolved to the municipalities who have more insight into what the problems are within their municipality and they can respond better.</p> <p>A first evaluation of the Act has been undertaken <a href="https://publicaties.zonmw.nl/eerste-evaluatie-jeugdwet/">https://publicaties.zonmw.nl/eerste-evaluatie-jeugdwet/</a></p>
<b>Key limitations</b> National level / local level	<p><b>General limitations</b></p> <ul style="list-style-type: none"> <li>– Young carers are not explicitly mentioned in this law which is 'the big problem'</li> </ul>

	<ul style="list-style-type: none"> <li>- There are challenges around the transition period (in all areas of youth rights) and connecting the support as children become adults.</li> <li>- 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. Care is segmented. An integrated approach is lacking, (for example around hospital discharge).</li> </ul> <p><b>Limitations to the Child and Youth Act (Jeugdwet) 2015</b></p> <ul style="list-style-type: none"> <li>- Decentralisation of responsibilities to the municipalities, has led to inconsistent support with differences between municipalities. Municipalities can decide for themselves what constitutes basic care provision.</li> <li>- There have been budget cuts for youth support and monitoring of goals and outcomes is not yet in order.</li> <li>- There is a lack of information and guidance for parents to support them and their children.</li> </ul>
<p><b>Evaluation of the current situation</b> National level / Local level</p>	<p><b>Legislative changes</b></p> <ul style="list-style-type: none"> <li>- The legislative changes are recent and the legislation may not have embedded smoothly everywhere and there is some dissatisfaction about how effective the new system is.</li> </ul> <p><b>Recognition of the issue and awareness of young carers</b></p> <ul style="list-style-type: none"> <li>- There is recognition that there are significant numbers of young carers.</li> <li>- In practice few professionals identifying them and often the link is not made between a parent being ill or disabled and a child being a young carer. More recognition of the issue of young carers is needed.</li> <li>- There is some knowledge and understanding about the issue of young carers. Although awareness is rising, this is primarily with regards to children caring for someone with mental ill-health. For these children there are evaluated interventions, but focused 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, even with doctors and there is a lack of guidance for parents.</li> </ul> <p><b>How young carers are perceived</b></p> <ul style="list-style-type: none"> <li>- There may be opposing views about the agency of children; whether or not children can choose to be taking on caring roles in the first place and at what age.</li> <li>- The reason why the support needs of adolescent young carers may not have been addressed in legislation or policy may be due to the perception of children and young people. Young people are seen as being children for perhaps longer than in some countries (such as African countries for example) 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.</li> </ul>

	<p><b>Lack of consistency across the country</b></p> <ul style="list-style-type: none"> <li>– Some initiatives exist, but the legal frameworks and policies do not. Where initiatives exist, they are not mapped out and may not be known about by families.</li> <li>– Support is not consistent across the country, but is dependent upon the local situation, local priorities and individuals.</li> </ul> <p><b>Child protection</b></p> <ul style="list-style-type: none"> <li>– For some young carers child protection measures will be appropriate. Where they are appropriate, they should be used.</li> </ul> <p><b>Support focused on parents – not on children</b></p> <ul style="list-style-type: none"> <li>– A lot of money is seen as going into care, however the money may not be necessarily be getting to all those who need it. For example, it may be going directly to those who are disabled, but not to the whole family.</li> <li>– In families where there is parental illness or disability or where or where there are disabled or ill siblings, support is currently focused on parents rather than on the support needs of other children who might be carers. Only when it is the child themselves who has the problem is the support child focused, with ‘one child: one plan’.</li> <li>– Children with caring responsibilities are not being noticed. Young carers are not recognising themselves as carers making it difficult for municipalities to know who the young carers are in their area.</li> <li>– Treatment is focused on parents and not the family. Children are not asked for their opinions whether they have support needs.</li> <li>– Children will not always be aware of their rights and support available. Parents are not receiving guidance.</li> <li>– Currently there are issues with privacy and sharing information. Children may not be given information about the situation of their parent for example or other information that would be helpful. Support may be given, but it is not systematic.</li> </ul> <p><b>Identification of young carers and education law</b></p> <ul style="list-style-type: none"> <li>– Young carers could be identified and supported if school attendance is disrupted, however this does not appear to be happening in a preventative manner. Teachers may not be aware of the family situations of their pupils and there is currently not a consistent approach to identifying young carers by schools.</li> </ul>
<p><b>Attitudes to existing policy responses</b></p>	<ul style="list-style-type: none"> <li>– Legislation is necessary in order to drive forward policies for young carers.</li> <li>– Young carers under 18 should be viewed differently from adult carers over 18 years old since they have different legal positions.</li> </ul>

	<ul style="list-style-type: none"> <li>- The recent changes in youth legislation have not yet yielded results but have led to increased bureaucracy and less available funding. One positive is that support can continue until aged 23.</li> <li>- Child protection measures: In some circumstances, being a young carer might necessitate initiating child protection measures.</li> <li>- Approaches to supporting young carers will in the future probably come through family care under the Wmo.</li> <li>- A lack of policy frameworks and laws could be explained by a country 'not noticing' young carers.</li> <li>- The United Nations Convention on the Rights of the Child (UNCRC) is viewed as very important because it is the first treaty worldwide, where it sums up all the rights for the children and because there is no other treaty worldwide that is ratified by nearly all countries. Several articles particularly highlighted such as Articles 12, 17 and 18 and that General Comment (No. 20, 2016) may have particular relevance.  <a href="https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f20&amp;Lang=en">https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f20&amp;Lang=en</a> </li> </ul>
<b>Suggested changes</b>	<p><b>General suggestions</b></p> <ul style="list-style-type: none"> <li>- Comparisons should be made with what is being done in other countries for example research undertaken as to how the 'Care Act' in England came about.</li> <li>- Young carers will have many ideas and should be consulted.</li> <li>- Good projects and initiatives should be researched.</li> <li>- A multi-faceted approach is necessary that includes training and education</li> <li>- More education about young carers and how to support families should take place in schools and in universities.</li> </ul> <p><b>Legislation and policy</b></p> <ul style="list-style-type: none"> <li>- Legislation and policy is important for laying the foundations and is necessary to bring about uniformity. This should then be enacted in different ways to accommodate the needs of such a diverse group.</li> <li>- Discussions about young carers should be integrated with discussions about adult informal carers.</li> <li>- Using a minimalist approach in order to keep things as normal as possible for young carers</li> <li>- The law (The Child and Youth Act (Jeugdwet) should be changed to a more prescriptive entitlement of provision of care</li> <li>- Not to separate the support for different groups of young carers, but rather have a more universal approach, along the lines of the Care Act in the UK. When you are working with an adult with care needs, the children are also assessed.</li> </ul>

	<ul style="list-style-type: none"> <li>– Take a collaborate approach towards policy making.</li> </ul> <p><b>Approaches</b></p> <ul style="list-style-type: none"> <li>– A preventative approach should be taken to lessen negative impacts and need for specialist support. Health insurance plans/programmes should include preventative care for young carers.</li> <li>– Support can be from multiple agencies.</li> <li>– The needs of young carers need to be assessed and support provided to meet those needs.</li> <li>– Children and families should be given information about their particular situation and support available to them.</li> <li>– Initiatives should be mapped and children and families informed about them</li> <li>– Information and support modules could be developed for young carers.</li> <li>– Use technology (e.g. an App) to help reduce negative impacts.</li> </ul>
<p><b>Future goals and hopes</b> National / local level</p>	<p><b>Inappropriate caring roles</b></p> <ul style="list-style-type: none"> <li>– Young carers should be protected against inappropriate caring and attention should also be given to what the rights should be.</li> </ul> <p><b>Legislation</b></p> <ul style="list-style-type: none"> <li>– In the future, legislation is seen as important for ‘laying the foundations’.</li> <li>– International Cooperation Agency of the Association of Netherlands Municipalities (VNG) <a href="http://www.vng-international.nl/">http://www.vng-international.nl/</a> could be involved to draw up legislation along the lines of the Care Act in England. Current social care legislation could be amended to include the assessment of the needs of young carers as in the UK.</li> </ul> <p><b>Recognition and understanding</b></p> <ul style="list-style-type: none"> <li>– 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.</li> <li>– 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.</li> </ul> <p><b>A preventative approach</b></p> <ul style="list-style-type: none"> <li>– Since the Netherlands is moving increasingly towards a preventative model of support it is hoped that</li> </ul>

	<p>children should also be part of discussion and specifically that preventative care for young carers would be helpful.</p> <ul style="list-style-type: none"> <li>- Identification of young carers needs to improve and new approaches need to be employed.</li> <li>- Schools should also play a key role as part of a preventative approach by identifying and assessing the needs of young carers. Discussion of subjects in schools, including informal caring should be normal. Practice developed for other groups – such as pupils with impaired hearing – could be followed.</li> </ul> <p><b>A collaborative approach and improved integrated working</b></p> <ul style="list-style-type: none"> <li>- Support can be from multiple agencies and collaboration between agencies would be a better approach. Improved integrated working would for example improve support for young carers at the transition period, when becoming adults.</li> </ul> <p><b>Family focused approach</b></p> <ul style="list-style-type: none"> <li>- There is hope for a more family focused approach and more of a defined legislation and directives such as in the UK.</li> <li>- Families should be assessed including assessment of the needs of children. Family support should be developed by enlarging their network of support.</li> <li>- The issue should be understood by all professionals and it should be standard practice that the issue is acknowledged, talked about with families and followed up with support.</li> <li>- Families to be signposted to local support by Neighbourhood teams could play a really supportive role by signposting carers to local support</li> <li>- Families to be strengthened by having support organised into a network of support</li> <li>- The whole family should be supported. Young carers should be seen and involved in a care plan. Their opinions need to be sought.</li> </ul> <p><b>Assessing the needs of young carers</b></p> <ul style="list-style-type: none"> <li>- A more systematic way of understanding young carers' needs to avoid pupils having to repeat their story multiple times.</li> <li>- The needs of young carers need to be assessed and support in place to address the different needs. E.g. Support for young carers with their education.</li> <li>- When there is a person with health problems in the family there should always be a check for how the children are doing and what their needs are.</li> </ul> <p><b>Support and Information for young carers</b></p> <ul style="list-style-type: none"> <li>- Young carers need information at different points in their life. They should be informed about what</li> </ul>
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	<p>support they can get and how to access it. In each municipality there could be a support point for young carers.</p> <ul style="list-style-type: none"> <li>– Legislation to increase visibility of support for example by explicitly stating for example that this support is available for carers.</li> </ul> <p><b>Improved transition work</b></p> <ul style="list-style-type: none"> <li>– Special attention should be taken to protect adolescent young carers as they are at a vulnerable period and developing their own identity. Just because they have reached a particular age, they should not be burdened by caring roles.</li> </ul>
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### 10.3. Case Study Slovenia

Categories	Results
<b>Specific legislation</b>	In Slovenia, no specific legislation protecting and supporting young carers and their families exists.
<b>Non-specific legislation</b> National level	<p><b>Social Security Act (ZSV):</b> <a href="http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAK0869">http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAK0869</a> (Zakon o socialnem varstvu)</p> <p>The Social Security Act is the basis for all the services within the family and for the family.</p> <p>The centres of social work have to intervene in families when there are difficult family situations. Their activities are regulated by the Social Security Act.</p> <p>Article 18b and article 18c define the family assistant as a person who provides assistance to a disabled person who needs it and who has the same residence as the care-recipient.</p> <p>Target age group: the whole family; a person is considered a child if she or he is younger than 18 years of age.</p> <p><b>Long-term care legislation (draft legislation):</b></p> <p>The idea of the new legislation is integration and coordination of different aspects of treatment and that the promotion of care should be a mutual responsibility between education, social and health care systems.</p>

**Domestic Violence Prevention Act,**

<http://www.pisrs.si/Pis.web/npbDocPdf?idPredpisa=ZAKO7373&idPredpisaChng=ZAKO5084&type=doc&lang=EN> (Zakon o preprečevanju nasilja v družini)

Measures to protect children are included.

Target age group: the whole family; a person is considered a child if she or he is younger than 18

**Law on Marriage and Family Relations:**

[www.mddsz.gov.si/fileadmin/mddsz.gov.si/pageuploads/dokumenti\\_pdf/zakonodaja/law\\_on\\_marriage\\_and\\_family\\_relations.pdf](http://www.mddsz.gov.si/fileadmin/mddsz.gov.si/pageuploads/dokumenti_pdf/zakonodaja/law_on_marriage_and_family_relations.pdf)

This law regulates marriage, relations between parents and children and among other relatives, adoption, fostering and the protection of the rights and benefits of young children and other persons who are not capable of taking care of themselves.

Target age group: the whole family; a person is considered a child if she or he is younger than 18

**Family Code (DZ),** [www.mddsz.gov.si/fileadmin/mddsz.gov.si/pageuploads/Druzinski\\_zakonik\\_ANG.pdf](http://www.mddsz.gov.si/fileadmin/mddsz.gov.si/pageuploads/Druzinski_zakonik_ANG.pdf)

The Family Code comes into force in May 2019.

The best interest of the child must be sought (Art. 7).

Within the family legislation there are provisions about how to take steps to protect the child and assessment if the child is endangered.

Target age group: the whole family; a person is considered a child if she or he is younger than 18

**Volunteering Act,** <http://pisrs.si/Pis.web/pregledPredpisa?id=ZAKO5532> (Zakon o prostovoljstvu)

Some measures from the Volunteering Act could make the situation more bearable for young carers. Only certain provisions are applicable to young people.

	<p>There is not a special Youth Volunteering Act in Slovenia.</p> <p>Target age group: not specified</p> <p><b>Education Law:</b></p> <p>There are some regulations within the education law that relate to how schools should communicate with the centres of social work, if they notice that a child needs special attentions.</p> <p>Target age group: a person is considered a child if she or he is younger than 18</p>
<p><b>Enactment of legislation</b> National level</p>	<p><b>Social Security Act:</b></p> <p>Centres of Social Work assess and work with families and children (under 18). They recognise that some children are taking on the care of other family members. They try to take away the caring role, empower the parents and make the family functional.</p> <p>If the assessment is that a child is endangered then a foster care placement is sought for the child.</p> <p><b>Legislation for families:</b></p> <p>The interventions are meant to protect children, to empower the family, to build the capacities, to make the family function better.</p>
<p><b>Changes in legislation</b></p>	<p><b>Family Code:</b></p> <p>In the past, the social workers had a double role: They worked with the family and they also decided if the child should be taken out of the family. The family code, which comes into force in May 2019, will put the decision making into the hands of the courts. Social workers will continue to work with the families and propose child protection measures to the courts, who will then decide if they should be adopted or not. The high workload of social workers was a driver for these changes.</p> <p>The legislation first appeared in 2011 but it did not come into force due to some internal discussions. After the analysis of other European legislations (especially the German one), the result was that the court should take decisions on child protection.</p>

	<p><b>Violence Protection Law:</b></p> <p>This law was the basis for the definition of violence and it states that a child, who witnesses domestic violence of a family member, is also a victim, even if she or he is not the direct victim.</p> <p>The changes were made mainly because some measures of that legislation could not be carried out only by the police. The centres have to protect the child in cases of family violence.</p> <p><b>Long-Term Care Act:</b></p> <p>In 2002 a special group was formed from the representatives of the Ministry of Labour, Ministry of Health, the Health Insurance Institute and some other experts with the aim to prepare a report for the government. One idea included in this report was that the long-term care should be related to the introduction of a compulsory long-term care insurance, which in turn would financially support home-based care.</p> <p>One of the greatest differences between the new proposal of the long-term care legislation and the old one is, that the old one was holistic and the proposal integrated all the support needed during the life span, while the new legislation will deal only with adults.</p>
<b>Specific policy and service frameworks</b>	<p>In Slovenia, no specific policy or service framework protecting and supporting young carers and their families exists.</p>
<b>Non-specific policy and service frameworks</b> National level	<p><b>National Programme for Youth,</b>  <a href="http://www.youthpolicy.org/national/Slovenia%20Youth%20Programme%202013%202022.pdf">http://www.youthpolicy.org/national/Slovenia Youth Programme 2013 2022.pdf</a></p> <ul style="list-style-type: none"> <li>– It is aimed at empowering young people</li> <li>– It deals with different policies related to young people, but it does not include young carers as a specific target group</li> <li>– There is a specific chapter within the National Programme for Youth that focuses on health (Chapter 5 Health and Well-being, page 37)</li> <li>– The Ministry of Labour and Social Affairs plays a key role in this programme</li> </ul> <p><b>Ministry of Labour, Family and Social Affairs:</b></p> <p>In the field of social protection and social care, the Ministry is adopting strategic documents on a national and local level and the focus of those documents is on long-term care. But so far there is no mention of the protection</p>

	<p>of young carers and their families within these documents adopted by the Ministry of Labour, Family and Social Affairs.</p> <p><b>Policy for young people with special needs:</b></p> <p>Slovenia provides very strong institutional care for young people with special needs (referring mainly to people who have a cognitive or physical impairment).</p> <p><b>Education:</b></p> <p>Within higher education, students who fall under a broad category of 'special status' are entitled to certain additional rights. Education policies include measures focusing on inclusion.</p>
<p><b>Non-specific policy and service frameworks</b> Local level</p>	<p><b>Youth Policy:</b></p> <p>Youth policy is strong in including young people with fewer opportunities; this is one of the important target groups of youth policy, especially in the field of youth work. Youth work is implemented mainly on a local level. Youth centres are important in implementing youth work at a local level and provide a range of support for young people in need.</p>
<p><b>Enactment of policy and service frameworks</b> National level</p>	<p><b>Social Protection System:</b></p> <p>Within the social protection system, related to long-term care, services and cash benefits can be provided.</p> <p><b>Social Work Centres:</b></p> <p>The main role of the social work centres is to make the family functional. Interventions within families will try to take away the caring role from the child and to empower the parents. If the children have to be taken out of the family, the first step is to find a foster family that would take all the siblings. If this is not possible, a placement is sought for the younger siblings and an older sibling would be left within the family.</p> <p><b>Healthcare Institutions:</b></p> <p>Healthcare institutions can inform the social work centres if they are aware of a difficult situation for a child, or if a person with children needs to be hospitalized.</p> <p><b>Education:</b></p> <p>"Youth with fewer opportunities" are prioritized in terms of various measures, from formal education to non-formal education, within youth programmes, etc.</p>

	<p><b>Financial Support:</b></p> <p>The implementation of instruments by the state or by ministries works well on the practice level when there is enough financial support.</p>
<b>Changes in policy and service frameworks</b>	<p><b>National Programme for Youth:</b></p> <p>Youth wings were able to get their own state secretary and they had the necessary political weight to support the introduction of the National Programme for Youth.</p> <p><b>Youth Policy Framework:</b></p> <p>The EU process promoting young people as a target group for different policies supported the policy development in Slovenia as well. The EU strategy that has been implemented since 2010 identified eight important fields of youth policy including education, employment, health and, culture. This provided a good basis for Slovenia when it started the process of preparing the youth policy framework (<a href="https://eacea.ec.europa.eu/national-policies/en/content/youthwiki/13-national-youth-strategy-slovenia">https://eacea.ec.europa.eu/national-policies/en/content/youthwiki/13-national-youth-strategy-slovenia</a>).</p> <p>The youth sector has become stronger in identifying different policies needed by young people. Prior to 2013 youth policy was dealing more with the youth sector and youth organizations, and this awareness helped Slovenia to have another perspective and to think in a broader way when preparing youth policy.</p> <p>The youth sector was involved, namely the National Youth Council, network of youth centres (<a href="http://www.mreza-mama.si/about-us/">http://www.mreza-mama.si/about-us/</a>), Youth centres themselves, some national youth organizations, and even the youth wing of some youth parties recognised as national youth organizations in Slovenia. Some Ministries were also involved, such as the Ministries of Education, Labour and Social Affairs and Health.</p>
<b>Recognition of young carers</b>	<p>So far, there has been no awareness of young carers and currently young carers are not taken into account in the preparation of policies. Youth policy and the National Programme for Youth do not include young carers as a specific target group. Awareness of young carers is probably higher in practice (e.g. counselling in schools).</p>
<b>Key strengths</b>	<ul style="list-style-type: none"> <li>– Tradition of a good care of children, child protection and family policies</li> <li>– Slovenia provides very strong institutional care for young people with special needs</li> <li>– Key stakeholders: youth centres with information and counselling; social workers, with expertise and</li> </ul>

	<p>authority, that makes the parents listen</p> <ul style="list-style-type: none"> <li>– State bureaucrats, who design legislation, have good knowledge of the system</li> <li>– A lot of good practice in some local communities</li> <li>– Youth centres are a place that include young people and involve them in informal education; they provide tailored support to young people with fewer opportunities</li> </ul>
<p><b>Key limitations</b> National level</p>	<p><b>General limitations:</b></p> <ul style="list-style-type: none"> <li>– Too many changes in legislation occurred in the past, which brought periods of adjustment with negative outcomes</li> <li>– Communication gap between those who are proponents of a new law and state bureaucrats (who translate the concepts into “administrative language”)</li> <li>– Bureaucrats are often disconnected from the problem</li> <li>– Lack of cross-sectorial cooperation</li> <li>– Lack of awareness about the topic of young carers and omission of young carers in policies</li> <li>– Lack of political willingness: nobody wants to collect additional data, they prefer to rely on existing measures rather than design new measures for a new target group</li> <li>– Political pressure to deliver a new legislation quickly (and therefore rushed)</li> <li>– Lack of an entrepreneurial mind-set and confidence to implement new initiatives</li> </ul> <p><b>Limitations in the enactment of legislation and policies:</b></p> <ul style="list-style-type: none"> <li>– Interventions are often too late</li> <li>– Evaluations are mainly done externally and the results do not reflect the reality</li> <li>– Too many guidelines: people do not know which guidelines to use, and in the end they do not read them anymore</li> <li>– National ministries are vertically-oriented, and as a consequence there is no cross-sectorial collaboration (e.g. between schools and centres of social work)</li> <li>– Lack of clarity in terms of goals and how to measure impact</li> </ul> <p><b>Limitations of the National Youth Programme:</b></p> <ul style="list-style-type: none"> <li>– Lack of cooperation and commitment from some ministries for the implementation of the National Youth Programme</li> </ul> <p><b>Limitations of the Long-Term Care Act:</b></p>

	<ul style="list-style-type: none"> <li>– Deals mostly with adults in need of long-term care and children are dealt with separately in other legislation</li> <li>– Young carers are neglected in the proposal of the Long-Term Care Act</li> <li>– Lack of an integrated approach, because the issue of long-term care is divided between different ministries (Ministry of Education, Ministry of Health, Ministry of Labour, Family, Social Affairs and Equal Opportunities)</li> </ul>
<b>Key limitations</b> Local level	<ul style="list-style-type: none"> <li>– Lack of resources: huge opposition from local authorities, because municipalities have not sufficient financial resources</li> </ul>
<b>Evaluation of the current situation</b> National level	<ul style="list-style-type: none"> <li>– The situation is poor with regards to legislation, policy and service frameworks. The legislation needs to be supported by a coherent and explicit national strategy or national programme with a clear budget, otherwise it will not work. Slovenia has a strong social policy, but it does not specifically address the situation of young carers and there is no awareness on young carers. Different regions need different approaches to improve the situation of young people.</li> <li>– With the Youth Policy, it is the first time that young people are a target group of a policy. Youth policy can be improved (e.g. the cooperation with other ministries, policies and on an evidence research level. The implementation of the National Youth Programme is not as effective as it could have been if there were more commitment and cooperation between ministries. The coordination by the Office for Youth, which is part of only one ministry, is problematic.</li> <li>– Slovenia is an ageing society; thus, a transition from institutional care to a more home-based care is needed. Long-term care legislation could relieve the burden carried by young carers, but it does not address them directly.</li> <li>– Support probably works better in practice than on a policy level. Interventions in the families are often too late and the impact of interventions is rarely monitored.</li> <li>– Research is important to identify specific target groups and their needs and to improve existing policies.</li> <li>– Sometimes external pressure for changes is necessary.</li> </ul>

	<ul style="list-style-type: none"> <li>– Transitional periods might be difficult, but with the proper communication and training, it is possible to overcome potential issues.</li> </ul>
<b>Evaluation of the current situation</b> Local level	In order to avoid the opposition of municipalities which are lacking financial resources, further financial support from the national budget should follow new measures that increase local responsibilities of municipalities.
<b>Attitudes to existing policy responses</b>	<ul style="list-style-type: none"> <li>– It should be determined whether a new legislation or policy framework would be most effective, or whether existing measures can be applied to the case of young carers</li> <li>– The concept of young carers is very distant to state bureaucrats</li> <li>– It is important to be careful when interpreting what is the “best interest of the child”: to preserve the family or to be given a foster care placement?</li> <li>– Changes in family and child protection policies will be beneficial, but the reform might also bring some problems</li> <li>– Young carers are not included in the long-term care act and this will be a problem in the future, when Slovenia will be faced with an increased need for carers</li> <li>– It is useful to have guidelines and agreements to support communication between institutions</li> <li>– In the past the work of home care nurses was really good practice, however these roles are now more limited to when a child is born</li> </ul>
<b>Suggested changes</b> National level	<p><b>Suggested changes in legislation:</b></p> <ul style="list-style-type: none"> <li>– The issue of informal care should be an integrated part of a new legislation, built on good practice</li> <li>– Wider focus of the target of the Long-Term Care legislation to include young carers</li> <li>– Make changes to legislation related to the education system and improve services which can support young carers in schools. The caring activity should be a part of curriculum in secondary schools.</li> <li>– Use a more bottom-up approach to identify problems and a top-down legislative approach based on evidence</li> <li>– Slovenia could find solutions from practice in other countries but this should not be copied directly</li> </ul> <p><b>Suggested changes in policy:</b></p> <ul style="list-style-type: none"> <li>– Policies need to be framed to correspond to the existing structures of the ministries to give a clear leadership</li> </ul>

	<ul style="list-style-type: none"> <li>- More synergies between different policies</li> <li>- Take advantage of the opportunity and include support to young carers in the national programme of social care</li> <li>- Provide more support to young carers in terms of counselling and respite</li> <li>- Research institutes should be better linked to policy makers</li> <li>- Quicker interventions to assess needs and policies adapted to different situations (e.g. taking into account the transition between school and work)</li> <li>- New technologies could be used to help protect and support young carers</li> </ul> <p><b>Involvement and coordination of key factors:</b></p> <ul style="list-style-type: none"> <li>- Include the active participation of young people and young carers, in order to better understand their situation</li> <li>- More cross-sectorial cooperation and coordinated approach</li> <li>- Key stakeholders for change are needed, e.g. a strong NGO or committed individuals</li> </ul> <p><b>Suggested changes in the enactment of legislation and policies:</b></p> <ul style="list-style-type: none"> <li>- Different approach for different regions and more support to local municipalities</li> <li>- More transparency about the monitoring processes, strong non-state monitoring and better data is needed</li> <li>- Clear goals and new indicators tailored to the target group are needed</li> </ul>
<p><b>Suggested changes</b> Local level</p>	<p>Improve the recognition of young carers as an important target group for policy makers.</p>
<p><b>Future goals and hopes</b> National level</p>	<ul style="list-style-type: none"> <li>- More support from the state and other organizations to relieve caring burdens on young people and for there to be few numbers of young carers</li> <li>- More awareness of young carers among the general public, education institution, companies and policy makers</li> <li>- Recognition of young carers as an important target group of people with fewer opportunities in policies and programmes</li> <li>- Earlier interventions in order to limit the negative impacts on young carers</li> <li>- More investment in local youth policies from the national budget</li> <li>- To achieve an objective of the national strategy, which is to include young people in society, in education and in the labour market</li> </ul>

- Adoption of changes in the long-term care legislation
- Multigenerational centres would be successful in reaching families

#### 10.4. Case Study Sweden

Categories	Results
<b>Specific legislation</b>	<p><b>Healthcare Act (Hälso- och sjukvårdslag (2017:30))</b>  <a href="https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag-sfs-2017-30">https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag-sfs-2017-30</a></p> <p>Chapter 3 Generally  1 §: The purpose of health care is good health and equal treatment for the entire population. The care should be given with respect for all people's equal worth and for the dignity of the individual. Those with the greatest need for healthcare should be given priority to care.  2 §: Health care services shall work to prevent ill health.</p> <p>Chapter 5 Operations  Generally  Special obligations regarding children  6 §: When healthcare is given to children, the best interests of the child shall be taken into account.  7 §: A child's need for information, advice and support should be taken into account in particular if the child's parent or any other adult the child lives permanently with</p> <ul style="list-style-type: none"> <li>- have a mental disorder or mental disability</li> <li>- have a serious physical illness or injury</li> </ul> <p>or</p> <ul style="list-style-type: none"> <li>- are addicted to alcohol or other addictive agents.</li> </ul> <p>The same applies if the child's parent or any other adult the child lives permanently with dies unexpectedly.</p> <p>Targeted age group: it applies to both adults and children (up to 18)</p>
<b>Non-specific legislation</b>	<b>Child Protection Legislation</b>

National level	<p>Child protection is dealt with under two different laws: the Social Services Act (Socialtjänstlagen) and the Care of Young Persons Act (LVU).</p> <p><b>Social Services Act (2001) (Socialtjänstlag (2001:453))</b>  <a href="http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453">http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453</a></p> <p>Chapter 4 Right to assistance  1 §: Anyone who cannot meet their needs or otherwise receive them is entitled to assistance from the social welfare committee for their support (supply support) and for their life-giving in general.</p> <p>Chapter 5 Special provisions for different groups  Children and young people  1 §: The Social Affairs Committee shall [among other things]  1. Promote children and young people to grow up under safe and good conditions  3. Carry out outreach activity and other preventive work in order to prevent that children and young get poorly  6. Pay attention to children and young people in environments that are harmful to them</p> <p>Targeted age group: children are entitled to support if needed, but only children over 15 can ask for support for themselves. For younger children the parent's consent is needed (Chapter 11, §2 and §10).</p> <p><b>The Care of Young Persons (Special Provisions) Act (1990) (Lag (1990:52) med särskilda bestämmelser om vård av unga (LVU))</b>  <a href="https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-199052-med-sarskilda-bestammelser-om-var-d_sfs-1990-52">https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-199052-med-sarskilda-bestammelser-om-var-d_sfs-1990-52</a></p> <p>If the parents of someone under the age of 18 cannot, for some reason, provide the young person with the support he or she needs, or if the young person her or himself lives a destructive life involving, for instance, substance abuse or criminality, it is possible for such a young person to be cared for according to the Care of Young Persons (Special Provisions) Act.</p>
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Targeted age group: children under 18 years old (and under 20 years old in so-called behaviour cases, if this is more appropriate than other care)

**The Education Act (2010) (Skollag (2010:800))**

[http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/skollag-2010800\\_sfs-2010-800](http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/skollag-2010800_sfs-2010-800)

Chapter 2 Chiefs and responsibilities

25-28 §§: Student health is supposed to support the student's development towards the educational goals. In the individually targeted work the student health has a special responsibility to eliminate obstacles to each student's learning and development.

Chapter 7 School and the right to education

Those who are required to attend school

2 §: Children living in Sweden are required to attend school in accordance with the provisions of chapter 7

3 §: According to chapter 2, section 18, first section of the Constitution, all children covered by the public school have the right to cost-free basic training in public schools.

Targeted age group: children under 18 years old

**Law (1993: 387) on support and services for certain disabled people (LSS)**

**Lag (1993:387) om stöd och service till vissa funktionshindrade)**

[https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa\\_sfs-1993-387](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387)

This Act provides for special assistance and special services for persons with physical or mental disabilities and conditions.

Targeted age group: it applies to all age groups.

**Patient Safety Act (2010); Patientsäkerhetslag (2010:659)**

<https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientsakerhetslag->

	<p><a href="#">2010659 sfs-2010-659</a></p> <p>Chapter 6 Obligations for healthcare professionals and others</p> <p>General obligations</p> <p>5 §: Healthcare professionals should pay particular attention to a child's need for information, counselling and support if the child's parent or any other adult the child lives permanently with</p> <ol style="list-style-type: none"> <li>1. Has a mental disorder or a mental disability,</li> <li>2. Has a serious physical illness or injury, or</li> <li>3. is addicted to alcohol or any other addictive agent</li> </ol> <p>The same applies if the child's parent or any other adult the child lives permanently with, dies unexpectedly.</p> <p>Provisions concerning the obligation to report to the Social Council that a child may need the protection of the committee is contained in Chapter 14, 1 § of the Social Services Act (2001: 453). Team (2017: 62).</p> <p>Targeted age group: it applies to both adults and children (up to 18).</p> <p><b>UNCRC and Swedish law</b>, <a href="https://www.government.se/government-policy/childrens-rights/">https://www.government.se/government-policy/childrens-rights/</a>.</p> <p>Targeted age group: children under 18 years old</p>
<p><b>Non-specific legislation</b> Regional level</p>	<p>None mentioned</p>
<p><b>Enactment of legislation</b> National level</p>	<p><b>In General</b></p> <ul style="list-style-type: none"> <li>– The National Board of Health and Welfare has an assignment from the Government to strengthen the support for children as next of kin. Among other things, they promote a family oriented approach, especially in social services, but also in psychiatry.</li> <li>– It is often the case that a situation is not regarded as one related to caring, but is rather related to parenting where a parent has a drug addiction or a mental health condition for example</li> <li>– The Law on Support and Services for Certain Disabled People (LSS) provides support for persons</li> </ul>

	<p>immediately surrounding a disabled person</p> <ul style="list-style-type: none"> <li>– There is a patchwork of support for young carers. However, children have not been thought about as young carers and they are invisible to a great extent.</li> </ul> <p><b>The Healthcare Act</b></p> <ul style="list-style-type: none"> <li>– The legislation that says that children have the right to information provides a very good opportunity to talk to the children about support, however, it is though that things could be improved.</li> <li>– Although children have the right to information and the right to participation for example, there is a concern that the child's best interests will not always taken seriously</li> </ul> <p><b>Education</b></p> <ul style="list-style-type: none"> <li>– Little is done for children in schools until there is an absenteeism rate of at least 15-20% [Interviewer]</li> <li>– There could be a lot more awareness of children than is currently done</li> <li>– There is an individual focus in the Swedish legislation. Working with an adult does not automatically assess whether there are children who are affected or whether the adult needs support with their parenting responsibilities</li> </ul>
<b>Enactment of legislation</b> Regional level	<ul style="list-style-type: none"> <li>– There are local guidelines that directly prohibit those who provide support to include children and family</li> </ul>
<b>Changes in legislation</b>	<p><b>The Social Services Act (2001)</b></p> <ul style="list-style-type: none"> <li>– Law (2015: 982) amended the Social Services Act (2001: 453)</li> <li>– The Social Services Act (Socialtjänstlag (2001:453) is undergoing a review where prevention work has been particularly highlighted</li> <li>– Additional directives are dealing with the elderly and how to ensure that children's rights are clarified and safeguarded in light of the Children's Convention becoming law</li> </ul> <p><b>The Healthcare Act (2010)</b></p> <p>The organisation Allmänna Barnhuset <a href="http://www.allmannabarnhuset.se/">http://www.allmannabarnhuset.se/</a> did quite a lot of work on children as next of kin and the regulation in the Health Care Act</p> <ul style="list-style-type: none"> <li>– A child's need for information, advice and support should be taken into account in particular if the child's parent or any other adult the child lives permanently with has a mental disorder or mental disability (a) or</li> </ul>

	<p>has a serious physical illness or injury (b) or are addicts of alcohol or other addictive agents (c).</p> <p><b>United Nations Convention on the Rights of the Child (UNCRC)</b></p> <ul style="list-style-type: none"> <li>– Sweden ratified the United Nations Convention on the Rights of the Child (UNCRC) on 29th June 1990 and a political process led the way to incorporating the Convention on the Rights of the Child into Swedish law</li> <li>– On 13 June 2018, the Riksdag (the Swedish parliament) adopted a bill on making the UN Convention on the Rights of the Child Swedish law. In order for the convention to have a greater impact, the Government is also proposing a guidance document, an education initiative and continued systematic transformation work. It is proposed that the act will enter into force on 1 January 2020.</li> <li>– The Children's Ombudsman has been involved</li> </ul>
<p><b>Specific policy and service frameworks</b> National level</p>	None mentioned
<p><b>Non-specific policy and service frameworks</b> National level</p>	None mentioned
<p><b>Non-specific policy and service frameworks</b> Regional level</p>	None mentioned
<p><b>Non-specific policy and service frameworks</b> Local level</p>	None mentioned
<p><b>Enactment of policy and service frameworks</b> National level</p>	<ul style="list-style-type: none"> <li>– Since practice has been specialised and individual focused since the 1970s, the family perspective has been lost a lot. There are sometimes local guidelines that directly prohibit those who provide this support to include children and families.</li> <li>– Changing views about children having their own rights and about their participation is a lengthy process.</li> <li>– There has been a shift in practice with an increase in family counsellors who now have to work with children.</li> </ul>

<b>Enactment of policy and service frameworks</b> Local level	None mentioned
<b>Changes in policy and service frameworks</b>	In general terms, over the years children have become viewed with increased agency and as citizens who have rights. Sweden has come a long way in terms of thinking about the impact on children when developing policies. For example, thinking about the child's perspective when building houses or roads.
<b>Recognition of young carers</b>	The term 'young carers' or 'young caregivers' is not used in Sweden. Barn som anhöriga (Children as next of kin or close relatives) is the term used by the Socialstyrelsen, see <a href="http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19114/2013-6-6.pdf">http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19114/2013-6-6.pdf</a> ; <a href="http://www.socialstyrelsen.se/publikationer2014/2014-5-10">http://www.socialstyrelsen.se/publikationer2014/2014-5-10</a> .
<b>Key strengths</b> National level	<ul style="list-style-type: none"> <li>– There is a well-developed welfare system in Sweden</li> <li>– Swedish legislation has a strong focus on the rights of the child. This has been further strengthened by the Children's Convention. When children know their rights they can probably more easily express their needs. It is commonly believed that children should not take on 'a big responsibility'.</li> <li>– The regulations and framework are open. There are no limitations to providing support and intervening with young carers (i.e. they are not restricted to certain groups). This can also be a weakness. It is therefore reliant upon the individual social secretary or the child protection professional. The same goes for the child protection regulations in the Care of Young Persons Act.</li> <li>– Schools have an obligation to ensure that all children receive the support that they need in order to acquire and complete their education</li> </ul>
<b>Key limitations</b> National level	<b>In general</b> <ul style="list-style-type: none"> <li>– There is an unwillingness to accept that the health care sector and social welfare are not taking care of the problems</li> <li>– People in the ministry of social affairs and the National Board of Health and Welfare, they do not want to accept that young people do a lot of caring.</li> <li>– The regulations and frameworks are open. There are no limitations to providing support and intervening with young carers (i.e. they are not restricted to certain groups). It is therefore up to the individual social secretary or the child protection professional. The same goes for the child protection regulations in the</li> </ul>

	<p>Care of Young Persons (Special Provisions) Act.</p> <ul style="list-style-type: none"> <li>– The regulations in the Young Person’s Act ‘allmänna råd’ [common advice] are really old and are to be updated  <a href="https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/12728/1997-10-15_1997_15.pdf">https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/12728/1997-10-15_1997_15.pdf</a></li> <li>– There is no definition of when caring roles are ‘over the limit’ and what is acceptable</li> </ul> <p><b>Resources</b></p> <ul style="list-style-type: none"> <li>– Provisions from the Social Services Act state that social services should work with a preventative approach, however, resources have reduced over the years</li> <li>– There is a problem if there are not sufficient numbers of good interpreters. This may therefore lead to the easier option being taken of using children to translate</li> </ul> <p><b>Healthcare Act</b></p> <ul style="list-style-type: none"> <li>– There are so many regulations with the Social Services Act. It has become a patchwork and does not have any overview or fit together logically</li> <li>– One regulation of the Healthcare Act relates to thinking about whether there are children involved, but this is not the case automatically with the Law on Support and Services for Certain Disabled People (LSS) or the Social Services Act. However, the Law on Support and Services for Certain Disabled People (LSS) contains provisions on the best interest of the child and the right of children to speak.</li> <li>– The possibility that children could be personal assistants for their parents was removed, illustrating that there is no holistic approach</li> <li>– There is a lack of clarity with the Healthcare Act for example, what should be done if parents refuse that information is given to their children and how it relates to the obligation to report to social services</li> <li>– Information that is given to a child has consequences for the child and on their perspective of their family and situation</li> <li>– The parental perspective of a family situation can dominate the child’s perspective and parents can withdraw from the investigation process and have the right to deny all kinds of suggestions of support</li> <li>– One problem can be finding out what kind of support children need as relatives</li> <li>– The legislation does not specifically include siblings or parents with developmental disorders [learning disabilities]</li> </ul>
<b>Key limitations</b>	None mentioned

Regional level	
<b>Key limitations</b> Local level	<ul style="list-style-type: none"> <li>– As consequence of a lack of resources, the interpretation of legislation can be narrowed at a local level</li> </ul>
<b>Evaluation of the current situation</b> National level	<p><b>In general</b></p> <ul style="list-style-type: none"> <li>– Support for children as carers is not regulated as it is for adults who are carers</li> <li>– There is an illusion that the welfare state would take care of adults with severe problems. It is therefore not considered that children will need to take care of family members but the reality is different. This is probably an explanation as to why this hasn't been discussed that much in Sweden.</li> <li>– Understanding needs to be developed about what level of caring is inappropriate and this needs to be addressed in policy and legislation</li> <li>– There is a patchwork of provisions that can be used to support young carers but with no clear regulation among the different laws. Children have not been thought about as young carers</li> <li>– There is a lot of work to be done. Support for the adults or children with care needs should be looked at carefully, rather than supporting children to continue to care</li> <li>– The Swedish systems should guarantee that children are being protected from taking on caring responsibilities and it is possible that this does happen</li> <li>– The Law on support and services for certain disabled people (LSS) should relieve children of caring roles but they may not be always happening in practice</li> <li>– Schools don't understand the issue and do not respond to indicators that there are problems at home due to caring</li> </ul> <p><b>The Children's Convention</b></p> <ul style="list-style-type: none"> <li>– The Children's Convention may be helpful as it gives a very clear indication that children must be considered in all contexts</li> <li>– The Children's Convention will be important. If it just gets attention then healthcare staff will increasingly ask parents if they have children at home</li> </ul> <p><b>Child protection and children's voices</b></p> <ul style="list-style-type: none"> <li>– There are no specific provisions, but if a young person or child has to take too much responsibility, which</li> </ul>

leads to a sort of neglect or a vulnerable situation then child protection measure could be taken. But it's not specifically mentioned.

- Children often don't want to be separated from their families. They feel responsible for their families and are not assured that someone else will care for their family
- The provisions in the Social Services Act as well as the child protection regulations in the Young Person's Act are not prescribed, but are very open and not limiting. The key therefore is about awareness and knowledge of the problems for children.
- Once children have taken on the responsibility of caring for a family member and they are removed from the family, they especially worry about the person they cared for
- There is a dilemma as to whether parents have the right to deny accepting support options from society and instead choose to use their children as carers
- Where parents have severe problems, children may not be talked to and asked about their situation. Children's voices could be strengthened a lot more and their views sought
- Whether or not a child's perspective is taken into account is not due to lack of legislation but rather down to social workers
- Participation of young people can lead to conflict with parents which in turn can be expensive to resolve

#### **Policy direction**

- The focus in Sweden is not on the caring roles of children but more about children as relatives/next of kin (including their responsibilities)
- Since the 1970's an individualised focus on support has been prevalent - a family perspective has been lost. Some local guidelines directly prohibit support to include children and family
- There is a conflict between family privacy and the interests of children which can result in children with caring roles remaining unseen
- There is a change in direction as to how the problem is being seen with a shift to seeing the child as a partner
- Children as next of kin is a new concept in the Swedish welfare state. The media is needed to awaken the debate.
- Many municipalities have now concluded that a family perspective is needed
- The Social Services Act review which emphasizes preventative work is one way to strengthen the family. With social services more available, children and adolescents might be more likely to ask for help and

	<p>support and parents may feel they can receive support. A really long assessment is not needed but help should be readily available.</p> <p><b>Awareness</b></p> <ul style="list-style-type: none"> <li>– In relation to the Health Care Act where work is being undertaken with an adult with a serious diagnosis, there could be more awareness of children. Where the problem is noticed, then one tries to help the children</li> <li>– As a result of their experience, family counsellors have become alert to children being ‘next of kin’</li> <li>– More can be done around awareness of children and supporting the whole family</li> <li>– Professionals firstly need to be aware of the problem and have a method of working to address the problem and support the whole family. Current support systems may work but it can be reliant on capabilities and empathy of individual professionals</li> </ul>
<p><b>Evaluation of the current situation</b></p> <p>Regional level</p>	<p>None mentioned</p>
<p><b>Attitudes to existing policy responses</b></p>	<ul style="list-style-type: none"> <li>– Training for the implementation of new policies is not sufficiently in depth to adequately change the understanding of professionals</li> <li>– A clear change in legislation is needed to bring about a broader, family support perspective (whole family approach) as well as adequate support for the person with care needs</li> <li>– Specific legislation for young carers is probably not necessary and could be limiting in a changing society</li> <li>– It’s important to see caring roles for children as something that should be limited and which should not restrict their normal life. This should not however restrict children’s participation.</li> <li>– When assessing adults, parental responsibility and support for children should be included</li> <li>– It’s a problem that the caring roles of children is not recognised</li> <li>– The Healthcare Act requires long-term implementation. One of the main obstacles to implementing it is the competence of adult care professionals in implementing the provision for children.</li> <li>– Children are taking on interpreting roles and more attention needs to be taken so children do not end up in these situations</li> <li>– The Parent Rule really tries to protect and strengthen the children’s position to actually be children</li> <li>– It is down to individual ministers who drive particular policy issues</li> </ul>

	<ul style="list-style-type: none"> <li>– There are no legal obstacles to working in a more coordinated way it is down to how things are organized</li> <li>– There is no holistic approach, but rather a patchwork of regulation that is inconsistent</li> <li>– It is about preventative measures. Children should not end up in these situations at all</li> <li>– Awareness of the issue must still be created</li> <li>– There is a sensitivity about parentification</li> <li>– The law based on the UN convention of children's rights will pass however, the consequences will be 'not so much' since it is without clarity on what it wants to achieve</li> <li>– Awareness of new vulnerable groups takes time</li> </ul>
<b>Suggested changes</b>	<ul style="list-style-type: none"> <li>– To include the 'family perspective' within the review of the Social Services Act</li> <li>– Awareness needs to be raised. This could be done by both specifically including young carers in legislation and a goal orientated framework <i>and</i> raising awareness by other means such as information campaigns</li> <li>– Make sure that children are listened to</li> <li>– Perhaps have a more sort of more flexible view on when you become an adult or what comes with becoming an adult</li> <li>– Raise awareness in schools</li> <li>– Update the regulations and handbook in the Young Person's Act (Allmanna rad) to include children as carers as an example of children at risk</li> <li>– Do not support children to continue caring, but look at the shortages in the support for adults and children who need care</li> <li>– If a child is informed that an addiction is a sickness it should also be stated that the parent has responsibility for their actions</li> <li>– Policy and legislation should include what is appropriate and inappropriate caring for children</li> <li>– For the media to wake the debate up</li> <li>– To think more about using the Patient Safety Act in relation to children's needs not being met</li> </ul>
<b>Future goals and hopes</b> National level	<p><b>In general</b></p> <ul style="list-style-type: none"> <li>– Children need to be protected from caring</li> </ul> <p><b>Awareness, understanding and discussion</b></p> <ul style="list-style-type: none"> <li>– More attention is paid to children and youths who support their parents. More information and knowledge is gathered about them including children who are interpreters</li> <li>– Awareness and knowledge about the topic of young carers</li> </ul>

	<ul style="list-style-type: none"> <li>– For a change in understanding about children as carers and for the issue to be more easily discussed. For mental health and addiction problems to be less taboo</li> </ul> <p><b>Children's voices</b></p> <ul style="list-style-type: none"> <li>– Children's participation is increased and children's voices and their rights are taken more seriously</li> <li>– To talk more to children about their views, experiences and their needs and to strengthen the provision in the Health and Care Act of providing children with information</li> </ul> <p><b>Legislation</b></p> <ul style="list-style-type: none"> <li>– That the review of the Social Services Act might lead to a more preventative approach</li> <li>– New legislation will improve organisational approaches with a more whole family approach</li> <li>– To address in legislation those instances where it is not an issue of caring, but where the issue relates to parental capabilities for example arising from a drug addiction or mental health condition of a parent</li> <li>– For professionals to check whether parents with an addiction problem have children and to have contact with those children</li> </ul> <p><b>Accessibility of support</b></p> <ul style="list-style-type: none"> <li>– To be in a position where people with care needs are able to receive the support they need and for families to feel they can accept support</li> <li>– There is hope that the Social Services Act can make support from social services more accessible. Support should be preventative, parents should be able to ask for it without fear and children should know they can receive support at an early stage.</li> </ul>
<b>Future goals and hopes</b> Regional level	None mentioned

### 10.5. Case Study Switzerland

Categories	Results
Specific legislation	In Switzerland, no specific legislation protecting and supporting young carers and their families exists.

<p><b>Non-specific legislation</b> National level</p>	<p><b>Federal Constitution of the Swiss Confederation</b> of 18 April 1999 (Status as of 1 January 2018),  <a href="https://www.admin.ch/opc/en/classified-compilation/19995395/index.html">https://www.admin.ch/opc/en/classified-compilation/19995395/index.html</a>          (Bundesverfassung der Schweizerischen Eidgenossenschaft vom 18. April 1999, SR 101)  <b>Art. 11 Protection of children and young people</b>          Children and young people have the right to the special protection of their integrity and to the encouragement of their development (paragraph 1). They may personally exercise their rights to the extent that their power of judgement allows (p.2).          Targeted age group: children (minors up to 18)</p> <p><b>Swiss Civil Code</b> of 10 December 1907 (Status as of 1 January 2018),  <a href="https://www.admin.ch/opc/en/classified-compilation/19070042/201801010000/210.pdf">https://www.admin.ch/opc/en/classified-compilation/19070042/201801010000/210.pdf</a>          (Schweizerisches Zivilgesetzbuch vom 10. Dezember 1907, SR 210);          Child and adult protection law (Kindes- und Erwachsenenschutzrecht)          Targeted age group: children (minors up to 18) and adults</p> <p><b>Convention on jurisdiction, applicable law, recognition, enforcement and cooperation in respect of parental responsibility and measures for the protection of children</b> (Hague Convention on the Protection of Children),  <a href="https://www.admin.ch/opc/de/classified-compilation/20061344/index.html">https://www.admin.ch/opc/de/classified-compilation/20061344/index.html</a>          Übereinkommen über die Zuständigkeit, das anzuwendende Recht, die Anerkennung, Vollstreckung und Zusammenarbeit auf dem Gebiet der elterlichen Verantwortung und der Massnahmen zum Schutz von Kindern (Haager Kindesschutzübereinkommen, HKsÜ), in Kraft getreten für die Schweiz am 1. Juli 2009, SR 0.211.231.011          Targeted age group: children (minors up to 18)</p> <p><b>Social Security Law</b>, in particular Art. 29 septies Federal Law on Old Age and Survivors' Insurance (AHVG), SR 831.10,  <a href="https://www.admin.ch/opc/de/classified-compilation/19460217/index.html">https://www.admin.ch/opc/de/classified-compilation/19460217/index.html</a>          Provides financial funding for families (care credits), thus indirectly relieves the burden on young carers as well.</p>
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	Targeted age group: adults
<b>Enactment of legislation</b> National/cantonal level	In Switzerland, the cantons and communities are responsible for the enactment of the legislation e.g. the UN Convention on the Rights of the Child (UNCRC). In order to get the legislation into force, the cantons and the communities have to translate it. The federation does a lot of recommendations how the cantons could do it but it is very diverse because of the differences in the individual cantons.
<b>Enactment of legislation</b> Regional level	None mentioned
<b>Changes in legislation</b>	<p>Legal provisions for carers in Switzerland are still developing.</p> <p>Regarding changes in legislation, there is a paradigm shift from the welfare approach to the right based approach. Today, it is very important that children are informed about their rights and this has changed. Children and parents are being more and more informed.</p> <p>Changes in legislation were achieved by private and political initiatives so far.</p>
<b>Specific policy and service frameworks</b>  National level	<p><b>Action plan for support and respite of relatives providing care</b> from December 5th, 2014  <a href="https://www.bag.admin.ch/bag/de/home/strategie-und-politik/politische-auftraege-und-aktionsplaene/aktionsplan-pflegende-angehoerige.html">https://www.bag.admin.ch/bag/de/home/strategie-und-politik/politische-auftraege-und-aktionsplaene/aktionsplan-pflegende-angehoerige.html</a>          (Unterstützung für betreuende und pflegende Angehörige, Situationsanalyse und Handlungsbedarf für die Schweiz, Bericht des Bundesrates vom 5. Dezember 2014)          Targeted age group: all carers, including minors</p> <p><b>Federal Research Programme "Support and Relief Offers for Carers 2017-2020"</b>  <a href="https://www.bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitspolitik/foerderprogramme-der-fachkraefteinitiative-plus.html">https://www.bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitspolitik/foerderprogramme-der-fachkraefteinitiative-plus.html</a> .          Targeted age group: all carers, young carers are explicitly included in the research.</p>
<b>Non-specific policy and service frameworks</b>	<b>Children and youth policy:</b> <a href="https://www.bsv.admin.ch/bsv/de/home/sozialpolitische-themen/kinder-und-jugendfragen.html">https://www.bsv.admin.ch/bsv/de/home/sozialpolitische-themen/kinder-und-jugendfragen.html</a>

National/cantonal level	<p>Defined in an <b>umbrella concept</b>, Health Promotion Switzerland has a uniform basis for the cantonal action programmes (KAP). It contains four modules and eight principles which the cantons use as a basis for their KAPs. <a href="https://gesundheitsfoerderung.ch/kantonale-aktionsprogramme/basisinformationen/dachkonzept.html">https://gesundheitsfoerderung.ch/kantonale-aktionsprogramme/basisinformationen/dachkonzept.html</a></p> <p>Counselling services (respite, support), Canton of Vaud, <a href="https://www.espaceproches.ch/">https://www.espaceproches.ch/</a></p>
<b>Non-specific policy and service frameworks</b> Local level	<p>Youth counselling in Zurich, <a href="https://www.stadt-zuerich.ch/sd/de/index/familien_kinder_jugendliche/jugendliche/jugendberatung.html">https://www.stadt-zuerich.ch/sd/de/index/familien_kinder_jugendliche/jugendliche/jugendberatung.html</a>; <a href="http://jugendberatung.me/jugend-blog/">http://jugendberatung.me/jugend-blog/</a></p> <p>Family counselling services, e.g. in the Canton of Zurich: Children and Family service –Centers (kjz). In almost every Canton there might be public services for young people and for families.</p>
<b>Enactment of policy and service frameworks</b> National level	<p>Four action fields in the “National Action Plan for Carers Support and Relief” from December 5th, 2014, <a href="https://www.bag.admin.ch/bag/de/home/strategie-und-politik/politische-auftraege-und-aktionsplaene/aktionsplan-pflegende-angehoerige.html">https://www.bag.admin.ch/bag/de/home/strategie-und-politik/politische-auftraege-und-aktionsplaene/aktionsplan-pflegende-angehoerige.html</a> :</p> <p>Action field 1: Better information and better data (including young carers)</p> <p>Action field 2: Respite options - Access and Quality (including young carers)</p> <p>Action field 3: Reconciling work and family care (young carers older than 16 years)</p> <p>Action field 4: Care leave for parents with children who are sick (field 4 does not apply to young carers) or alternative support options</p>
<b>Changes in policy and service frameworks</b>	<p><b>Action plan for support and respite of relatives providing care:</b></p> <p>This emerged from a political push from the Swiss Parliament and of the Federal Council as part of the agenda Health 2020 (<a href="http://www.euro.who.int/de/health-topics/health-policy/health-2020-the-european-policy-for-health-and-well-being">http://www.euro.who.int/de/health-topics/health-policy/health-2020-the-european-policy-for-health-and-well-being</a>). This started in 2011 and at the end of 2014 the action plan was adopted.</p>

	<p>In 2014 young carers were not included in the action plan. However subsequently, there was a petition from the Parliament addressing this exclusion of the situation of minors providing care for their relatives. Now the Swiss Federal Council explicitly mentions the situation of children who care for family members and plans to gather more information on this situation with a project that started in 2017 and that will continue until 2020.</p>
<b>Recognition of young carers</b>	<p>Young Carers are not specifically defined in the law.</p> <p>Carers Day: October 30</p> <p><a href="https://www.redcross.ch/de/rotkreuz-entlastungsdienste/entlastungsdienste-fuer-pflegende-angehoerige/tag-der-pflegenden">https://www.redcross.ch/de/rotkreuz-entlastungsdienste/entlastungsdienste-fuer-pflegende-angehoerige/tag-der-pflegenden</a></p> <p><a href="http://www.pflege-entlastung.ch/waadt">http://www.pflege-entlastung.ch/waadt</a></p>
<b>Key strengths</b>	<ul style="list-style-type: none"> <li>– Flexibility: legislation and services are regionally flexible which can make innovations easier. Regional variation is important since there are different needs in different regions</li> <li>– In general, basics needs in Switzerland are well supported</li> <li>– How legislation is translated into practice is set by law and this is well established in Switzerland</li> <li>– Child protection authorities are generally working well and in an interdisciplinary manner and usually there are established networks (health, education, protection, etc.) even on a regional level</li> <li>– In general, legislation is very clear and there is a lot of literature, e.g. in the area of parents of a disabled child</li> <li>– There is no discrimination, meaning that all the persons have equal rights</li> <li>– The Federalist system allows a “Me-too-effect”: when one canton has good practices, then other cantons will adopt them sooner or later</li> </ul>
<b>Key limitations</b> National level	<p><b>General limitations:</b></p> <ul style="list-style-type: none"> <li>– Young carers do not exist as a specific social group in Switzerland, and therefore they are not specifically addressed by support programmes</li> <li>– The legal provisions for caregiving only relate to working carers and supporting a balance between work and informal care. They do not take into account young carers who are studying or who are doing an apprenticeship</li> <li>– Terminology within the Swiss Civil Code such as “best interest of the child” is very open to interpretation. However, this is also a chance because it allows acting and reacting on an individual situation within individual circumstances.</li> </ul>

- The topic of young carers is addressed only for very specific issues, e.g. financial or insurance issues, but the need for support of young carers is not considered
- Laws, policy frameworks, and even some associations working with carers do not use an age-appropriate language for young people, so the information may not be accessible to young carers, who do not have an adequate level of literacy
- Lack of coordination between the different legal systems (e.g. social security system, family law, medical law, child protection, etc.)
- The healthcare system in Switzerland is expensive and this can affect vulnerable groups like young carers
- Situations where children are responsible for the caring of their parents are kept private in the family
- Patients who are filed (e.g. for a mental illness) might face problems in the future, e.g. if their child has been seen late at night on the street. File references by their nature have a long lifespan and there is a risk that such data will later be used for purposes or in contexts other than those for which they were originally created.

**Limitations of child protection authorities:**

- There is a marred history with respect to child protection in Switzerland, because in the last century it has happened that children were forced out of their families in the name of child protection under circumstances that would be seen from the perspective of today as grave violations of the rights of these children and their families.
- It is difficult to identify young carers, because the authorities (e.g. child protection services) are not promptly notified by healthcare institutions
- Child protection services can be frightening for families because they intervene in case of child abuse. It seems like there is nothing between “invisibility” of young carers and “mistreatment” (and consequently the intervention of child protection services)
- Child protection services generate high financial costs to the society
- The measures of child protection legislation can only be taken if the child's best interest is threatened, it is not sufficient that a child's best interest is not being fully achieved
- Child authorities have limited powers, it is only when there is no other way to avoid the threat to the child's best interest that the child protection authority can remove the child from the family
- The child protection authority only becomes involved if the problems of the young carer are visible
- The outcomes of the interventions taken by child protection authorities are not really evaluated and are therefore not known, therefore it is not clear if this is the right kind of help that young carers and their families need

	<b>Limitations of the Action Plan:</b> <ul style="list-style-type: none"> <li>– The Action Plan for support and respite of relatives providing care does not consider children as carers. It may be more relevant to young adult carers since it includes topics on financial benefits and insurances.</li> </ul>
<b>Key limitations</b> Regional level	<ul style="list-style-type: none"> <li>– The Swiss health system is not well developed for in-house support, e.g. family carers do not receive much financial support</li> <li>– Differences between how cantons implement the UN Convention on the Rights of the Child, despite the recommendations coming from the Federation</li> </ul>
<b>Evaluation of the current situation</b> National level	<b>Evaluation of the current situation in general:</b> <ul style="list-style-type: none"> <li>– In the legislation the topic of young carers is quite overlooked and the perspective of the young carers is not sufficiently taken into consideration</li> <li>– Soft laws<sup>6</sup> in Switzerland are quite important because they are not enforced by legislation but rather they are based on commitment</li> <li>– The Social Security Law is extremely important because it provides financial funding for families which can take the pressure off young carers</li> <li>– Young carers should be protected because they are in a role that might threaten their right to education and their development. Also the right to play and the right of spare time are very important for children and their development.</li> <li>– The awareness on young carers is low, but in Switzerland there is a solid legal system with a lot of protection for the children</li> <li>– There is a social problem, defined as “parentification”, which means that the children are acting like “the parents of their parents”. This is harmful for the child and can lead to negative consequences</li> <li>– Young carers’ right to education are not really being fulfilled</li> <li>– Hospitals may not routinely ask if a patient has children</li> <li>– Switzerland's general approach is to provide good conditions to prevent poverty</li> <li>– Many stakeholders are involved and should collaborate, e.g. schools, NGOs, health professionals, etc. Legislation and policy frameworks need to look more at structures and conditions for allowing professionals to work well together</li> <li>– Programmes are starting to think more about children as carers and including them as a vulnerable group.</li> </ul>

<sup>6</sup> Soft laws can be defined as “normative provisions contained in non-binding texts” (Shelton, 2000, p. 292).

	<p>Special programmes are well established for young carers who care for parents with mental health conditions</p> <p><b>Evaluation of the current situation regarding child protection authorities:</b></p> <ul style="list-style-type: none"> <li>– The child protection system is very well established and working well in Switzerland but the outcomes of child protection measures are not really known</li> <li>– Child protection authorities have the aim to help vulnerable children; however, this can be viewed as the state invading the private rights of families. Help may be not forthcoming however due to a climate of avoidance of such situations</li> <li>– In Switzerland there is a debate on child protection authorities: some think that children are not “property” of their parents and the State has an obligation to intervene, while others think that child protection authorities have too much power. This is due to the interpretation of terms in the Swiss Civil Code like “best interest of the child”</li> <li>– The child protection authority often work with young carers where the issue is parental mental-ill health but seldom where children care for parents with a physical illness.</li> </ul> <p><b>Evaluation of the current situation regarding the recognition:</b></p> <ul style="list-style-type: none"> <li>– At the moment, caregiving is an important topic in Switzerland. Therefore, this is the right moment to raise awareness on the topic of young carers</li> </ul>
<p><b>Attitudes to existing policy responses</b> National level</p>	<ul style="list-style-type: none"> <li>– The legal provisions might not really help the people affected, who might need more specific support (e.g. financial support for respite)</li> <li>– The UN Convention on the Rights of the Child (UNCRC) could be used as the basis for developing specific legislation or services</li> <li>– Child protection involvement in relation to young carers could be very good but has to be thought about carefully</li> <li>– There are a lot of discussions about the costs of child protection services</li> </ul>
<p><b>Attitudes to existing policy responses</b> Regional level</p>	<ul style="list-style-type: none"> <li>– Current efforts made towards supporting young carers at the moment are coming mainly from the cantons</li> </ul>
<b>Suggested changes</b>	<b>Suggested changes to the legislation:</b>

	<ul style="list-style-type: none"> <li>– It seems not necessary to have a specific legislation for young carers, because there are not specific laws for every group of people in need. However, in Switzerland there are many legal provisions that can be a basis for new frameworks or services addressing young carers</li> <li>– Existing legislation, policy and service frameworks could be extended to include young carers</li> <li>– In the Action Plan it is suggested to modify the labor law. Young carers who are working could then have a day off when needed</li> </ul> <p><b>General changes suggested:</b></p> <ul style="list-style-type: none"> <li>– Awareness on the topic of young carers must be raised. A possible solution is through NPOs or NGOs, which might have some ideas that could be supported by state funding. Everyone should be informed about this topic</li> <li>– Young carers and their needs should be recognised by applying the UN Convention on the Rights of the Child. However, it must be acknowledged that the best interest of the child is different for every child</li> <li>– Young carers should be defined, so that they can identify themselves as young carers</li> <li>– The communication (of legal provisions, policies, service frameworks, but also communications from associations working for carers) should be adapted and be more age-appropriate for young people</li> <li>– Professionals should be trained and made aware of the topic</li> <li>– Changes should be made within a Federal programme, but also on a cantonal level</li> <li>– It would be important to know which are the results of measures taken by child protection authorities</li> <li>– The existing programmes should be made more visible and also be more understandable for young people</li> <li>– The issue of young carers must be systematically addressed. More data is needed in order to find solutions to make these children visible</li> <li>– The different legal systems involved (e.g. social security system, family law, medical law, child protection, etc.) should be better coordinated</li> <li>– Parents should be better supported in realizing the situation of their children (including the specific needs) and be motivated to look for specific help and care</li> <li>– Stigmatisation must be avoided</li> <li>– Collaboration between health services, counselling services and child protection services should become self-evident (under consideration of the right to privacy)</li> </ul>
<p><b>Future goals and hopes</b> National level</p>	<ul style="list-style-type: none"> <li>– Have more data to make better decisions on the type of support needed by young carers and their families and in this way make evidence-based changes to the legislation</li> <li>– Recognise the importance of the role played by family carers</li> </ul>

	<ul style="list-style-type: none"> <li>– Young carers should be recognised by the health system, by schools, etc. in order to receive the support they need and they should be involved in this process</li> <li>– Look at every child's situation individually and hear the voices and opinions of young carers</li> <li>– Strong political commitment, as well as support of administration and private initiative like NPOs or NGOs</li> <li>– More awareness, everyone should be informed on the topic</li> <li>– Awareness and commitment from professionals in the health, social and educational fields</li> <li>– More support to young carers both on a political level and in a practical ways (e.g. helpline)</li> <li>– Identification of young carers, who also need to identify themselves as carers</li> <li>– A "life-course-approach", including all life-phases, because in every life-phase one can be a carers</li> <li>– Involvement of young carers and their families, give them the possibility to share their opinions about what their needs are and what kind of support can help them</li> <li>– More support (e.g. from social services) in hospitals for patients and their children</li> </ul>
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## 10.6. Case Study UK

Categories	Results
<b>Specific legislation</b> England National level	<p><b>Children and Families Act 2014</b>, <a href="http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted">http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted</a></p> <p>Targeted age group: children up to the age of 18 and families.</p> <p>PART 5 Welfare of children, Section 96 Young Carers</p> <p>Amends the <b>Children Act 1989</b>, <a href="https://www.legislation.gov.uk/ukpga/1989/41/contents">https://www.legislation.gov.uk/ukpga/1989/41/contents</a> with insertions under Section 17:</p> <ul style="list-style-type: none"> <li>– Defining young carers</li> <li>– Placing a duty on local authorities in England to assess young carers' needs and</li> <li>– To identify the extent to which there are young carers within their area who have needs for support.</li> </ul> <p>Section 17ZA Young carers' needs assessments: England</p>

(1) A local authority in England must assess whether a young carer within their area has needs for support and, if so, what those needs are, if—

(a) it appears to the authority that the young carer may have needs for support, or

(b) the authority receives a request from the young carer or a parent of the young carer to assess the young carer's needs for support.

Definition of young carer: a person under 18 who provides or intends to provide care for another person.

(12) A local authority in England must take reasonable steps to identify the extent to which there are young carers within their area who have needs for support.

Targeted age group: children up to the age of 18.

**Statutory Instruments, 2015 No. 527, Children And Young Persons, England, The Young Carers (Needs Assessments) Regulations 2015**, <http://www.legislation.gov.uk/uksi/2015/527/made>

Authorities must carry out a young carer's needs assessment considering the young carer's age, the family circumstances, their wishes, needs, and preferences, and whether young carers have a difference of opinion than their parents of what they want in terms of work, education, training, and opportunities.

Targeted age group: children up to the age of 18.

**Care Act 2014**, <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

An Act to make provision to reform the law relating to care and support for adults and the law relating to support for carers. It places a duty on the local authority to assess and meet the needs of a carer where care does not have to be substantial or inappropriate.

Targeted age group: focus on transition between childhood and adulthood. There is no set age when young people reach this point; every young person and their family are different, and as such, transition assessments should take place when it is most appropriate for them.

PART 1 Care and support, Transitions for children to adult care and support, etc., Section 63 Assessment of a young carer's needs for support

(1) Where it appears to a local authority that a young carer is likely to have needs for support after becoming 18, the authority must, if it is satisfied that it would be of significant benefit to the young carer to do so and if the consent condition is met, assess—

(a) whether the young carer has needs for support and, if so, what those needs are, and

(b) whether the young carer is likely to have needs for support after becoming 18 and, if so, what those needs are likely to be.

(2) An assessment under subsection (1) is referred to in this Part as a “young carer’s assessment”.

Section 64 Young carer’s assessment: requirements etc.

Sets out requirements of the ‘young carer’s assessment’

**Care and support statutory guidance (Updated 26 October 2018), Department of Health and Social Care,**  
<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>.

The aim of the Statutory guidance is to support the implementation of the Care Act 2014, Care and Support (Assessment) Regulations 2014 and Support (Eligibility Criteria) Regulations 2015.

*Chapter 6: Assessment and eligibility*

Whole family approach

6.65 The intention of the whole family approach is for local authorities to take a holistic view of the person’s needs and to identify how the adult’s needs for care and support impact on family members or others in their support network.

6.68 The local authority must also identify any children who are involved in providing care...

6.72 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

– *Chapter 16: Transition to adult care and support*

16.6 The Care Act contains provisions to help preparation for adulthood for 3 particular groups of people - children, young carers and child’s carers.

<p><b>Specific legislation</b> Wales National level</p>	<p><b>Social Services and Well-being (Wales) Act 2014</b>, <a href="https://www.legislation.gov.uk/anaw/2014/4/contents">https://www.legislation.gov.uk/anaw/2014/4/contents</a></p> <p>The Act provides the legal framework for improving the well-being of people who need care and support, and carers who need support, and for transforming social services in Wales. The Act gives carers a right to an assessment on the appearance of need.</p> <p>Definition of carer: a person who provides or intends to provide care for an adult or disabled child. But a person is not considered a carer if she/he provides or intends to provide care (a) under or by virtue of a contract, or (b) as voluntary work. (Section 3)</p> <p>Targeted age range: it applies to people of all ages.</p> <p>PART 3 Assessing the needs of individuals, Section 24-27 Assessing carers, especially Section 26-27 Refusal of a needs assessment for a carer aged 16, 17 or aged under 16.</p> <p>PART 4 Meeting Needs, Section 45 Power to meet support needs of a carer A provision for local authorities to meet the needs of carers</p>
<p><b>Specific legislation</b> Scotland National level</p>	<p><b>Carers (Scotland) Act 2016</b>, <a href="http://www.legislation.gov.uk/asp/2016/9/contents/enacted">http://www.legislation.gov.uk/asp/2016/9/contents/enacted</a></p> <p>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. (Section 2)</p> <p>PART 2 Adult Carers Support Plans and Young Carers Statements, Chapter 2: Young Carer Statements, Section 12 Duty to prepare young carer statement:</p> <p>(1) In this Act a “young carer statement” means a statement prepared by a responsible authority setting out— (a) a young carer’s identified personal outcomes, (b) a young carer’s identified needs (if any), and (c) the support (if any) to be provided by the responsible local authority to a young carer to meet those needs.</p> <p>Targeted age group: under 18 or a pupil at school having attained the age of 18 while at school.</p>
<p><b>Specific legislation</b> Northern Ireland National level</p>	<p><b>The Children (Northern Ireland) Order 1995</b>, <a href="http://www.legislation.gov.uk/nisi/1995/755/contents">http://www.legislation.gov.uk/nisi/1995/755/contents</a></p> <p>The Children Order ensures that children’s and young people’s development is not deterred in any way. It sets out when a child is to be taken as ‘in need’.</p>

	<p>PART IV Support for children and their families, Section 17A Assessments and services for children who are carers, Paragraph 1:</p> <p>There is a duty on an authority to assess children and determine whether a child is to be taken to be in need if 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 if the child requests an authority to carry out an assessment.</p>
<p><b>Non-specific legislation</b>  England  National level</p>	<p><b>National Health Service Act 2006</b>, <a href="https://www.legislation.gov.uk/ukpga/2006/41">https://www.legislation.gov.uk/ukpga/2006/41</a></p> <p>The National Health Service Act specifically mentions carers, promoting their involvement and how services should be working together.</p> <p><b>Education Act 1964</b>, <a href="http://www.legislation.gov.uk/ukpga/1964/82/enacted">http://www.legislation.gov.uk/ukpga/1964/82/enacted</a></p> <p>All children should be entitled to their education and because of that they should have their needs considered so that they can attend school.</p>
<p><b>Non-specific legislation</b>  Wales  National level</p>	<p><b>Children Act 1989</b>, <a href="https://www.legislation.gov.uk/ukpga/1989/41/contents">https://www.legislation.gov.uk/ukpga/1989/41/contents</a></p> <p>PART III Support for children and families provided by local authorities in England, Provisions of services for children and their families, Wales, Section 17 Provision of services for children in need, their families and others (10) For the purposes of this Part a child shall be taken to be in need if—</p> <p>(a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority under this Part;</p> <p>(b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or</p> <p>(c) he is disabled</p>
<p><b>Non-specific legislation</b>  Scotland  National level</p>	<p><b>Children and Young People’s Act (Scotland) 2014</b>, <a href="https://www.legislation.gov.uk/asp/2014/8/contents">https://www.legislation.gov.uk/asp/2014/8/contents</a></p> <p>An Act of the Scottish Parliament to make provision about the rights of children and young people; to make provision about investigations by the Commissioner for Children and Young People in Scotland; to make provision for and about the provision of services and support for or in relation to children and young people; to make provision for an adoption register; to make provision about children's hearings, detention in secure</p>

	<p>accommodation and consultation on certain proposals in relation to schools; and for connected purposes.</p> <p><b>PART 4: Provision of named persons</b>  Children and young people from birth to 18, or beyond if still in school, and their parents will have access to a Named Person to help them get the support they need. A Named Person will be a clear point of contact if a child, young person or their parents want information or advice, or if they want to talk about any worries and seek support.</p> <p><b>PART 5: Child's plan</b>  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.</p> <p>Targeted age group: children up to the age of 18, or beyond if still in school, and their families.</p> <p><b>Education (Additional Support for Learning) (Scotland) Act 2004,</b>  <a href="https://www.legislation.gov.uk/asp/2004/4/contents">https://www.legislation.gov.uk/asp/2004/4/contents</a>  Makes provision for the assessment of additional support needs of children and young people who could be young carers.</p>
<p><b>Non-specific legislation</b>  Northern Ireland  National level</p>	<p><b>Carers and Direct Payments Act (Northern Ireland) 2002 CHAPTER 6,</b>  <a href="https://www.legislation.gov.uk/nia/2002/6">https://www.legislation.gov.uk/nia/2002/6</a>  An Act to make provision about the assessment of carers' needs; to provide for services to help carers; to provide for the making of direct payments to persons in lieu of the provision of personal social services or carers' services; and for connected purposes.</p> <p><b>Children's Services Co-operation Act (Northern Ireland) 2015,</b>  <a href="https://www.legislation.gov.uk/nia/2015/10/contents">https://www.legislation.gov.uk/nia/2015/10/contents</a>  An Act to require co-operation among certain public authorities and other children's service providers in order to contribute to the well-being of children and young persons; to require the adoption of a children and young persons strategy; and for connected purposes.</p> <p>Targeted age group: children (up to the age of 18) and young people aged between 18 and 21 years who are</p>

	disabled people within the meaning of the Disability Discrimination Act 1995.
<b>Enactment of legislation</b> England National & local level	<b>Care Act 2014 and Children and Families Act 2014</b> 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 and specifically 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.
<b>Enactment of legislation</b> Wales National & local level	None mentioned.
<b>Enactment of legislation</b> Scotland National & local level	<b>Carers (Scotland) Act</b> The Scottish government have an implementation steering group which meets regularly. In terms of formal evaluations there is an implementation plan for the Act. 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 also differences in the implementation of the Carers Act. Some local authorities are quite confused about who is actually in charge of this.  <b>Children and Young People's Act (Scotland) 2014</b> 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.
<b>Enactment of legislation</b> Northern Ireland National level	<b>The Children (Northern Ireland) Order 1995</b> Young carers can ask for an assessment under the Children Order and if they are a child in need they can receive support.

<p><b>Changes in legislation</b></p> <p>England &amp; Wales</p> <p>National level</p>	<p><b>Children Act 1989</b></p> <p>Much of the Children Act 1989 applies to both England and Wales. As of April 2016, Part 3 of the Act (which refers to support for children and families provided by local authorities) has been replaced by Part 6 of the Social Services and Well-being (Wales) Act 2014.</p> <p>When it was first enacted, it did not specifically address young carers. The Act was amended by the Children and Families Act of 2014, which inserted specific provisions into the Children's Act, (section 17ZA), which makes it a duty on local authorities in England to undertake an assessment of a young carers' needs.</p> <p><b>Children and Families Act 2014 and Care Act 2014</b></p> <p>The Children and Families Act 2014 not only amended the Children Act 1989, but it also introduced a duty to say how many young carers there are in a local area.</p> <p>Both acts specifically mention young carers for the first time. The Children and Families Act and the Care Act made it clearer how young carers and their families should be identified, assessed and supported. In the previous legislation young carers were mentioned as a vulnerable group but it was not outlined that they had a right to an assessment of their needs.</p> <p>The changes were based on years of research, of academics working with other partners in the voluntary sector including national charities. Continuous awareness raising took place about young carers' needs and asking what needed to change.</p> <p>There were some key people within Government who helped to share messages directly from young carers about their needs. That built a picture of the whole family approach as opposed to caring for a young carer in a silo away from their family. Having those key people who were interested was important when the green papers for the Children and Families Act and Care Act were written. Consultation with young people took place over a number of years, and the right people were brought on board.</p> <p><b>Carers' Assessments</b></p> <p>Significant changes to carers' assessments, and to the rights of young carers and parent carers of disabled children, came into force on 1 April 2015. This is as a result of provisions in the Care Act 2014 and the Children</p>
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	and Families Act 2014 (England) and the Social Services and Well-being (Wales) Act 2014.
<b>Changes in legislation</b> Scotland National level	<p><b>Carers Recognition and Services Act 1995</b></p> <p>In 1995 it was proposed that the Carers Recognition Act covered carers of any age. The government opposed that but eventually they conceded.</p> <p><b>Education (Additional Support for Learning) (Scotland) Act 2004</b></p> <p>The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended 2009) places duties on local authorities to identify, meet and keep under review the needs of pupils for whom they are responsible.</p> <p><b>Carers (Scotland) Act 2016</b></p> <p>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 this 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.</p> <p>Some people questioned the need for legislation specific for young carers and questioned how the Young Carers Statement would dovetail with the Child's Plan.</p> <p>Many stakeholders were consulted including young carers who played a huge part in the development of the Act.</p>
<b>Changes in legislation</b> Northern Ireland	<p><b>Carers and Direct Payments Act (Northern Ireland) 2002 CHAPTER 6,</b>  <a href="https://www.legislation.gov.uk/ni/2002/6">https://www.legislation.gov.uk/ni/2002/6</a></p> <p>Amended the Children Order by inserting within it after Article 17, duties relating to assessments and services for children who are carers.</p> <p><b>Children's Services Co-operation Act (Northern Ireland) 2015</b></p>

	Driven by the desire for better, joined up, collaborative working which is needed to solve many of the issues faced by young people.
<b>Specific policy and service frameworks</b> England National level	<p><b>Carers Action Plan 2018 – 2020 Supporting carers today prepared by the Department of Health and Social Care,</b>  <a href="https://www.gov.uk/government/publications/carers-action-plan-2018-to-2020">https://www.gov.uk/government/publications/carers-action-plan-2018-to-2020</a></p> <p>This policy paper sets out how the government will improve support for carers in England between 2018 and 2020.</p> <p>Chapter 3 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.</p> <p><b>Working Together to Safeguard Children - A guide to inter-agency working to safeguard and promote the welfare of children,</b> July 2018,  <a href="https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/729914/Working_Together_to_Safeguard_Children-2018.pdf">https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/729914/Working_Together_to_Safeguard_Children-2018.pdf</a></p> <p>Statutory guidance. It has a number of references to young carers (paragraphs 6; 30; 41; 46; 55; 56).</p> <p>Definition of young carer: A young carer is a person under 18 who provides or intends to provide care for another person (of any age, except generally where that care is provided for payment, pursuant to a contract or as voluntary work). (p. 105)</p>
<b>Specific policy and service frameworks</b> Wales National level	None mentioned.
<b>Specific policy and service frameworks</b> Scotland National level	<p><b>Getting it Right for Young Carers - The Young Carers Strategy for Scotland,</b>  <a href="http://www.gov.scot/resource/Doc/319441/0102105.pdf">www.gov.scot/resource/Doc/319441/0102105.pdf</a></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> <p>Targeted age group: children or young persons aged under 18</p>

<b>Specific policy and service frameworks</b> Northern Ireland Regional level	<b>Children and Young People's Strategic Partnership Young Carers Group</b> , <a href="http://www.cypsp.org/supporting-young-carers-in-schools-in-northern-ireland/">http://www.cypsp.org/supporting-young-carers-in-schools-in-northern-ireland/</a> 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.
<b>Non-specific policy and service frameworks</b> England National level	<b>Pupil premium</b> , <a href="https://www.gov.uk/guidance/pupil-premium-information-for-schools-and-alternative-provision-settings">https://www.gov.uk/guidance/pupil-premium-information-for-schools-and-alternative-provision-settings</a> . The Pupil Premium is a pot of money that schools receive for disadvantaged pupils and that schools can use to implement additional support for their vulnerable groups of children.
<b>Non-specific policy and service frameworks</b> Wales	None mentioned.
<b>Non-specific policy and service frameworks</b> Scotland National level	<b>Getting It Right for Every Child</b> , <a href="https://www.gov.scot/Topics/People/Young-People/gettingitright">https://www.gov.scot/Topics/People/Young-People/gettingitright</a> It is the national approach in Scotland to improving outcomes and supporting the wellbeing of children and young people by offering the right help at the right time from the right people. It supports them and their parent(s) to work in partnership with the services that can help them. There are 8 indicators: Safe, Healthy, Achieving, Nourished, Active, Responsible, Respected, and Included.
<b>Non-specific policy and service frameworks</b> Northern Ireland National level	<b>Children and Young People Strategy 2017-2027</b> , <a href="https://www.education-ni.gov.uk/consultations/children-and-young-peoples-strategy-2017-2027">https://www.education-ni.gov.uk/consultations/children-and-young-peoples-strategy-2017-2027</a> The 10 year strategy includes eight parameters contributing to the well-being of children and young people. It identifies particular groups of young people who are a priority group. This includes 'children acting as carers'.  <b>Understanding the Needs of Children in Northern Ireland (UNOCINI) Guidance (2011)</b> <a href="https://www.health-ni.gov.uk/publications/understanding-needs-children-northern-ireland-unocini-guidance">https://www.health-ni.gov.uk/publications/understanding-needs-children-northern-ireland-unocini-guidance</a> . This guide is aimed at practitioners who provide services to children, young people and their families, whether they work in the statutory, voluntary, community or private sectors, which undertake or contribute to

	<p>assessments under the UNOCINI Assessment Framework.</p> <p><b>Strategy for Supporting Families 2015-2020,</b>  <a href="http://www.northerntrust.hscni.net/pdf/NHSCT_Strategy_for_Supporting_Families.pdf">http://www.northerntrust.hscni.net/pdf/NHSCT_Strategy_for_Supporting_Families.pdf</a></p> <p>This Strategy is an ambitious framework which is evidenced based and built upon best practice initiatives. It recognises the importance of multi-agency working and the services which focus on early intervention and prevention and the support that can be provided to parents/carers and families in their role as primary care givers.</p>
<p><b>Non-specific policy and service frameworks</b>  Northern Ireland  Regional level</p>	<p><b>Department of Health, Families matter - Supporting families in Northern Ireland (March 2009)</b>  Regional family and parenting strategy, <a href="https://www.health-ni.gov.uk/publications/families-matter-supporting-families-northern-ireland">https://www.health-ni.gov.uk/publications/families-matter-supporting-families-northern-ireland</a></p> <p>This strategy supported the aims and objectives of the 10 year strategy 'Our Children and Young People, Our Pledge' and set out the vision for improving support and services for families and children.</p>
<p><b>Enactment of policy and service frameworks</b>  England &amp; Wales  National level</p>	<p>There are guidance documents, which outline and explain what the duties mean for the whole family approach for practitioners and about young carer's assessments - what they include and what is good practice.</p> <p><b>The Care Act and Whole-Family Approaches,</b> <a href="https://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf">https://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf</a></p> <p>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><b>No wrong doors: working together to support young carers and their families,</b>  <a href="https://www.local.gov.uk/sites/default/files/documents/no-wrong-doors-working-to-27d.pdf">https://www.local.gov.uk/sites/default/files/documents/no-wrong-doors-working-to-27d.pdf</a></p> <p>A template for a local memorandum of understanding between statutory Directors of Children's and Adult Social Services – March 2015.</p> <p>A resource to help promote working together between Adult's and Children's social care services and enhanced partnership working with health and third sector partners. The final local text may be varied to reflect local circumstances and policies.</p>

<b>Enactment of policy and service frameworks</b> Scotland National level	<b>Getting It Right for Every Child</b> The 8 indicators (Safe, Healthy, Achieving, Nourished, Active, Responsible, Respected, and Included) are embedded in practice to make sure every child in Scotland is supported by these outcomes. If they are not, a child's plan is implemented.
<b>Enactment of policy and service frameworks</b> Northern Ireland National level	<b>Children and Young People Strategic Partnership Young Carers Group</b> The group includes voluntary organisations and statutory organisations that have responsibility for delivering services to children and it has a responsibility to implement and work the high level strategy for children. The partnership has to look at how the strategy will improve circumstances for young carers and it in turn has developed a working group for children in Northern Ireland. Having young carers visible within the children's strategy means that the statutory organisations and voluntary organisations are forced to support young carers. This organisation is also responsible for the monitoring and the social service department has to report on the number of young carers.
<b>Changes in policy and service frameworks</b> England & Wales	None mentioned.
<b>Changes in policy and service frameworks</b> Scotland	None mentioned.
<b>Changes in policy and service frameworks</b> Northern Ireland National level	<b>Children and Young People Strategy 2017-2027</b> (link see above) The Children's Strategy originally was the Northern Ireland's version of Every Child Matters ( <a href="https://www.gov.uk/government/publications/every-child-matters">https://www.gov.uk/government/publications/every-child-matters</a> ) and it produced good outcomes for children. The Children's Services Co-operation Act 2015 requires that Northern Ireland has a Children's Strategy and it requires that it addresses what is called the "intra-high-level parameters of well-being". Organisations in the voluntary and statutory sector are required to work together to improve outcomes for children. Key stakeholders were government departments, some of the voluntary community organisations, and the Children and Young People's Strategic Partnership. In the development of the Children and Young People Strategy there was some opposition since it was felt that

	this was not needed and that it created unnecessary bureaucracy.
<b>Recognition of young carers</b> England & Wales National level	<ul style="list-style-type: none"> <li>– Young carers are now recognised within legislation and local authorities have to identify and assess them. Young carers are therefore recognised as a specific group who receive support and who are included within local authority policies.</li> <li>– 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.</li> </ul>
<b>Recognition of young carers</b> Scotland National level	<ul style="list-style-type: none"> <li>– Young carers are recognised within legislation and local authorities have to identify and assess them. They are recognised as a specific group who receive support and who are included within local authority policies.</li> <li>– It is very difficult for people who have never experienced the situation of young carers, to actually conceive of the vast array of responsibilities a young child has to take on.</li> <li>– The main barrier is about identification</li> </ul>
<b>Recognition of young carers</b> Northern Ireland National level	<ul style="list-style-type: none"> <li>– 'Children who are carers' are recognised in The Children (Northern Ireland) Order 1995</li> <li>– The Children and Young People Strategy 2017-2027 identifies 'children acting as carers' as a priority group</li> </ul>
<b>Key strengths</b> England & Wales National level	<ul style="list-style-type: none"> <li>– Young carers are now recognised within legislation and local authorities have a duty to actively look for them and identify them</li> <li>– The Children and Families Act 2014 and the Care Act 2014 trigger a whole family approach</li> <li>– Comprehensive, explicit and detailed regulation for young carers</li> <li>– Engagement of young carers in implementing policies</li> <li>– Good support services: A really strong network of 'young carer services' which is mainly voluntary sector</li> </ul>
<b>Key limitations</b> England & Wales National level	<ul style="list-style-type: none"> <li>– There is a range of different definitions for the term "young carer", which sometimes do not consider that there are children with distinct needs</li> <li>– Children or their families do not recognise the term "young carer". As a consequence, they do not identify themselves as carers and they have no knowledge about their rights</li> <li>– The collaboration between different services does not work well due to the use of different computer</li> </ul>

	<p>systems</p> <ul style="list-style-type: none"> <li>– The implementation of a whole family approach does not work effectively because of the gaps between children’s services and adult services</li> <li>– There are some good practices but they are not equitably distributed across England</li> <li>– Young carers may not wish to come to the notice of statutory services for fear of being taken into care</li> <li>– Social services are stretched with limited resources. Austerity measures have impacted the capacity of local authorities</li> <li>– Respite activities for young carers does not prevent or reduce their caring activities</li> <li>– The actual support that families and young carers receive following their assessments is a bit vague</li> </ul>
<b>Key limitations</b> England & Wales Local level	<ul style="list-style-type: none"> <li>– 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.</li> <li>– The resources of local authorities for implementing the legislation, policy or service frameworks are tight</li> <li>– Some local authorities have massive waiting lists for assessments</li> </ul>
<b>Key strengths</b> Scotland National level	<ul style="list-style-type: none"> <li>– A legal definition of the term “young carer”</li> <li>– With the Education (Additional Support for Learning) (Scotland) Act 2004, which was amended in 2009, young carers are recognised in schools</li> <li>– Minister attending the Young Carers Festival and hearing messages directly from the young people</li> <li>– Strong young carer voice: several forums where the young carers voice is heard nationally</li> <li>– The voluntary sector has a very good, easy relationship with the Scottish Government</li> <li>– The Scottish Government’s implement steering group for the Carers Act is a very wide group and includes representation from health and disability groups</li> </ul>
<b>Key limitations</b> Scotland National level	<ul style="list-style-type: none"> <li>– There is a lack of awareness among the young carers themselves and knowing about their rights</li> <li>– Home-schooled kids and independent schools may not be as aware of the right to an assessment as they should be</li> <li>– Young adult carers are not defined as a group in legislation</li> <li>– Child’s plan went beyond the support that was needed and it was sometimes too complicated for the families</li> <li>– There is a wide variation of what is offered in different areas of Scotland</li> <li>– Capacity determines who actually gets a service</li> <li>– ‘Manpower’: Professionals might refuse to recognise a young carer if this would increase their workload</li> </ul>

	<ul style="list-style-type: none"> <li>– There is no national carer eligibility criteria</li> <li>– Carers don't always recognise themselves as carers</li> </ul>
<b>Key strengths</b> Northern Ireland National level	<ul style="list-style-type: none"> <li>– The Children Order 1995 creates a legislative requirement to undertake an assessment to identify children in need</li> <li>– The Children and Young People Strategy is a signal for organisations that young carers have to be taken into consideration</li> </ul>
<b>Key limitations</b> Northern Ireland National level	<ul style="list-style-type: none"> <li>– Difficult for young carers to identify themselves in the young carer role</li> <li>– Lack of awareness among the society</li> </ul>
<b>Evaluation of the current situation</b> England National level	<ul style="list-style-type: none"> <li>– The legislation in England is good but statutory guidance is needed</li> <li>– Evidence would suggest identification and assessment of the needs of young carers and families has not happened in the way it should have done. The law is not necessarily translating into practice</li> <li>– Adult service professionals still focus on the adult with needs and not on the child</li> <li>– The transition assessment brought confusion because there was not a set template for it</li> <li>– Governmental and political changes may have made engagement with government departments in relation to young carers more difficult</li> </ul> <p><b>Definition and stigmatisation</b></p> <ul style="list-style-type: none"> <li>– Definition of young carer: anyone under the age of 18 years who provides or intends to provide care for another person. The words "intend to provide" highlight that prevention is also important. This means that the law can be applied not only once a young carer has reached a point of having significant need, but it should also prevent children taking on excessive and inappropriate caring responsibilities.</li> <li>– Young carers are not as high up on the agenda as other vulnerable children or young people. Therefore it is important to highlight their situation and remind people about the duties on a local and national level.</li> <li>– There is a stigmatisation of the parents of young carers because they are seen as inadequate parents due to their disabilities</li> <li>– Young carers and their caring role are often presented in a negative way despite the positive elements of caring</li> </ul> <p><b>Evaluation of social services</b></p>

	<ul style="list-style-type: none"> <li>– Many social services failed previously to fulfil their legal responsibilities and now many social workers do not know that the law has changed</li> <li>– Social services tend to be person-specific and as a consequence, they do not look at the people around the person needing help</li> <li>– Young carers caring for someone with an addiction problem may not be noticed by social services because drug and alcohol misuse teams are not part of the local authority</li> <li>– Targets and budget cuts prevent increasing support to families</li> <li>– Social services are very stretched with limited resources and therefore having an assessment may not be seen as worthwhile by families</li> <li>– Integration between health and social care is a struggle</li> </ul>
<b>Evaluation of the current situation</b> Wales National level	<ul style="list-style-type: none"> <li>– The legislation is described as ineffective and as being more symbolic</li> <li>– The health and social care services are confused about how to deal with the legislation without enough resources</li> <li>– The legislation is fit for purpose but could do with a policy document</li> </ul>
<b>Evaluation of the current situation</b> England & Wales Local level	<ul style="list-style-type: none"> <li>– The translation of legislation and policy frameworks into practice is mixed across the different local authorities. Sometimes there is good practice with a merger of local steering groups and young carers. But there are also gaps between children's and adult's services in terms of understanding their different responsibilities. 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.</li> </ul>
<b>Evaluation of the current situation</b> Scotland National level	<ul style="list-style-type: none"> <li>– There are 32 local authorities so there is the potential to have 32 different types of statement</li> <li>– The voluntary sector has great ideas about how to change the situation but these ideas have to fit within the legislation</li> <li>– Social services prioritise other young people who are in their point of view in a greater need</li> <li>– The Carers Act is complicated and local authorities are confused about aspects of it such as who is responsible</li> <li>– Awareness about young carers varies across Scotland</li> </ul>
<b>Evaluation of the current situation</b>	<ul style="list-style-type: none"> <li>– There is a good network of professionals and key players coming from different sectors. They share their goals for improving things for young carer together.</li> </ul>

<p>Northern Ireland National level</p>	<ul style="list-style-type: none"> <li>- Beside the positive outcomes there are some worries about the transition to adult services.</li> <li>- Work is required to keep young carers on the agenda for adult social care</li> <li>- Identifying young carers is an ongoing issue</li> </ul>
<p><b>Attitudes to existing policy responses</b>  UK level</p>	<ul style="list-style-type: none"> <li>- Demand for numbers and quantification of the prevalence young carers from the government and a resulting dilemma between scientific integrity and the need to raise awareness among policy makers</li> <li>- The legislation includes guidance stating how practice should be carried out, but this does not mean that law will be necessarily translated into practice</li> <li>- As a consequence of the duty to identify young carers, local authorities could be picking up children with much greater needs as a consequence of very awful and difficult circumstances at home</li> </ul>
<p><b>Attitudes to existing policy responses</b>  England &amp; Wales National level</p>	<ul style="list-style-type: none"> <li>- Positive assessment of young carers' participation in forums, reviews and in making sure that the quality of services is high</li> <li>- Positive attitude towards whole family approach, but difficult to enact in practice</li> <li>- Critical view on detailed nature of central government legislation: it is hard to enact in practice because it is so detailed</li> <li>- Regulations explain in too much detail what that assessment should comprise</li> <li>- The huge level of detail in the English legislation is irrelevant</li> <li>- Definition of young carer: rather wide and questioned, division between ideological and pragmatic definition which produce different numbers i.e. anyone offering care (ideological) or only those seeking support (pragmatic). The government has recognised that there is not a risk of the floodgates being opened with an ideological definition, and this wider definition is welcomed by some experts.</li> <li>- 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)</li> <li>- The treatment of young carers in both countries is not great and the law has not made much difference</li> <li>- 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 nationally</li> <li>- The legislation does not have anything about support including the need for support from young carer groups. It is thought this makes them [the groups] feel quite vulnerable and sometime vulnerable with budget cuts</li> <li>- Not understood why more young carers assessments are not carried out and why more action is not being taken</li> </ul>

	<ul style="list-style-type: none"> <li>– Interventions for disabled people is seen as more appropriate than respite for young carers</li> </ul>
<b>Attitudes to existing policy responses</b> Scotland National level	<ul style="list-style-type: none"> <li>– Scotland is quite far ahead in terms of awareness</li> <li>– Positive attitude toward having the Carers Act</li> <li>– Disappointment that ‘young adult carers’ as a group were not mentioned in the legislation (Carers Act 2016)</li> <li>– Definitions need to set examples of where children are carers, because some people just do not get it. More detailed definitions are useful for professionals</li> <li>– Concern that young carers who decline a Statement may not get support they need e.g. from a young carers service</li> <li>– Expectations to produce Statements, without adequate personnel, could mean everyone will have to work a little bit harder</li> </ul>
<b>Attitudes to existing policy responses</b> Northern Ireland National level	<ul style="list-style-type: none"> <li>– Concern about the transition to adult services</li> </ul>
<b>Suggested changes</b> England & Wales National level	<p><b>In general</b></p> <ul style="list-style-type: none"> <li>– More structural support within the education system</li> <li>– Early help assessments, meaning that when an ill person is referred for support there should be questions around who is providing care in order to identify young carers</li> <li>– Training on three levels: front line practitioners, management level and strategic director levels</li> <li>– To look at these children as children in need, children who are affected by parental or relative illness or disability</li> <li>– Appropriately evidencing the needs of young carers</li> </ul> <p><b>More guidance</b></p> <ul style="list-style-type: none"> <li>– 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</li> <li>– More guidance for local authorities around what an assessment should actually look like</li> </ul>

	<b>More monitoring and evaluation</b> <ul style="list-style-type: none"> <li>– 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</li> <li>– More evaluation on how the implementation of legislation and policy frameworks is working</li> </ul>
<b>Suggested changes</b> Scotland National level	<ul style="list-style-type: none"> <li>– More efforts in raising awareness about who young carers are, so that they can be better identified and be offered support</li> <li>– Caution about suggesting changes before waiting to see common themes that emerge</li> <li>– Young carer statements should be produced for sibling carers, where this is not already happening</li> </ul>
<b>Suggested changes</b> Northern Ireland National level	<ul style="list-style-type: none"> <li>– A statement on young adult carers (18-24 years old) is needed, because now there is nothing between children's services and adult's services</li> </ul>
<b>Future goals and hopes</b> England & Wales National level	<ul style="list-style-type: none"> <li>– Greater international focus on young carers</li> <li>– To get some policy documents in England</li> <li>– Strengthening within legislation and policy the actual support that families and young carers should receive following their assessments</li> <li>– The State should be more responsive in improving the lives of the person needing care and, in turn, in improving the lives of young carers</li> <li>– National monitoring of the implementation of the legislation and policies and whether there are improvements for young carers and their families</li> <li>– A national strategy which defines what professionals should be implementing for young carers and their families</li> <li>– The Carers Action Plan 2018 – 2020 Supporting carers today will hopefully be a helpful instrument to embed the legislation</li> <li>– More support for vulnerable groups like children from parents with mental health problems or substance misuse</li> <li>– Reduce the stigma of those vulnerable groups</li> <li>– Make sure that young carers stay as a recognised subgroup of vulnerable children and do not slip off the agenda</li> </ul>
<b>Future goals and hopes</b>	<ul style="list-style-type: none"> <li>– To embed the legislation in every local area, so that there is an equitable service and access to support for</li> </ul>

<b>England</b> Local level	families
<b>Future goals and hopes</b> <b>Scotland</b> National Level	<ul style="list-style-type: none"> <li>– More universality and consistency across Scotland</li> <li>– More money that goes to the right places. More resources for funding support services</li> <li>– General awareness raising campaign, perhaps on television</li> <li>– Raised awareness of young carers about their rights</li> <li>– Maintaining consultation of young carers to keep their voice strong</li> <li>– At this stage, it is too early to change any element of the ongoing legislation. This would have an effect on many other areas</li> </ul>
<b>Future goals and hopes</b> <b>Northern Ireland</b> National Level	<ul style="list-style-type: none"> <li>– To continue working together with the education sector and supporting young carers in education</li> <li>– To develop services in terms of transition from children's services to adult services for young carers</li> <li>– Further work to improve how adult social care works together with the regional services to identify and respond to the needs of young carers</li> </ul>

## 11. Synthesis

Feedback from experts and from country partners was incorporated into the case studies. A synthesis was then carried out on each category from each of the countries to investigate commonalities and differences between the countries.

### 11.1. *Specific Legislation*

Experts discussed legislation that was both specific to young carers and non-specific. Legislation that was classified as 'specific' included explicit recognition of and/or a definition of young people with caring responsibilities. 'Non-specific' legislation relates to legislation that lacks any specific recognition or definition of young carers but nevertheless has the potential to protect and support children with caring responsibilities (par. 10.2).

Only the four countries in the UK (England, Wales, Scotland and Northern Ireland) make specific reference or specifically recognise children's caring roles within their legislation. Both England and Scotland define young carers whereas in Wales, children with caring responsibilities are included within the general definition for a carer. Within The Children (Northern Ireland) Order 1995, there is 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'.

Despite the explicit recognition of and/or definition of children who have caring responsibilities, the provisions in legislation related to young carers in England, Wales and Northern Ireland are themselves contained within broader and more general legislation. Only in Scotland does legislation for young carers sit within legislation that is specific to carers (Carers (Scotland) Act 2016). Here 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.

In England, provisions for young carers fall within The Care Act 2014 and the Children Act 1989 (amended) which work together in order to bring about a preventative and whole family approach to identification, assessment and support. Similarly in Wales, the Social Services and Well-being (Wales) Act 2014 provides the legal framework for improving the well-being of people who need care and support.

The legislation in Sweden could be viewed as falling somewhere between the specific and non-specific divide. There is no specific reference or provision for children with caring responsibilities within the Healthcare Act (2017) or the Patient Safety Act (2010). However, children with parents who have a mental disorder or disability, a serious physical illness or injury, or are addicted to alcohol or other addictive agents, or unexpectedly die, so called 'children as next of kin', are explicitly recognised as being a group of children who should be particularly taken into account; and some within this group of children are likely to have caring responsibilities.

In the other countries (CH, IT, NL, SI) recognition of the needs of children with caring responsibilities, and support for them and their families, is reliant upon ‘non-specific legislation’ related to education; health and social care; children, youth and families; carers in general; child safeguarding and child protection (see Table 5 below).

## **11.2. *Non-Specific Legislation with the potential to support AYC*s**

As discussed above, the UK alone has legislation that specifically addresses young carers. In the other European countries, recognition of the needs of children with caring responsibilities and support for them and their families is reliant upon ‘non-specific legislation’ related to education; health and social care; children, youth and families; carers in general and in particular child safeguarding and child protection. The analysis of ‘non-specific young carers’ legislation therefore considers whether countries have legislation in place that despite not being specific to young carers, could nevertheless be used to support or protect young people with caring responsibilities.

Non-specific legislation that either already supports children with caring responsibilities or has the potential to do so is found within each of the countries researched. However, the support and protection that is established stems from diverse legislative frameworks and would act in different ways:

- By supporting and protecting either children or adults with care and support needs (Health and social care legislation)
- By protecting children and young people generally and their development (Children and youth legislation)
- By supporting families and parental responsibilities (Family legislation)
- Through the rights of children to education, or mandatory schooling (Education legislation)
- By protecting children who are at risk (Safeguarding and child protection legislation)
- By supporting carers (Carers legislation)

### **11.2.1. *Health and Social Care Legislation***

Firstly, the support and protection established might act to prevent or reduce the necessity for children to take up caring roles in the first place by ensuring the needs of those with care needs themselves are met through health and social care. In Sweden, the Healthcare Act for example sets out that the purpose of health care is “good health and equal treatment for the entire population”. It states that those with the greatest need for healthcare should be given priority to care and that health care services shall work to prevent ill-health. In Switzerland the Social Security Law provides financial funding for families (care credits) and in the Netherlands the Social Support Act makes provision for the support of people who have difficulty participating in society or who cannot take care of themselves. Where the recipients of support are parents, siblings or families in general, this ought to lessen any need for a child to take on a caring role.

### 11.2.2. General legislation for children and families

Secondly, each country has in place general legislation to protect all children and families. This general legislation has the potential to safeguard children from being impacted negatively by caring responsibilities at various levels, such as (a) by recognising these children as a specific group with needs, (b) by supporting their identification, (c) through child protection measures and (d) by ensuring that they are attending school and being educated.

The Children and Young People's Act (Scotland) for example, ensures a single planning framework (Child's Plan) will be available for children who require extra support, whilst the Family Code, soon to come into force in Slovenia, makes provision to assess and protect children. In the Netherlands the Child and Youth Act aims to protect and support children through early identification and early intervention as well as by promoting parenting skills.

### 11.2.3. Education Legislation

Thirdly, education legislation was also discussed by experts. This related to the protection that a child's right to education could offer young carers in ensuring their attendance at school. It was also discussed in relation to the identification of AYC's by schools and their support - through the Education law in Slovenia for example, which regulates how schools should communicate with the centres of social work, if they notice a child with needs.

### 11.2.4. Safeguarding and child protection

Fourthly, the role of child protection measures was a common feature of the interviews. Experts in all six countries discussed child protection legislation within their own country such as the Swedish Social Services Act, the Civil Codes in the Netherlands and in Switzerland and how young carers at risk should be protected and supported by these laws.

**Table 5: Specific and non-specific legislation in the six European countries**

	Italy	The Netherlands	Slovenia	Sweden	Switzerland	UK
Specific legislation protecting and supporting young carers	Red	Red	Red	Orange	Red	Green
Non-specific legislation protecting and supporting young carers	Green	Green	Green	Green	Green	Green

Green: Exists / Red: Does not exist / Orange: Partly exists

### **11.3. *Enactment of Legislation***

Experts were asked about how the legislation, policy and services frameworks within their own countries translate into practice. The translation of legislation into practice depends on the existence of implementation guidelines, on the particular characteristics of local authorities and on the type of support underpinned by legislation.

#### **11.3.1. *Regulations and guidelines***

Some of the countries under analysis have regulations or guidelines in place to support legislation. In other countries, experts reported a lack of guidelines. For instance, in Italy, in order to use the resources of the Fund (art. 254 of the Law 5 February 1992, n. 104) to support carers (as defined from art. 255) it is necessary to wait for specific regulations which are not currently available. Differences were also found at the regional level. In Emilia-Romagna the implementation methods of the Regional Law 28 March 2014, n. 2 are defined, while in Abruzzo and Campania no implementation guidelines have been issued. In Scotland, the government has an implementation plan for the Carers (Scotland) Act and an implementation steering group which meets regularly.

In many countries, regional and local authorities are responsible for the enactment of the legislation. In Switzerland the cantons receive recommendations from the Federation about how to translate the legislation into practice; however the implementation varies from canton to canton. In the UK local authorities have a duty to identify and assess young carers, but different local authorities have different approaches about how to enact this legislation. Some local areas have set up local working groups to address the duties and how to implement them through a multi-agency approach, while in others there are still gaps between children's services and adult services and in understanding their responsibilities.

### **11.4. *Changes in Legislation***

#### **11.4.1. *Key drivers for changes***

Different key stakeholders were involved in the development of legislation in the six European countries. These stakeholders were, for example, different ministries (IT, NL, SI) family associations (IT), or private and state organisations (SE). Young people and carers were also involved in the process, for example in the UK.

Experts mentioned several key drivers that had helped bring about changes in legislation. One key driver mentioned by Slovenian experts was the high workload of social workers (for the Family Code) and of the police (for the Violence Protection Law). Another driver of legislation in Slovenia was the analysis of other European legislation which led to the changes of child protection measures.

In the UK experts highlighted the role played by academics conducting research and the partnerships they formed with the voluntary sector, which raised the awareness of young

carers and their needs.

Experts in several countries mentioned the importance of the ratification of the United Nations Convention on the Rights of the Child for their national legislation.

#### *11.4.2. Changes in the recognition and definition of young carers*

Young carers were mentioned for the first time in UK legislation in the Care Act 2014 and the amendments made to the Children Act (1989) by the Children and Families Act (2014). Now young carers and their families must be identified, assessed and could receive support. In Scotland, young carers were previously not mentioned in legislation because it was assumed that they were covered by the provisions within the Children and Young People's Act (Scotland). However, through consultation and the involvement of young carers, the Carers Act did finally explicitly include young carers.

Although Italy does not have a definition of “young carers” in the legislation, family carers have now for the first time been defined in legal terms by the Emilia-Romagna Regional Law (2014). Based on this regional law, draft laws for national legislation to recognise carers were submitted.

#### *11.4.3. Changes in paradigms*

The changes in legislation have often been associated with changes in paradigms. In the Netherlands, the introduction of the Child and Youth Act (Jeugdwet) brought about a huge decentralisation along with a transformation of approach. This approach focussed on the role of the family and social networks in the care process, prevention, and a better coordination and integration of services. In Switzerland, there was a paradigm shift from the welfare approach to a rights-based approach, which has meant that children are now better informed about their rights. In the UK a paradigm shift occurred when the approach to supporting young carers moved from supporting them separately from their family to supporting them through a ‘whole family approach’.

#### *11.5. Specific Policy & Service Frameworks*

Policy and service frameworks specifically targeting (adolescent) young carers were reported in Switzerland, England, Scotland and Northern Ireland. In Switzerland, the Action Plan for support and respite of relatives providing care and the Federal research programme target all carers, explicitly including minors. 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. The policy paper “Carers Action Plan 2018-2020” in England also addresses the issue of transition for young adult carers. The experts from the remaining countries (NL, SI, SE, Wales) did not report any specific policy and service frameworks for young carers and their families. Despite having no policy and service framework on a national level, one expert in Italy mentioned an education-directed tool on a local level. This tool allows more

flexibility concerning the school attendance plan and the expected attainments for young carers.

### **11.6. *Non-Specific Policy and Service Frameworks***

Experts were asked about the non-specific policy and service frameworks that can indirectly support young carers and their families. In Sweden, experts did not mention any non-specific policy and service framework, whereas many of them were reported in other countries. For example, the Dutch Ministry of Health, Welfare and Sports launched three programs with the aim that all disabled people and their relatives should be able to participate in society in line with their preferences, and in Italy the regional support tries to reconcile the studies with the care activity of the students. Slovenia supports young people with the “National Programme for Youth”, which aims to empower young people – especially those with special needs (referring mainly to people who have cognitive or physical impairments). Moreover, youth centres in Slovenia provide a range of support for young people in need. A similar approach was found in Switzerland, where the Federal Social Insurance Office has a child and youth policy and the organisation “Health Promotion Switzerland” supports cantonal action programmes, which are focusing, among others areas, on supporting the mental health of children and young people.

In the UK the non-specific policy and service frameworks differ among the countries. For instance, England has the Pupil Premium, which is an additional funding for publicly funded schools in England for disadvantaged pupils that can be used to implement additional support. Scotland has the national approach “Getting It Right for Every Child” which aims to improve and support outcomes for children. Experts in Northern Ireland mentioned several non-specific policy and service frameworks for example, strategies for children and their families (namely the “Children and Young People Strategy 2017-2027” and the “Strategy for Supporting Families 2015-2020”) as well as the guidance “Understanding the Needs of Children in Northern Ireland (UNOCINI)”, which is aimed at practitioners who provide services to children, young people and families.

### **11.7. *Enactment of Policy and Service Frameworks***

Many experts mentioned guidelines and indicators which act as useful instruments for the implementation of policy and service frameworks. In Scotland, eight indicators were developed in order to ensure that children are supported: safe, healthy, achieving, nourished, active, responsible, respected, and included. In England and Wales the template “No wrong doors: working together to support young carers and their families” helps to promote the cooperation between adult’s and children’s social services and enhances the partnership with health and third sector partners. The cooperation and collaboration between healthcare institutions and social services is one of the characteristics of enactment seen in many countries. For instance, in Northern Ireland a group of voluntary and statutory organisations has the responsibility to support children and in the Netherlands there is a national website for diverse groups (including professionals,

children, parents, municipalities) on the topic of children with parents with psychological problems or addiction problems with information on interventions and guidance on how to cooperate with other organisations in this field.

Another important point mentioned by experts in many countries is the family approach. The guidance document “The Care Act and Whole-Family Approaches” in England and Wales provides guidance for practitioners working in adult social care about considering the needs of the whole family. In Slovenia the main role of the social work centers is to empower parents, protect children and make families more functional.

Young carers also need support with their education. For example, in Slovenia, “youths with fewer opportunities” are prioritised according to different measures, from formal to non-formal education and within youth programmes.

In many countries, the experts stated that the enactment of policy and service frameworks works well when there is sufficient financial support. The example of Italy where local areas have a high level of autonomy regarding the use of funds, shows that the quality of social services can vary even between neighbouring areas.

### **11.8. *Changes in Policy and Service Frameworks***

Over the years there has been an increased focus on children's issues. For this reason, Sweden considers the impact that policies have on children. Young carers were not included in policy and service frameworks from the beginning. For instance, in Switzerland children were not included in the Action Plan in 2014, however, a petition from the Parliament addressed their exclusion and they are now explicitly mentioned in policy.

The changes in policy and service frameworks were supported by many different stakeholders, with the aim of improving the situation of young people. An example of this is Slovenia, where youth wings acquired their own secretary and therefore the necessary political weight to support the introduction of the National Programme for Youth. The youth sector was involved in the development of the Youth Policy Framework and also several ministries. The development of policy and service frameworks has faced some opposition. For example, in Northern Ireland, there was some opposition to the Children and Young People's Strategy 2017-2027 because it was felt that this might have created unnecessary bureaucracy.

The European Union's promotion of young people as a target group supported the policy development in Slovenia through the identification of eight important fields of youth policy, including education, employment, health and culture. This served as an important basis for the development of the youth policy framework.

### **11.9. *Evaluation of the Current Situation***

Experts from the six European countries were asked how they would evaluate the current situation regarding legislation, policy and service frameworks. They were also asked to

assess any key strengths or limitations and whether they would suggest any changes to the legislation, policy and/or service frameworks.

#### *Evaluation of the specific legislation*

The assessment by experts of the young carer-specific situation in their respective countries highlighted both similarities as well as substantial differences. In the countries of the UK (England, Scotland, Northern Ireland and Wales) despite their unique provisions from young carer-specific legislation, enactment of legislation specifically was assessed critically by experts. Experts described legislation as overly complicated (Scotland) and not enacted in practice as it should, due to a lack of statutory guidance (England), accompanying policy (Wales).

#### *Evaluation of non-specific legislation*

In countries with no specific young carer legislation, other approaches and legislative provisions are mentioned as important for the current situation for AYC's. In Switzerland, the omission of young carers in legal provisions is counter-balanced by a solid legal system with significant protection and support for children and providing conditions to prevent poverty. Soft laws were also assessed by experts as being useful, as they are based on commitment and not enforced by legislation. In Sweden, a patchwork of provisions can be used to support young people with caring responsibilities, but there is no clear regulation among the different laws. In Slovenia, the legal, policy and service frameworks are assessed as poor with regard to AYC's. However, the recently introduced Youth Policy is the first policy that targets young people and experts expect youth policy to be improved, especially with policies, further evidence from research and an increased cooperation between ministries. In the Netherlands, where legislative changes are recent and legislation may not have embedded smoothly everywhere, experts reported dissatisfaction about how effective the new system is.

#### *Family perspectives and best interest of the child*

Experts from different countries talked about the importance of whole family perspectives (England, Wales, SE). Herein lies a key conflict, which materialises on the level of social services in two opposing perspectives, one emphasising the importance of the family and the other the interests and rights of the child (CH, SE). One of the Italian experts discussed how the "best interest of the child" might be interpreted as removing them from their family without considering support interventions and that the effects of situations like this on young carers have to be evaluated. Related to this is the call by some experts for the increased participation of AYC's themselves and a view of children as partners, with regard to their own situation and policymaking in general (SE).

#### *Evaluation of the support offered*

With regard to support, one Italian expert reported that financial support without other strategies is insufficient. English experts stated a range of shortcomings of the current social services, for example, the lack of knowledge of professionals, a heavy dependence on individual professionals, the difficulties in identifying young people who care for someone

with an addiction problem, financial cuts and the difficulties arising from integration between health and social care. In some countries, child protection services are mentioned explicitly. In Switzerland, this is assessed by experts as being very good established and working well, but the outcomes of child protection measures are not really known. In Sweden, there are no specific provisions but if necessary, child protection measures can be taken. One expert highlighted the dilemma of whether parents have the right to deny support options from society and instead choose for their children to care for them.

#### *Evaluation of social and political changes and awareness raising*

AYCs' situation is heavily depending on social and political conditions and changes. The importance of the broad topic of caring in the current social and political climate might be high (CH), which is related by experts to a society that is ageing in general (IT, NL, SI). With regard to young carers specifically, awareness is assessed differently by experts in the respective countries: A lack of awareness (CH, IT, NL, SI), rising recognition of the significant numbers of young carers, with a main focus on children of parents with mental health issues (NL), which is also targeted by special programmes (CH). On the other hand, experts observe a rather decreasing awareness (England), for example because other vulnerable youth groups (England, Scotland) or parents (England, NL) get more attention and support.

#### *Stigma and identification of young carers*

Young carers are perceived as children who have to be protected (NL) and experts reported on the stigma that occurs when parents are being cared for by their children (England). Identification of young carers is also not working satisfactorily as AYC's do not often self-identify. Ensuring young carers are kept on the political and social agenda is called for (England, Northern Ireland, SE).

#### *Differences at the regional and local level*

Furthermore, experts made it clear that countries are not homogenous with regard to young carers' situation. A general lack of consistency with regard to support (NL, Scotland) and awareness (Scotland) is mentioned as well as an inconsistency in how legislation is enacted (UK) and financial funding (IT). In Slovenia and Italy, experts called for solutions adapted to regional characteristics and for stronger financial support for municipalities.

### **11.9.1. Key Strengths**

Several country specific characteristics were reported that are relevant to young carers, such as a tradition of a good care for children, child protection and family policies (SI), a well-developed welfare system (SE) or a federal system and good support of basic needs (CH). Experts' assessments of key strengths in the respective countries can be analysed at different levels.

### *Clarity brought by legal provisions*

Experts assessed the legal provisions positively because of the clarity they bring about. This refers particularly to the UK, where legislation defines young carers and their rights. Clarity is also brought about in relation to enactment and practice (CH, England and Wales), duties of schools and support services (England and Wales, SE). Legislation also brings clarity with regards to support (NL), assessment (NL) and identification (England, Wales, Scotland), as well goals and how to measure them (NL). Another key strength of legislation is the explicit strategic focus that it brings. In England and Wales for example, a whole family approach has been set out, and in Sweden, children's rights have been strongly developed.

On the other hand, where legislation is not restricted to specific target groups this is also described as a key strength (CH, SE).

### *Collaboration between different organisations and stakeholders*

With regard to services and support, the importance of collaboration was stressed by experts. Various organisations such as family associations (IT), local communities (SI), youth centres that work closely with young carers and their families (SI), schools (England, SE, Wales), and child protection authorities that work in an interdisciplinary way and as established networks (CH) were mentioned as positive examples. Besides strong governmental institutions (SI), the civil society or voluntary sector was mentioned as a key factor with regard to support provisions (England, Wales). A good relationship between the voluntary sector and the government (Scotland) is as important as the inclusion of regional stakeholders (CH and IT). From an expert perspective collaborative agreements can raise awareness of the topic (Northern Ireland) or regulate identification of young carers (IT).

### *Inclusion of AYC's in the development of legal provisions and policies*

The participation and inclusion of AYC's themselves in helping shape the development of policy and legislative changes was highlighted by experts as a key strength in the UK countries (England and Wales, Northern Ireland, Scotland).

### *Importance of local authorities*

The importance of local institutions and flexibility as well as a decentralised approach seems to be crucial as well (CH, IT). Switzerland's federal approach is described as providing the opportunity of finding solutions that fit with regional contexts and being a positive influence on innovation because of a plurality of solutions.

## **11.9.2. Key Limitations**

A set of key limitations with respect to legislation, policy and service frameworks appears to be essential as they are mentioned by experts of various countries.

### *Challenges in identifying AYC's*

Among them there was stated the challenge caused by the identification of young carers, which can be due to a missing legal definition (CH, IT), unclear regulations (CH, SE) or a

general omission of AYC's in specific legal frameworks, such as in the Care Act in Slovenia. The process of identifying young carers might be further hampered by a lack of cooperation between different institutions (CH). Children and their families might also not identify themselves as young carers due to a lack of awareness (England, Northern Ireland, and Wales) and AYC's might not be familiar with their rights (Scotland). The lack of awareness also applies to authorities and professionals (IT, SE) or society in general (Northern Ireland, SI).

#### *Lack of clarity and coordination*

A number of experts mentioned the lack of clarity as a key limitation to the young carers' situation in their respective countries. This can be with regard to general goals and strategies (SI), complicated and not in accord with actual needs (Scotland) or as expressed in a language that is not age-appropriate for young people (CH). In other countries, experts reported a lack of clarity regarding the procedures of the social services (IT) and a lack of guidance for parents (NL). A lack in communication and coordination was identified as another major shortcoming; either in the form of a lack of formalised national coordination (IT), or between bureaucracy and practice (SI) or between different services (England, Wales). Other experts highlighted a general communication gap among the relevant key stakeholders when it comes to AYC's (NL, SI).

#### *Lack of an integrated approach*

The different approaches advocated in the respective countries were also assessed critically: experts mentioned the absence of both a family and a preventive approach (IT), lack of an integrated approach (NL, SI) or limitations with enactment of a certain approach (England, Wales). On a practical level, some experts criticised a lack of guidance, for example the lack of an instrument to measure the impact (SI) or the absence of standard protocols and guidelines for support (NL) and templates for assessment (England, Wales); the resulting variations in local practices was likewise assessed critically by experts. This links up to another core aspect identified by some experts as relevant for their respective countries: differences between local areas. In Italy, one expert criticised the unequal allocation of resources. Differences in the quality of practice (England, Wales, and Scotland) and in the enactment of legislation and federal regulations on a local level (CH) are mentioned. A Slovenian expert related inconsistency regarding support to decentralisation. Another issue was the shortage of resources, which might be due to cuts (England, NL, SE, Wales) and becomes apparent in a low provision of staff (IT), a negligence of young carers to the advantage of other social groups (Scotland) or a conflict between national and local authorities who are given a budgets that are too restrictive (SE, SI).

#### *Country-specific limitations*

Besides these key limitations applicable to different countries, experts also discussed some limitations which are unique to their respective countries. In Italy, the law regulating paid leave was assessed critically by experts, as not offering concrete support and excluding those who are not working. In Slovenia the evaluations of how the legal and policy frameworks are translated into practice were criticised since they are mainly done

externally and the results did not reflect the reality. The overall situation in Slovenia was characterised by a lack of political willingness: one expert noted that nobody is willing to collect additional data and come up with innovative measures. Experts also noted a general lack of entrepreneurial mind-set and confidence to implement new initiatives. In addition, the political pressure to come up with new legislation was viewed critically, as it risked the development of poorly worked out legislation. In Sweden, very open regulations and frameworks - putting a lot of emphasis on individual social secretaries and child protection professionals - appear to be unique in comparison to the other participating countries. Another key limitation identified by experts was that the legislation does not specifically include siblings or parents with developmental difficulties. Similarly, the Swiss Civil Code was labelled as open to interpretation: a trait assessed as both a potential strength and limitation by experts, as it allows provisions for individually tailored solutions. However, the marred story of Swiss child protection services was seen as a key limitation by experts, because in the last century it has happened that children were forced out of their families in the name of child protection under circumstances that would be seen from the perspective of today as grave violations of the rights of these children and their families. In England and Wales, the fact that AYC's may not wish to come to the notice of statutory services for fear of being taken into care was mentioned as a specific challenge, as were the respite activities, which were thought to not actually prevent or reduce caring activities.

### *11.9.3. Suggested Changes, goals and hopes for the future*

#### *Recognition, awareness and understanding*

One major and fundamental goal for the future that was reported by experts in all countries is improved recognition and increased awareness by the general public, professionals and by policy makers of the situation of young carers, the difficulties they experience and the impacts (positive and negative) on their own lives and on their families. Awareness should be raised at all levels of society, for example with professionals in the health, social and education sectors and with the general public. Some possible ways to raise awareness were mentioned, e.g. through NGOs and by training professionals (CH, UK) and through information campaigns and the media (SE). Firstly, a definition for young carers is needed, so that AYC's can identify themselves. AYC's should also be recognised as an important target group for policy makers. In general, young carers and their needs should be recognised by applying the UN Convention on the Rights of the Child. However and it must be acknowledged that the best interest of a child can be different for every child (CH).

#### *Increased understanding*

More knowledge and data is still required to improve understanding of the young carers, their issues related to caring and their needs. Research should play a role and experts discussed the importance of a more evidence-based approach to highlight the relevance of the issue.

### *Children protected from caring*

The Netherlands and Sweden hope for a more whole family and preventative approach through legislation in the future and for legislation that protects children from (inappropriate) caring; the rights of AYC's therefore need to be known and taken seriously by society in general and by children themselves (NL, SE, UK).

### *Legislation, policy and service frameworks*

Experts have different views about whether legislation that specifically targets AYC's is required or whether existing legislation is sufficient. In Italy for example, experts talked about the draft national law for informal carers, which recognises the existence of student carers (and adapting it to recognise young carers) and in Sweden experts talked about using the Social Services Act to include the 'family perspective' and the Patient Safety Act in relation to children's needs not being met. One Italian expert reported that it would be ideal to have the same legislation for the whole country, with the opportunity for the regions to apply it differently. In Slovenia, experts also wish for a specific law for informal care. However, they also discussed the potential to adapt existing legislation, such as education law. Similarly, in Switzerland experts highlighted the potential to extend existing legislation (e.g. the labour law), policy and service frameworks to include AYC's and for legal systems to be better coordinated.

Legislation and institutions should consider the specific problems and needs of young carers to ensure there is adequate support in place (CH, IT, NL), e.g. by adopting a "life-course-approach" (CH). Furthermore experts wish to have more links between the different policy frameworks (SI). One relevant point mentioned by experts in different countries was that it is important to address the issue with situation-specific solutions, for example, based on the type of care activity provided (IT) or the transition between school and work (SI). This would accommodate the needs of diverse groups (NL). However, an expert in the Netherlands stated that support should not be separate for different groups of young carers, but would rather have a more universal approach, along the lines of the Care Act in the UK.

### *Development of legislation, policy and service frameworks*

It was suggested that comparisons could be made with what is happening in other countries to support developing practice and legislation (NL, SI) and initiatives researched (NL) and that research institutes should be better linked to policy makers. Experts reported the need to involve different stakeholders, e.g. different ministries (IT, SI), NGOs (CH, SI) and that discussions about young carers should be integrated with discussions about adult carers (NL). In Slovenia the importance of committed individuals and aligning policies to the existing structures of the ministries to bring clear leadership was highlighted.

### *Guidance for local authorities and monitoring*

Several experts mentioned the importance of developing improved guidance. For example, in England it was suggested that more guidance around what an assessment should look like is needed, and that the guidance about how to translate legal and policy frameworks into practice needs to be reviewed and adapted to local areas. In Sweden it was suggested

that policy and legislation should include what is appropriate and inappropriate caring for children and that the regulations and the handbook in the Young Person's Act (Allmänna råd) could be updated to include children as carers as an example of children at risk. In Italy, experts reported the importance of having guidance to establish who should intervene, how to intervene and with which tools. Moreover, monitoring processes, clear goals and indicators tailored to AYC's were thought to be needed (SI) and more monitoring and evaluation of how local authorities' duties are being implemented (UK).

#### *Enactment: Early intervention, prevention and consistency of support*

In order to limit negative impacts on young carers, early-help assessments (UK) and interventions should take place earlier (SI), children should know they can receive support at an early stage (SE) and support should be made more accessible (SE). Young carers should be provided with information (SE), including information at different points in their life, about what support they can get and how to access it (NL). To ensure an equitable service and access to support for families between regions (and to achieve more consistency within the countries), legislation needs to be embedded in every local area (UK); there should be fewer differences in the distribution of funds among regions (IT); and more money needs to be spent in general on local youth policies (SI) and support services (UK).

#### *A collaborative approach*

The need for improved collaboration between professionals and/or support services was highlighted (NL), notably at the transition to adulthood (UK), and between services and policy areas (IT). Initiatives should be mapped (NL) and schools and social services should play a key role in identifying and assessing the needs of young carers and their families (IT, NL). Suggestions made by the experts for reaching families included neighbourhood teams signposting carers to local support (NL) and multigenerational centres (SI).

#### *Family focused approach*

There is hope for a more family focused approach (SE) where Social Services monitor the family and react promptly (IT), families and children are assessed and there is more defined legislation and directives such as in the UK and with families being strengthened through a network of support (NL). Children shouldn't be supported to continue caring, but the shortages in the support for adults and children who need care should be looked at (SE). The whole family should be supported and young carers should be seen and involved in a care plan where their opinions need to be sought (NL). It is hoped new legislation will improve organisational approaches with a more whole family approach (SE). Other approaches suggested included tax deductions, care allowances and credits to facilitate the education of AYC's (IT) and the use of technology (NL).

#### *Transition support*

Experts highlighted the need to pay special attention to protect adolescent young carers as they are at a vulnerable period and developing their own identity (NL). Services need to be developed at the transition period from children's services to adult services (Northern Ireland) and quicker interventions to assess needs should take into account the transition

between school and work (SL). Improved integrated working would for improve support for young carers at the transition period to becoming adults (NL).

#### *AYCs participation*

The views and experiences of children with caring responsibilities need to be heard (CH, NL, SE) in order to improve understanding of their situation and to gather their ideas for improving support. Collaboration with AYC's therefore needs to take place and it is important that both AYC's as well as policy makers are involved in research.

## 11.10. Overview of the main AYC-specific and non-specific legislation, policy and service frameworks

Table 6: overview of the main AYC-specific and non-specific legislation, policy and service frameworks

	AYC-specific legislation	AYC-non-specific legislation	AYC-specific policy & service frameworks	AYC-non-specific policy & service frameworks
<b>IT</b>		<p>Law 23 December 1997, n. 451 (see p. 28)</p> <p>Law 28 August 1997, n. 285 (see p. 28)</p> <p>Law 22 June 2016, n. 112 (see p. 28)</p> <p>Law 27 December 2017, n. 205, paragraphs 254-255 (see p. 28)</p> <p>Law 5 February 1992, n. 104 (see p. 29)</p> <p>Law 11 February 1980, n. 18 (see p. 29)</p> <p>Law 28 May 2017, n. 71 (see p. 30)</p> <p>Emilia-Romagna Regional Law 28 March 2014, n. 2 (see p. 30)</p> <p>Emilia-Romagna Regional Law 30 July 2015, n. 14 (see p. 31)</p>	BES/SEN (Bisogni Educativi Speciali/Special Educational Needs) (see p. 32)	<p>Logistical facilitations for participation in university studies in Emilia-Romagna (see p. 32)</p> <p>“Patto regionale per il lavoro” in Emilia-Romagna (see p. 32)</p>
<b>NL</b>		Child protection (Dutch Civil Code, Book 1, Section 1.14.4,		Domestic violence and child

		<p>Article 1:254) (see p. 37)</p> <p>The Social Support Act (Wmo 2015) (see p. 38)</p> <p>The Child and Youth Act, January 2015, Article 2.1 (see p. 38)</p> <p>The Mandatory Protocol (Domestic Violence and Child Abuse) Act (see p. 39)</p> <p>Compulsory Education Act 1969 and Compulsory Education Act 2007, Article 4a and 4b (see p. 39)</p>		<p>abuse protocol (see p. 41)</p> <p>Child check instructions (see p. 41)</p> <p>Decision compulsory reporting code domestic violence and child abuse (see p. 42)</p> <p>Toolkit Mantelzorg (see p. 42)</p> <p>NHG Guidelines (see p. 42)</p> <p>Programmes of the Ministry of Health, Welfare and Sports (see p. 42)</p> <p>Guidelines Children of Parents with Mental Problems (KOPP) for youth care and youth protection (see p. 43)</p> <p>UNCRC (see p. 43)</p>
<b>SI</b>		<p>Social Security Act (ZSV) (see p. 50)</p> <p>Long-term care legislation (draft legislation) (see p. 50)</p> <p>Domestic Violence Prevention Act (see p. 51)</p> <p>Law on Marriage and Family Relations (see p. 51)</p> <p>Family Code (DZ) (see p. 51)</p> <p>Volunteering Act (see p. 51)</p>		<p>National Programme for Youth (see p. 53)</p> <p>Strategic documents on long-term care, Ministry of Labour, Family and Social Affairs (see p. 53)</p> <p>Policy for young people with special needs (see p. 54)</p> <p>Education (see p. 54)</p> <p>Youth Policy (see p. 54)</p>

		Education Law (see p. 52)		
<b>SE</b>	Healthcare Act (2017:30) (see p. 60)	<p>Social Services Act (2001:453) (see p. 61)</p> <p>The Care of Young Persons (Special Provisions) Act (1990) (LVU) (see p. 61)</p> <p>The Education Act (2010:800) (see p. 62)</p> <p>Law (1993:387) on support and services for certain disabled people (LSS) (see p. 62)</p> <p>Patient Safety Act (2010:659) (see p. 62)</p> <p>UNCRC and Swedish law (see p. 63)</p>		
<b>CH</b>		<p>Federal Constitution of the Swiss Confederation of 18 April 1999, Art. 11 Protection of children and young people (see p. 73)</p> <p>Swiss Civil Code of 10 December 1907, Child and adult protection law (see p. 73)</p> <p>Hague Convention on the Protection of Children (see p. 73)</p> <p>Social Security Law, Art. 29 septies Federal Law on Old Age and Survivors' Insurance (AHVG),</p>	<p>Action plan for support and respite of relatives providing care, 2014 (see p. 74)</p> <p>Federal Research Programme "Support and Relief Offers for Carers 2017-2020" (see p. 74)</p>	<p>Children and youth policy (see p. 74)</p> <p>Health Promotion Switzerland (see p. 75)</p> <p>Counselling services, Canton of Vaud (see p. 75)</p> <p>Youth counselling in Zurich (see p. 75)</p> <p>Children and Family service – Centers (see p. 75)</p>

		SR 831.10 (see p. 73)		
<b>UK</b>	<p>Children and Families Act 2014 (see p. 81)</p> <p>Care Act 2014 (see p. 82)</p> <p>Social Services and Well-being (Wales) Act 2014 (see p. 84)</p> <p>Carers (Scotland) Act 2016 (see p. 84)</p> <p>The Children (Northern Ireland) Order 1995 (see p. 84)</p> <p>Care and support statutory guidance, Department of Health and Social Care (see p. 83)</p> <p>Statutory Instruments, No. 527, Children And Young Persons, England, The Young Carers (Needs Assessments) Regulations 2015 (see p. 82)</p>	<p>National Health Service Act 2006 (see p. 85)</p> <p>Education Act 1964 (see p. 85)</p> <p>Children Act 1989 (see p. 85)</p> <p>Children and Young People's Act (Scotland) 2014 (see p. 85)</p> <p>Education (Additional Support for Learning) (Scotland) Act 2004 (see p. 86)</p> <p>Carers and Direct Payments Act (Northern Ireland) 2002 Chapter 6 (see p. 86)</p> <p>Children's Services Co-operation Act (Northern Ireland) 2015 (see p. 86)</p>	<p>Carers Action Plan 2018 – 2020 Supporting carers today (see p. 90)</p> <p>Working Together to Safeguard Children (see p. 90)</p> <p>Getting it Right for Young Carers - The Young Carers Strategy for Scotland (see p. 90)</p> <p>Children and Young People's Strategic Partnership Young Carers Group (see p. 91)</p>	<p>Pupil premium (see p. 91)</p> <p>Getting It Right for Every Child (see p. 91)</p> <p>Children and Young People Strategy 2017-2027 (see p. 91)</p> <p>Understanding the Needs of Children in Northern Ireland Guidance (see p. 91)</p> <p>Strategy for Supporting Families 2015-2020 (see p. 92)</p> <p>Families matter - Supporting families in Northern Ireland (see p. 92)</p>

## 12. Adolescent Young Carers Feedback

Young adult carers and former young carers in the six countries under analysis were asked their opinions on the future goals and hopes mentioned by the experts and on the enactment of legislation, policy and service frameworks within their own countries.

### *Future goals and hopes*

The future goals and hopes commented and/or reported by participants (AYCs, YACs and former young carers) concern several different aspects, e.g. the right of a child to be a child, awareness, the involvement of young carers in decision processes, the need for a new legislation or the adaption of existing legislation, and the need for better collaboration between support services.

Firstly, the need for supporting the role of the parents was highlighted (IT), because it is very important that children can experience their childhood instead of having to grow up too early (SE). However, one participant from the Netherlands questioned whether “inappropriate caring” is really “inappropriate”, or whether there can also be a positive side to it: can it be appropriate if there is a good balance? Nonetheless, the same participant stated that caring can only be positive if there is enough recognition of what young carers are doing and what their needs are. In regard to recognition, one Swiss participant reported that a future hope mentioned by experts (i.e. “Young carers should be recognised by the health system, by schools, etc. in order to receive the support they need and they should be involved in this process”) is very important. Regarding the involvement of young carers, this was mentioned as a relevant point by many participants (CH, SE, UK). In particular, both AYC and their families should have the opportunity to share their opinion about what their needs are and what kind of support could help them and they should be taken more seriously. However, young carers and their families need to be more informed in order to actively participate in decision processes. For example, a participant from the Netherlands agreed with the hope held by experts that young carers should be more informed about what support they can get and how to access it. Young adult carers and former young carers also considered it important to raise awareness about the topic of AYC among all those working with young people, the general public, and the young carers themselves (NL, SE, UK).

Another important topic mentioned by several participants is the need for a national legislation (IT, NL) or strategy (UK), or the need to adapt the existing legislation (SE, SI). For example, one participant mentioned the need for the Swedish legislation to be amended to allow children and young people to receive support from social services without the consent of parents or guardians. Furthermore, more equity among different regions in providing support to AYC was another future hope of participants in Italy and in the UK.

(A)YC need to be defined as well, so that they can be better identified (IT, NL, SE, UK). A participant from Sweden highlighted the importance of professionals checking whether

parents with an addiction problem have children and getting in contact with those children. Furthermore, each situation should be considered individually (CH, SE, UK). For instance, one participant in Sweden would like to see a greater focus on siblings, while the participants from UK and Italy mentioned the difficulties experienced by vulnerable groups, e.g. children of mentally ill parents or children of substance misusing parents. Moreover, it is important to reduce the stigma associated with those vulnerable groups (UK). The Swiss participant also reported her fear concerning stigmatisation, which could be caused by the hypothetical obligation of filling up documents to prove their young carer status.

The participants affirmed the importance of the future goals and hopes of experts concerning the need for more support. In particular, there should be more support and awareness raising in schools, where topics such as informal caring, resilience and mental health should be discussed (NL, UK). Adolescent young carers should be protected because they are developing their own identity and they are in a vulnerable transition period. The transition from school to work is also important and where adolescent young carers should be better supported, e.g. with more flexible working conditions (IT). For participants, prevention and early interventions are very important, too (IT, NL, SE, SI) in order to limit negative impacts on adolescent young carers. Better collaboration, communication and a clear division of responsibilities between different support services was also reported as a relevant future hope by participants (NL, SE, SI).

#### *How legal provisions and policy frameworks work in practice*

In general, participants reported some difficulties in commenting on the enactment of legal provisions and policy frameworks due to a lack of experience and knowledge of these. For example, in Switzerland it was reported that AYCs are not sufficiently informed about their rights and about the opportunities for support. In Sweden, the division of responsibilities is not clear and people do not know where they can get information and support. If there were coordinators, this would be a huge help for young people and their families. A former young carer in UK reported that she has no experience of any support because she was not identified as a young carer. She had needed more appropriate emotional support when she was caring for a parent with mental health issues. A problem highlighted by a former young carer in Italy is that there is no awareness of the topic. Therefore, the support offered is only general support for young people and not specific for young carers.

Another issue mentioned by participants in Sweden is the little information that AYCs receive, e.g. about the parent's illness. No one has the explicit responsibility for providing information and many professionals are not aware that children have the right to be informed. In Sweden, it was reported that the child protection legislation is not clear enough because it falls under two different laws (i.e. the Social Services Act and the Care of Young Persons Act). For this reason, the meaning of each law is not understandable enough for young people.

Several participants commented on the education legislation existing in their own countries. For instance, the Compulsory Education Act 1969 and 2007 in the Netherlands was assessed positively, because it protects young people from not attending school. However, as mentioned by one participant in Sweden, school is an important part of young people's development, but since there is the obligation to participate; this can be difficult for AYCS to meet. Unfortunately, in the case of absences, the tendency is to blame the children for being lazy or uncommitted, instead of questioning the reason. Therefore, the school environment should be more supportive (SE, UK).

According to the experiences of some participants, some existing laws are not working well in practice, e.g. the Healthcare Act, the Law on Support and Services for Certain Disabled People, the Patient Safety Act (SE), and the National Health Services Act and the Children Act (UK). In particular, the participants reported that they were not offered any kind of support and their role was not considered by health professionals. In Sweden, with the Social Services Act 2001, there is an issue with consent. Many children need support from social services but they are denied this because their parents do not agree to it. However, this law is considered important by one participant because it enables the problems experienced by young people to be identified and addressed at an early stage. In the Netherlands, one participant reported that health insurances expect AYCs to do more work at home and this prevents AYCs from moving out or attending college in a different city.

Some participants also reported their own hopes for the future. For instance, the UNCRC is not legislation in Sweden yet, but participants are looking forward to when it is. One participant in the UK wished for an expansion of the definition of care included in the Carers Action Plan 2018-2020: in particular, emotional support should be included. Moreover, she suggested having something similar to the statutory guidance "Working Together to Safeguard Children" for young adults, e.g. university students. In Sweden, more psychological support is needed, not only from an individual perspective, but also from a family one. Finally, to improve support, one Swedish participant wishes there were more forums where people can share their experience and help one another.

### **13. AYCs with migrant background**

Some of the experts reported cases in which migrant families had problems interacting with the social welfare or with councils. Furthermore, some migrants could not speak the language of their new chosen country of residence which complicated any dealings with the local support services. Experts also described that interaction between migrants and the local support services perhaps overstretches the ability of migrant families to adapt to the new expectations placed on them by the authorities – so the main issue relates to the low socio-economic status of migrants in general.

However, local authorities also need to be more aware of such difficulties. Raising awareness amongst social care workers is therefore really important – especially when children from migrant families often take on the responsibility for completing official documentation, since parents are not used to doing this or do not speak the language. For

example in Italy, migrant care workers are not aware of the work which migrant young carers undertake for their families. Sweden has developed a new support service where a nurse will visit families alongside a social worker when the immigrant has a new-born baby. The expert discussing this felt that parents were more open to support and information when a child is new born.

There is also a more sociological consideration that relates to the different views of childhood. The concept of childhood as a safe place where a child can develop and grow up under ideal circumstances appears to be a luxury which has developed in European countries where this has been affordable. It is therefore especially important that local authorities are aware of this different understanding of childhood, so that conflicts between local authorities and migrant families can be avoided as far as possible. Child protection services for example need to be aware that in some cultures it is normal for children carry out higher levels of care work than in some European countries. Families therefore can be deeply confused when local authorities intervene.

#### **14. Emerging dilemmas and “quo vadis”**

Before any steps are taken towards the development of legislation and policy in regards to AYC's it is important to recognise a range of dilemmas or questions that this research raises. For example, there is sometimes conflict between the privacy of families and the protection and support of AYC's which leads to the question as to whether the support and protection of AYC's is a private family matter or a public responsibility. The answer to this question is surely multi-layered and includes consideration of cultural expectations, child agency and child safeguarding and protection.

Another question that was raised and which drew different opinions from experts was whether or not specific legislation and policy were necessary to protect and support AYC's, or whether a better direction would be maintaining non-specific legislation/policy. Arriving at a definitive answer to this is complex and many things need to be considered that are specific to individual countries, such as 'how effective is the current non-specific legislation/policy at recognising, identifying, protecting and supporting AYC's?' and 'how would specific legislation/policy fit with what already exists?' By introducing specific legislation/policy for AYC's, how does this fit with the narrative that children should not be taking on caring responsibilities in the first place? Does this inevitably lead to a need to define what is an acceptable level of caring, similar to the 'inappropriate caring responsibilities' as set out in the statutory guidance to the Care Act in England? The findings in this study highlight that the support and protection that AYC's receive in practice does not always reflect the objectives of legislation and policy that is in place. Without an accurate understanding of the realities on the ground, assumptions regarding the efficacy of existing legislative and policy frameworks may be unknowingly leaving AYC's to fend for themselves without even the recognition of their existence. As stated by (Nordenfors & Melander, 2017, p.15) "A strong welfare state (from which the children's and the youths' parents and their next of kin should get support, care and assistance) together with ideas about children not having to perform care and take responsibility at

too high a level, have contributed to the notion that children do not need to become carers in this country. This means paradoxically that individual children are left alone without support, sometimes with a very high level of care as a result.”

A further issue relates to the best approach to take. Taking a family perspective (or whole family approach) was generally advocated by experts and in place in several countries, but to what extent should this approach be taken and does this approach meet the needs of AYC's? This leads to questions connected with some of the previous points regarding specific or non-specific legislation/policy, what already exists within a country to support and protect children and families and again the agency of children. Moreover, a whole family approach could support a preventative approach, something which was also highlighted as being important by experts. However, what is the most effective way to achieve a preventative or early intervention approach? Would prevention logically stem most effectively from legislation and policy that protects young people and families universally? And is reliance on child protection legislation preventative enough? On the other hand, would non-AYC-specific legislation risk AYC's as a group being excluded from and from benefitting from particular legislation?

The importance of recognition and awareness by professionals of children with caring responsibilities and their roles and the impacts on them, was consistently raised by experts. However, how are children reached who are not linked to professionals? And does this question infer that non-specific legislation might be the better approach to supporting children with caring roles and ensuring a preventative approach? If so, how should non-specific legislation be amended and/or extended to ensure that a preventative approach is working in practice?

Whether AYC specific legislation and policy is needed on a national or on a local level is another point of note which is likely to be dependent on country-specific structures and how health and social care in particular is enacted. The rationale for a national approach would firstly be to bring about consistency in the protection and support for all young people with caring responsibilities as well as consistency of support if and when AYC's move across regional or local boundaries or are educated in a different area to where they live.

And one final question that has emerged is whether soft laws and the commitment of professionals work better than enforcement through legislation and regulation? There is of course not the scope in this report to answer such a major question, however in relation to the protection and support of AYC's, several factors would likely be relevant. For there to be commitment in the first place, it is necessary for professionals to be aware of and recognise that children and young people do take on caring roles and that this can result in negative impacts. Secondly, for their commitment to be effective, professionals must know how to effectively support AYC's. Thirdly, commitment sometimes is insufficient. For commitment to be actioned, professionals require adequate capacity and the necessary resources. Where one or more of these factors are missing, then that is perhaps the role that specific legislation and policy should play.

## 15. Conclusions

England, Wales, Scotland and Northern Ireland were the only countries found to have specific reference or specific recognition of children's caring roles within their legislation. In Sweden however legislation did specifically target children with parents who were ill, disabled or addicted to alcohol or other addictive agents, or unexpectedly die. In the other European countries, recognition of the needs of children with caring responsibilities and support for them and their families is reliant upon 'non-specific legislation' related to education; health and social care; children, youth and families; carers in general and in particular child safeguarding and child protection. How legislation was found to translate into practice varied and depended upon a variety of factors including whether legislation was supported by guidelines and regulations. Soft laws were also assessed as being useful, as they are based on commitment and not enforced by legislation. In countries with no specific young carer legislation, other approaches and legislative provisions were identified as being important for protecting and supporting AYC's. The omission of AYC's in current legal provisions could be counterbalanced by a solid legal system with significant protection and support for children with caring responsibilities.

Policy and service frameworks specifically targeting AYC's were reported in Switzerland, England, Scotland and Northern Ireland, whilst the existence of non-specific policy and service frameworks in the majority of countries was reported. As with the legislation, various factors were found to impact on how policy and service frameworks were enacted, including the development of guidelines, indicators, collaboration and sufficient financial support.

The reality is that although governments across the six European countries have responsibilities, and even with a well-developed legal structure in some of the countries, AYC's still fall through the gaps in policy and legal safety nets, and between adult and children's services. In practice there is some distance between the legal foundation and the actual implementation of the law. Firstly, legal frameworks are complex and vary from one country to another, with an abundance of regulations and guidance for each country. Many professionals are not aware of the specific legal requirements and responsibilities placed upon them to identify and support AYC's (and their families in some cases). Secondly, there is a gap between the ambition and purpose of the law – to identify, recognise, assess and support AYC's – and the actual implementation on the ground by professional groups (including social workers, health and medical professionals, teachers and so on). Thirdly, 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.

We have shown that there is a range of different responses to the issue of AYC's across different countries. This varies from support for these young people in policy and legislation through to a total lack of recognition and support. The question therefore arises: what drives policy and legal change? What are the causative factors? Experts from different

countries talked about the importance of whole family perspectives as well as the need for the increased participation of AYC's themselves and a view of children as partners, with regard to their own situation and policymaking in general. The situation for AYC's is heavily dependent on social and political conditions and changes. In countries where legislation for AYC's is the most developed, 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 AYC's 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. Another key factor that was highlighted was collaboration. A good relationship between the voluntary sector and the government is as important as the inclusion of regional stakeholders.

The potential to extend existing legislation, policy and service frameworks to include AYC's was emphasised, as well as the importance of recognising and raising awareness about the role and difficulties experienced by young people with caring responsibilities. Awareness should be raised at all levels of society for example with professionals in the health, social and education sectors and with the general public. A definition for young carers is needed, so that AYC's can identify themselves. AYC's should also be recognised as an important target group for policy makers. Therefore a multi-faceted approach involving different stakeholders is needed, e.g. different ministries, the education sector and NGOs. AYC's should be involved as well, in order to improve understanding of their situation and to gather their ideas for improving support. Additionally, research should play a role by explicitly including policymakers and AYC's. Policymakers may prefer to have a home-grown research evidence base to inform their local and national decisions rather than drawing or relying on research from other countries, even when research findings are likely to be similar.

The findings from WP2 fill an important international research gap. For the first time there is a transnational analysis of legal structures, policies and service frameworks for younger carers and the 'gap' between legal provision and actual implementation. This enables us to develop evidence-based policy and practice responses to the needs of AYC's and their families, aimed specifically at promoting the development, education, health, well-being, future employability and life chances of AYC's in all European countries and worldwide.

The importance of cross-national studies cannot be overstated. Conducting transnational research on legislation, policy and service frameworks relating to AYC's enables us to identify benchmarks and the strengths and limitations of different systems. This will be particularly helpful for those countries where the legal structures, policy and service frameworks are only just emerging or are non-existent.

## 16. References

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## 14.2 Materials (Laws, Regulations)

in alphabetical order

### Italy

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Last but not least, we would like to thank the European Commission for its financial support of the project.

## Annexes

### *Annex 1: List of experts interviewed*

#### Italy

	<b>Name</b>	<b>Gender</b>	<b>Organisation/role</b>	<b>Date of interview</b>
1	Raffaele Focaroli	M	Juvenile Court – Rome (Honorary Judge)	02/05/2018
2	Alfredo Ferrante	M	Department of family policies; Italian Presidency of the Council of Ministers/Official - Coordinator for the promotion of services for the family, international and community relations	28/05/2018
3	Loredana Ligabue	F	Anziani e non solo & Associazione Carer/Responsible of the Care Area of Anziani e non solo & Secretary of Associazione Carer	02/07/2018
4	Benedetta Piola Caselli	F	Lawyer – Expert of rights of children	03/07/2018

#### Netherlands

	<b>Name</b>	<b>Gender</b>	<b>Organisation/role</b>	<b>Date of interview</b>
1	Prof. dr. M. Kalverboer	F	Kinderombudsman, part of the institute of the National Ombudsman/ Ombudsman for Children	09/05/2018
2	Dr. A.M.N. Huyghen	F	University of Groningen/ assistant professor	21/06/2018
	Dr. J. Knot-Dickscheit	F	University of Groningen/ Associate professor	21/06/2018
3	Drs. A. van Dijken	F	JetAlert/ Brussenboek/Journalist / expert on young carers	26/06/2018
4	Prof. mr. drs. M.R. Bruning	F	Leiden Law School / Leiden University/Professor of Children and the Law	12/07/2018

## Slovenia

	Name	Gender	Organisation/role	Date of interview
1	Tomaž Deželan	M	Faculty of Social Sciences, University of Ljubljana/Professor in political science	11/05/2018
2	Barbara Zupan	F	Office for Youth (under Ministry of Education and Sport)/Counsellor	13/06/2018
3	Ružica Boškić	F	Ministry of Labour, Family, Social Affairs and Equal Opportunities/Secretary, Member of the Ad hoc Committee for the Rights of the Child; member of the Expert group on the rights of the child on EC, DG Just	24/07/2018
4	Davor Dominkuš	M	Ministry of Labour, Family, Social Affairs and Equal Opportunities/Advisor	21/08/2018

## Sweden

	Name	Gender	Organisation/role	Date of interview
1	Pernilla Leviner	F	University of Stockholm, Law department/Associate Professor	08/06/2018
2	Merike Hansson	F	National Board of Health and wellbeing/Program officer Children as next of kin	07/08/2018
3	Annika Remaeus	F	Ministry of Social Affairs	09/08/2018
4	Elisabet Näsman	F	University of Uppsala/Senior professor in Sociology	07/09/2018

## Switzerland

	Name	Gender	Organisation/role	Date of interview
1	Sandra Stössel	F	Fachstelle Kinder-, Jugend- und Familienfragen, Amt für Jugend und Berufsberatung, BID Kanton Zürich	06/06/2018
2	Regula Ricka	F	Federal Office of Public Health	07/08/2018
3	Margot Michel	F	University of Zurich/Law	10/08/2018

			Professor	
	Claudio Ludwig	M	University of Zurich/Assistant	10/08/2018
4	Annie Oulevey-Bachmann	F	Institute of Health, University of Lausanne	18/09/2018

## UK

	<b>Name</b>	<b>Gender</b>	<b>Organisation/role</b>	<b>Date of interview</b>
1	Luke Clements	M	University of Leeds	02/05/2018
2	Jo Aldridge	F	Professor, Director and co-founder of the Young Carers; Research Group (YCRG) at Loughborough	15/06/2018
3	Helen Leadbitter	F	Operational Manager for the Include Project, The Children's Society	12/06/2018
4	Maurice Leeson	M	Chair of Children and Young People's Strategic Partnership (Northern Ireland)	23/07/2018
5	Louise Morgan	F	Director of Carers Trust Scotland and Northern Ireland	27/07/2018

## *Annex 2: List of YACs and former YCs providing feedback*

### **Italy**

	<b>Name</b>	<b>AYC/YAC/Formal YC</b>
1	Stefania	Former young carer

### **Netherlands**

	<b>Name</b>	<b>AYC/YAC/Formal YC</b>
1	Nynke	YAC
2	Loïs Naomi	YAC

### **Slovenia**

	<b>Name</b>	<b>AYC/YAC/Formal YC</b>
1	Matic	Former young carer
2	Gizela	Former young carer

### **Sweden**

	<b>Name</b>	<b>AYC/YAC/Formal YC</b>
1	Jessica	Former young carer
2	Susanna	To be added

### **Switzerland**

	<b>Name</b>	<b>AYC/YAC/Formal YC</b>
1	Anika	YAC

### **UK**

	<b>Name</b>	<b>AYC/YAC/Formal YC</b>
1	Amy	Former young carer

### *Annex 3: Consent form*

I have read and understood the information about the content of the expert interview – this includes the main topics for the interview that were sent to me beforehand, as well as the information letter.

I understand that I will be recognised as an expert in the report, but that anything I say will not be linked to my name.

On this basis, I consent to take part in the study and I give my consent for material from my contribution being used for the purposes of the report, research and publication.

I understand that I can withdraw from the research at any stage.

I also understand that all my contributions (including the audio file) will be stored in a locked filing cabinet, and ten years after the project is completed, these will be shredded and the audio files deleted.

Name of Interviewer: \_\_\_\_\_ Organisation: \_\_\_\_\_

Your name: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

#### *Annex 4: Feedback form for experts and country partners*

<b>Case study sections</b>	<b>Feedback or additions from experts</b>	<b>Comments country partner</b>
Specific legislation		
Non-specific legislation		
Enactment of legislation		
Changes in legislation		
Specific policy and service frameworks		
Non-specific policy and service frameworks		
Enactment of policy and service frameworks		
Changes in policy and service frameworks		
Recognition of young carers		

Key strengths		
Key limitations		
Evaluation of the current situation		
Attitudes to existing policy responses		
Suggested changes		
Future goals and hopes		

## Annex 5: Feedback form for AYCs



Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe: ME-We project



Hi **XY** (put in AYCs name),

Thank you very much for supporting our research. In our work package we would like to know more about how the legal provisions and policy framework work in practice and what your goals and hopes for the future with regard to the provisions are.

We are looking very much forward to your feedback.

In case you wish for your names to be credited on the final report please let us know ([youngcarers@careum.ch](mailto:youngcarers@careum.ch)).

Best wishes,

Team Young Carers, Careum Research, Kalaidos University of Applied Sciences

### Provisions for young carers: Future goals and hopes

Experts were asked about their goals or hopes for the future with regards to the development of legislation, policy and/or service frameworks for young carers.

#### The future goals and hopes of experts

- 1) [Text]
- 2) [Text]
- 3) [Text]
- 4) ...

Do you agree or disagree with any of these goals and hopes for the future?

In your opinion, which are most important?

Do you have any different goals or hopes for the future?

### How legal provisions and policy frameworks work in practice

From your experience, please comment on what the experts said about how legal provisions and policy frameworks work in practice in [country].

For example, you may wish to comment on:

- The accuracy of the statements
- Whether the statements reflect reality
- How useful these provisions are

Please feel free to give brief examples from your own experience to back up your responses.

You do not need to write a comment about every piece of legislation – only when you have something to contribute.

<b>Specific legislation</b>	<div>[Text]</div> <div></div>
<b>Non-specific legislation</b>  National level	<div>[Text]</div> <div></div> <div>[Text]</div> <div></div> <div>[Text]</div> <div></div>
<b>Non-specific legislation</b>  Regional level	<div>[Text]</div> <div></div>
<b>Specific policy and service frameworks</b>  Local level	<div>[Text]</div> <div></div>
<b>Non-specific policy and service frameworks</b>  Regional level	<div>[Text]</div> <div></div>
<b>Non-specific policy and</b>	<div>[Text]</div>





More information: [www.me-we.eu](http://www.me-we.eu)  
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