

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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ME-WE



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Foreword

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. 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 and/or persons closely associated with them. 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.

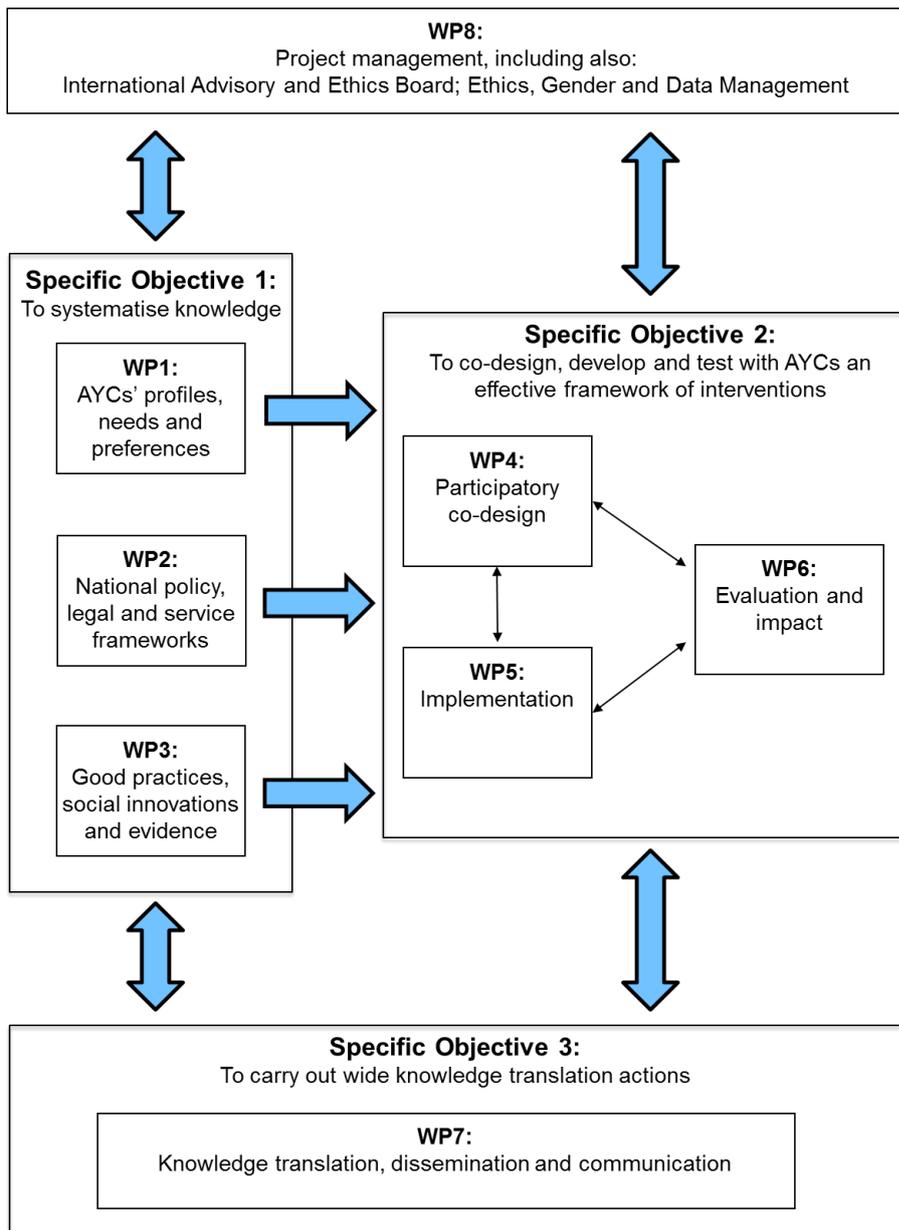


Figure 1: PERT chart of interrelations between work packages

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 AYC's 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 WP2 deliverable reports on 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 6AYCs, experts and country partners.

The deliverable for WP3 is presented in this report and provides 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 AYC's. 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 Eurocarers¹ 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), Capri 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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¹ Eurocarers is a European Association working for and with informal carers, consisting of 67 carer and research organisations in Europe

Executive Summary

This deliverable presents the results from three activities to provide an in-depth systematic overview of successful strategies to improve Young Carers (YCs') mental health and well-being. The results form a base for a consolidated strategy and theory for the ME-WE intervention and app to be further developed in WP4. A Delphi study gathered insights into the visibility, awareness, interventions and future needs of YCs in six European countries and on an international level. In addition, a systematic literature review, a general literature review, and social media analyses were carried out. Following these tasks, a rating, ranking and consolidation task was performed to iteratively build a dynamic ranked high impact list with national and international strategies and programmes that can serve as exemplars for the ME-WE intervention.

In total, sixty-six experts participated in the ME-WE Delphi study, from 10 different EU countries. The experts were people working on the topic of YCs or related topics (e.g., child rights) in the field of academia, policy, education, and care. The main goal of the Delphi study was to gain insights into the visibility and awareness raising of (A)YCs² on a local, regional, and national level; current strategies, interventions and/or programmes to identify support (A)YCs (pros & cons) and finally, future needs to support the mental health and well-being of (A)YCs. In the second Delphi round, the experts commented on the summaries from the first round, consisting of a general overview of the results, country specific results, and an in-depth overview of the country results of the experts.

From the Delphi results it became apparent that there is a lack of visibility and awareness about YCs at all levels in all countries. Visibility and awareness seems to be highest in the UK and Sweden. Visibility and awareness are increasing. Identification, visibility, and awareness implicitly mean recognising YCs as an issue, which could contrast with the idea of a family where it is viewed as natural for family members to help and support one another. Most experts agreed that we should consider the needs of young carers and that YCs themselves might not want attention whenever we target this group by creating visibility. Experts mentioned that there are differences in the level of awareness on the topic of young carers in organizations such as schools, welfare organizations and social services and there is a need for integrated care. Television programs and social network campaigns are considered as good ways for improving awareness. To identify YCs, we first need a shared/common definition of YCs across the world, which is crucial for identifying them. In the UK, it is quite unique that there is already a carers assessment. However, it is crucial to have a follow-up, and such actual help is deemed to be problematic in the UK due to a lack of adequate funding.

The Delphi results further showed that overall, to support YCs, many interventions are running on a local level in the various EU countries, a variety of which are described in this deliverable. In respect to welfare, interventions should focus on the provision of information by e.g., information flyers, children's' helplines or a national information campaign. Most experts suggested activities in which YCs could relax and get a break from their care responsibilities to promote their individual development and get in contact with peers. Multiple experts expressed their preferences for providing online support by means of sites or mobile applications. Furthermore, a considerable number of experts expressed the need for

² (A)YCs, and YCs are used throughout the Deliverable, i.e. (Adolescent) Young Carers

YC specific laws and regulations to formalize the rights of YCs on a national or European level. However, other experts expressed that the rights of YCs are already covered in existing (non YC specific) legislations or could be included in existing legislations. Professionals need to be educated about YCs, about their situation and what professionals can do to support them. Creating flexibility for children/students at school is essential, e.g., by means of a carers' ID. There seemed to be some disparity in views about the need for economic support and/or funding needed across the various countries. Experts stressed the need for integration of the different sectors related to YCs (educational, health, social) to build up flexible and family-based interventions, tailored to YCs' needs and age. Overall, culture and values define people's expectations and opinions in respect to children providing care, which is particularly relevant in the case of migrant YCs. Many experts agreed that the programmes should be designed with and for YCs, i.e. in co-creation. Experts expressed the need for an EU or world young carers organization and the NGO can – among other activities - disseminate knowledge and coach teachers/people at schools. The existing Eurocarers Young Carers Working Group - which is actively running - could further take up this role and become more visible across Europe. Other important tasks to support YCs are to gather an insight into actual numbers, identification support and tools, raising awareness, arranging support at schools, further strengthening the whole family approach, and ensure screening at for example primary health care settings.

The academic literature review showed that the topic of YCs is a relatively small and young research field. From the database searches, 201 studies focused on YCs. Most of these studies were describing cases of YCs and what the risks are of being a YC for their own mental health and development. In the current study, 15 papers were included, as these studies evaluated an intervention or a support program for YCs. At least three of the studies (in)directly built on resilience theory and how to strengthen resilience among YCs (Richardson, Jinks & Roberts, 2009; Cunningham, Shochet, Smith & Wurfl, 2016; Fraser & Pakenham, 2008). In addition, two studies focused on developing self-efficacy and reducing stress by means of introducing different coping strategies and expanding the social network (Barrera, Atenafu, Schulte, Nathan, Hancock & Saleh, 2018; Elf, Skarsater and Krevers, 2011).

Most of the studied interventions focused on one particular target group. For instance, YCs with a parent with a mental health problem, or a YC who is a sibling of a child with special needs. It is known that YCs like to have contact with other YCs, preferably with the same age category. But whether they like to come in touch with the YCs with the same illness in the family is unknown. Several issues within the literature need to be taken into consideration for a successful implementation of the ME-WE intervention and mobile application. First, awareness must be raised, and the stigma must be reduced. YCs do not recognize themselves as YCs and are not looking for help or support. Also, family members tend to protect one another because they are afraid to be split up as a family when professionals see what is going on in the family. Health care professionals, school teachers and social workers can play an active role in identifying YCs, reducing the stigma by means of classes on YCs and supporting the whole family. When this first step has been taken the intervention has a higher chance of being successful.

The intervention itself should have a component of peer-support. A prerequisite is that the ME-WE application is developed in co-creation, otherwise there is a high risk that YCs will not use the app. Also, there should be a form of face-to-face contact as well, YCs want to know with whom they are having contact. In all studies it was evident that YCs have a high feeling of responsibility, they are very mature, so what is important is that they also have the chance to

be a child or adolescent instead of the wise adult. Therefore, peer-support should not only contain psycho-education and training of coping strategies or resilience, but also contain fun activities, offer respite and let YCs think of something else other than the caring situation at home. Besides the focus on peer support, a whole family approach is found to be an important factor in the literature. It makes the life of YCs and the life of parents much easier if the whole family is being supported and not only the YC her/himself.

The general literature review showed that intervention programs, whether they are technological or not, should be aimed at supporting young carers to use adaptive coping strategies instead of maladaptive coping strategies. In addition, it is important to make sure that YCs are in a constant dialogue, either with friends and family and/or professionals. The literature study identified the need for an experienced person – e.g. at school - who gives advice and encouragement to YCs. This person could give both emotional and instrumental support (e.g., respite as desired by young carers themselves). Young carers would greatly benefit from a mentor who gives both emotional and instrumental support, advice, and encouragement. Also, YCs would greatly benefit from recognition and social support from their peers, both fellow YCs and friends.

Finally, YCs should sometimes temporarily be relieved of their caring responsibilities, in order for them to keep their spirits high. A ME-WE YC App should inform young carers, organize and promote events, and connect YCs with each other and with health and social care professionals.

The first social media analysis showed that YouTube, Facebook, Twitter, Instagram, Tumblr, WhatsApp, Snapchat, Pinterest and Google+ are popular social media platforms among young people. Online social media platforms for YCs should inform, organise and connect. However, from the first social media analysis it appears that a lot of social media items are about raising awareness for YCs and promoting events, which included giving information about this topic. For a ME-WE application it is important to focus on the concept of trust and privacy for YCs, because many groups for YCs are private (Facebook and Instagram) and questions are asked anonymously (Tumblr).

Functional requirements for ME-WE include a News/Events page; Asking questions to experts or other YCs; Possibility to create groups or a community; Possibility to share experiences (possibly in blog format); possibility to follow association/organisations/foundations; possibility to befriend other users; information in the form of messages, videos or photos. Non-functional requirements include: the possibility to choose for specific regions/neighbourhood; either anonymity or confidentiality (e.g. nickname); possibility to create either private or public groups based on a subject (e.g. autism, sick mother) or region; confidentiality of an account (e.g. nickname); search other YCs based on location/region or topic (e.g. autism, sick mother); possibility to filter information of a subject (e.g. a specific disorder, sick mother, brother, sister etc.).

The second social media analysis explored the supply of supportive interventions for YCs specifically in the Netherlands. Results showed that most of the support interventions found on regular internet were aimed at providing information to and about YCs and at offering a fun activity. Twitter was mostly used to promote fun activities, such as BBQ's or bowling. Most interventions found were offered offline, e.g., a sports activity. The few online interventions that were found were mostly providing information in a non-interactive way. Interventions aimed at the entire family of youngsters were not found in our online search. Concerning the

use of Twitter, it was found that most messages were posted by professionals. The amount and type of supply of supportive interventions on websites is not the same across municipalities, for some municipalities multiple different types of interventions for youngsters were found, whereas for other municipalities no single support for this group was presented on their website.

The rating & ranking study provided a comprehensive overview and insight into thirty-nine interventions, programmes, and methods to support Young Carers across Europe that were identified from the Delphi studies, literature reviews, social media analyses and Blended Learning Networks (WP4) (see table 1 below). We gathered knowledge as to what extent – according to experts and YCs - the interventions influence several criteria such as the well-being and other psychosocial factors of YCs and the contribution to support strategies for YCs. At least two of the programmes were formally evaluated – according to the academic research study - namely the Crossroads young carers project (Nr. 23) and Bernardo’s Action With Young Carers (AWYC) Project (Nr. 15) (Richardson et al., 2009; Grant et al., 2008).

Table 1: List of 39 interventions with short descriptions³

Nr	Intervention	Description
1	Who Cares?!	Who cares?! Is a programme for schools that asks attention for youngsters who grow up with a (mental)ill, disabled or addicted family member.
2	Ervaringsmaatjes	Ervaringsmaatjes is a buddy project to provide individual support for young carers.
3	Week of the young informal carer	The week of the young informal carer is an annual awareness raising event in The Netherlands held in many municipalities across The Netherlands.
4	Vanzelfsprekend?!	Vanzelfsprekend?! is a platform for recognizing and acknowledging young carers where they can ask questions and being listened to.
5	Superhands	Superhands is a hub and point of contact for children and adolescent who look after sick relatives.
6	Online Young Carer test	This online test is a tool for the recognition of young carers.
7	TV show ‘Jinek’ 2015	During a TV talk show, young carers told about the problems they face.
8	SIJ Twente	SIJ Twente organizes activities and courses for young informal carers in different municipalities in the east of the Netherlands.
9	ACE	ACE can be used to identify young carers. There are ten types of childhood trauma measured in the ACE study.
10	Training for professionals	This is a training for professionals in healthcare, welfare, youthwork and education who work with young people who grow up with an ill family member.
11	Who cares?!	To give young carers easy access to all of the information on the Carers NSW website, they have developed a mobile application called who cares?!
12	Barnkraft	Barnkraft has parallel groups: child group and parent group. The goal of these support groups is to learn about the mental illness or addiction.
13	Beardslee’s family intervention	Beardslee’s family intervention is a family-based approach for the prevention of depressive symptoms among children at risk.
14	Hash zitt (Do you have time?)	Forum for questions and suggestions on different topics such as health, love and friendship, money and housing, parental home, education and jobs and hobbies.
15	Barnadro’s action with young carers	This project focusses on young carers up to the age of 25 and provides - among others - assessments, specialist one-to-one support for each child, and group work.
16	Fora barnen pa tal	Family focused approach in which the professional meets the parent(s) on two occasions and together talk about the children and their situation.
17	Mind Matters	School mental health programme to strengthen the mental health over the life competence over the resource, and then it has in there also most diverse products.”
18	Carers Allowance	Financial benefit offered through the government for those 16 years old and older caring for someone.
19	Kinderseele	This institute offers children and youngsters of a parent with a psychiatric illness support and relief.
20	Talk-Link	Talk-Link is a type of support, provided by Carers NSW in Australia. Talk-Link offers telephone group counselling for young carers for free.
21	Book for COPMI	A miniguide for survival for daughters and sons who live with a mother and/or father with a mental health problem.
22	Young carers/YA carers projects	Non-profit organizations to offer supportive psychosocial activities for young carers and young adults carers, respite activities, and peer support.
23	Crossroads young carers project	The goals of the crossroad project are to offer respite, recreation and peer support.
24	Carers South Australia Young Carer Services Model	Carers South Australia has designed a model focusing on early intervention. The goal of the programme is to strengthen the resilience of young carers.
25	The about time grants programmes	The overall aim of the programme is to provide practical support to young adult carers, helping them to transition positively into adulthood, leading to long-term change.
26	Online Peer Support Group	A safe online private space active 24/7 and run by lived experience volunteers where are allowed to share their difficult situations.
27	Whole family interventions pilot programme	The overall aim is to improve the life chances of the most isolated and vulnerable young carers under the age of 24 across the UK
28	Progetto Giovani Caregiver	The ‘Young carers Project’ is the umbrella project that includes all activities offered by ANS to support young carers.
29	Young Carers in School Programme	An England-based initiative to help schools better support young carers and awards good practice by means of face to face contact and online resources.
30	Express yourself	Workshop for adolescent young carers aimed to help them express their emotions through artistic means, such as photos and video-production.
31	Regional relaxing weekend breaks	Relaxation activities, contact with peers, a breathing space, combination of informal and relaxing, realize that you are not alone, being able to speak.
32	YoungSibs	YoungSibs is a website and support service for children and young people who have a brother or sister who is disabled.
33	BRA-Samtal	BRA-samtal is a model for talking with children as next of kins.
34	Pro Mente Sana Schulprojekt	It is a school programme about mental health issues discussed by a professional; a carer and someone experiencing MH issues.
35	Young Carers Festivals	Often run throughout the country, the longest running young carers festival takes place in Southern England through the Children’s society.
36	Edinburgh Young Carers Project Forum	The forum is the main way that Edinburgh Young Carers Project consults young people about their views and encourages them to become involved with the project.
37	Psychoeducational Programme for Siblings	This is a psycho-educational programme targeting adolescents/young adults who are siblings of a person with a disability.
38	NHS Young Carer Health Champion Programme	The Young Carers Health Champion programme was established in 2015 to support - among others - improved health literacy, promote health and well-being.
39	Our Time Foundation	Non-profit organization that works to - among others - identify and provide explanation-based interventions to children affected by parental mental illness.

For the ME-WE intervention, governmental body or NGOs, to support YCs on as many criteria possible, it is advised to draw on the experiences of the Barnardo’s Action With Young Carers

³ For more elaborate descriptions, see table X in chapter 3 on rating and ranking study.

(AWYC) project in Liverpool, the Italian progetto Giovani Caregiver of ANS (Young Carers Project) with various programs and the Dutch Vanzelfsprekend project, a platform for recognizing and acknowledging carers. Other overall high scoring projects are the Carers Projects, Carers SA, Crossroads, Ervaringsmaatjes, Express yourself, Our time, Psycho education, The about time, Weekend break, Who Cares?!, YC in school, and YCs festivals.

Overall, all interventions are mature enough to be applied, and nearly all are open with little costs except for the YCs festivals. It is interesting to note - and supported by the Delphi studies described in chapter 1 - that a relatively low number of interventions seem to have been developed in co-creation with YCs (according to the raters). E peer-support, Jinek (TV show), and Vanzelfsprekend scored highest on co-creation. Nearly all interventions have a low risk for adverse outcomes and are applicable in other countries than their origin.

The influence on mental health and well-being is highest for Crossroads, Ervaringsmaatjes, Weekend break for respite and the Whole family approach, the latter also being discussed in the Delphi as an essential and relevant approach to successfully support YCs and the family. The relationship with the parents is most - according to the raters - influenced by Beardslees, Föra barnen, and Weekend break, followed by AWYC and Whole family. To support the social life of YC and also to possibly increase social connectedness among YCs, it is advised to look into the SIZ Twente approach, Ervaringsmaatjes, Vanzelfsprekend and the YCs festivals in the UK and to organize group sessions; look into Crossroads, Pscho education, and SIZ Twente.

For schools to support YCs in education, progetto Giovani Caregiver, Who Cares?! and YC in school are relevant candidates to explore. To support caring activities, AWYC, Barnkraft and Whole family score highest and in respect to the interventions' influence on positive impact of care giving (e.g., fulfilment), AWYC, Ervaringsmaatjes, and SIZ Twente scored highest. Progetto Giovani, SIZ Twente, and Whole family scored highest on an influence on the negative impact of caregiving.

Supporting and building resilience is a main focus in ME-WE and Ervaringsmaatjes, Pscho education, and SIZ Twente scored highest (mean) in building resilience. Before you can build resilience, it is essential - as reported in the Delphi studies - to first identify YCs, which is - according to the raters - to a great extent possible by Who Cares?!, YC in school, and the Young Carer Test. Identification is important, just as raising awareness on the topic, which can be supported by TV shows such as Jinek in The Netherlands, a (national regional) Week vd JMZ (week of young carers), and programmes such as Who Cares?!

The extent to which the interventions, programmes, and methods contribute to policy making or legislation is difficult to conclude, except for awareness programmes such as TV shows and festivals with a relatively high potential impact on society. To facilitate informal respite care to some extent, Carers SA, SIZ Twente, and Vanzelfsprekend scored highest and to contribute to informal care AWYC, Carers SA, and Föra barnen scored highest.

For ME-WE it is essential that an intervention and/or supportive information can also be translated to a digital platform. Online platforms or mobile applications were also reported by the Delphi experts as suitable media carriers for YCs. In ME-WE it is advised to investigate the existing online applications such as the Superhands website, the Who Cares App, and the Young Carer Test. From a usability perspective it was advised to, 'do as everybody else does'. Other programmes that - according to the experts - are relatively suitable to transfer to an online app for Young Carers are E peer-support, Häscht Zitt?, Vanzelfsprekend and YoungSibs.

From the activities in WP3 we can provide a consolidated strategy and theory (see also Chapter 7) with requirements for an (online) intervention or support app. For ME-WE, an approach that brings about mutually beneficial forms of provision for multiple parties involved, including a more family centered approach, should be strived for. The intervention and app should support young carers building trustworthy relationships and being in a constant dialogue, either with friends and family and/or professionals, which is also important to prevent loneliness and enhance coping. For the intervention, The Resourceful Adolescent Program (RAP-A) could be adapted and used to build resilience by aiming to promote positive mental health and prevent adolescent depression. The ME-WE app could provide (indirect) access to professionals or people who have been YCs themselves, who can provide both instrumental support (advice) and emotional support and encouragement to young carers. The ME-WE intervention should rather support respite, just as the RAP-A resilience building camp, and the ME-WE app could promote and share activities for respite such as summer camps or YC festivals to provide a temporary relief from caring responsibilities.

Overall, the ME-WE app should support identification and recognition (e.g., via a YC assessment); provide and create a strong group identity and provide the possibility to create groups yourself; support social interactions via chat and/or localisation features (which could imply just a link to WhatsApp or other communication apps) and promote actual offline contacts; facilitate sharing experiences with other YCs; inform YCs about national and local events, interventions and activities targeting YCs (news & events); provide (indirect) access to professionals.

For interface and interaction design for the ME-WE app, it is important to learn from popular social media platforms such as Tumblr and ensure privacy and anonymous communication to enhance trust among members; target all YCs including migrants; support fun activities; and overall the app should be meaningful and beautiful.

List of acronyms

ACE	Adverse Childhood Experiences
App	Application
AWYC	Action With Young Carers
(A)YC	Adolescent Young Carer
CATI	Computer assisted Telephone Interviewing
CH	Switzerland
COPMI	Children Of Parents with Mental Illness
DOA	Description Of Action
E(Number)	Participant number
EU	European Union
GP	General Practitioner (primary health care physician)
ICT	Information and Communication Technology
IT	Italy
JMZ	Jonge MantelZorgers (Young Carers in Dutch)
Mage	Mean age
MOS	Mean Opinion Scale
N or n	Number
NGO	Non Governmental Organization
NSW	New South Wales
P(Number)	Participant number
R(Number)	Delphi Round
SCP	The Netherlands Institute for Social Research
SD	Standard Deviation
SE	Sweden
SE	Standard Error
SiS	The National Board of Institutional Care (Sweden)
UK	United Kingdom
WP	Work Package
YC	Young Carer
YIC	Young Informal Carer

1. Introduction

Background

In families in which one of the family members has a physical or mental health problem, children or adolescents are often involved in caregiving roles (Pakenham & Cox, 2014). They have a certain level of responsibility and carry out significant or substantial caring tasks that would usually be associated with adults (Leu & Becker, 2017). Among others; administrative, or household tasks, personal or nursing care or providing company to an ill family member (De Roos, De Boer, & Bot, 2016). 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). Besides these caring tasks, YCs often worry about their family member. So, it is not only the practical, visible tasks YCs are engaged with, but also the worries in their head and in their hearts (Klinkenberg, 2016).

Being an adolescent YC (AYC), is particularly recognized as a risk factor for mental health and well-being, with 50% experiencing care-related stress and 40% experiencing mental health problems (Carers Trust, 2016). Also, being an (A)YC increases health inequalities during the life-course (Aldridge & Becker, 2003; Becker & Leu, 2014; Cree, 2003). It is known that (A)YCs often experience the consequences of social exclusion, with higher absenteeism and drop-out rates from education and lower employability than their peers without an ill family member (Aldridge & Becker 1993; Becker & Leu, 2014; Hamilton & Adamson, 2013).

The number of recognised (A)YCs is relatively low, but varies per country and region (Leu & Becker, 2017). Hence young carers need to be supported and recognized, in order to positively influencing their well-being and mental health. A promising way to facilitate this could be the use of technology, such as online supporting groups or gamified apps, that could support the young carers and strengthen their resilience as they transition to adulthood (Ali, Krevers, Sjostrom, & Skarsater, 2014; Elf et al., 2011). However, since little is known about young carers and the way they are being supported, it is important to gather insights in the current support programs and supporting applications.

Goal of ME-WE project and Workpackage 3

The overall goal of the ME-WE project is to strengthen the resilience of (A)YCs 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. As mentioned in the forword, the ME-WE project contains of 8 work packages (WPs). This current deliverable reports on the work of WP3. The goal of WP3 is to provide a systematic overview of succesful strategies to improve (A)YCs' mental health and well-being.

Structure of report

This deliverable presents the results from three activities to provide an in-depth systematic overview of successful strategies to improve YCs' mental health and well-being. The results of the three activities provide the foundation for a consolidated strategy and theory for the ME-WE intervention and app. In chapter 2, we describe a Delphi study which gathered insights into the visibility, awareness, interventions and future needs of YCs in six European countries and on an international level. Chapter 3 provides results from a systematic literature review

of all academic evaluations of interventions and good practices for YCs. Next, chapter 4 continues with a general literature review, combined with social media analyses. Finally, in chapter 5, the results of the activities are combined and lead to the rating, ranking and consolidation exercise. This task was performed to iteratively build a dynamic ranked high impact list with national and international strategies and programmes.

Yes, we just really ask those children what they want [...] we can make it up ourselves, but if we start doing things they don't like, then there is no point. (P7, R1, NL)

Above all, the European project allows to identify and share best practices among the various countries. This is essential." (E2, R2, IT)

...with such a delphi study, and I find that very important. I think on the level of getting money for research or even offers it is important that you can also empirically prove what you want to do, why you want to change something. And I think that's good. (E5, R2, CH,)

"Making young carers visible is one point which could be done in the whole Europe. I think this is the most important point which relates to all other points like support." (P5, R2, Germany)

I absolutely agree that the programmes should be designed in cooperation with them (YC), so we would be able to really originate from their needs (P7, R2, Slovenia).

"On a global level [...] more Delphi studies [...] international conferences on... about young carers. Because you need ... you need to read about it, you need to meet others about it, you need to find forums to find common terms and also, yes, to share experiences [...] Something happens when you participate in a study and when you consider other's results" (E3_R2_SE).

I think we need to address this topic despite not having funding for it. (...) Because we are a country that has many/extreme 'financial' resources (E3, R2, CH)

"There should be less inequalities within and between countries." (E8_R2_SE).

"I think that [whether programs have actual benefit] probably seems to be the case anecdotally but we don't actually know for sure. I think there has been very little research on this.. I mean, certainly talking to young carers and practitioners seems to be the case but we don't know systematically if it is". (P3, R2, UK)

"...by using the child's right framework, you can talk about whether [care by children] is violating a child's right. The child's right to their own care and protection, the child's right to education, the child's right to play, the child's right to be heard, for their best interest to be a primary consideration." (P4, R2, Ireland)

2. Delphi study on successful strategies

2.1 Introduction

In this chapter we present the Delphi study performed in six European countries and on an EU level. A Delphi study is named after the oracle of Delphi and was originated between 1950 and 1960 by Olaf Helmer and Norma Dalkey to gather opinions of multiple experts within in a new field of study with relatively little consensus⁴. The Delphi method is an acknowledged method to gather consensus of opinion and choice about a topic⁵. Within a Delphi study, interviews are performed to structure information and ask iterative feedback in multiple rounds. It is vital that all information is anonymous, and this is a major difference of a Delphi study compared to focus group rounds. Interactive forecasting is key based on previous rounds. In the ME-WE Delphi study we organized two rounds (see Figure 2 below for a schematic overview of Delphi rounds).

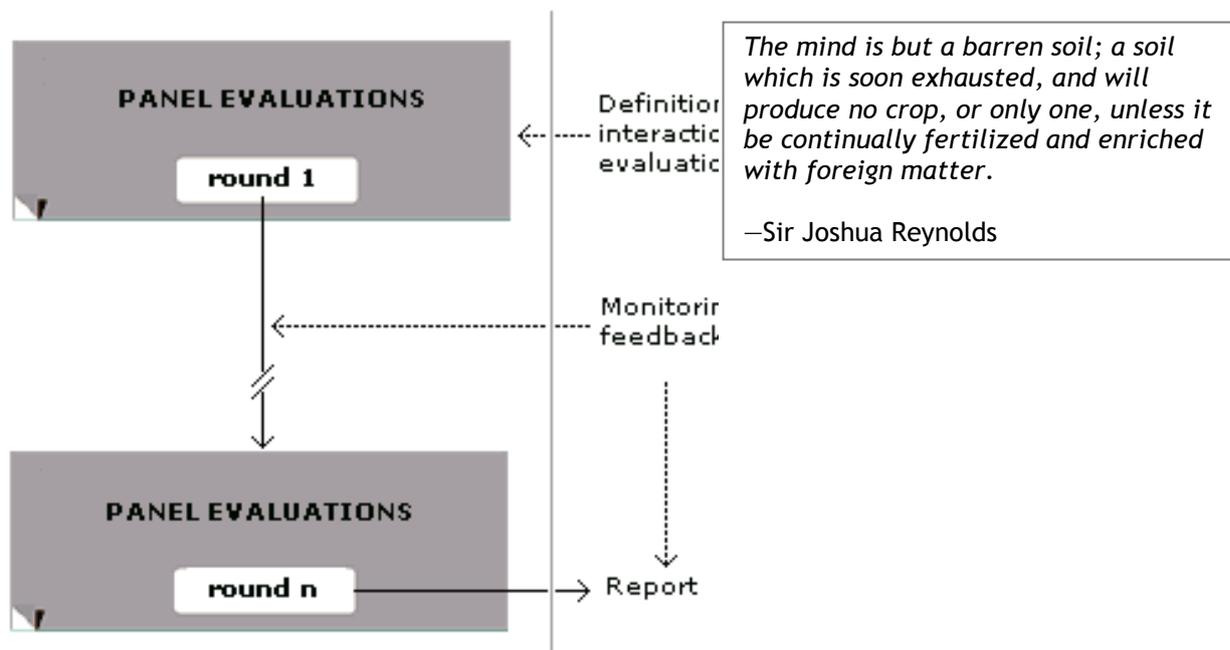


Figure 2 Schematic overview of the Delphi rounds (Dalkey & Helmer, 1963; Ryan et al., 2001).

⁴ N. Dalkey and O. Helmer, "An Experimental Application of the Delphi Method to the Use of Experts," *Management Science* 9, No. 3 (April 1963), p. 458.

⁵ Ryan M, Scott DA, Reeves C, Bate A, van Teijlingen ER, Russell EM, et al. Eliciting public preferences for healthcare: a systematic review of techniques. *Health Technol Assess.* 2001; 5(5):1-186. PMID: 11262422.

2.2 Method

Vilans and the other consortium partners identified the target groups for the Delphi study. The Delphi study was carried out by the consortium partners with a total of 66 experts from 6 countries and on an International/European level. We also invited experts from other countries than the participating countries, to gain a clearer picture of YCs across Europe and beyond, in particular, not to miss relevant interventions or theory. The experts were leading people from academia, policy, industry, and end-user organisations, including people identified in WP2. Furthermore, a number of experts already provided their intent to participate in the Delphi study (see letters attached to ME-WE DOA).

Two rounds were organized; round 1 to gather an insight into experiences of the target group in respect to the topic of interest and to gain knowledge about the barriers and drivers of existing strategies and programmes (if available) to improve (A)YCs' mental health and well-being; round 2 to gather an insight into optimizing programmes and developing future scenarios to optimally support young carers. Per round, experts were interviewed for approximately 1 hour. The questions were semi-structured to be able to compare the results across experts, regions and nationalities, and also to ensure flexibility for individual input. The Delphi study used – where available - relevant insights from the online survey study in WP1 and results from WP2 on national policy, legal and service frameworks. The themes and strategies gathered from both rounds are combined and reported in this chapter⁶.

For the project and also WP3 we defined **Young Carers (YCs)** as “young carers' are children who provide care for another person (normally for other family members). They often assume significant responsibility for care on a regular basis. This responsibility is something normally associated with adults (Becker, 2000). The person needing care is usually a parent. However, it may also be a sibling, a grandparent or another relative with a physical, mental or cognitive health issue.” In ME-WE we focus mainly on **Adolescent Young Carers (AYCs)**, who are aged between 15-17 years.

Since it might be difficult (if not impossible) for the participants in WP3 to focus solely on the age range 15-17 years, we rather considered children who go to secondary school / high school, however examples on interventions for (A)YCs aged 8-12 are also relevant to ME-WE. As an interviewer it was feasible to have the flexibility to widen the age range for gaining necessary insights (the individual interviews in the Delphi study are semi-structured).

In the ME-WE project there are three groups* of countries; **1. UK** (at advanced level, with systematic policies and responses), **2. The Netherlands, Sweden and Switzerland** (at different degrees of development level), and **3. Italy and Slovenia** (at an initial stage of awareness). The procedure for the Delphi study varied to a certain extent between these groups of countries, in particular between the first-second group, and the third group (Italy & Slovenia). Research and policy on (A)YCs in Italy and Slovenia is still premature, therefore it was sufficient for the experts to have a professional or academic interest in caregiving, young people, or Long-Term Care. The questions were altered to these topics. Furthermore, in **Sweden** there was an initial focus on **'children as next of kin'**, then within this broader group of children, the experts were all asked questions about young carers.

⁶ The in-depth Delphi procedures, questionnaires and scripts are available via https://www.dropbox.com/s/hez5dzmce25csye/Appendices_D3.1.docx?dl=0

2.2.1 Participants

In total, 66 participants, i.e. 'experts' (49 female) participated in the ME-WE Delphi study, of which 10 in both rounds in Italy (8 female), 10 in The Netherlands in Round 1 (8 female) and 9 in Round 2 (7 female), 9 in Slovenia (2 female), 10 in both rounds in Sweden (9 female), 10 in both rounds in Switzerland (4 female, 4 male & 2 missing), 11 in both rounds in the United Kingdom (8 female and 3 male), and 6 in both rounds on an International/European Level (3 female). For the selection of the experts, the researchers from the participating countries identified experts on (A)YCs or related fields (see above) in their country from the field Academia ($n = 3-4$); Policy ($n = 3-4$); Health and/or Social care ($n = 3-4$).

For the International/European expert group, we invited experts from Austria, Germany, Canada, Australia, Belgium, and Ireland. An expert from Austria, Germany, Belgium and Ireland agreed to participate and to increase the group we added two more experts from the UK that did not participate in the UK Delphi study, yet, were highly acknowledged in the research field of (A)YCs. All the experts had been working in the field of (A)YCs (or related fields if not available in country) with an identifiable track-record (e.g., peer-reviewed publications, organization of events/programmes for (A)YCs and/or young adults, development and support of care or social policies; practice: in health, social care or education fields). The eligibility of the experts was cross checked by the national investigator teams. The participants were interviewed by a qualified researcher (MSc or PhD) with multiple years of experience in performing qualitative research.

2.2.2 Material

After the national recruitment period and on a European level, the experts received an invitation for the individual interview by email (see Appendix 1) from the WP3 leader, including a link to an (online or written) questionnaire in the national languages (translations made by national project members) to gather some basic characteristics such as demographics, education level, occupation and experience with the topic of (A)YCs, and an informed consent form (provided by the WP3 leader to the national investigators who translated it from English into their national language) in which consent is asked for their participation and audio recordings of the interview (see Appendix 2). The email also contained a link to an online planning website (e.g., Doodle.com for The Netherlands) on which the experts could note down their availability (pseudonymized) for the first Delphi study round with a unique number (March-April 2018) and second Delphi study round (June).

The individual interviews in both round 1 and 2 were conducted via telephone using a script (see Appendix) and recorded by means of - for example - a voice recorder or a mobile application (e.g., ACR for Android). All individual interviews were transcribed in a text editor and relevant quotes translated to English. All national investigators and the WP3 leader discussed all the preliminary national and international results in May 2018 and the discussion was summarized by the WP3 leader. After this, a code tree with an initial set of broad concepts and a legend was shared with the national investigators by the WP3 leader after the discussion / first Delphi round in April 2018 with sufficient flexibility to share the regional and national themes. This was followed by a thematic analysis on a national level, and the interviews were further labelled and coded by means of - preferably - MAXQDA, NVIVO or ATLAS. After analysis on the national level, then themes with relevant quotes were

sent by the national investigators to the WP3 leader and analysed to gather insight into generic overall themes, but also on cultural or regional specific themes.

2.2.3 Questions

A semi-structured questionnaire was used for the individual interviews with the experts in the six participating countries and on the European level, with an introduction on (A)YCs and (A)YCs. Based on the first academic and grey literature search (see chapter 2), including a search on social media, the following 3 main topics were selected for the open-ended questions in the first Delphi round:

1. visibility and awareness raising of (A)YCs* on a local, regional, and national level;
2. current strategies, interventions and/or programmes to identify support (A)YCs (pros & cons);
3. future needs to support the well-being and health situation of (A)YCs

Whenever there was a lack of personal and public awareness on (A)YCs, then (A)YCs was replaced by young adults in the themes for discussion.

2.2.4 Procedure

First, identified experts received an invitation sheet for participation (see Appendix 1, translated to the national language). As described above at material, after accepting the invitation, the participants received an information sheet (in the national language) with a link to an online questionnaire to collect the participants' characteristics (such as age, level of education, job occupation, years of experience in the field of (A)YCs and/or related fields) and an informed consent form was filled in which stressed that the Delphi study was fully anonymous in respect to data collection and analysis. Information was given about the Delphi procedure in two telephone interview rounds and participants could identify preferred dates for the first and second round of the Delphi study (first round in March-April, 2018; second round in June, 2018) and received a confirmation about the actual dates within one week. Participants received a reminder for the individual telephone interview five days before the date/time. The participant was rung up on the planned date and time and were given a short introduction about the interview and the topic of (A)YCs; this was followed by discussing the three main topics as described above. The interviewer tried to provide at least ten minutes per topic for discussion. The main topics and answers were summarized at the end of the interview, followed by an informal debriefing with the participants. In this informal debriefing, the participants were asked if they had additional questions, thanked and information was given about the second round of the Delphi study.

The first Delphi round took about forty-five minutes per participant and varied per country. The interviews were transcribed and themes were extracted and summarized on a national and international level to be used as input for the second Delphi round. The WP3 leader further analysed the results and shared these with the national investigators. The procedure for the second Delphi round was similar to the first, starting with a reminder for the telephone interview five days before the date/time and a summary of the previous interview, both on a national and international level. After this, the interview focused on the overall summary of the most successful strategies identified to support Young Carers (YCs), and in particular

Adolescent Young Carers (AYCs) across Europe and the future needs by various end-users and stakeholders to support the well-being and health situation of (A)YCs (with flexibility for group 3). The participants could reflect on these findings from the first round and adjust their own views and options to reach consensus, mainly on a national level, yet also with focus on an international level. Again, the interview lasted for forty-five minutes and the participants were asked if they were willing to participate in future studies on (A)YCs.

2.3 Results

In the following sections, summaries are provided of the qualitative data analyses from both rounds of the Delphi interviews per code (themes/topics) with a number of supporting quotes (see Appendix 1 for all the detailed Delphi results with supporting quotes).

We gathered in-depth information on young carers from groups of experts from six EU countries and from experts on an international level. Rich qualitative country and international reports showed the level of visibility and awareness raising, known strategies, interventions and programs to support (A)YCs and future needs to support the well-being and health situation. In this overall findings section and discussion, we first present a narrative synthesis of the overall findings from across all six countries from the first Delphi round, according to the main interview topics of visibility and awareness raising, strategies, interventions and programs to support (A)YCs and future needs to support health/wellbeing. This is followed by overview tables that provide a summary of the core findings per country and at EU/international level. The overall findings from the second Delphi round are presented in narrative form, according to the main interview themes in section 2.4.1 accompanied by discussion to reach consensus on the data.

2.3.1 Narrative Synthesis of Overall Findings from the First Round

Visibility and awareness raising

From the first round it became clear that there is a low visibility of young carers across Europe, including a lack of systematic studies on the subject of young carers. The term young carers is not recognizable in all the countries, which makes identification challenging. Low visibility and awareness is mainly on a national level, so when visibility and awareness is raised then this mainly takes place on a local level. Experts did share that despite a lack of visibility, awareness has slowly been increasing in recent years supported by attention in the media (television/newspapers) on the topic of (A)YCs and activities intended for young carers are initiated. It is relevant to note that there are also differences within countries between regions. Whether formal support is available for (A)YCs or not can depend on regional availability of care. Most care systems across Europe still work in silos with a lack of integrality. This also contributes to difficulties in identifying and reaching young carers because they can fall in between different care or support systems/legislations. There is a key role addressed for GPs/primary health care physicians and teachers (education) in the identification of (A)YCs, for example by a carers assessment (UK).

Strategies, interventions and programs to support (A)YCs

The Delphi studies showed that in most countries there are support programs, projects and activities relevant for young carers. However, these programs do not always target young carers in particular as shared by experts from Italy and Switzerland. The programs differ in their approach by targeting individuals or groups, the duration (once or regularly) and demonstrated effectiveness of the program. The experts shared a variety of strategies, interventions and programs, such as support groups for children/adolescents with a parent or sibling with a disability or illness where (A)YCs are provided with information and realize they are not alone. In addition, there are multiple initiatives in schools to raise awareness on the subject of young carers in school plays, guest lessons or workshops.

Respite care is also important to support (A)YCs with activities in which (A)YCs can relax and detach from their home situations for a while and to get in contact with fellow young carers for peer-support. To follow a whole family approach, support groups for families have been set up in various countries and some programs provide a combination of the above-mentioned programs. Finally, training programs exist for professionals how to identify and support (A)YCs. Within the interventions and programs, it is advised to focus on a number of coping strategies of young carers, such as providing (A)YC ways to try to gain control over the situation. In addition, (A)YCs feel responsible to do what's in their power and might ignore their role as a (A)YC which they find normal and they do not know any better. Furthermore, according to a number of experts in the first round of the Delphi studies (A)YCs do not like to draw attention to themselves (they are not the one in need).

Future needs to support well-being / health situation

The experts in the Delphi study expressed the future needs for (A)YCs in respect to their well-being and health situation. Adults and professionals need to be more trained in identifying young carers, as such that it is known who and where they are, as such that they are seen and possibly be offered with support. Experts shared that we should notice children who are young carers and that we should listen to them (with our eyes and ears). Some experts expressed the need for specific legislation for the group of young carers and that there should rather be less inequality within countries for access to support services. For (A)YCs themselves it is relevant that they have the ability to get in touch with fellow young carers (face to face and/or digital), according to the experts.

Furthermore, schools should rather be more flexible to the group of young carers in respect to school times and deadlines. As reported earlier in respect to existing programs on the whole family approach and integrated care, there is an increasing need to adopt a perspective or approach in which the whole system and family is involved with collaboration between stakeholders from socialcare, healthcare, government, and education. Such an integral approach is needed in which knowledge is shared and disseminated. Experts shared that there is a need to accept the existence of (A)YCs and reduce the stigma of care giving. Whenever support is developed – in digital or non-digital form – then this support should always be developed in co-creation with (A)YCs to fit their needs.

2.3.2 Summary country findings and EU Findings- First Round

For increasing the readability of this WP2 deliverable, we present summaries of the data starting with a table presenting the results from the first Delphi round for the visibility and awareness raising, strategies, interventions and programs to support (A)YCs, and future needs to support (A)YCs' well-being / mental health situation in the United Kingdom, Sweden, Switzerland, Italy, The Netherlands, Slovenia and on an International/European level (see table 1 below). In Appendix 1, all qualitative data analyses can be found from the Delphi studies, supported by quotes.

Table 1: Summary of the Delphi results from the first round per country.

	Visibility and awareness raising	Strategies, interventions and programs to support (A)YCs	Future needs to support well-being / health situation
United Kingdom 	<ul style="list-style-type: none"> - Different abilities/accessibility of formal care for YCs in different regions - On a national level an increase of awareness by television programs 	<ul style="list-style-type: none"> - Current policy is 'The Care Act' and 'The Children and Families Act' (2014) working together to give (A)YCs legal right to a carers assessment on appearance of need - Well known are hundreds of young carer projects across the country (however, severe cuts in funding) - Young Carer Health Champions programme of the NHS - Child and Adolescent Mental Health Service teams (CAMHS) 	<ul style="list-style-type: none"> - Need for general public to know about (A)YCs - Austerity policies have a negative impact on their situation - New legal rights for young carers in Care Act and Children and Families Act have little actual benefit.
Sweden 	<ul style="list-style-type: none"> - Lack of visibility, to very low regarding (A)YCs - Children as next of kin is the term commonly used. - Childhood should be free from having a caring role - (A)YCs not directly mentioned in Swedish legislation 	<ul style="list-style-type: none"> - Swedish Health Care Act 2010, children have right to receive info. about their parents' illness - Health care professionals have a legal obligation to provide children of a parent/s with mental illness, serious physical illness or disability or have unexpectedly died, with information, advice and support - People with disabilities or severe illnesses have certain rights for help, for (A)YCs this could possibly be arranged - Parental support - Group activities for families in grief - Relaxation in e.g. summercamps 	<ul style="list-style-type: none"> - Identify fragile families at an early stage and provide support they need - Make (A)YCs visible - Reduce stigma - Legislation needed - Digital group meetings - Have someone to listen to their story - Education about (A)YCs - Funding and digital solutions to provide help and support - Increase child's knowledge of their parents' illness - Provide opportunities for children to talk about their situation, to meet and get support - Opportunity to relax together
Switzerland 	<ul style="list-style-type: none"> - Difference in coping between Swiss migrant children was mentioned. Where Swiss children hide problems because they consider them as private, migrant children find their caring role more normal - Interventions successful at schools (local level) - On a national level no visibility - Difficult to reach group (do not communicate situation to their GPs) 	<ul style="list-style-type: none"> - Few programs to support (A)YCs - Focus on relieving relatives (e.g., organizing summer camp) - Role of child protection service and <18 legislative framework - Different programs have been carried out in schools to increase awareness - Differences between Swiss children and migrants in respect to coping (migrants caring role 'normal') 	<ul style="list-style-type: none"> - Schools should support (A)YCs to a greater extent - Increase awareness - Children under 18 should not take on board too many responsibilities - More flexibility needed in schools - Whole society is responsible and need for a cultural change

Italy**Visibility and awareness raising**

- Lack of visibility and awareness on (A)YCs at all levels
- Couple of examples of visibility/awareness raising (schools & hospital)
- Visibility dependent on experience of teachers or medical professionals

Strategies, interventions and programs to support (A)YCs

- Couple of known interventions (support action in a school and by ANS in area of Carpi)

Future needs to support well-being / health situation

- Need for information and training for all professionals and policy makers and also teachers
- Long-term multi-actor programs (ICT app)
- Promote self-awareness
- Ministry of Education, Welfare and Health are responsible, as schools and regional school offices
- Funding (public with private and non-profit)
- Many other actions that could be applied/transferred to (A)YCs
- Need for a law on informal carers
- Local authority as main actor
- Role for schools and teachers in supporting (A)YCs (awareness raising)
- Long term programs and whole-family approach

The Netherlands**Visibility and awareness raising**

- Low visibility and (A)YCs do not always recognize themselves as (A)YCs.
- Differences in visibility between regions, municipalities are responsible (struggle)
- Formal policies exist on informal care, but not young carers
- Schools could play an important role for visibility
- Welfare organizations and youth healthcare try to raise visibility

Strategies, interventions and programs to support (A)YCs

- Plays at schools and programs to support leisure activities, resilience training, support groups, etc.
- Awareness programs at high schools
- Guest lessons
- Share point for (A)YCs
- Children's Ombudsman

Future needs to support well-being / health situation

- (A)YCs should be seen as a specific group of informal carers
- Focus on (A)YCs own strength and do not 'problematize' the group
- Integral approach is needed.
- Strive for regulation.
- Reduce stigma.
- Acknowledgement of the group.
- Create funding (e.g., via municipalities) for young carers.
- Recognition of (A)YCs that they are (A)YCs
- Need for specific policy and support for (A)YCs by scheduling the subject.
- Need to focus on parents of children who are responsible for their care.
- Need for co-creation with (A)YCs.
- Need for integral approach (welfare, healthcare, educational and local governments that work together)

Slovenia**Visibility and awareness raising**

- (A)YCs are an overlooked subject in Slovenia and also not regulated under any law
- The importance to develop a definition, emphasizing that it does

Strategies, interventions and programs to support (A)YCs**Future needs to support well-being / health situation**

- Develop an integral approach, coordinated by different ministries, with cooperation of schools and other public institutions and NGOs, connected to children and their wellbeing.

- not relate to short-term, but long-term care
- Organizations that are in contact with young people should be responsible for detecting the problem (primarily school, physicians and also organizations engaged in the field of social home care)
- There is no awareness about (A)YC in the educational field.

- The need to build on what we have
- There is no need to develop a new system, what is needed is a cooperation between existing systems and infrastructure, good prevention programmes in the community
- Raising awareness and getting in contact with (A)YC in the social media
- Need to develop awareness and stigmatisation programmes
- Need to develop working relationships with the family in which (A)YC is living
- Empower (A)YCs with needed information about caring and also where he/she can turn to for support
- It is important that the (A)YC is voluntarily caring for relatives and that he/she is not under constraint
- Need for early recognition (important role for schools)

International/ Europe



Visibility and awareness raising

- Overall, visibility is low (e.g., also in Germany).
- Large differences in visibility and level of awareness between countries.
- Higher numbers than one would expect.
- Focus on all children, not only 15-17 years old
- Schools play a role
- Conference on (A)YCs raises awareness
- Awareness raising at European Commission by - among others - Saul Becker

Strategies, interventions and programs to support (A)YCs

- Media echo of TV shows (Germany)
- Brochures at schools and doctors
- Events to share experiences
- Website in Austria (Superhands)
- Holiday activities
- Carers' card in UK
- Peer groups

Future needs to support well-being / health situation

- Raise awareness
- Early prevention (ACE 'Adverse Childhood Experiences' screening)
- Improve skills
- Look and learn from support systems for children in similar situations (parent in prison)
- Support the person
- Ensure that children are aware of and can access their rights
- Should be less inequality within and between countries
- Need for support for themselves, awareness of peers
- More funding and staff at schools.
- There is shared responsibility (family, parents, local authorities, occupations therapists, etc.)
- More visibility of (A)YCs in society, for example carers week
- Reduce Stigma
- Practical and emotional support in schools
- Need for recognition
- Focus on a local level
- Children have rights

2.3.3 Second Round Results Delphi studies & General Discussion

The overall results, the summary country findings, and an in-depth overview of country specific results from the first round were sent to the experts prior to the second round. All country and international findings from the second round were read, analyzed and summarized (see Appendix 1 for all the country results). The synthesized findings and discussion are presented in narrative form below according to the main identified themes.

Visibility

All experts agreed on a lack of visibility and awareness about (A)YCs at all levels in all countries. On a positive note, awareness does seem to increase in some of the EU countries supported by increasing (social) media coverage. Visibility and awareness seems to be highest in the UK and Sweden and according to UK experts, other countries are currently at the beginning of a journey, a journey that started in the UK in 1999. However, some experts did expect more awareness and visibility in the UK because of the laws and regulations for (A)YCs in the UK. To support the visibility of (A)YCs across Europe, most experts expressed the need for a European NGO with structural funding independent of national budgets and there should be less inequalities within and between countries. The existing Eurocarers Young Carers Working Group - which is actively running - could further take up this role and become more visible across Europe.

Experts from The Netherlands reported that visibility and awareness are increasing, and this was evidenced by the experts themselves from the first round of interviews to the second round. However, they also stressed that much improvement is still required. They mentioned a lack of recognition and knowledge among those actors working with young carers. Experts also agreed that we need a new and similar study to the one of Leu and Becker (2016)⁷ in which data was gathered on awareness numbers across and within the countries, e.g., also within the four nations within the UK with diverse political contexts. Experts agreed that a unified system is needed within nations and Europe.

One of the Slovenian experts stressed that the reason for low visibility might be in the generosity of the welfare state, while another expert claimed that (A)YCs are a symptom of multi-governmental approach failure. In Switzerland it was stressed that low visibility is also related to Swiss families not speaking about these issues because they fear interference from the social services. In Swiss families, children tend not to talk about their caring roles which is something private and hidden.

According to experts, an increased visibility of (A)YCs might also have a negative effect. Visibility means recognising YCs as a problem, which could contrast with the idea of a family where it is viewed as natural for family members to help and support one another. Most experts agreed that we should consider the needs of young carers and that (A)YCs themselves might not want attention whenever we target this group by creating visibility.

Relevant to the ME-WE project, media and social media are needed to improve the visibility and awareness. Experts are happy that various activities are organized for young carers across Europe. To increase visibility, Italian experts shared that actions – currently targeting

⁷ Leu, A., Becker, S. (2016). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies*, Vol. 20, No. 6, 750-762.

other groups – could be applied /transferred to (A)YCs: an ICT app to share information about health and social services, peer-support, workshops in schools, reflecting teams, support to children of parents with mental illnesses, programs to prevent earlier educational system drop outs, alternative school programs, assistance support and more generally the application of a whole family approach.

Awareness Raising

As presented above, awareness is steadily increasing. Experts did mention that there are differences in the level of awareness on the topic of young carers in organizations such as schools, welfare organizations and social services. Moreover, concerning the role of schools, it is questioned by some experts what the extent of the responsibility of school concerning problems of (A)YCs is.

Television programs and social network campaigns are considered as good ways for improving awareness, which is also relevant to the ME-WE project whenever we want to increase awareness and recruit participants for future studies in the other WPs. By sharing individual stories in lectures or films, awareness can be raised according to experts. There is increasing attention in most countries on awareness raising, however, it can be questioned whether a campaign would be useful or would have any effect regarding visibility and awareness rising. Some experts stressed that campaigns only create some awareness for a short period of time and sustainability of interventions and awareness raising is highly needed. Long-term awareness is not necessarily guaranteed in most countries, even in countries scoring relatively high on awareness of young carers, such as the UK. According to one expert, raising awareness is meaningless, because (A)YC's involvement is never voluntary. Some Swedish experts reported that the (A)YCs they know like to get attention, which contrasts with the results from some other countries. Again, the Dutch confirmed the increasing national awareness on young carers with a considerable shift compared to the first round of interviews.

Identification

From the results it implicitly becomes apparent that countries struggle with 'formally' identifying (A)YCs. Whenever we identify (A)YCs, we seem to acknowledge (A)YCs and need to put formal support in place. Identification implies acknowledgement that (A)YCs exist and it contrasts a strong – mainly Western - value that young adults should not take up roles reserved for parents (parentification), i.e. (un)paid work. Finally, we should acknowledge that children may be afraid that whenever they are identified, that they will be taken away from their home by social services.

To identify (A)YCs, experts acknowledged that there needs to be a shared/common definition of (A)YCs across the world (see following paragraphs on definition), which is crucial for identifying them. In respect to responsibilities for identifying (A)YCs, the primary responsibility is – according to some experts - on the school system while the responsibility for developing programmes and strategies is primarily on the state, to support and develop laws and regulations, considering (A)YCs, and to provide them with information and additional help to relieve (A)YCs. An expert from Switzerland did not agree that school teachers are good in identifying young carers as supported by a recent study where it was found that teachers see themselves as good reporters but - also internationally - schools report only a few cases of incidence of child maltreatment in Switzerland.

Many experts agreed that it should be a routine that health care professionals always ask about children and whether they have any needs when a parent is ill. Screening, assessment and early identification is needed, and several experts agreed that adverse childhood experiences (ACE) screening could be used as a tool to identify young carers⁸. Social conditions of a child should be screened when enrolling to kindergarten/school and ACE could support herein.

In the UK, it is quite unique that there already is a carers assessment⁹. However, it is crucial to have a follow-up, which was also as being a problem in the UK to provide actual help as funding is lacking. Experts stated that without proper services in place, the identification can feel meaningless at best, and harmful at worse. Immediate referral to a young carers service may not be what a young carer needs, particularly at the first instance of a parental health diagnosis. Experts admitted that there is no value in assessment without having a follow-up and money, time and people are needed to provide follow-up. Current cut backs in services across Europe, Brexit, and the increasing welfare, care, and health costs are barriers for effective follow-up and interventions.

Definition

As described before, there is a need for a shared definition of (A)YCs. However, it should be noted that young carers experience their caring role differently, so a common terminology might not reflect the definitions of (A)YCs themselves and labels can have different meanings. The question comes to mind if there should be a common definition. According to some (A)YCs themselves in the UK, they are someone who watches over their household.

Most experts agreed that there is a need for a general language or terminology across Europe. Swedish experts reported that to go ahead and develop functional and effective support interventions, the distinction between the terms 'children as next of kin' and '(A)YC' must be defined, clarified and disseminated. Experts from Slovenia also emphasized the importance of developing a definition of (A)YCs and stressed that it is important to be cautious not to invent the problem by forming a too broad definition of (A)YC. We should be cautious that the term (A)YC has a negative connotation and becomes a label, in particular in research where academics try to solve problems. In respect to the families of a group of (A)YCs, one UK expert preferred the term 'fragile families' in Sweden compared to the 'vulnerable families'.

Whole family approach

According to most experts, a family perspective is needed with a family focused approach to support (A)YCs. Most of them agreed that we need to work with a family and to empower them, so that (A)YCs would not need to be burdened with care work. Whenever you start from a family perspective it can open opportunities for identifying (A)YCs and the roles and needs of all family members. In addition, starting from a whole family approach can provide concrete, practical and emotional support to all family members, thus relieving (A)YCs and arrange follow-ups.

Experts reported that there is a need for better services for the person (A)YCs care for, for relief and respite. An expert pointed out that whenever the socio-economic status of families is increased, families have more resources to gain additional help. For interventions to be

⁸ See chapter 4 on the rating & ranking, where ACE did not score high(est) on identification. Possibly, the focus on adverse childhood experiences might not resonate well with young carers.

⁹ The UK carers assessment scored relatively high in the rating & ranking study (see chapter 4).

successful, it is also relevant to have the whole family involved in the intervention. According to an expert, the weakness of support interventions is that they typically only reach (A)YCs and not the whole family. Next to a family-oriented perspective, it is important to look beyond the family and include the broader social network, such as friends and neighbors. It is interesting that most experts point to what is wrong in a family, yet, according to an UK expert, we could also investigate the positive aspects of a family, what is great for you as family and how this contributes to the well-being of the (A)YC and the family.

Interventions and personalization

The results show that many interventions exist on a local level, and then mainly in the UK, Sweden, and The Netherlands. In the UK, the voluntary sector has historically provided the most support for young carers compared to the governmental sector which lags behind in providing support. This finding is similar to the other EU countries, but not explicitly reported. The findings reveal that young carers might not always need or want support, for example from professional caregivers who should not always think in terms of care or help that needs to be provided, as young carers may not want or need that.

From the results it can be seen that it is important not just to focus on and create new programs and interventions just for (A)YCs, as we could also include support for (A)YCs in already existing interventions and programs designed for e.g. informal carers or children in general. Many existing programmes and interventions are in place; however, they have not been specifically designed for young carers. These existing programmes could be accepted as support by (A)YCs since they do not specifically focus on their role as a carer.

Overall, to support (A)YCs, many – mostly local – interventions are running in the various EU countries. Again, a reasonable group of experts said themselves that we should not accept that children perform a role as a carer and therefore there is a need for gatekeeping and screening to prevent children from having to fulfil these roles. Other experts found this view naïve and strongly emphasized that (A)YCs exist and likely will be there for many years to come, so we should focus on how to support them and follow up on their needs. According to one of the experts, a carer's assessment as a programme or intervention is the only instrument that might bring us a bit further (e.g., the UK assessment tool or ACE). As noted by an UK expert, it seems that countries are overly proud of their work for young carers, hereby minimizing the amount of work still needed.

Experts suggested flexible interventions and tailored to different (A)YCs' needs, that could differ for social, financial and individual conditions. Experts appreciated or found it crucial that interventions are based on a whole family approach, aimed at supporting (A)YCs and, at the same time, to minimize the care burden; for this purpose, training and information for school professionals and other professionals are needed. As described in the 'Whole family approach section', follow-up is needed and can be arranged by having recurring activities repeatedly. (A)YCs need interventions based on their individual needs, i.e. personalized support, according to the experts.

Some experts pointed to providing support and interventions at schools. In the Netherlands and in other countries several interventions within schools are running, such as a SharePoint for young carers, expertise lab, elective course, student symposia, drama, guest lectures and awareness programs such as the 'Who Cares' programme. Despite some successes, experts acknowledged that the interventions are – without creating new specific professions or roles - too dependent on the workload and possibilities of teachers, whenever it is not their main

responsibility to support (A)YCs. Following the results on the whole family approach, one expert pointed out that UK legislation describes the rights of the person with care needs and the young carer. A number of experts pointed to services aimed to help (A)YCs recognizing and expressing their emotions. Yet, it is striking that the family is missing in the strategies and interventions while they are part of the relationship.

In respect to welfare, interventions should focus on the provision of information by e.g., information flyers, children's helplines or a national information campaign. In addition, group support for young caregivers such as peer groups are needed. Mentoring and individual support, fun activities and respite care or as in the UK the carers card so a young carer does not need to explain his/her situation in certain settings. Schools should rather be flexible when a student-carer may not be able to do their school work because of their situation at home. Experts pointed out some limitations of interventions used in the welfare sector. These revolved around three issues:

1. interventions not matching the needs of young carers,
2. good interventions that remain underused because people are not familiar with them,
3. a lack of research to substantiate the effectiveness of interventions in the welfare domain.

Experts emphasized the value and effectiveness of peer support and the need for flexibility in the school and long-term commitment of schools to the topic of caregiving. Peer group support provides children with the insight that they are not alone which can also empower them. Hereby supporting those children to move on but also to build on their experience as building their own resilience. As highlighted by some of the experts, to use and/or create interventions, it is important to recognize the diversity in needs of young carers and to learn from other sectors, such as the situation of children with parents in prison and how to support them.

Respite Care

Most experts suggested activities in which (A)YCs could relax and get a break from their care responsibilities to promote their individual development and get in contact with peers. To meet this goal, experts suggested summer camps or peer support groups. Overall, there were a lot of reflections about the needs for relief. The experts discussed how this relief could be achieved and if (A)YCs will receive support in their caring role, or if the support should be that someone else is taking over the care responsibility completely. A quiet, fun weekend with friends and parents - without having to care for their parents - can be of great value to (A)YCs.

Online support and interest in apps

Multiple experts expressed their preferences for providing online support by means of sites or mobile applications. Overall, modern and concrete approaches are needed to raise awareness and support young carers, such as YouTube films, social media and apps, according to experts. According to the experts, there is a need for an individual approach which is based on self-organisation and is easy to access by means of e.g., an information platform or app. UK experts also pointed to digital online based peer support to be most effective with (A)YCs, which is also advised for the ME-WE project. However, experts from a variety of countries pointed out that whenever we create or arrange something like an app for (A)YCs, then the organizations behind the initiative also have a responsibility for control by means of moderation and support of dedicated professionals, so it does not result in adverse outcomes such as encouraging suicide or supporting taking one's life. Besides control and moderation, structural financing is needed as it is acknowledged that the national online support space in

the UK has been closed because of lack of funding. None of the experts shared ideas about using eHealth technologies to support (A)YCs. Experts highlighted that whenever we accept that (A)YCs exist and need support, then supportive technologies developed for informal/unpaid carers could also be of benefit to (A)YCs.

Laws and regulation

A considerable number of experts expressed the need for laws and regulations to formalize the rights of (A)YCs on a National or European level. The idea of a specific law is considered positive according to some experts, to give visibility and promote the integration of interventions but, at the same time, it is important that it is not a rigid law and that it does not become reduced to purely financial support. Some experts are impressed by the "Health Care Act", "Care Act" and the "Children and Family Act" in England. However, it is relevant to note that - according to the UK experts - the current legislation has little real benefit for young carers. Overall, according to some experts, we should rather highlight the group of (A)YCs and support them where necessary, instead of requiring some specific legislation without being able to enforce the law and provide follow-up due to a lack of funding.

Even though the term '(A)YC' does not exist in Swedish legislation, there are some legislation texts that could be used to promote (A)YCs health and well-being. The Swedish National Board of Health and Welfare uses the term 'Children as next of kin'. The interpretation of the Swedish Social Care Act is discussed, as well as the fact that the Convention of the Rights of the Child is going to be incorporated into Swedish law, from January 1, 2020. The Swedish Social Care Act is perceived as sufficient in its present form, municipalities are responsible for ensuring a safe and secure childhood for all children in Sweden. Like the UK experts, a Swedish expert pointed that although laws are reformulated, there is a risk that this will have a very small actual significance for the individual. Experts from Slovenia also emphasized that there is no need for a creation of a new system/legislation or a new law, while some of them stressed the need to create a small body or pressure group to address the problem of (A)YCs. Existing laws on e.g. long-term care or youth care should be sufficient to protect and support (A)YCs where necessary. Young carers in Switzerland could be protected by the legislative framework for young persons under the age of 18 and according to Swiss experts, changing the legislative framework in Switzerland is extremely difficult due to the political structure. Therefore, in Switzerland it would be better to create a new national policy first. A couple of experts point to international children's rights that are sufficient to protect them where needed. Most countries signed the Children's Rights Charter, so there might not be a need for a specific legislation for young carers. Following an expert from Slovenia, it would be better to improve the cooperation between existing systems. Despite some differences between countries, experts acknowledged that there is a lot of similarity in respect to the approaches.

Training, Education & the Role of Schools

Overall, there is a need for increasing the efforts in training and educating care and welfare professionals about (A)YCs and how to support them. In addition, schools should be involved more to identify and support (A)YCs with trained personnel, while considering scarce available time among teachers.

Experts explained that professionals need to be educated about (A)YCs, about their situation and what professionals can do to support them. There could be training days, or form networks that meet regularly and work with various themes. Such education for professionals should be included in the professionals' basic education programs. Experts admitted that training should rather be organized for all sectors (health, educational, social); training for

teachers to understand the situation and feelings of (A)YCs, training for health professionals, statutory training, training for schools of all types and level, information and training for students to improve dialogue and support. Experts argued that there is a need for a common knowledge base containing: how to meet children, young people and parents; how to identify (A)YCs; how to continue once a professional has identified an (A)YC; available support efforts. Furthermore, experts noted that there is a need for tools to support professionals in conversations with young carers.

Experts considered the school and its educational staff as an important actor in identification and planning (A)YCs support, but they are aware that unfortunately they still do not play this role. Thus, they suggested integrated actions in which educational, social and health services should be involved. In Italy, one of the main weaknesses of the Italian educational system in managing (A)YCs is the lack of awareness and knowledge among school professionals, in particular school teachers and the absence of a multidisciplinary team in the school embedding psychologists.

Besides possible advantages of involving schools in identification and support, some of the experts expressed their concern with too much expectations from the schools due to limits in availability, time, and formal responsibilities. According to several experts, teachers already have so many things to do. The importance of developing certain protocols was additionally stressed, and it was added, that in schools there should be a screening process in place. As noted before, experts emphasised that early detection of the problem is of crucial importance, because when children are 14-17 years old, it could be too late to "save" them. Whenever you want to support a child, you should start saving him/her from kindergarten, according to an expert. An idea was raised by some experts that (A)YCs could get a special status in schools, similar to the status of sportspersons. As noted earlier, creating flexibility for students was also mentioned, for example with support of the carers card. With the carers card a (A)YC does not need to explain his/her situation in certain settings. Schools should rather be flexible when a (A)YC may not be able to do their school work because of their situation at home.

Financial support & funding

According to a considerable group of experts, more funding is needed to better support (A)YCs and it is important to broaden the scope in respect to age, raise awareness, gather more data and improve systems. Economic support could be useful for (A)YCs, but it should be added to other type of actions and support such as psychological, educational, relational, to promote a harmonious development of (A)YCs and let them express their own abilities. Public funding is the main channel to promote interventions targeting (A)YCs: for the national level, institutions could be involved such as the Ministry of Education and the Ministry of Welfare and Health, whereas at European level it is desirable that (A)YCs become a topic in the European project design. Multiple experts stressed the importance of having sufficient funding/financing for supporting (A)YCs. For example, after awareness raising and identification, there should be money for follow-ups. Whenever a (A)YC needs additional support, then this should rather also be possible.

Next to the group of experts that expressed the need for more funding, some experts from a variety of countries seemed to disagree on this need for financial support. For example, in Switzerland there are relatively few supportive efforts, while it is not a low-budget country according to a Swedish expert. It seems to be dependent on choices and priorities and as one expert shared, changes do not always have to cost money. Furthermore, there was disagreement that child protection services have got scarce resources. One expert pointed to

'shameful financing' or funding for a problem and stressed the importance for general financing. It is noteworthy that an UK expert pointed to the increasing focus on building resilience to lessen the dependency of young carers onto formal support services, particularly in times of budget cuts and reduced services available. UK experts expected that the Brexit will have negative effects on supporting the future needs of young carers.

Integrated approach

In general, experts agreed with the development of an integral approach or 'integrated care'¹⁰. They emphasized that the integration should occur on a systemic level, and that the approach needs to be flexible. Experts stressed the need for integration of the different sectors related with (A)YCs (educational, health, social) to build up flexible and family-based interventions, tailored on (A)YCs' needs and age. They suggested playful activities, peer support group and a contact point in the different services where (A)YCs could share their difficulties and needs. Experts confirmed the importance of developing an integral approach across multiple domains and of exchanging lessons learned within and between different regions; state, municipalities and NGOs need to be involved in a collaboration around children, adolescents and their families. According to an expert from Slovenia cooperation between different actors is needed, since the problem will probably only increase in the future.

Practical support to (A)YCs, as well as to the family as a whole, may exist locally in some places. Practical support may, for example, involve the healthcare, social care, and other community services, working together, in order to get professional interpreters instead of using children as interpreters in various situations.

In relation to Austria in particular, an expert pointed to the role of social workers and the fact that they are not involved in long-term care and hence possibly not recognizing (A)YCs. These observations are consistent with research in The Netherlands, where it was found that the silos between different care systems (long-term care, youth care & social care) hinder transitional care through life¹¹. Furthermore, there is need for more awareness among GPs and other clinical actors. The current limited role of GPs in identifying and supporting (A)YCs experts argued was remarkable and most experts stressed the importance of their role to enhance integrated care.

Responsibility

Experts reaffirmed the role of local authorities as the main actor for its knowledge of the local needs and stressed the role of the third sector to promote awareness and actions by politicians. Furthermore, they considered it is desirable to have an involvement on a national level to define a clear proxy and political acknowledgement, and a European institution (e.g., an NGO) that gives the same inputs to different countries in supporting (A)YCs. For one expert regional authorities should plan interventions in according with local authority.

In Sweden, the reflections in respect to responsibilities concerned the upcoming changes in the Social Care Act; implementation of the Convention on the Rights of the Child in Swedish law; a new commission report on provision of interpreters; the concept (A)YC needing a definition and a place in legislation; and the necessity of regarding each individual as a next of kin from the moment of birth. In Slovenia, most of the interviewees argued that the primary

¹⁰ Minkman, M.M.N. (2012, January 19). Developing Integrated Care: Towards a development model for integrated care. Kluwer Bedrijfswetenschappen, Deventer. Retrieved from <http://hdl.handle.net/1765/30972>

¹¹ <https://www.vilans.nl/docs/vilans/publicaties/uitvoering-van-wet-langdurige-zorg-kent-nog-uitdagingen.pdf>

responsibility to acknowledge (A)YCs and to address the issue lies with the State and again there was agreement that the responsibility lies with the whole society educational, health and social system and NGOs.

Migrant families

In the first round of the Delhi study, Swiss experts shared their knowledge on migrants in Switzerland and the children in migrant families who often can have a heavy and complicated responsibility burden. (A)YCs in migrant families can perceive their caring role as normal but this does not remove the burden of caring. Experts across Europe agreed that the situation in Switzerland with migrant families will be similar to other countries. Overall, it was recognised that culture and values define our expectations and opinions in respect to children providing care. Experts argued that an intervention or programme to support (A)YCs should consider the needs of migrants and how to involve and support them.

Caring about instead of caring for - Children's Rights

Overall, experts agreed that children should care about, and not care for family members. Children and adolescents should not have a caring responsibility according to some experts. However, experts also acknowledged that (A)YCs exist and (are in of) need support and relief. There is some debate among experts whether or not to accept that children and young people are taking a caring role, and to support them in their caring work. This is – as noted earlier – a fundamental debate. Experts acknowledged the dilemma in that whenever we focus on identification, support, respite and interventions, there is a risk for acceptance. One expert also agreed that coping strategies are not an appropriate solution, since the goal should be not to have (A)YCs and not to teach them how to cope. Yet, according to an expert, if we have these zero tolerances then we will not see them until it is too late. Some experts shared that (A)YCs report that being a carer is a good experience and results in fulfilment. One expert carefully described that the idea that children should be free from having a caring role is understandable, yet a lofty goal which may be unrealistic. It is unrealistic to ensure that children have no caring roles anymore and we should therefore rather provide interventions, support programmes and methods to prevent or lower the care burden among (A)YCs.

Co-creating support and interventions

Many experts agreed that the programmes should be designed with and for (A)YCs. Experts reflected positively on the results from the Netherlands where experts stated the need for co-creation with young carers. So overall, experts confirmed the importance of involving young carers themselves, while also stating that this is currently not done sufficiently. To support future needs, co-creation is essential.

Programmes

Experts acknowledged that there is a need for programmes and support groups that are specifically targeted towards (A)YCs. There is need for relief and experts suggested to include support for (A)YCs in existing interventions and programmes. Programmes and support groups should run through all levels of education. Experts shared that we need to be aware and observant of the risks with support groups, for example, that participants in the group influence each other negatively. Experts agreed that excellent programmes tend to be localized. In respect to capacity, experts noted the relative difficulty to arrange formal support programmes on a national level (lack of school nurses). According to experts, the diversity of support activities should be offered to be able to match individual young carers' diverse needs. Self-help groups are a method to support, e.g. for children of parents with an addiction.

Experts explained that theatre plays in school and support for leisure-time activities can support identification and respite. There are great needs for relief, according to the experts. Getting away from home and participating in summer camps and other activities together with children/ young people in similar situations, but also being given the opportunity to be involved in completely ordinary activities with children / young people who do not have similar experiences. From the Swedish results, to be able to explain what they need and want, (A)YCs first need help reflecting on their situation, their perceptions, experiences, thoughts and feelings. They need to receive information about their rights. Furthermore, (A)YCs need access to tools and support to find useful coping strategies which is a relevant requirement for intervention and support programmes.

Some experts stressed that it is important not to create new programs and interventions just for (A)YCs; it would be better to include support for (A)YCs in already existing interventions and programs. Some experts agreed it could be a good thing whenever not all support programs are specifically designed for young carers, as these programs may be sensitive to problems with other aspects of young carers' lives than caring alone but may also not be sensitive enough to the specific needs of (A)YCs. Furthermore, there are some good interventions and programmes, but it is hard to reach (A)YCs. It would be important to improve the communication and promotion of such interventions and programmes.

An important issue was raised by a number of experts that programmes and support should run through all levels of education, from primary school to university, i.e. transition support or transitional services. This support is important due to the gap in transitional services which remains a problem for (A)YCs. Furthermore, experts reported that young carers sought more holistic support, i.e., guidance on career choices, nutrition, and life management skills.

Overall Needs

Experts recognized that support programs need to be sensitive to the individual situation of carers and aim to

- (i) raise awareness and identify (A)YCs early on,
- (ii) improve skills and provide emotional support to move on and strengthen resilience- also at as early a stage as possible in the care process (prevention and gatekeeping),
- (iii) provide support for the person that is being cared for,
- (iv) ensure that children are aware of and can access their rights, and
- (v) reduce stigma about mental illnesses and increasing the reputation of care (in Germany).

Experts noted that channels that could be used for dissemination of knowledge are reports, brochures, films, social media, and mass media such as TV, radio and the press. Globally knowledge could be disseminated at international conferences. The information should include a definition of the term (A)YC, (A)YCs' life situations, what are (A)YCs' rights, their families' rights, available support, etc. An introduction of a national/ international day for (A)YCs is proposed.

Stigma & Problematization

Although minor, some experts reflected on statements about the 'silent culture' and stigmatization of the role of (A)YC, and also the stigmatization existing about mental illness in for example Germany and addiction. The question was raised if we contribute to the stigmatization when we create separate support groups for children of parents with mental

illness and/ or addiction. Attention is again drawn to the discussion about acceptance of the responsibility (A)YCs take. A couple of experts agreed on the comments from The Netherlands that we should be aware not to over psychologize the problem of (A)YCs. According to one expert we should not see issues as problematic when (A)YCs themselves do not see them as a problem.

NGO for young carers - European Expertise Centre on Young Carers

Across the countries, experts stressed the need for an independent organization, an NGO for young carers, similar to organizations for informal carers, people with Alzheimer's disease or other specific groups. Such an organization should be responsible for identifying the problems of (A)YCs, with structural financing. As noted earlier, the Eurocarers Young Carers Working Group could further take up this role and become more visible across Europe. It was noted there are needs for an agreement regarding the overall responsibility for the collaboration to work. Otherwise everyone's responsibility can easily become no one's responsibility. Experts argued that collaborations between the community-based services and NGOs should be in place. They recognized that there was a need to have a young carers organization and the NGO can – among other activities - disseminate knowledge and coach teachers/people at schools. Other important tasks identified were to gather an insight into actual numbers, identification support and tools, raising awareness, arranging support at schools, further strengthening the whole family approach, and ensure gatekeeping at for example GPs.

2.4 Discussion & Conclusion

In this chapter we present the results from two rounds of Delphi studies with a total of sixty-six experts from 10 different EU countries. In-depth insights were gathered in these two rounds on the visibility and awareness raising of (A)YCs on a local, regional, and national level. In addition, several strategies, interventions and programmes were identified by the experts to support (A)YCs. Finally, experts shared their knowledge on future needs to support the well-being and mental health of (A)YCs.

Similar to the study of Leu & Becker (2017), the Delphi study shows that there is a lack of visibility and awareness about YCs at all levels in all countries, in particular Slovenia and Italy, with the exception of the UK and Sweden. However, visibility and awareness are increasing in most countries and there are many initiatives to support YCs on a local level, however these are less visible. Successful awareness campaigns use television and social networking and the media echo of these activities can be quite large, such as in Germany or The Netherlands. Experts acknowledge the level of visibility and awareness across Europe and express the need for a common definition and possibilities for young adults to identify themselves as YCs. Since YCs have difficulties in identifying themselves as YCs and vary in their experiences and care they provide, a general overall definition and concept might be difficult to construct. In respect to identification, other countries can learn from the UK, where there already is a carers' assessment, which could in potential be transferred to the ME-WE app. Whenever YCs are identified and made visible, then society most recognise YCs and also acknowledge it as a problem that needs formal support. Providing formal support can be difficult since informal care is – according to Hoefman (2015) - emphasized by the fact that care is provided on a voluntary basis and usually without financial compensation. How should policy makers deal with the caring role of young adults whenever it is voluntary, something that is part of life? According to some experts YCs should actually not be carers in the first place, which is a

Child's right. Other experts stress that there will always be YCs and we should provide the support they need, such as – among others - respite care, information, social contacts, support at school. We gained insights in the UK successes and the hundreds of programmes and interventions to support YCs. Sadly, these initiatives are mostly based on temporal funding, so now when the UK economy is bearish and the Brexit might even cause more cuts in care and support, actual help and follow-up is lacking. This implies that YCs' support should be an integral part of (social)care or welfare. For ME-WE, it is also essential that the partners become aware that whatever we provide to YCs (interventions, knowledge/information, an app, etc.) should be grounded into existing care or policy structures, and/or adopted by an NGO to ensure continuation and follow-up.

Overall there is a need for integrated care and support for YCs, in which schools, welfare organizations and social services work closely together. By integrated care we can potentially improve the quality of care, better performance management, interprofessional teamwork, make clear the different roles and tasks including commitment (see, Minkman et al, 2009). The Delphi results further show that overall, to support YCs, many – mostly local – interventions are running in the various EU countries, a variety of which are described in this deliverable. Access to interventions and programmes vary between countries, states, municipalities, and even between schools. This is a major rationale for providing YCs a time, distance, culture and language independent support platform which is envisaged by the ME-WE project. An online ME-WE open access platform – website or app – is ideal to overcome physical and time barriers and ensure that all YCs can receive a basic level of support. In fact, the development and/or provision of an online platform or app for supporting YCs is preferred by many of the experts that participated in the Delphi study. The existing Eurocarers Young Carers Working Group - which is actively running - could possibly be the product owner of such a platform. In addition, the Eurocarers Young Carers Working Group could also become more visible and accessible to further take up this role and become more visible across Europe. Experts across Europe also advise to create a European or Worldwide NGO for YCs (possibly the working group) to disseminate knowledge and coach teachers/people at schools. Other important tasks to support YCs are to gather an insight into actual numbers, identification support and tools, raising awareness, arranging support at schools, further strengthening the whole family approach, and ensure screening at for example GPs. It is interesting to note that besides discussions on awareness, interventions and needs, experts were also asked to discuss theories on resilience and coping strategies for psychoeducation of YCs. None of the experts provided helpful insights into these theories that could further be used for a consolidated strategy and theory to be used as a framework for the ME-WE interventions.

We should provide YCs with activities in which they could relax and get a break from their care responsibilities to promote their individual development and get in contact with peers. An online platform can serve as an information channel with an agenda to activities in various localities (see also next chapter on the literature review and social media analyses). Online welfare interventions could focus on the provision of information by e.g., information flyers, children's' helplines or a national information campaign. Furthermore, a considerable number of experts expressed the need for YC specific laws and regulations to formalize the rights of YCs on a national or European level, however, other experts expressed that the rights for YCs are already covered in existing (non YC specific) legislations or could be included in existing legislations. All in all, the ME-WE platform can serve as – among others - an information platform on rights and legislations across Europe, which will also be relevant for policy makers across the EU to learn about- and exchange best practices. Professionals need to be

educated about YCs, about their situation and what professionals can do to support them. Education by online learning can be part of an app or platform. Creating flexibility for children/students at school is essential, e.g., by means of a carers' ID and a ME-WE app could provide exemplars for schools and YCs to use. Overall, culture and values define our expectations and opinions in respect to children providing care, which is relevant to cover in particular for migrant YCs. ME-WE should rather take migrants into account in the development of an intervention or app, possibly supporting the Arabic language and – if wished for - targeting migrants via personalized channels. Overall, co-creation is KEY for the success of any intervention or app, and all stakeholders and end-users (including migrants) should be part of the co-design process.

In the following chapter we will present and discuss the results from a series of literature review and social media studies to provide the foundation for a consolidated strategy and theory for the creation of an AYC support intervention in the ME-WE project.

3. Empirical literature review

3.1 Introduction

First the theoretical framework will be discussed based on a literature snow-balling method (see also¹²). Secondly, the method for the systematic literature search on interventions for (A)YCs is outlined and thirdly the results of the literature review are presented, including an overview of proven interventions and good practices, and lastly a chapter with the discussion is included. There are several good practices identified in the whole ME-WE project. The academic literature has been studied to gain insights into the empirical evaluation of the good practices. The good practices will act as a useful source of knowledge for the subsequent co-design of the ME-WE support intervention, including the mobile application.

3.2 Theoretical framework

To support (A)YCs' mental health and wellbeing, it is relevant to understand psychological and physiological mechanisms and theories that contribute to the mental health of humans, such as stress, coping, self-efficacy, and resilience. These mechanisms explain how we deal with challenges and imbalances through life and can form a basis for strategies to support YCs coping with their caring role.

Stress and coping

In the 1930s, Hans Selye began research that put the word stress on the map, ultimately reintroducing it into the English language (McEwen & Lasley, 2002). Hans Selye introduced the theory of a 'General Adaptation Syndrome' (GAS), which is the body's generalized response to challenges. GAS consists of three stages; the first stage is the 'alarm reaction;' the second stage is 'resistance,' and the third, when stress was persistent, 'exhaustion' (Doublet, 2000). After much opposition from the scientific community, he added the concept 'stress' to his theory (Doublet, 2000). It is interesting to note that according to Selye, stress is not a deviation from homeostasis, because any biologic function causes marked deviations from the normal resting state in the active organs. Furthermore, stress it is not anything that causes an alarm reaction; it is the stressor that does that (see Doublet, 2000).

Until the 1960's stress research was conducted mainly in the field of physiology, and little attention was paid to psychological stress. Not everyone reacts the same way to the same events, and this lead to theories involving the concept of "appraisal" (see Doublet, 2000). According to Lazarus and DeLongis (1983), appraisal refers to the way a person construes the significance of an encounter for his or her wellbeing, that is, as irrelevant, benign, harmful, threatening, or challenging, the latter three being forms of stress appraisal. Coping processes are initiated to manage a stressful encounter (see Cooper & Dewe, 2004; Lazarus & DeLongis, 1983), and how a person copes with this encounter determines his or her emotional response (Lazarus & DeLongis, 1983). The two main classes of coping strategies are problemfocused coping and emotion-focused coping (Lazarus & Lazarus, 2006). In problem-focused coping, a

¹² https://www.dropbox.com/home/WEME_H2020/3%20MSc%20reviews%20ME-WE

person's attention centers on what can be done to change the situation to eliminate or lessen the stress, whereas in emotion-focused coping, no effort is made to change the situation but rather the way a stressful encounter is construed or attended to and therefore the emotional reaction to it (Lazarus & DeLongis, 1983; Lazarus & Lazarus, 2006).

In the late seventies, several models have been developed to get an understanding of stress and coping. To understand why people experience stress, how they deal with it and why some people who are in a difficult situation develop ill health, while others in the same situation are continuously healthy (Antonovsky, 1979; Bandura, 1977; Ursin & Eriksen, 2004). Ursin & Eriksen (2004) explain in their Cognitive Activation Theory of Stress (CATS) that stress is the result of a discrepancy between expectations and reality. They also found that stress is not a health threat. On the contrary, stress is functional if one can act on it, believes that he can do something about it and has the resources to deal with the situation. The resources were also found very important in the model of salutogenesis (Antonovsky, 1979). These resources could be psychosocial, genetic or constitutional, for example; knowledge/intelligence, social support, commitment, cultural stability. According to Antonovsky, health is seen as a movement in a continuum between ill health (dis-ease) and health (ease). It depends on whether people have available resources to deal with a stressor and if they have the capacity to use the resources available, which is called a sense of coherence (SOC). The SOC consists of the comprehensibility, meaningfulness and manageability of a situation (Antonovsky, 1979). This theory explains why people despite stressful situations and hardships stay well. The theory is the opposite of the pathogenic concept, where the focus is on the obstacles and deficits (Lindstrom, 2005).

One of the relevant coping theories is the self-efficacy theory, first described by Bandura (1977). In Bandura (1982), self-efficacy is defined as a personal judgment of "how well one can execute courses of action required to deal with prospective situations". Bandura states that judgments of self-efficacy determine whether coping behaviour will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles and aversive experiences. People will avoid activities that they believe exceed their coping capabilities, but they undertake and perform assuredly those that they judge themselves capable of managing. Additionally, people's judgments of their capabilities will influence their thought patterns and emotional reactions during anticipatory and actual actions.

In the 1980's a new term came into being within the field of stress: "allostasis". It comes from the Greek root *allo*, meaning variable, and *stasis*, meaning stable (Ropeik, 2004). Allostasis emphasizes the point that allostatic systems help keep the body stable by being themselves able to change and to provide enough energy to cope with any challenge – not just the life-threatening ones (McEwen & Lasley, 2002). Allostasis is similar to Bernard's "milieu intérieur", and Cannon's "homeostasis" and "fight or flight" response, although allostasis is more in line with natural selection and the organism's ability to adapt to his environment. If people only try to remain stable by staying the same (homeostasis), they cannot respond to abrupt changes in the environment (see Sterling, 2004). In situations in which people cannot cope with a challenge, allostatic load denotes a failure of the body's efforts to remain stable. According to McEwen & Lasley (2002), allostatic load is like two sumo wrestlers on a seesaw – the seesaw may be in balance, but it is under a strain that may eventually cause it to break. Allostatic load refers to the 'wear and tear' that the body experiences due to repeated cycles of allostasis, and it can be created by for example unhealthy diets, low social support (loneliness), and aging (see McEwen & Lasley, 2002).

In the last couple of years, Green et al. (2016) identified two categories of coping. Maladaptive coping by wishful thinking: I wish the problem would go away, I wish I was smarter, I wish someone would solve the problem for me. Adaptive coping by problem-solving: think of ways to deal with or fix the problem, ask others for help or ideas, and try to fix the situation. Similarly, Metzger-Blau & Schnepf (2008) developed two central phenomena: 'keeping the family together', which encompasses how families cope with chronic illness and which tasks are being shifted and redistributed to manage everyday life, and 'to live a normal course of life', which describes the aspect of hope as well as concrete wishes and expectations towards outside support. It comes down to either actively trying to fix the issue or just hoping the issue will be fixed for you.

Resilience

The resilience framework is comparable to the theory of salutogenesis and the concept of coping and allostasis. Resilience has been defined as 'a dynamic process encompassing positive adaptation within the context of significant adversity' (Luthar, Cicchetti, & Becker, 2000). This term does not represent a personality trait or an attribute of the individual (Luthar et al., 2000). Rather, it is a two-dimensional construct that implies exposure to adversity and the manifestation of positive adjustment outcomes (Luthar & Cicchetti, 2000). Young carers unquestionably face significant adversity and improving their resilience would strengthen them and prevent negative outcomes. There are only two studies evaluating a resilience based intervention for (A)YCs. These studies will be highlighted in the result section (Cunningham, Shochet, Smith, & Wurfl, 2017; Fraser E. & Pakenham K.I., 2008). Moreover, resiliency building interventions have shown to improve depressive symptoms in young people in general (Neil & Christensen, 2007). So improving resilience can have a positive effect on the mental health of young carers.

According to several scientists, a problem of applying the resilience framework could be that this construct can be misinterpreted as representing a personal characteristic of the individual (Luthar et al., 2000). It could be perceived as suggesting that if only (A)YCs had a particular characteristic, then they could withstand difficulties. This perspective can lead to blaming the individual for not possessing characteristics needed to function well and can lead some political leaders justify limited protection to children, with the argument that children should be responsible for their own pathway through risk and towards success (Doll & Lyon, 1998). Therefore it should be clear that resilience is a process or phenomenon and explicitly clarifying that it is not a personal characteristic of the individual (Luthar & Cicchetti, 2000). In addition, following stress and coping theories, the process of resilience can cause fatigue and 'wear and tear' whenever a person is exposed repeatedly to allostatic loads.

Coping and providing (informal) Care¹³

Families and friends often form 'the backbone' of care for patients with long term health needs. Central in most definitions of informal care is that (i) the need for care is caused by health problems, disability or infirmity due to old age, (ii) caregivers¹ and care recipients already had a social relationship prior to the start of caregiving, and (iii) that, although perhaps perceived as forced by the circumstances, care is provided on a voluntary basis and usually without financial compensation. The importance of informal care is emphasised by the

¹³ This subchapter is based on 'The Impact of Caregiving - The measurement and valuation of informal care for use in economic evaluations by Renske Hoefman, 2015' <https://repub.eur.nl/pub/78028/Proefschrift-Renske-Hoefman.pdf>

fact that many caregivers lend care during several years. Informal care can be both mentally and physically burdensome for caregivers. For instance, in the context of patients with psychological disorders or in case of severe illnesses, providing care can be emotionally and mentally straining.

Care can be physically demanding when caregivers repeatedly have to perform care tasks such as helping a patient in and out of bed or with bathing and clothing. All carers (including YCs) often have to combine care tasks with other responsibilities, such as looking after their children, going to school or performing paid work. Combining these different roles can lead to additional strain. It follows that caregivers often experience diverse problems, such as stress, depression or physical health problems. In the literature, the consequences of caregiving are usually described in terms of:

- a) objective burden,
- b) subjective burden
- c) health, or
- d) well-being of caregivers.

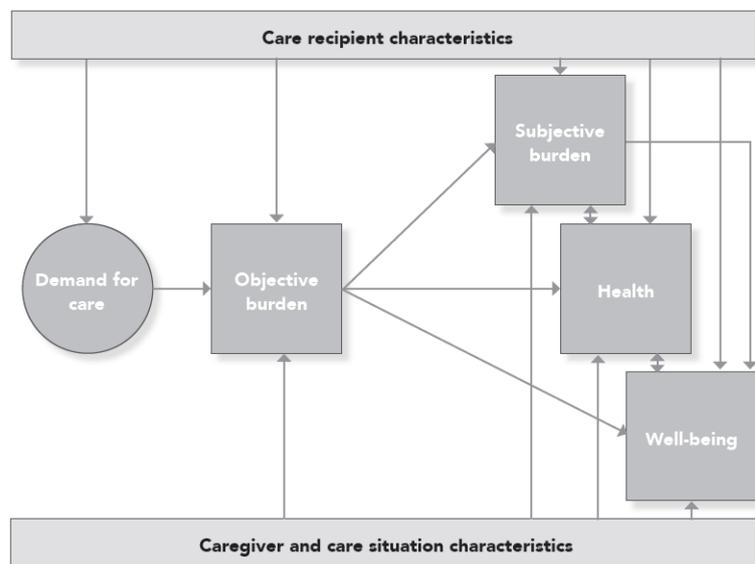


Figure 3 Conceptual model of the impact of caregiving

Figure 3 above, presents the conceptual model of the impact of caregiving on caregivers. This conceptual model is based on the stress process model of Pearlin et al. (1990) and the appraisal model of Lawton et al. (1989; 1991) and Yates et al. (1999). In this model, family and friends are confronted with a demand for care of the care recipient. The provision of informal care is described in terms of objective burden. Objective burden concerns the 'objectively' measurable characteristics, or inputs, of informal care. The objective burden of caregiving may influence caregivers' subjective burden, health and/or well-being. First, subjective burden concerns the strain from caregiving as experienced by caregivers (Brouwer et al., 2010). It is well-established that caring can be straining, even though most caregivers consider it to be a natural consequence of their relationship with the care recipient (Boer et al., 2009; Brouwer et al., 2005). The level of subjective burden that caregivers experience depends on their evaluation of the positive and negative effects of caregiving and their ability to cope with these effects (Koopmanschap et al., 2008; Van Exel et al., 2008). Examples of positive effects of informal care are improving the relationship with the care recipient, the feeling of performing a meaningful task, acquiring (management) skills, increasing knowledge of health issues, experiencing personal growth and obtaining more appreciation for everyday life (Boer et al., 2009; Brouwer et al., 2005). Negative effects of caregiving may be diverse as well and include factors such as disruptions of personal or social lives, marital problems, family conflict and social withdrawal due to caregiving (see, Brouwer et al., 2004; Chappel et al., 2002; Zegwaard et al., 2011; Al-Janabi et al., 2010; Van Exel et al., 2004; Neubauer et al., 2009; Wolfs et al., 2012; Dixon et al., 2006). Furthermore, caregivers may face financial strain or even increased risk of poverty and health consequences¹³. While some studies report certain positive health effects of caring, such as decreased depression or anxiety over time

(Beach et al., 2000), most seem to indicate that caregivers may experience considerable health problems. For example, caregivers may experience psychological symptoms, such as stress, depressive disorders or anxiety. Thirdly, studies also report consequences of caregiving in terms of lower general well-being or overall quality of life (Brouwer et al., 2005). The four outcomes of caregiving (objective burden, subjective burden, health and well-being) are influenced by characteristics of the care recipient, the caregiver and the care situation.

Whole family approach

A whole family approach is an important factor in the prevention of problems and support for young carers (Cooklin A., 2010; Frank & Slatcher, 2009; Grant, Repper, & Nolan, 2008; Nagl-Cupal & Hauprich, 2018; Schlarmann, Metzling, Schoppmann, & Schnepf, 2011). As Figure 2 shows, all four elements are inextricably connected and all have influence on one another.

A whole family approach aims to improve outcomes for the person with a health problem, reduce the burden of care for families and provide a preventative and supportive function for children. By incorporating the elements of the approach, strategies can be developed that facilitate consumer, child and family coping and strengthen individual and family resilience (Foster, O'Brien, & Korhonen, 2012).

First, a whole family approach can relieve the burden of caring (see Figure 4). When health care professionals have interest in the family as a whole, identify and develop strengths of the family, both the person with care needs as well as the rest of the family, including (A)YCs will benefit. Especially when a parent suffers from mental health problems, it is important to support the parent in being a parent. When parents are having more confidence in their role as parent, develop

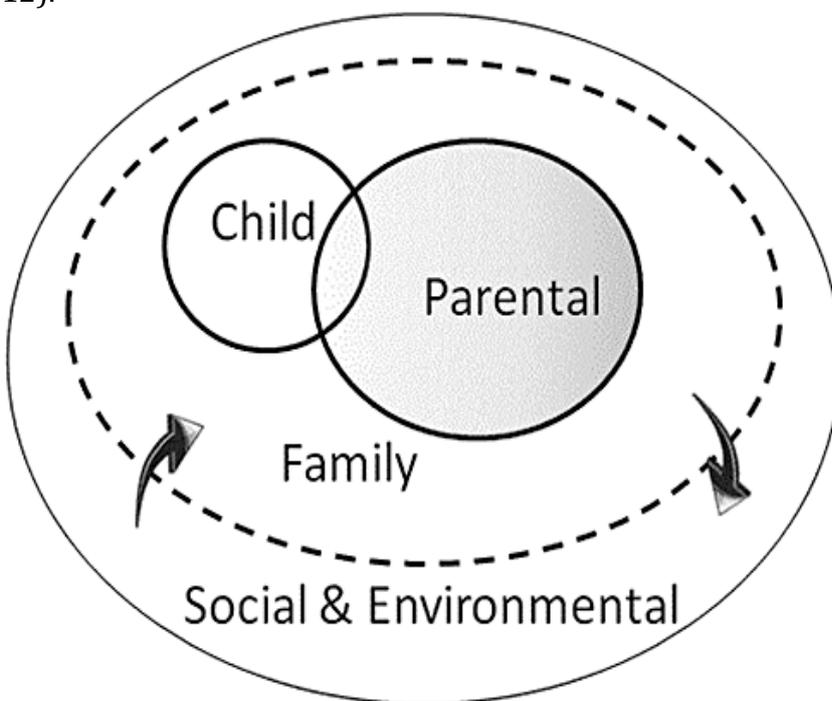


Figure 4: Family-focused care (adapted from Foster, O'Brien & Korhonen, 2012)

strengths and skills, they can recover as they find a balance between attending to their own

lives and caring for their children. When parents are recovering, (A)YCs will benefit, as they have less caring responsibilities or worries (Ende, Busschbach, Nicholson, Korevaar, & Weeghel, 2016; Foster et al., 2012).

Secondly, if the situation of the health problem does not change and (A)YCs still have the caring responsibility and/or worries, young carers do not care in isolation from the rest of their family. Although they may need support for themselves, their needs should also be considered and met in the context of their whole family. It is important to find resources within the family or nearby, which can help (A)YCs. Thence, professionals can stay at a certain

distance and (A)YCs have the chance to grow up as a normal child (Ende et al., 2016). In the family there are always resources and strengths which can benefit the (A)YC. Therefore, it is important to consider the family as a whole for the identification of these strengths as it can help in building resilience (Frank & Slatcher, 2009).

3.3 Method

We provided an overview of the theoretical model(s) of stress, coping, salutogenesis, resilience and the positive impact of the whole family approach on the well-being of (A)YCs. As previously mentioned, an open search was used with snowballing. The main academic systematic literature review focused specifically on interventions to support (A)YCs. The systematic literature search was executed in the PubMed, Psychinfo and Embase databases for articles published about young carers ((A)YCs). The search strategy involved the requirement of MeSH terms or words in title or abstract relating to (1) young carers and (2) interventions or support programs. An initial search strategy was revised after pilot testing for accurate identification on (A)YCs. An expert of the VU Amsterdam Library conducted the search (see Appendix 2 for search terms for the academic literature review searches)

Two team members (LL and NJ) of the MEWE project screened all titles and abstracts for possibly relevant articles. In this first round, articles were included if the population were young carers under the age of 24 and when the paper was written in English or Dutch. After this first round, we decided to make more strict exclusion criteria, as the first round of title/abstract screening resulted in a large amount of papers (n=200), of which many were not related to interventions or support programs. The second round of title/abstract screening we focused on whether the paper was *evaluating* an intervention or support program. If this was the case, the paper was included for full text assessment. The full text assessment was executed by three researchers (MB, AW and NJ). In this phase the studies were only included if there was an evaluation of an intervention mentioned (see figure 3 below).

3.4 Results

The search in the digital libraries was conducted in August and September 2018. The searches resulted in 2,603 unique articles of which 200 were about young carers. In the second round of title/abstract screening focusing on the interventions and support programs, we retrieved 57 papers for full-text assessment and in total we included 15 articles in the final review (see Figure 3 below). The reasons for exclusion are listed in Table 3 below and in Appendix 3.

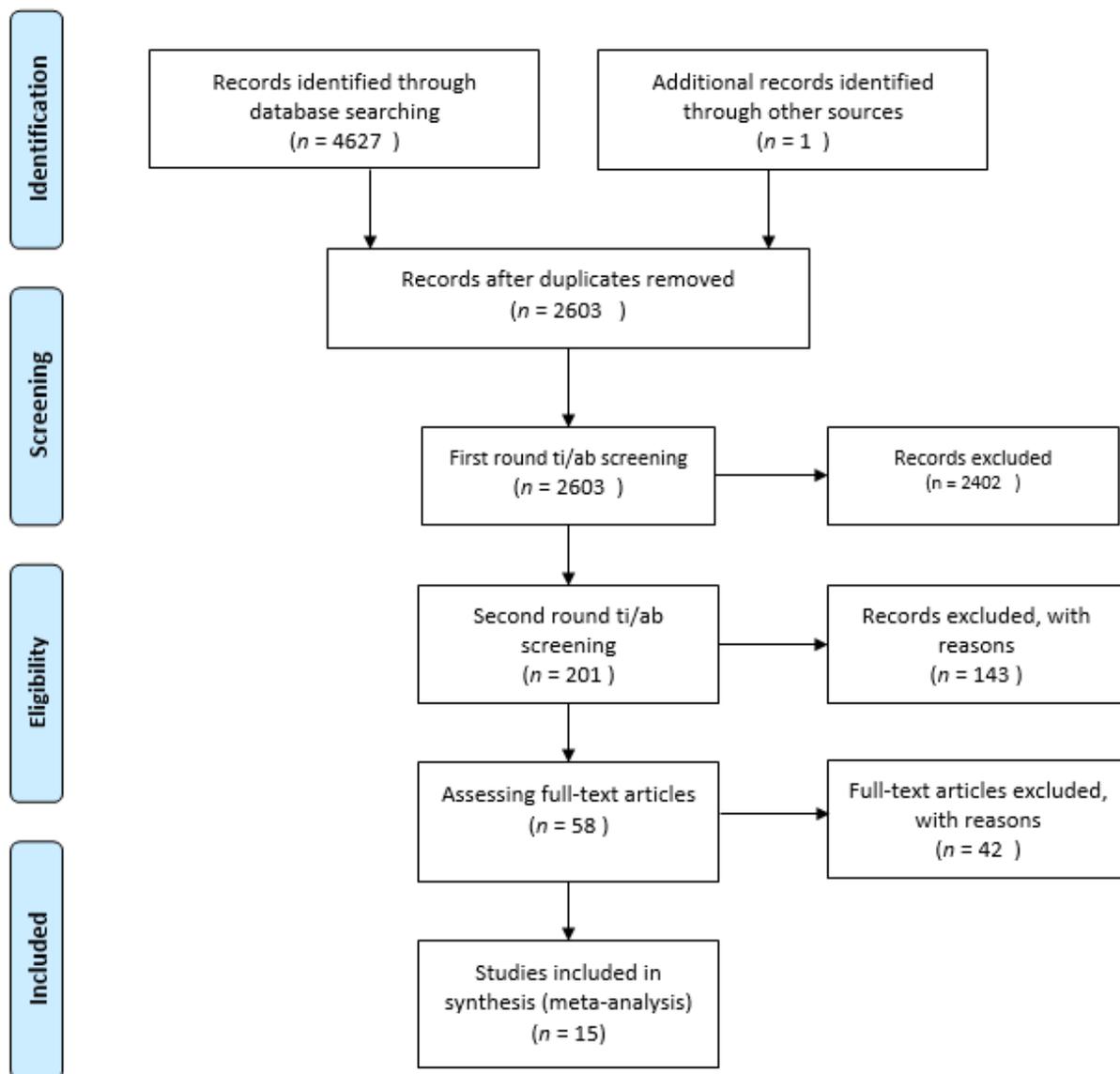


Figure 5: Flow chart of the empirical literature review process

Interventions

The 15 included articles evaluated different types of support programs or interventions. Details were also provided of the research method, the type of illness of the family member and the relationship with the ill family member (see Table 3). In this chapter, the papers are structured and discussed by means of the type of intervention which has been evaluated.

Table 3: Description of included articles

Publication Author	Country	Intervention/support program for young carers & theory	Illness family member	Relation ship with family member	Research method
1) A., Cooklin, 2006 2) A., Cooklin, 2010	UK	'Kidstime' project Using a family focused approach. Whole family approach	Mental health problems	Parent	No method section. Evaluation by means of data from questionnaires of the organization?
3) Schlarmann, Metzging, Schoppmann and Schnepf, 2011	Germany	Creating support program for (A)YC and their family. Young carers project 'SupaKids' Whole family approach	Somatic illness	Parent	1. problem-oriented interviews with a) children (n=5), b) parents (n=4) and c) project staff (n=4), focusing on their experiences with the project. 2. extensive case-files of every family, as recorded by the project's staff (social workers, family-health nurse) 3. participatory observation during the young carers groups, focusing on how the children behave in the group.
4) Grant, Repper and Nolan, 2008	UK	Bernando's Active With Young Carers (AWYC) project Whole family approach	Mental health problems	Parents	Face to face interviews with (A)YCs N=10
5) Coles & Pakenham, 2007	Australia	6 day camp intervention; 'Fun in the Sun- camp' 1) 8 group sessions providing education about MS, opportunities to share experiences and training in coping strategies and life skills. 2) Recreational activities (e.g. visiting themepark, boating, minigolf) Fun activities, trainings and psycho-education, based on coping and resilience theory.	Multiple Sclerosis	Parent	Questionnaires for both (A)YCs (n=20) and parents (n=14) pre- and post-intervention.

6) Richardson, Jinks and Roberts, 2009	UK	Crossroads young carers' project. Fun activities, trainings and psycho-education with a focus on building resilience.	Unspecified	Unspecified	Three focus groups with (A)YCs were held and analysed N=24
7) Cunningham, Shochet, Smith & Wurfl, 2016	Australia	An innovative resilience-building camp for young carers. Adapted from the Resourceful Adolescent Program (RAP-A). Fun activities, trainings and psycho-education with a main focus on building resilience.	Chronic illness or disability	Parents, siblings or grandparents	Semi-structured telephone interviews with (A)YCs were conducted 1 month after the camp. Thematic analysis of the data. N=15
8) Fraser & Pakenham, 2008	Australia	Group psychosocial intervention Adolescent Group Program (KAP) Support groups, based on resilience.	Mental health problems	Parent	Treatment and waitlist-control design. 8 week follow up. Treatment: n=27, control: n=17 N=44
9) Barrera, Atenafu, Schulte, Nathan, Hancock and Saleh, 2018	Canada	Siblings Coping Together (SibCT) Support groups, based on coping and self-efficacy theories.	Cancer	Siblings	Randomized controlled trial (RCT) with 2 arms/groups: SibCT (n=41) and a control group (n=34). N=75
10) Gettings, Franco and Santosh, 2015	UK	Sibling support group/audio conference; Support groups	complex neurodevelopmental disorders	Siblings	Longitudinal design, pre- and post-intervention questionnaires and interviews thematic analysis N=6
11) Ali, Krevers, Sjoström & Skarsater, 2014	Sweden	Intervention: Web-based support Co-intervention: Flyer Support groups, with a focus on reducing stress and increasing well-being.	Mental health problems	Parent	RCT. Randomly assigned to folder (n=120) or web based information (n=121). Stress and well-being were measured with validated scales. N= 241
12) Elf, Rystedt, Lundin and Krevers, 2012	Sweden	Web based support system Support groups	Mental health problems	close friend, partner or relative	Interviews with (A)YCs, content analysis N=8

13) Elf, Skarsater and Krevers, 2011	Sweden	Web based support system Support groups, based on coping and stress theories.	Mental health problems	close friend, partner or relative	Interviews with (A)YCs, content analysis N=12
14) Kavanaugh, Howard and Banker-Horner, 2018	U.S.	Training protocol Support group	ALS	Family member	Peer group experiential young caregiver model based on theories of self-management and self-efficacy, N=6
15) McAndrew, Warne, Fallon and Moran, 2012	UK	World café Event Support group	Mental health problems	Parent	No specific method section Methodological approaches most closely associated with participatory qualitative research. The age range of these young people was 13-17 years of age.

3.4.1 Whole family approach

In the following three interventions the whole family has been involved. All these interventions reported a positive influence of the available parents and/ or siblings also being part of the intervention.

Kidstime project

The Kidstime project is developed in the UK and evaluated by means of discussions with the young carers over the past 5 years (Cooklin A., 2010). The Kidstime project designed to introduce family thinking into the practice. Kidstime workshops are monthly events for children and their parents. The workshops are run by a combination of mental health, social care and voluntary workers and last 2.5 hours after school. The workshops begin with a short seminar for the children and parents together, in which some aspect of mental illness, or questions about it, are discussed. This is followed by separate groups for the children and for the parents. The children's group starts with games and warm-up exercises, then the children tell stories about family life. They are helped by a drama teacher to make theatre plays of it. At the end parents and children gather as a single group to eat pizza and watch the filmed plays. Finally, there is a group discussion of what the children have produced and of issues raised in the parents' group. The importance of this project was that it included both parents and the children. The project aims to (i) have a better understanding about the illness, including young carers own ideas about the cause of the illness, and access to information, (ii) learning how to recognize the signs of an impending illness, (iii) issues to do with hospitalization, (iii) advice about management of the illness, including coping with the effect on themselves as well as on their parent (Cooklin A., 2009).

SupaKids

SupaKids is a young carers project which was implemented in 2009 in a large German city. The aim of the project was to focus on supporting enrolled families to prevent negative effects. The project contained several modules. Firstly, having someone to talk to. This was covered with counseling for children, counseling for parents and family conferences. Secondly, support for children. Therefore, leisure time activities were organized. Also, information and education about illness and care were provided, included a first-aid course. Besides, a schoolwork-assistance was offered. Lastly, support for parents was offered in a breakfast for parents, administrative support and counseling, flexible help with everyday life activities and family festivities. The program has been evaluated by means of interviews with (A)YCs, parents and project staff. Besides the interviews, case-files were evaluated, and observations were carried out. (A)YCs were observed on how they behaved in the group. Both parents and children perceived the project as a shelter where they are among others allowed to be as they are, don't have to explain themselves, meet others in similar situations, deposit their sorrows, have a first port of call for any problem, experience a hiatus from the domestic situation, and find friends and peers. All enrolled families value this shelter as a copious relief. The family orientation seems to be appropriate. The project relieves the entire family (Schlarmann et al., 2011).

Bernando's Action With Young Carers (AWYC) Project

Bernando's is a social welfare organization, which organizes (A)YCs projects. Within this project a child- and family centered approach is used. The AWYC project contains several

activities; family-centered work (e.g. help for the 'looked after' person, mediating family conflicts), one-to-one work (problem-solving, surrogate parents, laid back and fun), group work (forming friendships, respite, outside recognition). The evaluation of this project has been carried out by means of face-to-face interviews with (A)YCs ($N = 10$), caring for a mother with mental health problems.

First of all, the findings indicate that, despite their vulnerability, young people supporting mothers with mental health problems have agency and can clearly articulate and reflect on their experiences. However, it has also been demonstrated that when these youngsters initially present themselves to a project like the AWYC, this is not always the case. As some have admitted in telling the stories of their experiences, it can take months to build up the confidence to speak more freely about their lives, and to convince themselves that they are not betraying family secrets about mental health in disclosing their experiences to project workers (Grant et al., 2008).

3.4.2 Fun activities, trainings and psycho-education

In the interventions listed in this paragraph, training and psycho-education have been combined with fun activities. Activities in which (A)YCs do not have to think about their home situation, helps to take their mind off their home situation and improves the bonding with other (A)YCs, besides the group sessions of peer support and/or psycho-education (Richardson, Jinks, & Roberts, 2009).

Fun in the sun-camp

In Australia the 'Fun in the sun-camp' is developed, implemented and evaluated. This camp is a 6-day camp intervention for children of parents with Multiple Sclerosis. The camp has two elements, (i) 8 group sessions providing education about MS, opportunities to share experiences and training in coping strategies and life skills. The group session program was adapted from an Australian treatment protocol developed by Nesa and Strohm (2004) called Groups for Siblings of Children Who Have Special Needs. (ii) recreational activities (e.g. visiting a theme park, going boating, pool games or minigolf). The camp has been evaluated by means of a single group, longitudinal design. (A)YCs ($n = 20$) and parents ($n = 14$) completed questionnaires for both pre- and post-intervention and approximately 3 months after the intervention as a follow up. The results of these questionnaires show significant decreases in distress, stress appraisals, caregiving compulsion, increases in social support and knowledge of MS. The most frequently reported form of assistance gained from the camp by children and parents was an increased knowledge and understanding of MS. Findings offer preliminary support for the use of a stress- and coping-based intervention for supporting children and their families with parental MS (Coles, Pakenham, & Leech, 2007).

Crossroads young carers' project

In the UK, Crossroads organizes young carers projects. The goals of the Crossroads projects are; to offer respite, recreation and peer support. The project contains: fortnightly club night, meeting other (A)YCs, have fun, learn that you're not alone. One to one: talk with someone (volunteer/professional) of Crossroads, in complete confidence. Trips out: Days out during the school holidays (e.g. Thorpe park, Joss Bay). Information and advice about getting the help you need and about the illness.

The Crossroads projects have been evaluated by means of three focus groups ($N = 24$). Participants aged 11-16 years. Participants were drawn from the membership of three different Crossroads young carers' projects groups in the Merseyside area. There was an even split of boys and girls participating in the focus group discussions. The majority were aged 13–15 years; most helped to look after their mother, and they were not the only carer involved. Analysis of the focus group data revealed five main data themes: the experiences of being a young carer; peer support; opportunities for time out; purposeful activities; and practical issues. The value of peer support became clear, the common affinity of being a carer. Knowing that there are other young people sharing a common experience was found to be an important support mechanism (Richardson et al., 2009).

Resilience-building camp

In Australia a 3-day camp has incorporated the aspects of the Resourceful Adolescent Program (RAP-A). The overall aim of RAP-A was to build upon existing resources and strengths of (A)YCs, increase their resilience and help them to manage difficult situations. The RAP-A program has been combined with recreational activities, such as circus workshops, campfires and sports.

The camp has been evaluated by means of a semi-structured telephone interview. The interviews were transcribed and analyzed with the use of thematic analysis, to identify key themes. Two themes came forward: (i) *coping self-efficacy* with three codes; affect regulation, interpersonal skills and functioning and confidence and recognition of strengths social benefits and (ii) *social benefits* with two underlying codes; opportunity for respite, opportunity for social engagement.

Overall, this study provides preliminary evidence that young carers perceived a resilience camp based on RAP-A to be engaging and enjoyable and that they believed that they experienced benefits from attending. The results of this study suggest that the camp format raised a sense of connectedness and social engagement for participants and provided respite. The camp format also ensured participants could attend the sessions in their entirety, thus maximizing the opportunity for programme engagement and effectiveness. Indeed, participants reported developing a range of new skills through their participation in the RAP-A sessions. A combination of the camp setting, specific focus on young carers and the strengths-based nature of RAP-A may have contributed to young carers feeling that their challenges were validated, and the unique circumstances of their lives recognized, acknowledged and understood by their peers and the facilitators. These preliminary insights into young carers' perceptions of an innovative resilience-building camp provide guidance for future programmes that aim to create and measure meaningful improvements in well-being for young carers (Cunningham, Shochet, Smith, & Wurfl, 2017).

3.4.3 Support groups

Peer support groups are a way of sharing experiences and helping one another which leads to an increase in resilience and decreased feelings of loneliness (Gettings, Franco & Santosh, 2015; Grant, Repper & Nolan, 2008). There are several ways support groups are being organized. In our search 4 different kinds of organizing peer support are mentioned. Namely; face to face, via the web or via audio conference.

Koping Adolescent Group Program (KAP)

Adolescent Group Program (KAP) is a peer support intervention for adolescents with a parent with mental illness (copmi) aged 12-18 years. KAP adheres to a resilience framework, and consequently is designed to improve adjustment outcomes for copmi by modifying risk factors such as social isolation and inadequate mental health literacy and by strengthening protective factors such as an adequate repertoire of coping skills and intact peer relationships. To evaluate the intervention a waitlist-control design study with a pre- and post- treatment, and 8 week follow up, was carried out. The treatment (n=27) and control (n=17) groups were compared on three variables: (i) intervention targets, (ii) adjustment, (iii) caregiving experiences (Fraser E. & Pakenham K.I., 2008).

Group comparisons failed to show statistically significant intervention effects. However, the reliable clinical change analyses suggested that compared to the control group, more intervention participants had clinically significant improvements in mental health literacy, depression, and life satisfaction. These treatment gains were maintained 8 weeks after treatment. Participant satisfaction data supported these treatment gains. Given the modest support for the effectiveness of KAP it is important that this and other similar interventions continue to be revised and undergo rigorous evaluation (Fraser E. & Pakenham K.I., 2008).

Siblings coping together (SibCT)

SibCT is a program which is developed in Canada. It is a manualized intervention consisted of cognitive-behavioural, problem-solving sessions, using role-playing, arts and crafts, games, group discussions, and homework, planned around specific themes. The intervention has been evaluated by means of a randomized controlled trial with 2 arms. SibCT (n=41) and the control group (n=34).

No main effects of group or time were found in sibling scores. A group \times gender interaction ($P < .05$) indicated that in the intervention group female siblings reported less total anxiety symptoms than male siblings, with no significant gender differences in the control group. Caregivers' total anxiety symptoms declined over time ($P < .02$). A group \times on/off treatment interaction in physiological/panic subscale ($P < .03$) indicated that when an ill child was on treatment, caregivers of siblings in SibCT reported less anxiety compared with caregivers of the control group. There was no clear SibCT intervention effect. SibCT may benefit female siblings, and caregivers whose ill child is on active treatment. Contextual factors (e.g. gender) seem to influence psychosocial intervention in this population (Barrera M. et al., 2018).

Audio conference

To overcome travel distances, audio conferencing for young carers has been studied as a different way of peer support than face to face. In this study, 6 siblings of children with complex neurodevelopmental disorders were participating. Four one-hour weekly sessions were held face-to-face and the other four using audio-conferencing. Pre- and postintervention questionnaires and interviews were completed and three to six-month follow-up interviews were carried out.

This study demonstrated that audioconferencing is a feasible and effective means of facilitating sibling support groups to overcome geographical barriers to accessing support. Siblings' social network widened, and problem-solving skills were cultivated, thus enhancing protective factors for strengthening resilience (Gettings, Franco, & Santosh, 2015).

Web-based support system (WBSS)

Three studies from Sweden reported about different stages of the development of a web-based support system for young carers. Web-based support could offer strategies for finding social support in a low threshold and it could reduce time spent searching the internet for information and resources. All the three studies focused on (A)YCs caring for a relative or close friend with mental health problems.

Firstly, Elf, Skarsater & Krevers (2011) gained knowledge about the specific needs that a web-based support system for (A)YCs must meet. The authors conducted interviews (n=12) to answer the question of which needs must be met. The results could be organized in three themes; knowledge, communication and outside involvement. For (A)YCs, learning about different aspects of their own situation, sharing experiences, and getting advice may be valuable tools to survive everyday life. Round-the-clock availability and the possibility to be anonymous can ease use and contact.

Virtual contact may, however, not be enough. Several (A)YCs interviewed in this study also wanted to get in touch in real life, and sometimes they also needed health care or social care to offer direct help. Although web-based support cannot deal with such needs, it can facilitate them (Elf, Skarsater, & Krevers, 2011).

With the results of their first study in mind, Elf, Rystedt, Lundin and Krevers (2012) continued with a second study, in which they developed, in co-design with young carers, a web-based support system. In this study the aim was to discover (A)YCs views of designing a WBSS directed to them. Participatory design was used as a method to support a process of democratisation and empowerment and to design an artefact of high usefulness and compliance to the needs of young carers. The four themes that were revealed, led to the key parts in the design of the WBSS: (i) communicating the message, (ii) ideational working principles, (iii) user interaction and (iv) user interface. The study also suggests that early user involvement and critical reflection in the design process itself may be crucial to discern differences in perspective between designers and users (Elf, Rystedt, Lundin, & Krevers, 2012).

Lastly, Ali and colleagues (2014) conducted a randomized controlled trial, which compared the impact of an intervention and a co-intervention, respectively: a web-based support and a folder support for young carers who care for a relative suffering from mental illness. The website provided access to asynchronous information; concrete advice; tips about taking care of themselves, where to turn to for help, how to know when it is time to seek help and information about mental illness. The co-intervention group received a folder with information on both sides of 24 different kinds of available support services in the community or society. In the RCT, 241 (A)YCs participated, the (A)YCs were randomly assigned to a folder or WBSS. Stress and well-being were measured with validated scales. No significant differences in stress level between folder/web-based information. Both groups showed high stress levels at baseline but decreased significantly in the folder group. The web group showed an increase in well-being. Each intervention can be effective, depending on individual preferences. This highlights the importance of adopting a person-centred approach, in which young persons can choose a support strategy themselves (Ali, Krevers, Sjostrom, & Skarsater, 2014).

Young carers skills training model

The training model is a program developed for (A)YCs with a family member who has amyotrophic lateral sclerosis (ALS) or motor neuron disease. It is aimed to develop skills in a peer based, multidisciplinary setting, based on prior (A)YCs request for peer support and normalizing experiences. It comes from the knowledge that the well-being of adult carers increases as they develop skills and knowledge. The hypothesis is that this will be the same for (A)YCs.

The training lasted one day and contained several skills, such as communication, basic care and assistive devices. The training was evaluated in between each module, during the check in sessions. The post final evaluations assessed overall and had suggestions for future programs. The training model is found feasible for both youth and therapists. Youth found benefit, skill acquisition, and mastery by asking questions, teaching basic skills to the group and engaging with peers. This project demonstrates young caregivers will participate in training and engage with "like" peer group. Future projects will focus on developing a structured survey and observation, testing efficacy in larger groups (Kavanaugh, Howard, & Banker-Horner, 2018).

World Café Event

The World Café event is a participatory project aimed at better understanding of the needs of young people. The World Café event provides a platform to create important opportunities for collaboration between young service users and carers, the voluntary sector, health and social care practice, and education. Key objectives of the event encompassed exploration of opportunities for future collaboration in promoting greater understanding of the mental health needs of young people, strengthening representation of young service users and carers with mental health needs within our School's overall participation strategy, and further the research agenda for young people whose mental health might be or is compromised.

Four topics came up from the young carers presentation: (i) stuck in the here and now, (ii) ignoring the future, (iii) a hole in the net and (iv) ensuring the hidden. The audiences' response reflects issues that have arisen in previous literature relating to the impact of being a young carer on one's mental health. The implications of this impact for health and social care professionals should not be underestimated. The complex challenge in addressing the needs of young people caring for a parent and/or significant other with a severe or chronic illness can be overwhelming in terms of their mental well-being (McAndrew, Warne, Fallon, & Moran, 2012).

3.5 Discussion

It is clear that the topic of young carers is gathering increased attention within the empirical literature. From the electronic database searches, 201 studies focused on young carers. However, most of these studies described the case of young carers and what the risks are of being a young carer for their own mental health and development. In this current study, 15 papers were included which involved studies that evaluated an intervention or a support program for (A)YCs.

Methodological quality

Most of the identified studies were of a low methodological quality. For example, some studies were lacking a method section and most of the studies had a relatively small convenience sample ranging from 6 to 12 approximately. A lot of the conclusions mentioned preliminary findings and suggestions for more research as the results did not provide enough power to make conclusions. We identified at least three studies which were performed with scientific rigor and were methodologically sound. First, the study of Fraser and Pakenham (2008) on a group psychosocial intervention Adolescent Group Program (KAP) with a treatment and waitlist-control design. Second, the study of Barrera, Atenafu, Schulte, Nathan, Hancock and Saleh (2018) on the Siblings Coping Together (SibCT) support groups. They performed a randomized controlled trial (RCT) with 2 arms, and the study of Ali Krevers, Sjoström & Skarsater (2014) on the difference between a web-based support intervention vs a co-interventive (flyer), also using a RCT in which (A)YCs were randomly assigned to two groups. At least three of the studies (in)directly built on resilience theory and how to strengthen resilience among (A)YCs (Richardson, Jinks & Roberts, 2009; Cunningham, Shochet, Smith & Wurfl, 2016; Fraser & Pakenham, 2008). In addition, two studies focused on developing self-efficacy and reducing stress by means of introducing different coping strategies and expanding the social network (Barrera, Atenafu, Schulte, Nathan, Hancock & Saleh, 2018; Elf, Skarsater and Krevers, 2011).

Target group

Most of the studied interventions focused on one particular target group. For instance; young carers with a parent with a mental health problem, or a young carer who is a sibling of a child with special needs. Seven of the 15 publications focused specifically on (A)YCs of a parent with mental health problems. Six studies focused on physical illnesses. The physical illnesses are more specified to young carers with a family member suffering from cancer, ALS or MS. The choice to focus on one specific illness is made, because an organization for patients with ALS or MS is offering or supporting the intervention. It is known that (A)YCs like to have contact with other (A)YCs, preferably with the same age category. But whether they like to come in touch with the (A)YCs with the same illness in the family is unknown. In the case of ALS, (A)YCs mentioned that it is sometimes confronting to be around other (A)YCs with ALS in the family, as it gives them an example of how worse the illness can become (Kavanaugh et al., 2018).

Practical implications for the ME-WE project

Several points from the academic literature review are relevant for a successful implementation of the ME-WE intervention and mobile application. First, awareness must be raised, and the stigma must be reduced. (A)YCs do not recognize themselves as (A)YCs and do not actively seek help or support. Also, family members protect one another because they are afraid to be split up as a family when professionals see what is going on in the family. This is especially the case in families with a parent with mental health problems (Cooklin A., 2010). Health care professionals, school teachers and social workers can play an active role in identifying (A)YCs, reducing the stigma by means of classes on (A)YCs and supporting the whole family (Schlarmann et al., 2011). When this first step has been taken, the intervention has a higher chance of being successful. The intervention itself should have a component of peer-support. In almost all the evaluations of the included studies this is one of the points (A)YCs continuously mentioned, when they are asked what they like about the intervention;

to come into contact with other (A)YCs, notice that you're not alone, receive and give support to peers. This peer-support can take place via the web, teleconferences or face-to-face.

A mobile application can be a suitable way of connecting (A)YCs. A prerequisite is that this application is developed in co-creation, otherwise there is the risk that (A)YCs will not use the app (Elf et al., 2012). Also, there should be a form of face-to-face contact as well, (A)YCs want to know with whom they are having contact (Elf et al., 2011). In all studies it is clear that (A)YCs have a high feeling of responsibility, they are very mature, so what is important is that they also have the chance to be a child or adolescent instead of the wise adult. Therefore, peer-support should not only contain psycho-education and psychotherapeutic training of coping strategies or resilience, but also contain fun activities, offer respite and let (A)YCs think of something else other than the caring situation at home (Coles et al., 2007; Cunningham et al., 2017; Richardson et al., 2009). Besides the focus on peer support, a whole family approach is found to be an important factor in the literature. It makes the life of (A)YCs and the life's of the whole family better, if everyone is being supported and not only the (A)YC (Grant et al., 2008; Schlarmann et al., 2011).

The academic literature review provided an overview of the range of interventions and programmes targeted at (A)YCs within the empirical literature and the current 'state of the art' in the field. The following chapter will focus on three further review activities. Namely, a general review and two social media analyses with a specific focus on YCs' needs and preferences with respect to (online) support.

4. General Literature Review and Social Media Analyses¹⁴

4.1 Introduction

In addition to the academic literature review presented in the previous chapter, three other reviews were performed by MSc students¹⁵ and supervised by Vilans and SCP. First, a general literature review was performed consisting of a further – shorter – academic literature review, a review of the grey literature and preliminary social media analysis (see 4.1). Second, a general social media analysis was performed (see 4.2), and third we present the summary of a country specific social media analysis which was performed focusing on interventions in The Netherlands (see 4.3). In order to help inform the ME-WE project in this chapter we focus on the selection of a number of relevant results from all three reviews. The chapter concludes with with an overall discussion of the results (see 4.4). The full reports can be downloaded from¹⁵.

4.2 General Literature Review

4.2.1 Introduction

A systematic review was carried out to search for scientific publications and ‘grey’ literature available in the area of YCs, and a preliminary social media analysis. Inclusion and exclusion criteria were set out and search concepts were defined in Dutch and English. Besides the scientific literature study, a search was also carried out of the grey literature. The search engine Google was used, using the same inclusion and exclusion criteria as in the scientific review. Furthermore, a social media analysis was performed to gain insight into the level of awareness and various types of support that are offered and shared via social media.

The main goal of the general literature review is to gather insights into the current knowledge on YCs and the strategies they use to cope with their situation based on an academic search, a grey literature search and a preliminary social media analysis. The focus lies on YCs aged 12 to 25 years. The goal and focus leads to the following research question:

What recommendations can be made for a technology that aims at supporting young carers?

Sub-questions:

- *What strategies do young carers use to cope with their role as an informal carer?*
- *What needs for support and respite do young carers have?*
- *Which formal ways to support them already exist in western countries, with a focus on the UK and Australia?*

¹⁴ See deliverable contributors for authors of the literature studies (beginning of Deliverable)

¹⁵ The full reports were deemed by the internal reviewer, Q & I Manager and PI to be too lengthy to be included in the main text and the full report and appendices can be downloaded from: <https://www.dropbox.com/sh/seqa437te52xwxs/AAAbrKkQLX-6JPPPgpGQ-Sxba?dl=0>

- *How do social media, websites, and online fora support young carers?*

4.2.2 Method

Scientific literature, 'grey' literature, and social media were reviewed with a focus on young carers, their coping strategies and supportive services. The systematic review was conducted in March 2018 using the SpringerLink, PubMed, ERIC, Web Of Science, ACM Digital Library, PsycARTICLES, Google Scholar, and PsycINFO scientific databases with combinations of keywords including 'young carer(s)', 'informal young carer(s)', 'adolescent young carer(s)', 'young caregivers', 'eHealth', 'strategies', 'intervention', 'coping strategies', 'Agnes Leu', 'Saul Becker', and 'support'. For the purpose of the MSc students' assignment, the focus was on the Netherlands, the UK and Australia as these are countries are deemed to be further ahead in terms of awareness and legislative, policy and support for young carers (Leu & Becker, 2016) and were therefore taken into account as well in the systematic review of scientific literature.

Grey literature included all information that was not found via the scientific databases named above. This part of the research was, however, not performed systematically and focused predominantly on the Netherlands. Websites of organisations, work from professionals and mobile applications were found with the use of search engine google. News websites were accessed, web sites of research institutes (Vilans, SCP, NJI, Universities, EC), bureaus for advice in long-term care and youth studies, client organizations, and regional and national policy/government websites. Among others, the self-efficacy theory (Bandura, 1977) and cognitive activation theory of stress (Ursin & Eriksen, 2004) was explored for understanding the relationship between wellbeing, self-efficacy, and cognitive functioning, within the theoretical and conceptual framework of the project. Moreover, a research on YouTube, Facebook and Twitter was performed. Different search terms were used and the number of hits were recorded (see¹⁶).

With the initial academic search, a total amount of 2150 articles were obtained. The number of hits that were acquired with each search criterium in the databases were noted down schematically. The first 25 articles of each database were reviewed and filtered based on their title and abstract. The number of articles was also narrowed down by prioritizing articles that were published after 2010. However, some articles published prior to 2010 were still considered relevant, since these seemed to be useful and there was no newer alternative to be found at the time. Prioritizing did also not apply when searching for relevant theories, as they were mainly established in the 1970s. The 67 articles that remained after filtering were reviewed by abstract by groups of two people with the use of a template that had to be filled in, which can be found in Appendices. The two people reviewed each article individually, in order to reduce bias.

The template contained questions such as: 'Is there a reason to exclude the paper from further analysis?' and 'How relevant is the article with respect to the research question?' Groups of two people discussed their findings with each other, in order to give a judgement on whether or not to include an article, according to its relevance. All results were bundled together and the findings were discussed with the entire group. It was decided to keep all articles that were marked a 3 or higher and leave out the rest, because these articles were either not relevant,

¹⁶ <https://www.dropbox.com/sh/seqa437te52xwxs/AAAbrKkQLX-6JPPPgpGQ-Sxba?dl=0>

written in a language other than Dutch or English, or had an inaccessible full text. The remaining 45 articles were divided over the group. Each group member extracted information from the articles on the following subjects: ‘general young carers’, ‘coping strategies’, ‘needs of young carers’, ‘existing support’ and ‘ideas for support/recommendations’. It was decided that general information about young carers would be summarized in the introduction and the rest of the subjects would be part of the results. A distinction has been made between support in the Netherlands and support abroad, in which grey literature has been used to find examples of informal support in the Netherlands.

4.2.3 Results

A total of 37 articles, books and websites are included in the review. The articles were published in 22 different scientific journals. The most common journal was *Journal of Youth Studies*. For a schematic overview of the results see Figure 6 below.

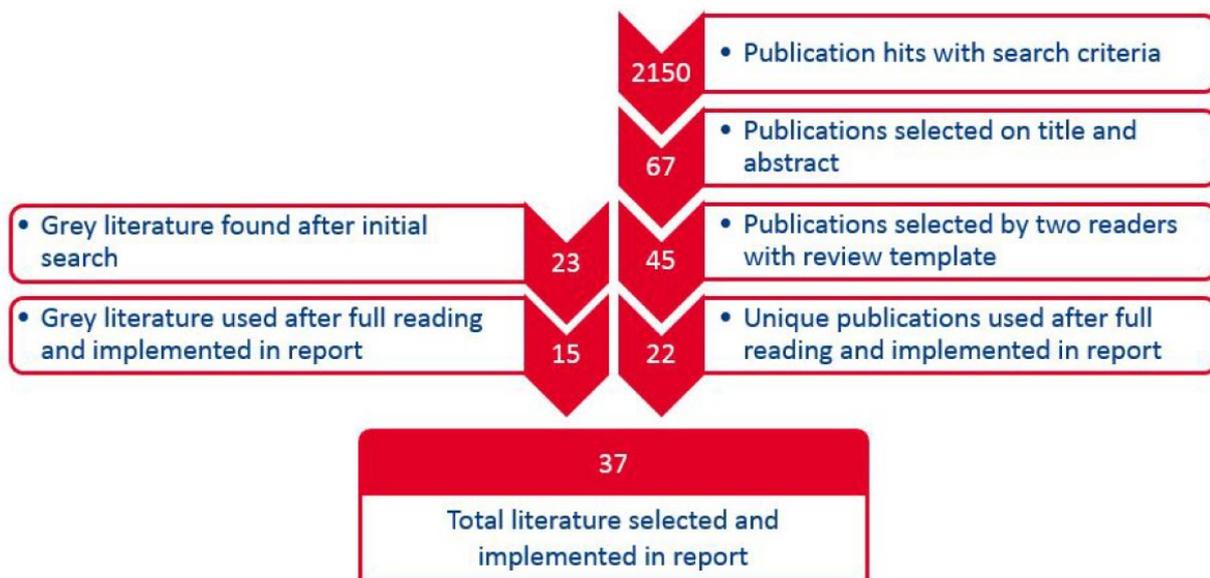


Figure 6: Flow diagram of study selection process.

In respect to the **needs of YCs**, it appeared from the academic literature review that some studies have identified the need for someone who is experienced and who gives advice and encouragement to informal young carers (Ali, 2013; Joseph et al. 2009). It is important for young carers to be “noticed”, instead of having to reach out themselves (Ali, 2013). Most policies are aimed at the patient, and the carer consequently feels ignored (Ali, 2013). This is the case – according to one of the studies - for young informal carers in Sweden, who according to the study do not feel encouraged to seek help. Policies should undertake a joint approach towards preventing the high care-taking demands (Aldridge, 2008). Young carers are in need of support services for themselves and for the people they care for (Purcal et al. 2012). Ali (2013) has divided the needed social and care support into two categories; emotional and instrumental support. Emotional support is aimed at dealing with stressors like sadness, loneliness, and anxiety. Care (instrumental) support is aimed at relieving the care duties of young carers. Horrell et al. (2015) have identified more specific individual needs:

- Having access to appropriate information
- Knowing what their patient's needs are
- Having free time which they can spend on their own interests and on friends
- Less common: support to safeguard themselves against abuse
- Less financial strain
- A longer period of time away from their responsibilities as respite

Most of these can be categorized as instrumental support needs. Respite has been mentioned as a desire for young carers in another study as well (Joseph et al. 2008). They would like to have a temporary relief from their responsibilities. Adolescent young carers are also often isolated from their peers and are therefore in need of social integration (Gray et al. 2007). Additionally, this group of young people already experiences a stressful transition to adulthood due to studying and moving out.

To **support** YCs in their caregiving role, there are already some existing support services. Many of these support services are found in the UK and Australia (Day, 2015). Other papers, Stamatopoulos (2015) and Purcal et al. (2012) for example, also confirm that the UK and Australia are very much focused on young carers. This section aims to give an idea of what support services already exist in these leading countries in the field of identifying and supporting YCs. In doing so, a summary of several analyses of these two countries is given below. Additionally, the results of a study on supporting carers through social media and a study on supporting caregivers through telehealth are presented.

Support in the UK

In the UK, there is a widespread national awareness and recognition of young carers due to advanced young carer movements (Stamatopoulos, 2015). The government provides information about the rights that young carers have and what resources are available to them. For example, there is a phone line called 'Childline', that young carers can call to speak to someone about their issues and they will be given advice and support. Furthermore, Stamatopoulos (2015) found that collaborations between charities, policy makers, and school officials have led to the development of a Young Carer ID: an officially recognized young carer identity, which informs adults about their added responsibility and makes it easier for the young carers to ask for deadline extensions in school, for example. But what really makes the UK stand out, according to Stamatopoulos (2015), is the amount of nationally dispersed social service projects for young carers that "remains unmatched by any other country", with more than **350** dedicated young carer projects serving approximately **30,000 young carers** and employing hundreds of workers and volunteers.

Among these targeted interventions are leisure and respite activities offering young carers a break, such as group outings and summer camps (with a nationwide 'Young Carers Festival' organized by the Children's Society), but also more help-based workshops designed to counter some of the educational and emotional difficulties that young carers face. As also described in the academic literature review before, one of the projects in the UK that supports young carers specifically, described by Grant et al. (2008), is the Barnardo's Action With Young Carers (AWYC) project in Liverpool. This project focuses on young carers up to the age of 25, so this includes young adult carers as well. The AWYC project placed a high value on building close and trusting relationships with each young person to help them feel relaxed, valued and free to talk about their needs, hopes and anxieties. 'Just talking' helped a lot for the

young carers. They knew they could talk about anything, while their privacy was secured. Furthermore, the AWYC project provides texting possibilities to contact and speak to project workers, group work activity, and respite care.

Next to services and projects, there is also a book in the UK called *The Really Useful Book of Learning & Earning for Young Adult Carers* from the Learning and Work Institute (Learning and Work Institute, 2016). This book contains a lot of information on school-going and working while also having a caregiving role in your family. This book in itself acts as a support mechanism for young carers. It also contains a list of useful websites and helplines. One example is Carers Direct, a service that provides information, advice, and support for carers, including information especially for young carers. However, Carers Direct is not a nationwide initiative, and is only accessible in certain areas. Another example is the Carers Trust, a major charity for, with and about carers. The Carers Trust provides information, advice, emotional support, and access to “much needed breaks” for carers of all ages. They also have some services specifically for young carers, and they actively contribute to more awareness of young carers.

Support in Australia

In Australia, the amount of support for young carers is increasing, as shown by Moore & McArthur (2007), Purcal et al. (2012), and Day (2015). Moore & McArthur (2007) found that young carers receive a lot of support from within the family. There is also assistance from the service system, such as respite, in-home occupational therapy or rehabilitation support, and community nursing. The young carers who had used these forms of support found that the assistance was useful, but that the level of support provided was limited or not of high enough quality.

Purcal et al. (2012) developed a framework of the support services in Australia. Three categories of support are distinguished: **assistance**, **mitigation**, and **prevention**. Assistance services help young carers to cope with their role and provide information for additional help on a short-term basis. An example of this type of support is Talk-Link, provided by Carers NSW in Australia. Talk-Link offers telephone group counselling for young carers for free. Mitigation services are long-term and more intensive than assistance services, they reduce caring responsibilities and negative long-term effects. An example of mitigation support is the Young Carers Respite and Information Services Program. It aims to help young carers attend school regularly, complete their homework and feel connected to their school community. Lastly there are the prevention services, which coordinate service provision when a chronic illness manifests itself, looking at the family as a whole. These services should aim to help the entire family from the moment informal care is needed for the patient.

One example of a program that incorporates elements of a prevention approach is Carers Link in South Australia. The model offers a flexible range of support to meet the individual needs of the carers to help them maintain their health and well-being. Purcal et al. (2012) concludes from the framework analysis that the vast majority of services in Australia regarding young carer support focuses on addressing the negative outcomes for young carers rather than avoiding them in the first place. The Carers NSW has a separate program for young carers under the age of 25 living in NSW, Australia. As a form of formal support they offer at home support, which includes respite for young carers. They also offer different kinds of counselling, including the aforementioned Talk-Link. The benefits of counselling for young carers, according to their website (Carers NSW Young Carer Program, n.d.), include building

coping skills, increased feelings of confidence and a sense of control, and linking to relevant supports and services.

Online support in Australia

The Carers NSW Young Carer Program also has an online community. This community features a forum where young carers can post messages and read messages from other young carers. Furthermore, there is a stories page called 'YC Voices'. This page contains experiences of young carers, but also poems or songs that they have written about their lives and beloved ones. It is however not possible to comment on these stories, so they do not act as a form of discussion platform. To give young carers easy access to all of the information on the Carers NSW website, they have developed a mobile application called *Who Cares?* ('Who Cares?' Young Carer Mobile App, 2015). On this app, young carers can find all of the information and links to services that are available on the website, as well as the stories from other young carers. In addition, the app also features a function that allows young people to test whether they could be classified as young carers themselves.

Policies in Australia

Day (2015) concludes, in a review of the concept of young adult carers in Australia, that there are actually no targeted approaches proposed to support Australian young *adult* carers, so specifically the age group 18-25. According to Day (2015), this is due to the fact that the National Carer Strategy, developed in 2010 in Australia, places care-recipients first and their carers second, while they actually should be equally important. Additionally, the National Carer Strategy is targeted at school-aged young carers. Hereby it excludes the young adult group (18-25), even though this age period is the transition phase from adolescence to adulthood. This makes it a very important but also vulnerable period for the young adults, claims Day (2015). Stamatopoulos (2015) argues that the UK however has done this right with their Carers (Recognition and Services) Act (1995) and the amended Care Act (2015) that *is* targeted on carers of all ages, so including young adult carers. This amendment gives the local authorities the responsibility to assess a carer's needs for support based on the appearance of need, which is a more preventative approach.

Research on online support in other countries

Almost all of the support services found for young carers in the literature have been offline services, with the exception of the online community of the Carers NSW project¹⁷. Very little research has been done on investigating the feasibility of online support services for young carers: no scientific literature has been found on this topic. Some literature has been found that investigates online support for carers in general. Bateman et al. (2017) has done a media-based feasibility study that compares crowdsourcing and friendsourcing to support Alzheimer's disease (AD) caregivers. These caregivers were all above the age of 30, which makes the results not directly applicable to young carers. Bateman et al. (2017) states that "online peer support activities can help AD caregivers reduce the stress of caregiving and enhance hands-on knowledge and self-efficacy". For the study, a Facebook group (friendsourcing) had been created where the AD caregivers could post questions, but also the crowdsourcing website Amazon Mechanical Turk. The results of this study showed that friendsourcing can really offer a lot of emotional support for caregivers, because of shared experiences that were posted in the Facebook group. Furthermore, the post from the

¹⁷ This does not imply that there are no other apps for YCs. A search on Goog Play (18/12/2018) found at least four apps specifically for YCs: Young Carers App, Young Carers in Hertfordshire, weKonnekt, and Young Savers.

Facebook group were also put in the News Feed of the Facebook friends of the caregivers. Their friends would respond with emotional supportive messages. Bateman et al. (2017) concludes from this study that friendsourcing through a Facebook group can really offer caregivers the (sometimes much needed) emotional support. The numbers of the US are relatively large as 29% of the adult population were family caregivers in 2009. Together their unpaid services had an economic value of approximately \$450 billion per year. Chi & Demeris (2014) researched telehealth tools to support adult caregivers in the US. They stated that technology can support caregivers and facilitate better coping. Also the adult caregivers reported that technology can help them to make caregiving more efficient, effective, safer and less stressful when delivering care to the patients. The data on adult caregivers can undoubtedly be used in identifying the needs of young caregivers. The technologies used in the systematic review of Chi & Demeris (2014) included video, phone based and web-based information and telemetry/remote monitoring. They concluded that video was the most common used technology. The technologies were used to deliver six different types of support, namely: education, consultation, cognitive behavioral therapy, social support, data collection and monitoring and clinical care delivery. Above all, using such telehealth technologies proved to have significant value for caregivers.

Social media support

To conclude all the results on supporting mechanisms in other countries, some examples of the social media results are presented. On Twitter many existing examples of support for young carers can be found. The search term 'young carer' leads to many tweets from countries other than the Netherlands. A very active Twitter account is the Young Carers Project in Canada (@YOUNGCARERSP). In one of their tweets they promote a supporting project for young carers is from 23 of March 2018.

"Many #youngcarer programs run on donations. These programs are vital & provide young carers with a much needed break, & opportunities to meet peers who understand. It's heartbreaking when they close/cannot provide service to those in need, due to funding. <https://buff.ly/2ueUMJg> "

Another example is one from Scotland in which they shout out to all young carers. This tweet is from @WLYoungCarers and tweeted on 26 March 2018.

"If you are a #youngcarer #carer in Scotland, did you know the new #carersact comes into force on 1 April? The Carers Charter could help you understand your rights under the Act. It's all here <http://bit.ly/2GtFvJq> #1weektogo"

Facebook is used as a more interactive means to get into contact with young adolescent carers and provide them with information and support, be it in groups consisting of young carers living in the same specific region or via pages of regional organisations. Several organisations have pages that actively and regularly post events and educational posts. These organized events include informal drop-ins during which young carers can get to know the organisation, workshops and classes in which they can relax, have fun and develop new skills. Festivals and sportweeks are also organized as a means of respite. The more serious activities are focus groups and free dental treatment days (the Lumino Day in New Zealand). Furthermore, these pages share information on reports of informal care, they provide information and tips on helplines and speaking with medical professionals; they also share easy recipes and fun books

to read. Furthermore, via posts they ask for donations to individuals or charities involved in (young) informal care.

To gain more insights into YCs' preferences and use of social media, an additional in-depth social media analysis was performed by another group of MSc students under supervision of Vilans. To ensure a timely and effective study, we focused on social media in English and Dutch.

4.3 Young Carers on Social Media: an Analysis¹⁸

4.3.1 Introduction

Social media 'are digital media and technologies that enable users to exchange information and to create media content individually or in community with each other' (Denecke et al., 2015). Nowadays, social media increases in popularity as a supportive tool in healthcare processes. To begin with, social media can help with gathering and sharing information. Additionally, social media can make it easier to bring people together (Eckler, Worsowicz & Rayburn, 2012; Moorhead, Hazlett, Harrison, Carroll & Irwin, 2013). For instance, it can help in activities organized by the community consisting of young carers or activities organized by health care professionals (Eckler et al., 2012). When a health care professional from an organization organizes an event for young carers specifically, social media can help to spread the word and reach more young carers. Moreover, one of the key benefits of social media is providing private social and emotional support between users (Moorhead et al., 2013). Currently, Twitter, Facebook, LinkedIn, Wikis and blogs are already used by health professionals (Hawn, 2009). This underlines the importance of social media in care. There are many different types of social media platforms.

Blogs are a well-known type of social media. An example of a platform for blogs is Wordpress (wordpress.com). Blogs are mainly used to provide open access information by healthcare professionals. In contrast, microblogs such as Twitter and Tumblr are popular social media platforms for communication among young adults. Messages are usually limited in characters. Twitter is used to provoke discussion in educational context and can be used as a medium for consultation (Farmer, Bruckner, Cook & Hearing, 2009). Social Networking platforms such as Facebook are also popular among young adults. They are used to create social connections and update other users with new information. The most common type of groups on Facebook are centred on specific medical conditions, peer-to-peer support and fundraising (Farmer, Bruckner, Cook & Hearing, 2009). Media sharing platforms are sites such as YouTube, Flickr, Myspace and Medting are platforms to share pictures and videos. Their popularity is dependent on the content that is uploaded by the users. Communities can be created through the comment feature of the site. Other media sharing platforms are Instagram and Snapchat, which have been gaining popularity with young adults in the past years (Grajales et al., 2014).

Overall, social media has potential to help young carers with coping. Features from social media might thus be important to implement in a new app aimed at young carers, such as the ME-WE app. Therefore it is crucial to find out which features from social media are used by young carers and for which purposes they are used. To find out which features might be

¹⁸ See deliverable contributors for authors of the social media analysis.

important to implement in a new app aimed at young carers, such as the ME-WE app, the following research question was formed:

Which features of social media are used by and popular among young carers?

To answer this research question we will need to examine existing social media platforms that might be used by young carers. In addition, the following sub-questions should be investigated to help answer the research question:

1. *On which social media platforms are young people (under the age of 24) currently most active in the Netherlands and English speaking countries?*
2. *Which features of social media platforms are most used by young carers?*
3. *Which of these features could become requirements for the ME-WE app?*

Hypothesis

Based on the relevant theory outlined in the academic literature study, we assume that YC communities need to offer three important elements. Our hypothesis is that relevant features of social media platforms will express these elements in a way that is popular for young carers. The first element is **information** on how to be a 'good carer', preferably provided by (experience/practical) experts. Perhaps social media platforms have fora where questions could be answered. Secondly, **organisation** of events might be an important element of social media platforms. These events should be aimed at respite, because literature suggests that young carers like to be distracted from their role as carer in their leisure time (Joseph et al., 2008). Lastly, **connection** to other young carers or a community of young carers might be important, because other young carers may have a similar or a comparable home situation. Social media platforms that offer (one of) these elements might be popular among young carers.

Since different online groups have different purposes, they need different elements to make the online community work (Matzat, 2009). We expect that the online community for young carers is focused on social support and self-help. According to Matzat, such online groups work best if they have a strong group identity, for example by means of recognizable symbols. This social embeddedness is a needed element which makes the group closer. Lastly, a high level of trust among members is a needed element to keep members part of the communities. All these elements could be meaningful to take into account when making a new app for young carers. It is expected that some of the above-mentioned elements will be expressed in features of social media platforms on which young carers are currently active and that features incorporating several of these elements will be popular among young carers.

4.3.2 Method phase one of the social media analysis

In the first phase of this study, the social media monitoring tool Coosto was used to identify which keywords gave the most results regarding the social media use of young carers (Coosto.com). In addition, a literature study was conducted to find out which social media platforms were most used by young carers (or possibly people or organisations related to young carers). This was done to narrow down the platform possibilities to a few (most used) platforms to analyse in our research, to find relevant terms to locate activity of young carers

on social media and to locate social media platforms with features that could be popular among young carers. Subsequently, we went into more detail by analysing social media platforms without monitoring software. This is called the second phase of our study throughout the report. This analysis was a more in depth and qualitative way of dealing with the given data that was available on social media platforms. In the social media analyses (both phase one and phase two), Twitter, Facebook, YouTube, Tumblr and Instagram are searched for the following keywords:

- 'young carer' and derivations;
- 'jonge mantelzorger' and derivations.

During the first phase, the goal was to find keywords that could be used in a later stage of the research to locate young carers. Although young carers might not view themselves as young carers and might use other words in their conversations or to other words to refer to themselves, no other relevant keywords to specifically identify young carers were known at the start of this phase. Because of this, these keywords were chosen.

4.3.3 Coosto analysis

For the first phase of the research, the social media monitoring tool Coosto (<https://www.coosto.com/nl>), which was launched in 2010, was used. One can use the tool to look at e.g. amount of views a page gets, page visitors, amount of posts with a specific hashtag and more. The tool was used to follow the activity around the keyword young carer and jonge mantelzorger (and their derivatives) on social media. With this, we hoped to gain more insight in which platforms are most popular among young carers. The platforms we will use in phase one of the study are: Twitter, Facebook, YouTube and Instagram. Unfortunately, Tumblr had been left out of this analysis because Coosto does not provide the software to analyse this social media platform.

4.3.4 Results phase one

Activity and sentiment

From the sentiment analysis of the posts could be deduced that the sentiment of the posts were quite similar for all keywords. 18 to 28% of the results was written positively and 7 to 12% of the posts was written negatively. It is important to mention that the vast majority of the posts has a neutral sentiment (64 to 71%). This indicates that these posts give information rather than opinions. Coosto gives a visual overview of the amount of activity on social media platforms with regard to the keywords explained earlier.

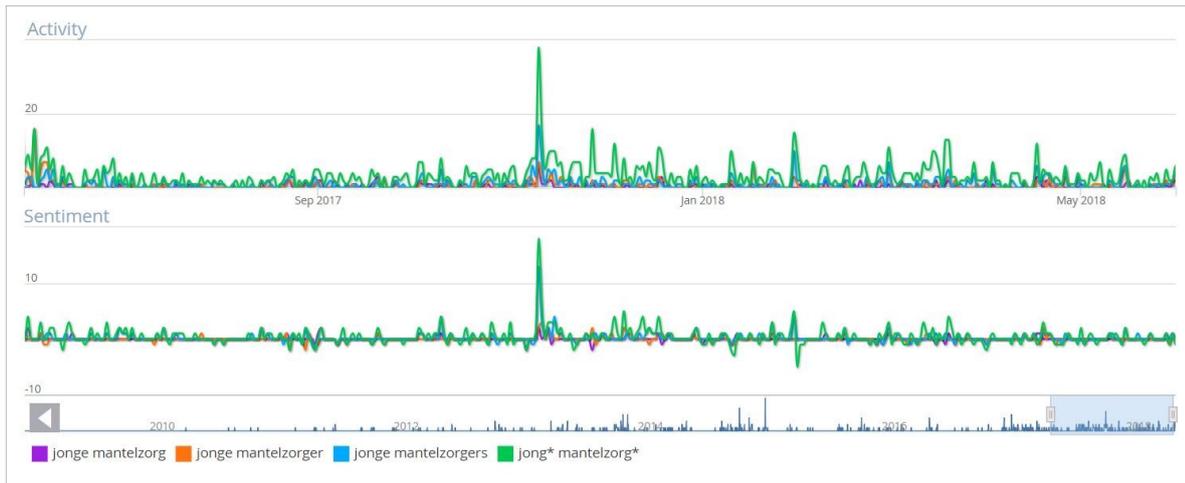


Figure 4: Graph of results activity and sentiment, 31 May 2017 - 31 May 2018. Source: coosto.com

One can identify certain peaks in the activity on social media with regard to ‘jonge mantelzorgers’, as can be seen in the figure above. The clearest peak can be found on the tenth of November (2017). With a further analysis of the posts posted on this date, we discovered that this date was a national day for informal caregiving (Dag van de Mantelzorg). The sentiment of the posts on this day was 58% positive. Looking at the content of the posts, most of them were about bringing attention and respect to young carers (‘jonge mantelzorgers in het zonnetje zetten’). A second big peak was found between the 4th and 9th of June 2017 (action week for young carers (Week van de Jonge Mantelzorger)). However, other peaks did not indicate one special day or event, and the content was mostly about raising awareness or promotion of various events instead of one. In this part of the analysis, we made an exception for the set time and decided to investigate the activity of the keyword in a larger time frame to see if it led to more influential dates. Interestingly, the activity on social media platforms with regard to the used keywords has increased in the past decade. This can be seen in the graph below.

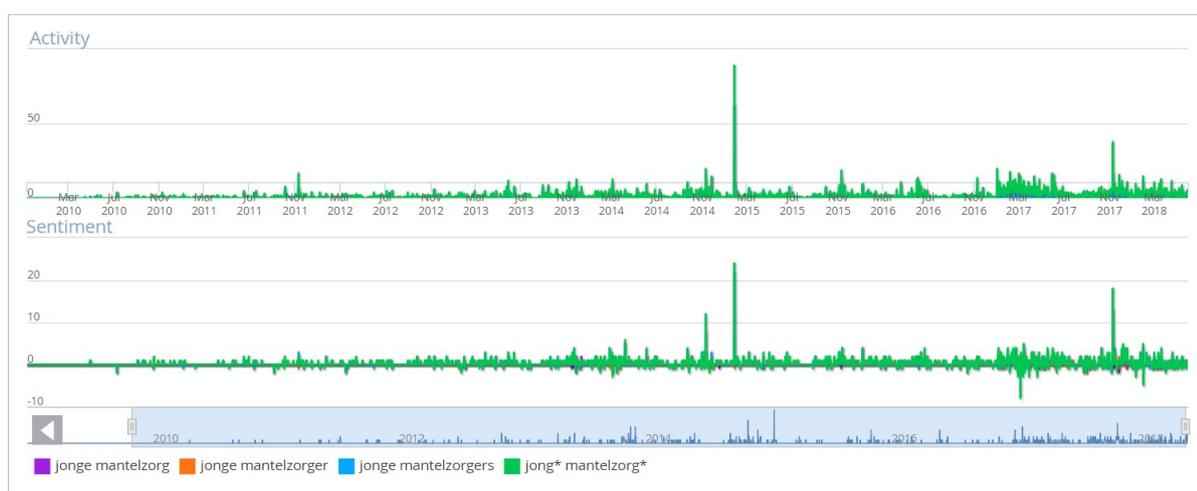


Figure 5: Graph of results and sentiment, 2010 - 2018. Source: coosto.com

A big peak in 2015 could be found, which indicated a day on which the subject young carers was brought to people's attention in the Dutch TV show 'Jinek' (found when examined this date further). Other findings from the coosto analysis – such as media reach sources - can be found in the whole report¹⁹.

4.3.5 Method phase two

Participants and design

In the second phase of the analysis, a systematic social media analysis by hand was performed. The goal was to analyse the current usage of social media in the context of young carers. This consists of, for example, counting the amount of online support groups on different social media platforms and counting the amount of posts that were posted on each platform with the given keyword(s). In phase two, the same keywords are used as in the first phase²⁰.

4.3.5.1 Twitter

Microblogs such as Twitter (<http://twitter.com>) are popular social media platforms for communication among young adults. Messages are usually limited in characters. For Twitter this is limited to 140 characters. Twitter is used to provoke discussion in educational context and can be used as a medium for consultation (Farmer, Bruckner, Cook & Hearing, 2009). "Twitter users follow others or are followed. Unlike on most online social networking sites, such as Facebook or Myspace, the relationship of following and being followed requires no reciprocation. A user can follow any other user, and the user being followed need not follow back. Being a follower on Twitter means that the user receives all the messages (called tweets) from those the user follows." (Kwak, H., Lee, C., Park, H., & Moon, S., 2010).

When tweets were searched for those that included 'young carer' we found 152 tweets about young carers. These included many information tweets from organisations. After analysing these tweets, it was found that most of these link to their website. By filtering out all links there were just 49 tweets left from the nine days. Some of these were 'retweets' from an original tweet. These 'retweets' can be found by the leading 'RT', which we can filter out. 44 tweets remained, which are either alone-standing tweets or are replies at ongoing conversations. We noticed that some of these tweets were probably tweeted by YCs themselves. But this was not the case for all of these tweets. Approximately half of the tweets were tweeted by YCs. It is however not possible to say this with a high probability, unless we contact these users. An example of the tweets we found were as follows:

"Bayliss_j94 May 28, 8:18pm: Bank Holidays are officially rubbish as a young carer :(#youngcarer #youngcarers #stressed #whatbreak"

It could be concluded that we have to filter out a large part to get to the more interesting tweets, for example personal stories. It was found that most organisations link to an external website, which we could therefore filter out. However, this could also filter out tweets

¹⁹ <https://www.dropbox.com/sh/seqa437te52xwxs/AAAbrKkQLX-6JPPPgpGQ-Sxba?dl=0>

²⁰ See full report on social media analysis for in-depth methodology descriptions and keywords: <https://www.dropbox.com/sh/seqa437te52xwxs/AAAbrKkQLX-6JPPPgpGQ-Sxba?dl=0>

tweeted by young carers. Furthermore, this analysis is limited a period of nine days, which if it would be extended could lead to more interesting tweets.

4.3.5.2 Facebook

Facebook (<https://www.facebook.com>) is a social networking site where the user can contact and talk to other users and share media or their own comments publicly or privately. Each user has their own profile on the platform. On the Facebook profile, users can link to other web addresses, share short texts, pictures, videos and gifs. There is no limitation on quantity. Photos, comments and notifications from friends or from within groups will be displayed on a personal newsfeed. Users with common interests can join and make groups to interact with each other. Facebook also has public pages promoting or sharing content about specific topics that users can like and follow. Facebook also allows members to react to ads and to publicize events. The public pages, groups, public posts and user profiles can be accessed by everyone. However, private groups and chat messages cannot be accessed by others. There is a search bar on the platform where you can search for public posts, profiles, groups and pages. On Facebook users mainly interact by befriending users and chatting with them, following liking and sharing pages, liking, commenting or sharing posts and joining and creating groups.

When using the term young carer, most of the pages found are pages from organisations and communities that provide activities for young carers. The student association and the fundraising page had significantly less followers and likes than the support-oriented pages. The term young carers only yielded support-oriented pages, but the pages had a relative large number of followers and likes.

Jonge mantelzorger and jonge mantelzorgers

Searching for jonge mantelzorger (young carer) gave six results. Five results were organisations or communities supporting young carers. One of the results was a blog from a Dutch young carer. The blog could also be found when searching for the term jonge mantelzorgers. When searching for the terms jonge mantelzorgers, the largest amount of results was found. 29 pages were found, with mostly support oriented pages. Additional pages were the aforementioned blog and a chat group community. The chat group had not been active for a long time and had a relative small number of followers, while the blog was very active and had a large number of followers.

Comparison

In the Netherlands and in the UK, Facebook is mainly utilized by charities, communities and organizations. However, searching for the Dutch terms also resulted in more private pages, for example from bloggers or companies and websites. It is strange that the most pages were found when searching for the Dutch term 'jonge mantelzorgers', because in the UK, far more official support is provided for young carers than in the Netherlands (Leu & Becker, 2016). The reason for this could be that results from countries that the user is not native to are filtered out by the algorithm on Facebook, which is designed to reflect the interests of the user. Additionally, support for young carers is more decentralized in the Netherlands, which might result in more support-oriented pages with less members.

Groups

Young carer and young carers

For the terms young carer and young carers, 6/14 and 9/17 of the groups found had not had any activity for the past 30 days. Both of the terms gave five common groups that were notably active. They consisted of three groups that supported young carers, one parent support group and one private group with an unclear function. Searching for the term young carer yields one additional active group. It was a group that plans activities for young carers. Three of the five groups had been founded more than two years ago. All the other groups had been founded in the time between a few months and a year ago. It was noticeable that only two identifiable chat groups for young carers on Facebook could be found. All recently active groups were private.

Jonge mantelzorger and jonge mantelzorgers

For the terms jonge mantelzorger and jonge mantelzorgers, 0/1 and 8/9 of the groups found had not had any activity for the past 30 days. The terms yielded different groups. The term jonge mantelzorger yielded one support-oriented group that focuses on organising activities that was only a little active in the past 30 days. It was founded two years ago. The term jonge mantelzorgers yielded one active group that had only one post in the past 30 days. It was a chat group and it had been founded two years ago. There are a total of three chat groups. It was notable that there was a relatively small number of identifiable chat groups for young carers in general on Facebook. Additionally, most groups were private. All recently active groups were private.

Comparison

While a variety of groups in the UK were active groups, only a few Dutch groups were active. Additionally, the groups in the UK were much more active and had more members than the Dutch groups. There was a higher percentage of identifiable Dutch chat groups, but a lower percentage of active chat groups. From both the UK and the Netherlands, most groups were private. And all recently active groups were private.

Public posts

It was clear that most public posts on Facebook were promotion for activities for young carers or posts to raise awareness for young carers. Both in the UK and in the Netherlands pictures from old events are put on Facebook and surveys are conducted on Facebook. The UK has yearly nominations for young carers and public fundraising events for young carers. When searching for the English terms for young carer, much more tips for coping or for caring can be found (for the specific data see appendix 3).

4.3.5.3 Tumblr

Tumblr (<https://www.tumblr.com>) is a social media platform where users can share all sorts of content. Each user has their own blog on the platform and can follow other blogs. On the user's blog they can share typed stories, pictures, videos, gifs and audios. It is also possible to 're-blog' and add to the posts of other people so that also these will show on your blog. There is an explore option on the platform where you can type in a subject or phrase. The platform will now show you all posts tagged with this phrase and blogs related to this phrase. An example of how this explore page looks like, can be found in the following page. Tumblr has more ways for users to interact, besides re-blogging, liking and commenting on other users'

blog posts. Once two users follow each other they can talk using the ‘chat’ function, but also when users do not follow each other, they can still interact by using the ‘ask’ function). Here users can ask a blog any question, anonymous or not. A user can choose to answer or ignore the question, but if answered it will appear on their blog. This feature is often used to ask questions to celebrity bloggers or get anonymous advice on something.

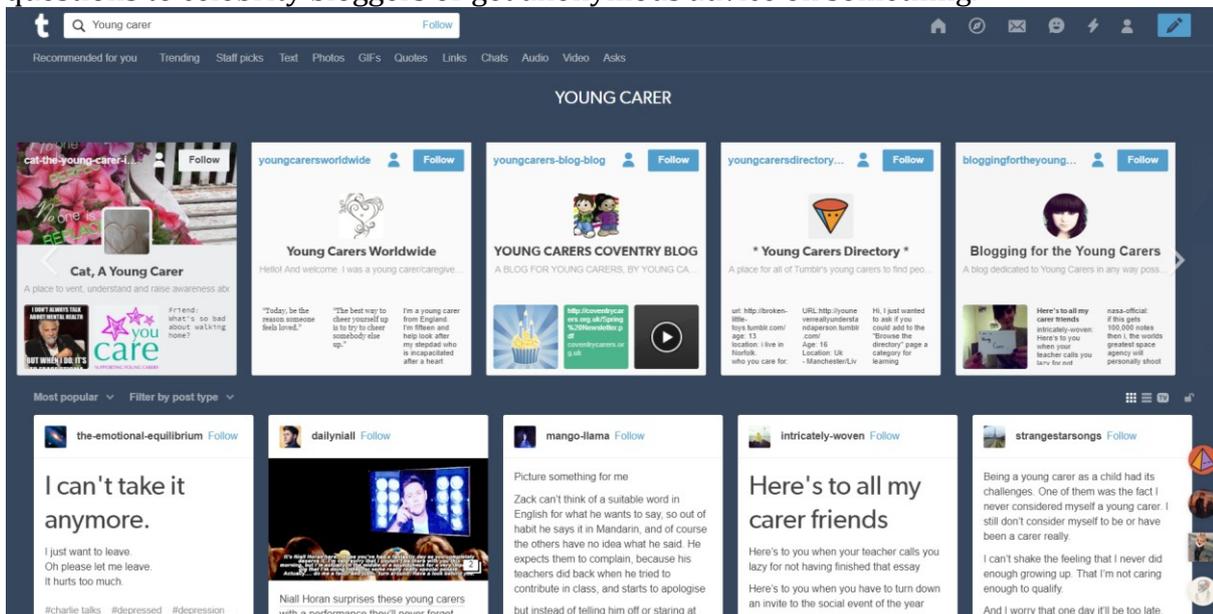


Figure 6: An example of the results found on Tumblr. Source: Tumblr.com

The Tumblr analysis was divided in four parts: English blogs, English posts, Dutch blogs and Dutch posts. The amount of results in this analysis was counted by hand on the 23th of May 2018. After scanning the results it was noticed that the Tumblr search engine only showed posts results for the exact hashtag. When searching for ‘young carers’ no results were shown for ‘young carer’, ‘young’ or ‘carers’. However, since it is common to use many hashtags below a post, there were a lot of similar posts when searching for ‘young carer’ and ‘young carers’. This is simply because the posts were tagged with both hashtags.

The found posts were filtered on one important criterion: it was vital that all the results were about *young* carers and not about (informal) care in general. This was checked by reading each of the posts individually. Posts with one or more reblogs and or likes are ranked by means of ‘20 most popular’ by Tumblr as of 23/5/2018²¹.

Dutch posts

The first aspect that was striking when looking at the results of the analysis is the fact that there are no Dutch results. This can have multiple reasons. Perhaps the platform is not as popular in the Netherlands as it is in English speaking countries or Dutch users of the platform share their content in English to reach a wider audience. Before conclusions could be drawn about this, more research is needed.

English posts

As can be seen by looking at the list with ‘20 most popular’ posts using the hashtag young carer, most English posts seem to be posted by YCs themselves. The majority of the posts has

²¹ For an overview of the keywords, see <https://www.dropbox.com/sh/seqa437te52xwxs/AAAbRkQLX-6JPPPgpGQ-Sxba?dl=0>

a diary format. Young carers were talking about their daily lives and complaining about their struggles. *“I phoned my school and said I wouldn’t be in because my mum is in a horrible state and can’t even walk and do you know what they said? “That’s no excuse” Like seriously? If a parent’s child was sick they would let them go home with no sassy pants comment. ITS THE SAME PRINCIPLE! I am legally a carer for my mum and this is what we get for trying to do OUR JOBS?! i am so pissed”* posted by blog m0xley-blog is a good example of this. Having a place to vent, possibly hoping to find recognition by peers, can be a great way for young carers to lift their spirits. It might be claimed that the reason for this open vulnerability on the platform is its anonymity. Because of nicknames there are no traces back to their personal life, so there is no reason to worry that peers from school will find out about their situation. We therefore suggest that usernames would be the best equivalent to possibly use in the new ME-WE project. As it provides the freedom to be vulnerable. But the use of usernames also provides the opportunity to create relationships and possibly friendships with other users that are taken away when working with complete anonymity.

Blogs

The found blogs were filtered on the topic *young* carers, by opening the blogs individually, reading their bio (blog description) and scrolling through their latest posts. Blogs containing content that is not suitable for minors were also not included.

Just as with the posts, there were no Dutch results for blogs found. There were however several English blogs dedicated to young carers present on the platform. Noticeable about the English young carer blogs was that these blogs did not necessarily posted venting posts tagged with young carer. The blogs mainly posted supportive posts. *“Just wanted to say...All young carers out there face hardships everyday regardless of whether its first thing in the morning or last thing at night, physical or emotional and I want you guys to know I’M HERE FOR YOU xxxx”* posted by the blog cat-the-young-carer-in-the-hat is a great example of that. Many of these blogs also state in their bio’s that they are open for so called ‘asks’. Asks are a feature by Tumblr where users can ask a blog a question, anonymous asking is an option. When the blog chooses to respond to these asks, this response (and the question) will be posted on that blog.

A possible reason for this clear content division between posts tagged with young carer and blogs dedicated to young carers is the fact that individual Tumblr users who happen to be young carers have a life next to being carer. On their blogs they also seem to want to share stories about e.g., TV shows, books or video games. Whereas blogs dedicated to young carers seem to want to stick to the theme. Knowing that all their followers will most likely be young carers, they seem to do their best to help them cope and brighten their day by posting or reblogging supporting posts.

4.3.5.4 Instagram

Instagram (<https://www.instagram.com>) is a social media platform where the user can share photos and insert a caption along with it. Besides that, hashtags may be used, so other users can search for a specific hashtag and find your photo. New features are released once in a while, so now also ‘stories’ are available. The user can make a photo or boomerang (short

video) and post this in his or her stories for 24 hours. The user can add text and smileys or gifs. An example of how Instagram looks like, can be found in the figure below.

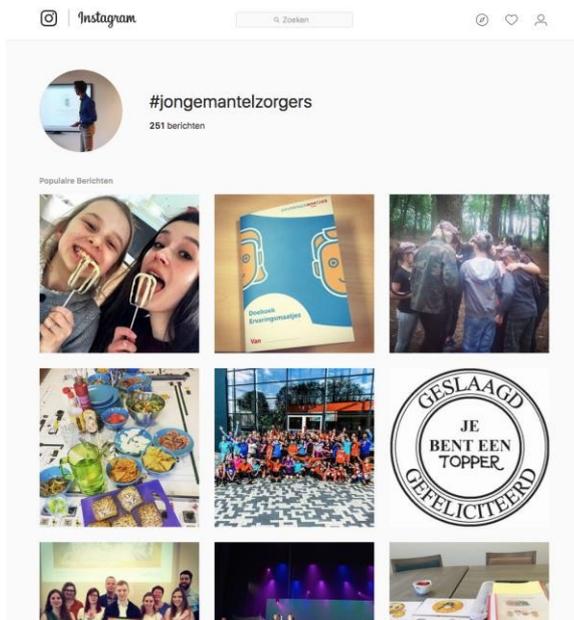


Figure 7: An example of how the Instagram feed looks like, when searching for the hashtag #jongemantelzorgers. The pictures are the most popular posts with this hashtag. Source: Instagram.com

The Instagram analysis focused on hashtags/posts and accounts. From there on, Instagram gives you other hashtags the user might find interesting. The following hashtags were recommended by Instagram and also used in the Instagram analysis: #youngcarersawareness, #youngcarersfestival, #youngcarersbreaks, #youngcarersday, #youngcarersproject, #specialsiblings.

There are more English than Dutch hashtags and accounts are present. The hashtags #youngcarers and #youngcarer accounts for 6.542 and 1.153 posts respectively, and almost every day new posts are added with one of these hashtags. The Dutch hashtags #jongemantelzorger and #jongemantelzorgers account for 32 and 217 posts, respectively. For both English and Dutch the accounts focusses on young carers in a specific region (e.g. Glasgow & Cheshire and Lelystad & Zwolle). Also, for both languages there were also private accounts, so posts were not visible to the general public. These accounts were excluded from this analysis. Moreover, posts/hashtags are doing 'better' than accounts, if we compare the number of posts (e.g. 'young carer' [1.153] and 'youngcarersbsg' [358]). Besides that, the activity of the English accounts is quite regular.

The posts and accounts can be divided into two groups: informative posts/accounts and platforms from institutes that try to help young carers, and posts/blogs that are posted or managed by the young carers themselves. Posts or accounts of the latter case are quite hard to find on Instagram. It might be the case that people gather in groups on Instagram. Unfortunately, these groups are not accessible for the public.

4.3.5.5 YouTube

YouTube is a media sharing platform. The account of a user is called a 'channel', on which videos can be uploaded. These channels could also be managed by more people or an association or foundation. Users can follow other channels, which is called 'subscribing'. Videos can be liked or disliked by users. The YouTube analysis was divided in four parts: Dutch videos, Dutch channels, English videos and English channels.

Videos

The found videos (both Dutch and English) were filtered on one important criterion: it was vital that all the results were about young carers and not about (informal) care in general. For the Dutch results, this was done based on the description of the video. In case of doubts, a short fragment of the video was watched. Subsequently, the results were ranked based on the amount of views. This way of ranking (not ranking based on amount of comments or likes) was chosen based on a non-systematical pilot analysis. In this pilot analysis was found that many (especially Dutch) videos have limited likes or comments, although they do have a great number of views. The English results were filtered after the ranking, because the scope of the results was substantial.

Dutch videos

After filtering, 212 Dutch results remained that were actually about young carers. Of these results, the videos with more than 700 views were picked to analyse further, which resulted in 28 results. These videos were fully watched, labelled with a video type (e.g. documentaries, short film or music video) and there was searched for extra features that appeared in the video (e.g. event promotion, talking to expert). After the detailed analysis of these 28 results, a few overarching themes were found. First, almost all videos with more than 700 views were news fragments or documentaries (18 videos). In these videos, young carers are followed for a day, during which they explain what it is like to be a young carer, what they do and how they feel. In a few of the videos, the children give tips to other young carers. Children and young adults are telling their story in the videos. In some news fragments, events for young carers, organized by young carer clubs or foundations, were promoted. In these videos, raising awareness for young carers is the most important topic. The only four other video types found in these 28 results were three songs and one vlog. Only six videos have more than ten likes, and four videos have three to nine comments, all about giving respect.

English videos

The English videos were first ranked on having 700 views or more, leading to 141 results. After ranking there could be decided that all 141 results were about young carers, based on title and description. Of these 141 results, the first 28 were fully watched and analysed the same way as the Dutch videos. The amount was kept the same as the Dutch videos, because the assumption was made that these 28 videos were enough to deduce the most important topics of the videos. The first thing that was noticeable, was that most of the videos were British of origin (24 out of 28), which indicates that in Great Britain there is more awareness of the term 'young carer'. This fits perfectly with the research of Leu & Becker (Leu & Becker, 2016). The overall video types were documentary, news fragment, promotion of events and promotion of foundations. In a lot of videos, activities or discussions during meetings of young carer foundations are filmed, interviewing the young carers to hear their opinion. Furthermore, in three videos, (British) celebrities are involved in to raise even extra

awareness for young carers. The celebrities come to an event or the home or school of a young carer to give him/her a surprise present.

The English videos contain more likes and comments of which comments are most interesting in the social media analysis. For some of the videos, the comments are disabled. These comments that have been placed have themes as respect for young carers, judgement of how horrible a situation is (documentaries), heart-warming (events organized by foundations) and appreciation of the information provided by the video. However, for seven videos, comments of other young carers have been placed. In the video 'Becca has to Care for her Mum who has Fibromyalgia' one of the comments was: "I am a young carer for my mum with Complex mental health issues, recently recovering from meningitis and looking after my sister with cerebral palsy and learning difficulties, so I know exactly how it feels. I'm 18 and I struggle, let alone a 9 year old" This indicates that young carers do watch videos on YouTube.

Channels

Dutch channels

The keywords 'jonge mantelzorger' and derivatives of it all result in 60 channels. The channels are again filtered on the criterion 'must be about young carers. For the channels analysis, the criterion 'must have more than one video' is included. After this, only nine channels remain, of which one is the channel of vlogger 'Mantie Bee', who also appeared in one of the results of the Dutch video analysis. This seems to be the only channel made by a young carer herself. Other channels are channels of (young) carer foundations, sometimes with a link to their website, channels that promote a certain young carer event or channels that have uploaded various different young carer documentaries. No discussions can be found on the channels homepages, one channel makes proper (more than three videos) playlists and shares them. The channels have less than 500 views (except for 'Vanzelfsprekend') or the amount of views is not available on their page.

English channels

Searching for English channels, 694 results were found. After filtering on young carers and channels with more than two videos, 27 channels with 'young carer' (or a derivative) in the title or description remained. These results were analysed and ranked based on amount of followers. Another 51 were channels that were only partly meant for young carers, but also for older carers or children and young adults in other difficult situations (such as foster children, depression, etc.). These channels were not analysed further.

Again, most channels are promotion for foundations and upload documentaries or news/radio fragments, interviews and videos of children telling their personal stories. There are also a lot of videos on these channels about events, activities or courses organized for young carers, sometimes filmed in a vlog-like manner. Some videos show an interview with an expert, promoting a foundation and giving information. Unlike the Dutch channels, various English channels have uploaded videos of interviews or stories with animations, likely to be meant for children. Lastly, three of the 27 channels are vlogs.

Few channels share playlists or links to other channels. There are no channels with an active discussion page. Two vloggers have the most followers (114 and 115). Striking is that the channel of Jen-O, with most followers, has not uploaded any video. She only shares her liked videos, 'other helpful channels', the channels she follows and a link to her blog.

Conclusion YouTube

It is crucial to realise that the majority of the videos and channels might not be meant for young carers themselves, because they are focussed on raising awareness. Vlog and music videos are rare, although they may be more intended for the young carers among each other. Because of the comments, it can be claimed that at least some young carers watch videos with the keyword 'young carer' in it. Possibly because they can relate to the situation and might gain knowledge from experience of other young carers.

Both in Dutch and English videos, it is striking that young carers often do not know that they are carer, they do not like the label and they do not want any extra compassion. They seem to underestimate their situation or sometimes do not even tell other people they have a task as carer at home. Most young carers accept their situation, but do not like the fact that they miss out on certain activities their friends are doing. This might be the reason that not a lot of young carer blogs can be found. It is important to mention that YouTube is much used for sharing blogs by young adults. Putting one's self in the spotlight does not seem to be something the young carers like to do. Moreover, both English and Dutch channels on YouTube do not have an active community. Not too many comments on videos are places by young carers themselves, although a few cases can be found. Although the analysis was limited due to the chosen keywords, from our findings could be concluded that young carers might not be a very active community on YouTube. This could be because this platform's features may not fit with the needs of the young carers, as a group of people.

4.4 Summary of Country Specific Social Media Analysis - The Netherlands²²

This summary describes a social media analysis study performed at the SCP in June 2018 exploring which supportive interventions for young caregiver providing care for an ill or disabled family member (aged 18 years or younger) are available in the Netherlands in the first half of 2018. Searches were performed using (1) regular internet, (2) Twitter, and (3) websites of selected municipalities in the Netherlands. For search 1, search engine Google was used using the search terms 'young caregiver', 'support' and '2018'. The software program Coosto was used to search within Twitter in search strategy 2 with search terms based on the information obtained in search 1, being (synonyms for) young caregivers, support and specific interventions. In search 3, webpages of 16 municipalities in three regions with different levels of urbanization in the Netherlands were examined for content on young caregivers' support. For analysis, five criteria were used to classify interventions, being (i) the interventions' aim, (ii) type (e.g., a workshop or Fun day), (iii) whether the intervention was online or offline, (iv) target group, and (v) geographical location of intervention or author (of website or message). For tweets, two additional criteria were used: the author of the message and whether the tweet was positive, neutral, or negative towards more support for young caregivers.

121 interventions in search 1, 60 tweets in search 2, and 28 interventions in search 3 were analyzed. Results showed that most of the support interventions found on regular internet

²² See the full report for the extended research report <https://www.dropbox.com/sh/seqa437te52xwxs/AAAbrKkQLX-6JPPPpGQ-Sxba?dl=0>

were aimed at providing information to and about young caregivers and at offering a fun activity (search 1). Concerning search 2, Twitter was mostly used to promote fun activities, such as BBQ's or bowling. Material support or practical help, e.g., financial support or extra domestic help, was rarely offered on internet or discussed on Twitter. Most interventions were aimed at young caregivers themselves, followed by professionals who work with young caregivers.

Most interventions found in both search 1 & 2, were offered offline, e.g., a sports activity. The few online interventions that were found were mostly providing information in a non-interactive way, e.g., by providing information on a website without for example the possibility to chat with a youth worker or care professional. Interventions aimed at the entire family of youngsters were not found in our online search. Concerning the use of Twitter, we found that most messages were posted by professionals. None of the tweets on support were posted by young caregivers. No indications for negative sentiment on support for young caregivers was found in the tweets. Interestingly, the attention for the topic of young caregivers on Twitter seems to (temporarily) increase during specific periods of time, such as during an awareness raising event in the Netherlands called 'Week of the Young Carer'.

The third search on websites of selected municipalities showed that the amount and type of supply of supportive interventions is not the same across municipalities, for some municipalities multiple different types of interventions for youngsters were found, whereas for other municipalities no single support for this group was presented on their website. It should be stressed that we only analyzed information available on websites and hence support services for young carers offered 'offline' that were not promoted online were not included in the report.

4.5 Conclusions and ideas for support/recommendations²³

The conclusion of the results from the general academic literature review and social media analyses are first summarized in tables, starting with the advantages and drivers for online support interventions for YCs, followed by general requirements for an (online) intervention or support app based on academic literature. Finally, the main social media analyses findings & requirements are presented followed by a discussion on future research.

Advantages and drivers for online support interventions for YCs

- Overcome logistical barriers (availability of transportation, insufficient time) to participate in support programmes and respite care such as summer camps. Banks et al. (2002)
- Online services and social platforms are the primary media channel for YCs, so focus on distribution of supportive services, health services, and information via technology. (Greene et al., 2016)
- Internet is turning into a fundamental part of the lives of young persons, its potential to provide person-centered support and counselling to YCs is enormous. (Ali et al., 2012; Banks et al., 2002)
- Possibility to communicate with health care organizations or support services to receive advice on how to cope with their caregiving role and where to go for help.
- Social media allows caregivers to interact with other people who are in a similar situation. (Bateman et al., 2017)
- Social media can enhance the availability of supportive information and emotional support.
- Group experience via social media can empower YCs.
- Events that facilitate respite are promoted on social media.

General requirements for an (online) intervention or support app

- Approaches that bring about mutually beneficial forms of provision for multiple parties involved, including a more family centered approach, should be strived for in order to better address the needs of the YCs (Banks et al., 2002)
- Provision of support should be non-intrusive.
- Enable young carers to feel comfortable about discussing their caring role.
- Online support services should shift more towards operating as a primary prevention of risks of caregiving. Purcal et al. (2012).

²³ For further discussion, conclusions and limitations on the general literature review and social media analyses, see <https://www.dropbox.com/sh/seqa437te52xwxs/AAAbrKkQLX-6JPPPgpGQ-Sxba?dl=0>

- Intervention programs should be aimed at supporting young carers to use adaptive coping strategies instead of maladaptive coping strategies, by helping them solving problems and asking for help. (Green et al., 2016)
- Young carers should rather be in a constant dialogue, either with friends and family or professionals. (Gray et al., 2007)
- Need for an experienced person who gives both instrumental support (advice) and emotional support and encouragement to young carers. (Ali., 2013; Joseph et al., 2009)
- Support services should not be to just reach out to the adolescent young carers, but also to create a trustworthy relationship. (Chikhradze et al., 2017)
- Need for respite, a temporary relief from caring responsibilities. (Joseph et al. 2008)

Main social media analyses findings & requirements

- Number of hits on social media increased (tweets, videos or pages), as in indication that awareness for young carers is slowly increasing.
- Features of social media platforms for young carers should *inform, organise and connect*.
- The (amount of) supply of supportive interventions differed across municipalities - on a local level - in The Netherlands.
- Supportive interventions offered/promoted via online channels mainly aimed at YCs themselves.
- Interventions aimed at both the young caregiver and the parents or at the entire family were not found.
- Use social media to promote fun activities and respite care.
- Most of the support found on internet – mainly websites - was aimed at providing information to young caregivers.
- Most results on social media are about raising awareness for young carers and many – mostly on Facebook and YouTube - were about promoting events for YCs.
- Groups on Facebook are a good example of connecting young carers.
- Twitter was particularly used by adults to tweet about young caregivers, not by

youngsters themselves.

- Young caregivers themselves make use of other forms (of social media) to communicate about this topic, such as Tumblr in the UK.
- Online communities for young carers should have:
 - o a strong group identity (e.g., logo from an association or foundation)
 - o high level of social embeddedness (promotions on social media)
 - o high level of trust among members (private groups and anonymous questions)

As discussed in this chapter, technology can play an important role in supporting and connecting YCs with each other, facilitating communication between young carers and professionals, and organising and promoting events that are aimed at respite.

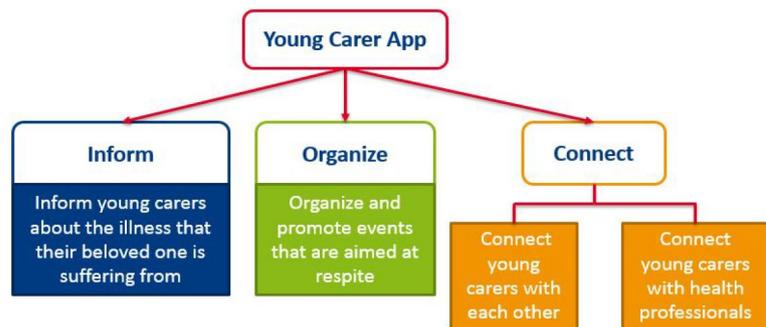


Figure 7 Schematic representation of proposed content for the ME-WE app

In Figure 7, we present a schematic representation of the main content sections and functionalities for a Young Carer App based on the general literature review.

We further formulated functional and non-functional requirements to describe and clarify these features (See Table 4 below).

Table 4: Functional and non-functional requirements for the ME-WE app

Requirements

<i>Functional requirements</i>	<i>Non-functional requirements</i>
News/Events page	Possibility to choose for specific regions/neighbourhood
Asking questions to experts or other young carers	Either anonymity or confidentiality (e.g. nickname), possibility to locate experts or other YCs

Possibility to create groups or a community	Possibility to create either private or public groups based on a subject (e.g. autism, sick mother) or region. Also to increase trust.
Possibility to share experiences (possibly in blog format)	Confidentiality of an account (e.g. nickname), anonymity & trust
Possibility to follow association/organisations/foundations	Add logo and ownership/support of association or foundation to increase trust and group identity
Possibility to befriend other users	Search other young carers based on location/region or topic (e.g. autism, sick mother)
Information in the form of messages, videos or photos	Possibility to filter information of a subject (e.g. a specific disorder, sick mother, brother, sister etc.)

Via the Internet and social media, it can be an easily accessible and effective to offer interventions and support for young carers, but also to spread awareness about young carers and how others can help them (Bateman et al., 2017). However, the main challenge that can be dealt with using social media is to enable young carers to feel comfortable about discussing their caring role. Only then can services provide optimal support (Banks et al., 2002). Future research should thus be aimed at investigating the consequences of support services and communities on social media, and how they can be implemented to support young carers in their caring role.

What **recommendations** can thus be made for a technology that aims at supporting young carers?

1. Young carers would greatly benefit from a mentor who gives both emotional and instrumental support, advice, and encouragement.
2. Also, young carers would greatly benefit from recognition and social support from their peers, both fellow young carers and friends.
3. Finally, young carers should sometimes temporarily be relieved of their caring responsibilities, in order for them to keep their spirits high.

Future research is needed to further investigate whether the current supply meets the needs and desires of these young caregivers. For example, do they need more (online) information about the topic or do they wish for more practical help? Moreover, it can be questioned whether young caregivers, who often struggle with combining their caregiving tasks with school, sports, friends, etc., actually have time for all fun activities that are offered for them? And, is it desirable that hardly any intervention targets the entire family or do young caregivers need their family members in their support? Finally, and perhaps most interesting for the design of the ME-WE online intervention, do young caregivers wish for more online interactive tools to support them or do they prefer offline support? In sum, future researchers

should get in contact with young caregivers themselves in order to examine how we can optimally match the supply of supportive interventions to the needs and desires of those who need it most.

5. Rating, ranking and consolidation

5.1 Introduction

This chapter describes the rating, ranking and consolidation of the findings mainly from the Delphi study and literature reviews. The Delphi study (T3.1) and literature reviews (T3.2) provided a pool (i.e., 'long-list') of multiple interventions, programmes, and methods to support (A)YCs across Europe together with relevant findings in several cases from the social media analyses and Blended Learning Networks (WP4). The long-list provides relatively little knowledge on how they score in relation to each other and which are preferred to use as exemplars for the ME-WE intervention and app (see WP4-WP6). To gain insight into the – perceived – strengths and weaknesses of the interventions, programmes, and methods, on different criteria, we chose to perform a rating and ranking exercise with experts and (A)YCs. The method has been successfully applied in the field of AAL applications (Active & Assisted Living) in the ReAAL project funded under CIP-ICT-PSP.2013.3.2 (Nap, Berlo, Wichert, 2015)²⁴. In the ReAAL project, partners worked on a portfolio of open and personalised solutions for active and independent living connected to the universAAL platform and were evaluated on socio-economic benefits.

5.2 Method

The criteria for the rating of successful strategies and theories to improve (A)YCs' mental health and well-being were identified from the WP3 studies and also the Blended Learning Networks (BLNs) from WP4. The criteria were discussed with an expert panel from Vilans and SCP with a background in long-term care and youth care, and three (A)YCs themselves evaluated the criteria set. Furthermore, the criteria were based on the projects' conceptual framework (see Description of Action). A (preliminary) portfolio of 39 programmes, interventions, and methods was gathered in T3.1 and T3.2 (see Table 4 on page 71), described and archived. At least two of the programmes were formally evaluated – according to the academic research study - namely the Crossroads young carers' project and Bernardo's Action With Young Carers (AWYC) Project. Crossroads was evaluated by means of three focus groups and the value of peer support became clear from the study (Richardson et al., 2009). Bernardo's Action With Young Carers (AWYC) Project was evaluated by means of 10 interviews and results show that young people supporting mothers with mental health problems have agency and can clearly articulate and reflect on their experiences (Grant et al., 2008). Many other interventions of the list show similarities with formally evaluated interventions with a focus on the whole family approach, respite care, psycho-education and fun activities, and support groups (see Academic literature study this deliverable).

The portfolio of 39 interventions, programmes, and methods was shared in an Excel file- see Table 5 below with experts and young carers and rated on several criteria – among others – the current status, openness, developed in co-creation, or the influence on well-being or

²⁴ Nap, H.H., Berlo, A. van, Wichert, R. (2015). [Quantitative and Qualitative Rating and Ranking Studies for Consolidation of an Application Portfolio for Large Scale Pilots](#). Ambient Assisted Living - Advanced Technologies and Societal Change, pp 171-178.

resilience (see below for the criteria and explanations). The raters were informed about the procedure and young carers provided informed consent. The portfolio list should rather be dynamic and can be iteratively updated to accommodate advancing insight throughout the project phases of ME-WE. A sub-set of experts in the field of long-term care and youth care and young carers themselves rated the aforementioned criteria on a Mean Opinion Score (MOS) scale from 1 (low) to 5 (high). See Figure 8 below for an overview of the ME-WE rating and ranking study process.

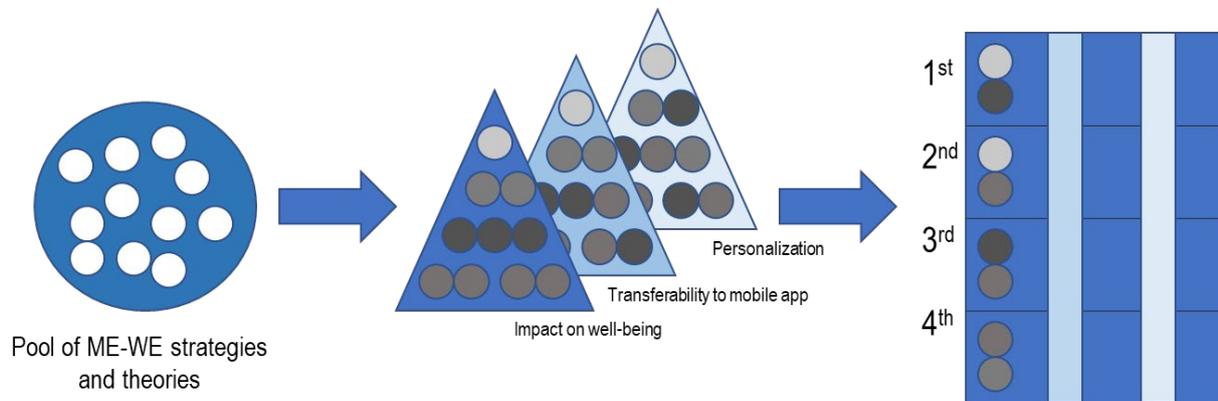


Figure 8: Process for the ME-WE rating and ranking study in which the pool of ME-WE strategies (step 1) is rated on various criteria (step 2), resulting in a ranked list of interventions, programmes, and methods.

Table 5: Concise description of the 39 interventions, programmes, and methods to (in)directly support (A)YCs used in the rating study, with country of origin, links to online material and from which study the intervention was selected.²⁵

Nr.	Intervention	Country	Online Material	Selected From	Description
1	Who Cares?!	The Netherlands	https://www.markant.org/over-markant/wat-we-doen/whocares/	Delphi Study	Who cares?! Is a programme for schools that asks attention for youngsters who grow up with a (mental)ill, disabled or addicted family member. The goals are: recognition by teachers and mentors, recognition for young carers themselves, and better support for young carers.
2	Ervaringsmaatjes	The Netherlands	http://ervaringsmaatjes.nl/	Delphi Study	Ervaringsmaatjes is a buddy project to provide individual support for young carers. The buddy is a volunteer or student who were also a young carer and has expert experience on this subject. The buddy offers a listening ear, supports with practical issues and is there to provide social support. The buddy supports in gaining insight into the (A)YC's needs and wishes.
3	Week of the young informal carer	The Netherlands	https://www.markant.org/de-week-van-de-jonge-mantelzorger-2017/	Delphi Study	The week of the young informal carer is an annual awareness raising event in The Netherlands held in many municipalities across The Netherlands. The ultimate goal is to enlarge and enhance the support provision for young carers. In different cities - during this week - there are activities on this subject.
4	Vanzelfsprekend?!	The Netherlands	https://www.vanzelfsprekendjnz.nl/	Delphi Study	Vanzelfsprekend?! is a platform for recognizing and acknowledging young carers where they can ask questions and being listened to. Together the young carer and Vanzelfsprekend?! look at the (A)YC's situation to see what he/she needs and to refer to formal care where needed. Vanzelfsprekend?! organizes activities like 'chill-evenings', and other events, for young carers to relax and have the space to share experiences with fellow young carers.
5	Superhands	Austria	https://www.superhands.at/	Social Media Analysis	Superhands is a hub and point of contact for children and adolescent who look after sick relatives. The aim of superhands is to inform, to advise and to relieve in the best possible way, so that children and adolescents can live a childhood without care responsibilities. The offer of superhands is aimed at caregivers and multipliers, such as teachers, doctors, nurses, psychologists, social workers and many more. Superhands offers help and advice. It is free and anonymous, by phone and online.
6	Online Young Carer test	The Netherlands	http://www.surveygizmo.eu/s3/90005207/jonge-mantelzorgers	Delphi Study	This online test is a tool for the recognition of young carers. How do you know if you, or someone you know, is a young carer? This test raises questions to identify young carers. After you completed the test, the website provides tips and tricks for young carers and people who know young carers.
7	TV show 'Jinek' 2015	The Netherlands	https://evajinek.kro-ncrs.nl/artikelen/jonge-mantelzorgers-verplegen-eigen-moeder	Social media analysis	During a TV talk show, young carers told about the problems they face as young people in the long-term care of their parents, brothers, sisters of other family members. These three young carers are ambassadors during the week of the young carer and they aim to raise awareness for the situation of young carers. A danger that threatens, when it is no longer possible to combine 'all extra' tasks, with all the physical and emotional consequences that entails. But also becoming invisible to the care services is a big problem.
8	SIZ Twente	The Netherlands	https://www.siztwente-jmz.com/cursussen	Delphi Study	SIZ Twente organizes activities and courses for young informal carers in different municipalities in the east of the Netherlands. SIZ Twente focusses on children who care for or care about a brother, sister or parent with a chronic illness, disability, addiction or mental problems. SIZ offers activities, courses, individual support and experienced buddy's, in order to support the young carer and the social network in which the own development of happiness and resilience of the young carer are centralized.
9	ACE	England	https://acestoohigh.com/got-your-ace-	Delphi Study	ACE can be used to identify young carers. There are ten types of childhood trauma measured in the ACE study, of which five are personal, and five are related to other family members. Each type of trauma counts as one. So a person who's

²⁵ The experts were provided with a more elaborate description of the interventions, programmes and methods. The descriptions are left out of this deliverable due to page constraints. See detailed procedure below for an example of a description.

			score/		been physically abused, with one alcoholic parent, and a mother who was beaten up has an ACE score of three. ACE scores do not measure positive experiences in early life that can help build resilience and protect a child from the effects of trauma.
10	Training for professionals	The Netherlands	https://markant.org/thema/producten-en-diensten-voor-professionals/training	Delphi Study	This is a training for professionals in healthcare, welfare, youthwork and education who work with young people between 12 and 25 years old who grow up with an ill family member. The goals of this training for professionals are being able to identify young carers, being more alert for situations that ask for support, and being able to offer local support for young carers.
11	Who cares?!	Australia	https://www.facs.nsw.gov.au/data/assets/pdf_file/0003/392781/NSW-Carers-Strate	General Literature Review	To give young carers easy access to all of the information on the Carers NSW website, they have developed a mobile application called who cares?! On this app, young carers can find all of the information and links to services that are available on the website, as well as the stories from other young carers. In addition, the app also features a function that allows young people to test whether they could be classified as young carers themselves, so a function for identification.
12	Barnkraft	Sweden	https://www.umea.se/umeakommun/omsorgochhjalp/familjbarnochungdom/stodtillbarnochungdom/stoderupperforbarnochunga/barnkraftvidpsyiskohalsaellermisbrukifamiljen.4.620856de12d4bd3b4618000904.html	Delphi Study	Barnkraft has parallel groups: child group and parent group. The goal of these support groups is to learn about the mental illness or addiction and how it influences the family. Also, to reduce shame and feelings of guilt. Both groups are at the same moment.
13	Beardslee's family intervention	Sweden	http://www.anhoriga.se/metoder-och-stod/modeller-och-meto	Delphi Sweden	Beardslee's family intervention is a family-based approach for the prevention of depressive symptoms among children at risk
14	Hash ziit (Do you have time?)	Switzerland	https://haeschziit.ch/	BLN - Switzerland	Forum for questions and suggestions on different topics such as health, love and friendship, money and housing, parental home, education and jobs and hobbies.
15	Barnadro's action with young carers	UK	https://www.barnardos.org.uk/youngcarersnorthwest.htm	General & Academic literature review (Grant et al., 2008).	This project focusses on young carers up to the age of 25 and provides assessments, specialist one-to-one support for each child, out-of-school and out-of-home activities, counselling and group work. The project also emphasizes indirect work with local agencies that include strategy planning, development, training and promotional work to ensure that local services were joined up. The project acts as a signpost to other services.
16	Fora barnen pa tal	Sweden	http://www.anhoriga.se/anhorigomraden/barn-som-anhoriga/	Delphi Sweden	Family focused approach. 'Fora barnen pa tal' is a manual based method in which the professional meets the parent(s) on two occasions and together with the parents talk about the children and their situation. During the meetings they use a structured logbook as support.
17	Mind Matters	Switzerland	https://www.radix.ch/Gesunde-Schulen/Psychische-Gesundheit	Delphi Switzerland	School mental health programme. Quote: "The goal of mind matters is to see in the school from the school management over the teacher up to the children that beneficial measures are implemented, and that the mental health is strengthened over the life competence over the resource, and then it has in there also most diverse products."
18	Carers Allowance	UK	https://www.gov.uk/carers-allowance	Online search	Financial benefit offered through the government for those 16 years old and older caring for someone.

19	Kinderseele	Switzerland	https://kinderseele.ch/uber-uns/	Delphi Study	This institute offers children and youngsters of a parent with a psychiatric illness support and relied. They focus on prevention and try to connect local, national and international partners. The goal is to prevent and recognize psychiatric disorder in children and youngsters. The activities are online information platform, personal telephone and email contact with professional, peer support via the web, educational films, family intervention programme and coordination of regional support providers.
20	Talk-Link	Australia	https://carernsw.org.au/news-events/events/counselling	General literature review	Talk-Link is a type of support, provided by Carers NSW in Australia. Talk-Link offers telephone group counselling for young carers for free. The groups run over a course of six weeks and are facilitated by professionally trained counsellors either in person or over the phone via Talk-line. The goals of this intervention are to help young carers to cope with their role as young carer, share feeling and fears, being accepted and reducing the sense of isolation, and to provide information for additional help on a short-term basis.
21	Book for COPMI	Italy	http://quandomam.maopapa.pages.liberto.it/	Referral from COPMI website	A miniguide for survival for daughters and sons who live with a mother and/or father with a mental health problem. The books want to change the 'pact of secrecy' of being a young carer by contributing to create a safer environment, a more understanding society so to ensure that parents access proper treatment in time and their children can talk freely about what happens at home without being judged. The book also helps COPMI to better understand the impact of their parent's illness and it present a collection of projects that are dedicated to a better outcome for young carers. The miniguide is also a useful too for professionals, teachers, social workers, policy makers etc.
22	Young carers and young adult carers projects	UK	https://www.childrensociety.org.uk/youngcarer/young-carers-services	Delphi Study	Non-profit organizations to offer supportive psychosocial activities for young carers and young adults carers, respite activities, and peer support. Funded by governments funds and private donors. Located across the UK.
23	Crossroadss young carers project	UK	http://www.carerskm.org/Home/YoungCarers	Academic literature (Richardson et al., 2009).	The goals of the Crossroads project are to offer respite, recreation and peer support. The project contains fortnightly club night, one to one, trips out and information and advice. Form academic evaluation, these aspects were found to be important and successful in this intervention.
24	Carers South Australia Young Carer Services Model	Australia	https://www.carers-sa.asn.au/are-you-a-care/young-carers/	BLN 4 - input via Francesca Centola	Carers South Australia has designed a model focusing on early intervention. The goal of the programme is to strengthen the resilience of young carers. The approach is holistic, taking into consideration that the young carer is embedded within a much broader environment. Hence, engagement of schools, education providers and employers as well as close collaboration between service and community networks are vital.
25	The about time grants programmes	UK	https://professional.s.carers.org/About-Time-Grant-Evaluations	BLN4 - input via Anna Morris	The overall aim of the programme is to provide practical support to young adult carers, helping them to transition positively into adulthood, leading to long-term change. The specific objectives are to focus on the young adult carer themselves with an understanding of their caring role, to provide access to tailored support, to enable activities which create an environment where young carers are able to build a network of support, and to support a flexible response to the needs of carers in the local area.
26	Online Peer Support Group	Italy	http://www.comip-italia.org/cosa-facciamo/gruppo-ama-online-figli/	Delphi Study	A safe online private space active 24/7 and run by lived experience volunteers where young carers are among other carers of different ages and are allowed o share their difficult situations and have a positive mentorship by 'older' COPMI.
27	Whole family interventions pilot programme	UK	Not available	BNL 4 - input via Anna Morris	The overall aim is to improve the life chances of the most isolated and vulnerable young carers under the age of 24 across the UK. Specifics aims are to improve general well-being, family relationships, self-esteem and confidence of parents and young carers by working with the whole family, including the young carer. The programme involves a partnership between the skills of young carer services and family support services to provide better outcomes for young carers. The support provided ranges from practical, through relational to emotional.
28	Progetto Giovani Caregiver	Italy	www.giovanicaregiver.it	Delphi Study	The 'Young carers Project' is the umbrella project that includes all activities offered by ANS to support young carers. It includes actions such as workshops for teachers and students delivered in schools to raise awareness on (A)YC's and their needs, and one-to-one support offered to (A)YC's in need of a social or psychological support.
29	Young Carers in School Programme	UK	https://youngcarersinschool.com	Delphi Study interviews	An England-based initiative to help schools better support young carers and awards good practice by means of face to face contact and online resources.

30	Express yourself	Italy	http://www.ep-yc.org/being-a-young-carer-photos-and-video-exhibition-in-carp-italy/	Delphi Study	Workshop for adolescent young carers aimed to help them express their emotions through artistic means, such as photos and video-production. The workshop was conducted by a psychologist and a photographer and it aimed to provide (A)YC's some basic knowledge on video-production and photography while encouraging them to use these means to tell about their families, their lives, their emotions.
31	Regional relaxing weekend breaks	Sweden	Not available	Delphi Sweden	Relaxation activities, contact with peers, a breathing space, combination of informal and relaxing, realize that you are not alone, being able to speak. Quote: "then we have also.. initiated meetings for children with a severely sick parents with cancer, and this is possible thanks to a contribution from the regional cancer centre north."
32	YoungSibs	UK	https://www.youngsibs.org.uk/information-for-professionals/	Online search	YoungSibs is a website and support service for children and young people who have a brother or sister who is disabled, has special educational needs or serious long-term condition. It is for siblings in the UK aged 6 to 7. The YoungSibs service is run by Sibs, the UK charity for siblings of disabled children and adults.
33	BRA-Samtal	Sweden	http://www.allmanabarnhuset.se/projekt/pagaende-projekt/b	Delphi Sweden	BRA-samtal is a model for talking with children as next of kins. A model for talking with children as next of kins, in order to ensure that the children get opportunities to talk about their situation, be involved, and be aware of their rights. BRA-samtal are structured conversations with a child, with the aim to investigate the child's current life situation, followed by one conversation which has a more supportive form.
34	Pro Mente Sana Schulprojekt	Switzerland	https://www.promentesana.ch/de/angebote/schulprojekt.html	Delphi study	It is a school programme about mental health issues discussed by a professional; a carer and someone experiencing MH issues. The goals of this programme by talking about MH are to reduce anxiety, create less stigmatization and prejudices, give hope and courage and help to prevent future mental illnesses.
35	Young Carers Festivals	UK	https://www.childrensociety.org.uk/youngcarer/home	Online search	Often run throughout the country, the longest running young carers festival takes place in Southern England through the Children's society. The festival provides the young people with the opportunity to have fun, relax, socialize and have their voices heard about issues that affect them. The outcomes from participatory consultations inform future work and are communicated to the government.
36	Edinburgh Young Carers Project Forum	Scotland	https://youngcarers.org.uk/evcp/evcp-forum	Delphi study interview	The forum is the main way that Edinburgh Young Carers Project consults young people about their views and encourages them to become involved with the project. The service of need is to encourage leadership and self-advocacy skills for young carers, providing an opportunity for young carers to influence the practices of their young carers project by means of face to face group meetings.
37	Psychoeducational Programme for Siblings	Italy	Not available	Delphi Study	This is a psycho-educational programme targeting adolescents/young adults who are siblings of a person with a disability. The programme includes three sessions of 1.5 hours each. The first one is aimed at allowing participants to get to know each other and to help understand how much they share with the rest of the group. The second one aims to help participants to become more aware of their emotions and their needs. The last one aims to support them to develop coping strategies.
38	NHS Young Carer Health Champion Programme	England	https://www.cypnow.co.uk/cyp/news/2005388/government-pledges-to-improve-young-carer-identification-and-support	Delphi Study	The Young Carers Health Champion programme was established in 2015 to support improved health literacy, promote health and well-being and develop the capacity of young carers to participate in planning and the development of young carer friendly services. It aims to support service change through young carer voices. It does so by means of group sessions and one-to-ones with support workers.

39	Our Time Foundation	England	https://ourtime.org.uk	Delphi Study Interview	Non-profit organization based in England that works to identify and provide explanation-based interventions to children affected by parental mental illness, inform and train education and healthcare professionals to identify and support children affected by parental mental illness, lobby for proper recognition of children affected by parental mental illness and their needs, and work with groups such as peers, parents and the general public to build understanding of the needs of children affected by parental mental illness.
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Participants

18 raters participated in the study, of which 8 were young carers ($M_{age} = 21.6$, $SD = 6.8$, 6 female) and 10 experts ($M_{age} = 45.1$, $SD = 12.6$, 7 female). The young carers were from the UK ($n = 5$), Switzerland ($n = 1$), The Netherlands ($n = 1$), and Slovenia ($n = 1$). The experts were from Italy ($n = 3$), UK ($n = 1$), Sweden ($n = 1$), Switzerland ($n = 1$), The Netherlands ($n = 1$), and Slovenia ($n = 1$). The 5 young carers for the UK divided the 39 interventions between themselves and rated approximately 8 per participant.

5.2.1 Criteria for rating: template for interventions

The criteria for the rating study were based on the project conceptual framework (see Figure 9 below). Interventions, programmes and methods could influence (A)YCs' mental health & well-being, education, and social life. Furthermore, influences are foreseen on caregiver burden, the caring activity, and positive and negative aspects of the caring activity (see left of the figure). Furthermore, the impact on resilience is also included as a criterium for the rating.

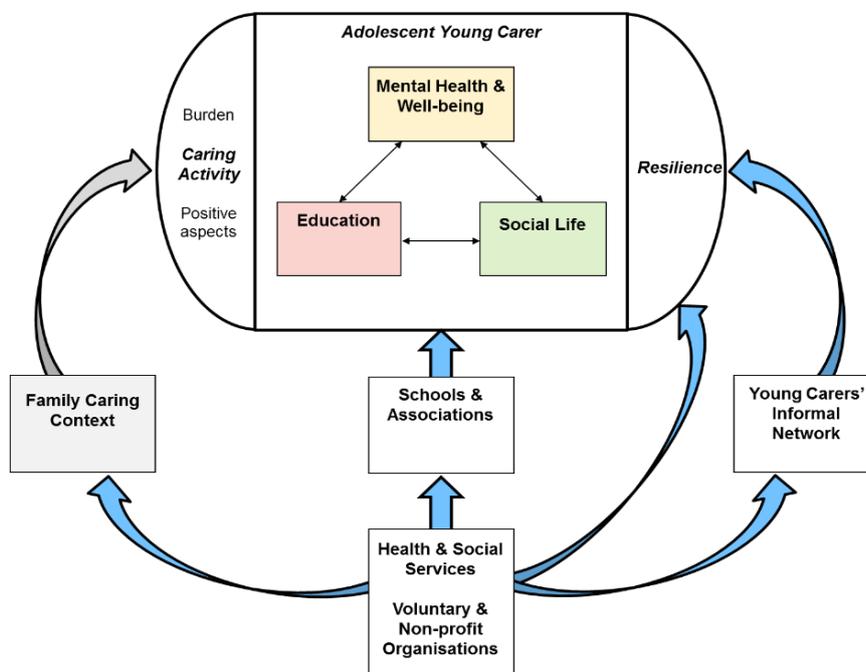


Figure 9: The ME-WE project conceptual framework: counterbalancing caring burden with support and resilience empowerment

From the Delphi study and literature studies, we gained insights into a variety of ways to contribute to support strategies, such as identification and group sessions. These were also added to the rating criteria (see Table 6 below).

Table 6: Descriptions and criteria of the interventions, programmes, and methods to support (A)YCs (first column), including explanations (second column).

Name:	Name of the intervention, method or procedure to directly or indirectly support (A)YCs
Intervention number:	Unique number to be used as an identifier
Country:	Country of origin

Online Material:	<i>Web-site or other online material available</i>
Organization:	<i>Organization that developed and/or distributes(ed) the intervention, method or procedure</i>
Selected from	<i>It was selected from the ME-WE: Delphi study, Academic Literature study, Social Media Analysis, BLN (Blended Learning Network)</i>
Screenshots/Images	<i>Image material of intervention, method or procedure</i>
Description:	<i>Description of the methodology + if available, a quote from a study.</i>
Service of need:	<i>For whom and the type of intervention, method or procedure (e.g., providing information, recognition, awareness)</i>
Duration of program:	<i>Duration in time (e.g., 1 hour, 3 weeks, 1 year with monthly sessions of 2 hours)</i>
Reported impact:	<i>The impact known on the intended stakeholders (e.g., a significant rise in resilience in Young Carers over the course of the training).</i>
Language of Programme/Intervention	<i>Available languages of the training (e.g., English & Italian)</i>
Status:	<i>Current status of the intervention, method or procedure. Is it still running? Is it available for organizations to use? Is it open, what are the costs?</i>
Similar interventions:	<i>Available interventions with similar goals, means, procedures (if known, also from other countries)</i>
Online Material:	<i>Online material of similar interventions.</i>

Rating and Ranking

[HERE THE RATING STARTS]

1. General:	
ID number:	<i>Unique number to be used as an identifier</i>
Status:	<i>Current status (mature, in development)</i>
Openness:	<i>Open, without costs, or with a fee (low to high fee)</i>
Main involved target group:	<i>Select the target group of the intervention (focus on family, care professional, school, etc.)</i>
Developed in co-creation:	<i>To which extent is it developed together with the involved target group themselves in co-creation (e.g., with Young Carers providing information, suggestions, ideas during the creation, design of the materials)</i>
Applicability in your country/culture:	<i>Is it possible to use the intervention in your country/culture in respect to language, means, methodology</i>
Risk on adverse outcomes:	<i>Are there negative/adverse outcomes foreseen or noted whenever the intervention, programme or method is applied.</i>
2. Influence on:	
mental health (e.g., stress)	<i>The general concept of mental health -> the influence of the intervention, method or procedure on e.g., stress of the intended stakeholder (mostly the (A)YC)</i>
well-being (e.g., happiness)	<i>Well-being/happiness of intended stakeholder</i>
social life (e.g., contact with friends)	<i>Influence on social life, e.g., friends or intended stakeholders</i>
education (e.g., school progress)	<i>School duration, ability to attend, outcomes, homework</i>
caring activities (e.g., household tasks)	<i>Support and substitution on caring tasks (other people supporting, respite care), reducing and making it easier to perform caring tasks</i>
positive impact of care giving (e.g., fulfilment)	<i>Experience and feelings of care giving tasks (subjective, positive such as life fulfilment, better relations)</i>

negative impact of care giving (e.g., high care burden)	<i>Negative outcomes -> experiences</i>
resilience (e.g., coping)	<i>Resilience to deal with life events, to cope with</i>
relationship with parents	<i>Experience of the relation that the (A)YC has with his/her parents</i>
3. Contribution to support strategies (direct or indirect):	<i>(ways to provide the support)</i>
Identification	<i>Knowledge about your own Young Carer role/identity (you know, could also be another stakeholder group (e.g., teacher)</i>
network building	<i>Development of network around the Young Carer, consisting of different stakeholders (could also be the family/informal network)</i>
group sessions	<i>Facilitate young carers meeting other young carers or professionals in a group</i>
awareness raising	<i>Information/dissemination about Young Carers and their role of being an informal carer in society (their challenges, e.g., on TV, newspaper, Internet, etc.)</i>
policy making	<i>Official/government documentation/regulations/policy frameworks on the topic of Young Caregiving</i>
social connectedness with young carers	<i>The extent to which the contact with other is supported (experience or feeling of connected care, could be virtual online)</i>
Legislation	<i>Formal legislation on rights for Young Carers, children, and other stakeholder</i>
use of informal care (family or volunteers)	<i>Facilitate informal respite care</i>
use of professional care (for (A)YC or care recipient)	<i>Facilitate formal care for young carer or family member(s) in need of care</i>
4. Transferability to online app for Young Carers	
Transferability	<i>To which extent is the method, intervention, procedure transferable to an online environment such as an app or website.</i>

5.2.2 Detailed procedure

Below the detailed procedure is presented that was used in the UK, The Netherlands, Switzerland, Sweden and Slovenia, followed by an adjusted procedure for the Italian experts.

Rating Study Procedure

In the rating study you will go through a number of national programmes, interventions and methods across the world, that are developed to support young carers, and rate these on a number of criteria. It will cost you 1-2 hours to fill in and please do save the file whenever you changed it. You have the opportunity to stop whenever you want and continue when you want.

Step 1.

Open the Excel file named 'Rating_Study_ME-WE' and you will find multiple tabs with the first one entitled 'General Questions' (see below). In this tab you will fill in our age, gender, country and role in the yellow field. (see descriptions). Make sure you will save the file after you filled in the fields.

	A	B	C	D	E	F	G	H
1								
2								
3								
4								
5								
6								
7	1. Age:		(type in your age in years)					
8	2. Gender:		(type in male, female, other)					
9	3. Country:		(type in the country of residence)					
10	4. Role:		(type in your role for the rating study: young carer or expert)					
11								

Step 2.

Go the second tab called '001 - Who Cares' - which is the first intervention, programme or method to support young carers. Your first task is to read the first part and gain an insight in the goals, duration, etc. Whenever there is an Internet link, click on it to gain some more information if available (see below). Several websites are in a foreign language (this first example is in Dutch). You can use the translation function of your browser to read the site in English and get an impression.

	Task 3.3 - Rating & Ranking
<i>(hover over topic for more detail)</i>	
Name:	Who Cares?!
Intervention number:	001
Country:	The Netherlands
Online Material:	https://www.markant.org/over-markant/wat-we-
Organization:	Markant
Selected from	Delphi Study
Screenshots/Images	  
Description:	<p>Who cares?! is a program for schools (secondary schools & intermediate vocational education) that asks attention for youngsters who grow up with a (mental)ill, disabled or addicted family member. The goals are:</p> <ol style="list-style-type: none"> 1) Recognition by teachers and mentors 2) Recognition for young carers themselves (self-identification) <p>The program has 4 components:</p> <ol style="list-style-type: none"> 1. Information for teacher (1 hour); 2. Workshop for pupils (1 hour); 3. Talkshow by expert experienced young carer (2 hours); 4. Advice for schools in assurance of support for young carers in school care structure. <p>Quote from delphi study:</p> <p>"During that conference we also talked about 'Who Cares', a program which they roll out in different schools in the Haaglanden region. (...) That is a program for recognizing and acknowledging young informal caregivers within education. They have different activities for this. And with that they have a reasonably large reach within education. I think they have reached 50 classes with students last year and they will reach 80 next year. Anwau, that is really about recognizing and</p>
Service of need:	All young carers. Recognition and acknowledging YCs.
Duration of program:	Half a day
Reported impact:	At least 50 classes reached a year
Language of Programme/Intervention:	Dutch
Status:	Not currently in practice but still available.
Similar interventions:	Jonge Helden (Young Heroes)
Online Material:	https://www.mezzo.nl/pagina/voor-professionals/kennisbank/wat-is-mantelzorgjunge-

Step 3.

Whenever you have read the information and gained insight in the programme, intervention or method to support young carers, you can go to the rating part which is placed below the information (see below). Your task is here to start with the rating for '1. General' and first fill in the 'Status' on a scale from 1 (not mature at all) to 5 (mature to a great extent). If you cannot provide the rating for the reason that the information is not available or you do not know, then you select 'Not applicable'. It is important that you rate the different criteria such as status, openness, developed in co-creation, etc. based on your knowledge (you are the expert).

1. General:	
ID number:	001
Status:	Scale 1 (not mature at all) to 5 (mature to great extent) or Not applicable
Openness:	Scale 1 (not open at all) to 5 (open to great extent) or Not applicable
Main involved target group:	Select the main involved target group of programme, intervention, method
Developed in co-creation:	Scale 1 (not co-created at all) to 5 (co-created to great extent) or Not applicable
Applicability in your country/culture:	Scale 1 (not applicable at all) to 5 (applicable to great extent) or Not applicable
Risk on adverse outcomes:	Scale 1 (no risk at all) to 5 (risk to great extent) or Not applicable
2. Influence on:	
mental health (e.g., stress)	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
well-being (e.g., happiness)	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
social life (e.g., contact with friends)	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
education (e.g., school progress)	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
leisure activities (e.g., household tasks)	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
positive impact of care giving (e.g., fulfillment)	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
negative impact of care giving (e.g., high care burden)	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
resilience (e.g., coping)	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
relationship with parents	Scale 1 (no influence at all) to 5 (influence to great extent) or Not applicable
3. Contribution to support strategies (direct or indirect):	
identification	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
network building	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
group sessions	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
awareness raising	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
policy making	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
social connectedness with young carers	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
legislation	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
use of informal care (family or volunteers)	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
use of professional care (for YC or care recipient)	Scale 1 (no contribution at all) to 5 (contribution to great extent) or Not applicable
4. Transferability to online app for Young Carers	
Transferability	Scale 1 (no transferability at all) to 5 (transferability to great extent) or Not applicable

Whenever you hover over the red triangle, you will get some additional information and support in a yellow comment box what to fill in (see below).

1. General:	
ID number:	001
Status:	Scale 1 (not mature at all) to 5 (mature to great extent) or Not applicable
Openness:	Scale 1 (not open at all) to 5 (open to great extent) or Not applicable
Main involved target group:	Select the main involved target group of programme, intervention, method
Developed in co-creation:	Scale 1 (not co-created at all) to 5 (co-created to great extent) or Not applicable

You will continue filling in the scores per criterium at '2. Influence on:', '3. Contributions to support strategies (direct or indirect):' and '4. Transferability to online app for Young Carers'. Whenever you have filled it in, please save the file again.

Step 4.

After you have filled in the '001 – Who Cares' tab and saved the file, you will continue with '002 – Ervaringsmaatjes', save again and go the 003 tab, etc. Whenever you have filled in all tabs until the tab that is called 'FINAL TAB', you are ready to save once more and send the file back to the email address below.

The procedure for Rating and ranking study in Italy: mixed techniques for collecting data

For the rating and ranking study, Vilans provided an excel file, named "Rating_Study_ME-WE", with 39 sheets, each of which described a different programme, intervention or method to support young carers. Every sheet was divided in two parts: the first one aimed to describe the main characteristics of the project (e.g. goals, duration etc.), while the second part named "rating and raking study" was aimed to evaluate the project, considering four different sections (e.g. general, influence on, contributions to support strategies (direct or indirect) and transferability to online app for young carers); each section was divided into different items. After reading the first part of each sheet, the experts could fill "rating and raking study" in the excel file and express their opinion by assigning a score, ranging from a minimum of 1 to a maximum of 5 to each item that concerns the four rating sections. Italian partners left the

experts free to choose the Computer assisted Telephone Interviewing²⁶ (CATI) technique or the possibility to fill in the questionnaire autonomously.

CATI TECHNIQUE

The CATI technique was chosen in this study because it was deemed useful to support experts in answering questionnaire by providing explanations for a correct understanding of the questions. Moreover, we supposed that the excel file may not be user-friendly for all the experts involved in the study, so CATI could provide a correct data collection by transferring to a researcher the task of transcribing data in the excel file. Thus, starting from the excel file described above, the CATI technique chosen by Italy is divided in four different steps:

1. **Step one:** translation into Italian of the contents of the excel file "Rating_Study_ME-WE". In particular, the main characteristics of the project (first part of the excel sheet) was translated in Italian, while the items concerning Rating and raking study section (second part of each excel sheet) was translated in a questionnaire and transcribed in a word file. The final questionnaire was composed by 25 questions (Annex 1); these were asked to the experts by applying CATI technique.
2. **Step two:** experts were contacted by email that described the CATI procedure and they were asked to confirm their participation. In particular, the mail explains that they were contacted by telephone and a researcher asked them a date in which they could be willing to carry out the CATI. Moreover, the experts received two files attached to the same email, one named "Rating Study" translated in Italian, that showed the description of the projects, the second with the questionnaire for CATI.
3. **Step three:** a researcher contacted the experts by telephone to agree an appointment for CATI
4. **Step four:** in the date chosen by the expert, a researcher contacted him/her by telephone and started to collect data by applying CATI technique.

Feedback from the Italian respondents

In Italy, only one expert chose the CATI techniques, while in the other 2 cases the questionnaire was filled in by experts autonomously. At the end of this study, the three experts gave feedback about the survey. In particular, in their opinion the questionnaire was interesting but very long; in particular, the questions of the first section (general) were the most critical because these concerned some characteristics of the projects that were difficult to evaluate from the synthetic descriptions contained in the excel file. Moreover, in the question about the main involved target group, they could select only one option, while in many cases the eligible options were multiple.

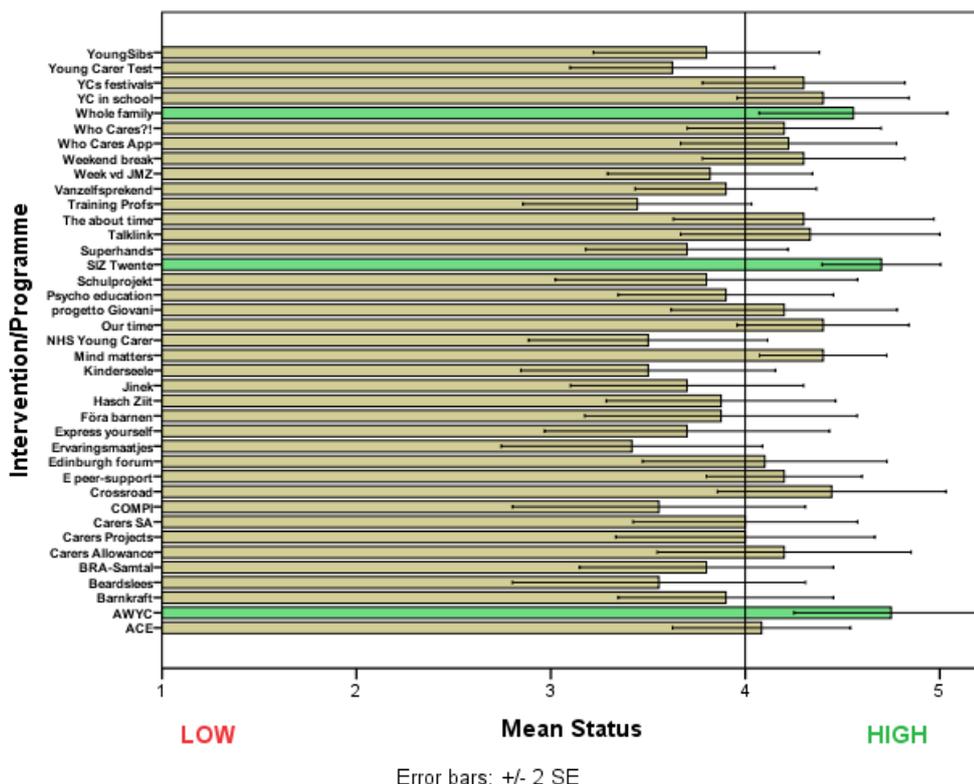
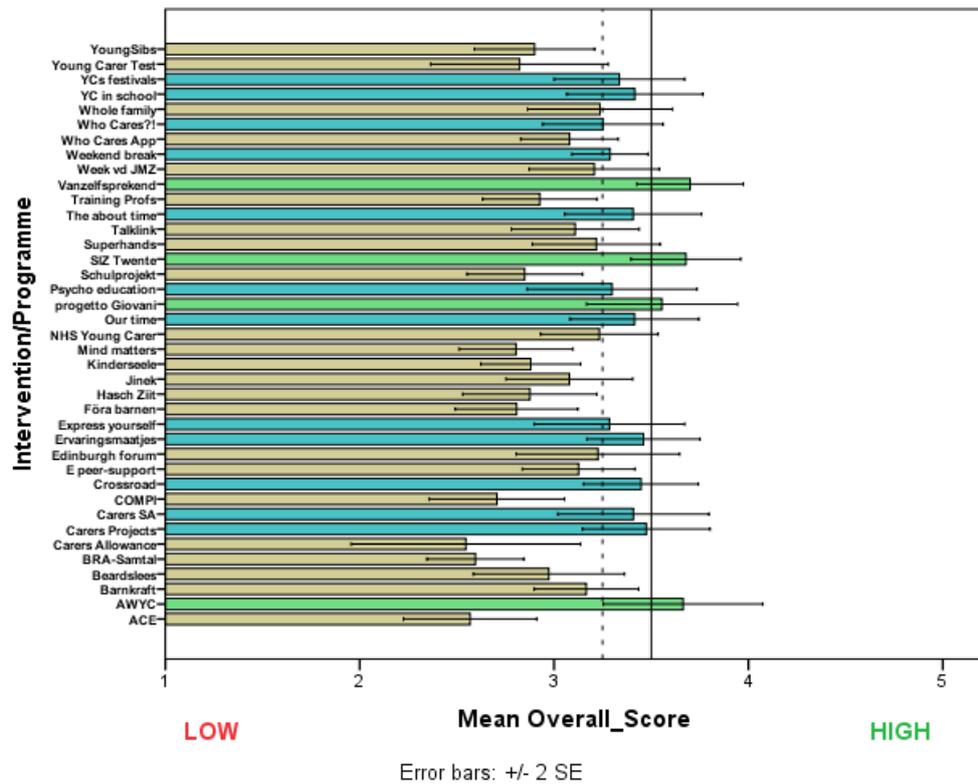
5.3 Results

The 18 participants rated in total 39 interventions resulting in 13.104 MOS data points. The means per criterium were calculated and plotted in bar graphs with error bars (+/- 2SE). In principle, all mean scores higher than 3 (scale mid-point) represent a positive score. We used a reference line at the scale point of 4 to support the visualization of the highest scoring interventions. The three highest scoring interventions, programmes or methods were

²⁶ For more information: https://en.wikipedia.org/wiki/Computer-assisted_telephone_interviewing

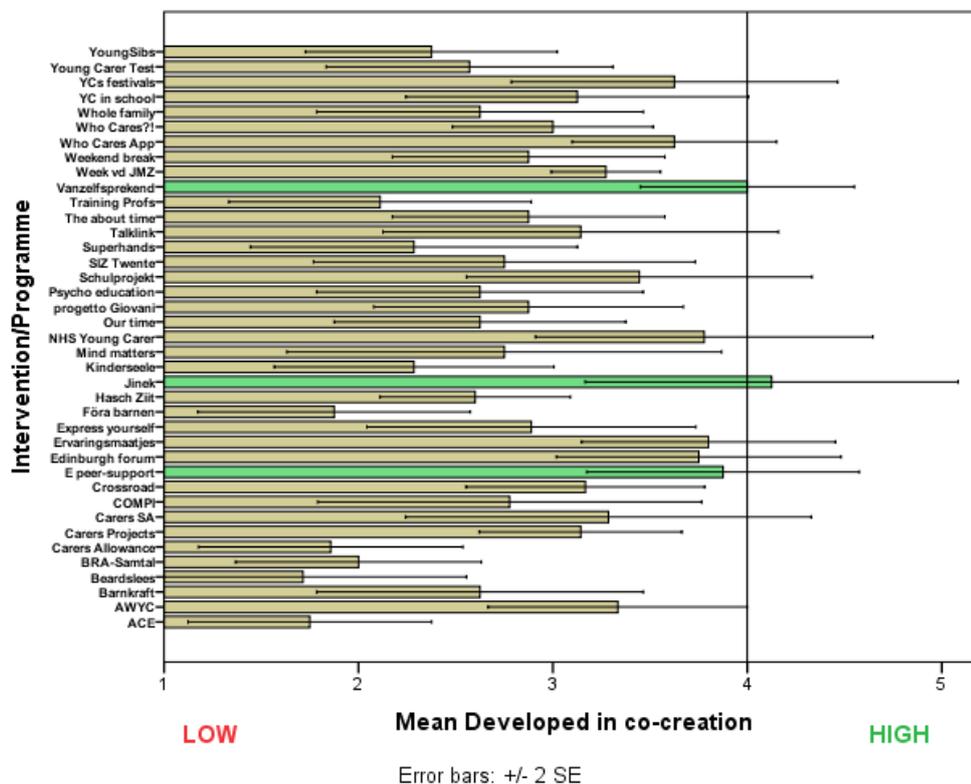
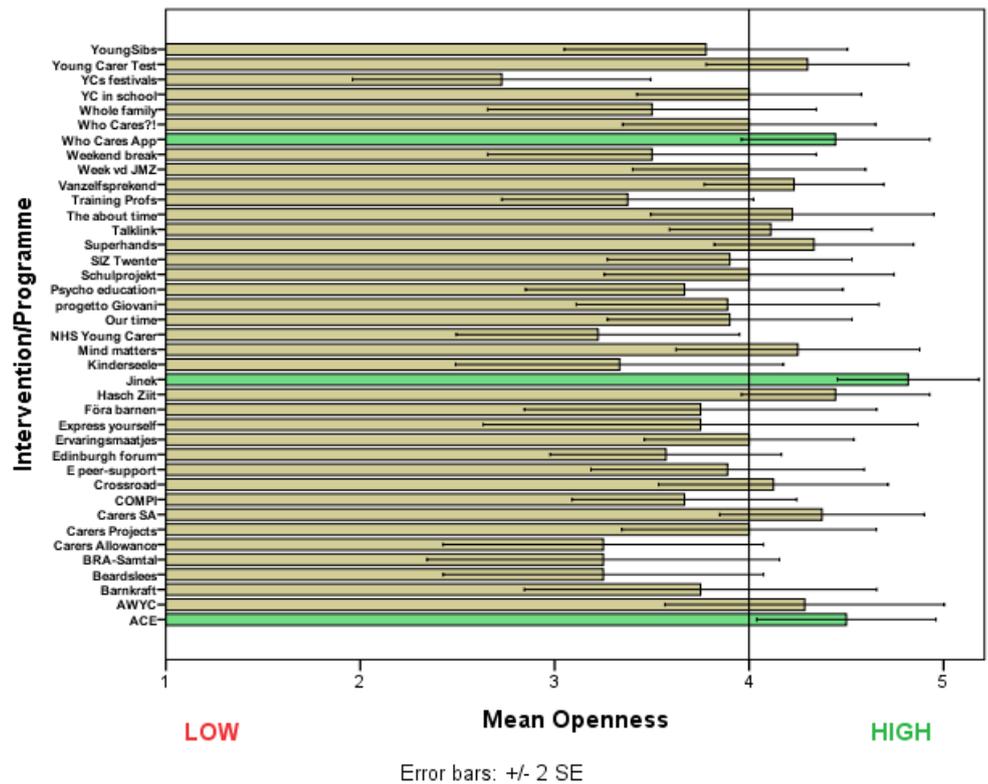
coloured green. It should be noted that this does not imply that somewhat lower scoring interventions did not score well (i.e., all scores above the scale mid-point are on the positive side of the scale). An overall mean was also calculated to gain insight into the intervention that overall scored highest (see first graph). 'Risk on adverse outcomes' was recoded to ensure that low and high scores represent an increasing positive scale.

From the overall score we can report that AWYC, progetto Giovani Caregiver and Vanzelfsprekend have the highest overall mean scores from all 39 interventions, programmes, and methods for supporting and identifying (A)YCs. The standard error (SE) is the standard deviation of the mean within a dataset, providing a measurement for the spread and the smaller the error, the more accurate the dataset. The top 3 are followed by Carers Projects, Carers SA, Crossroads, Ervaringsmaatjes, Express yourself, Our time, Psycho education, The about time, Weekend break, Who Cares?!, (A)YC in school, and (A)YCs festivals.



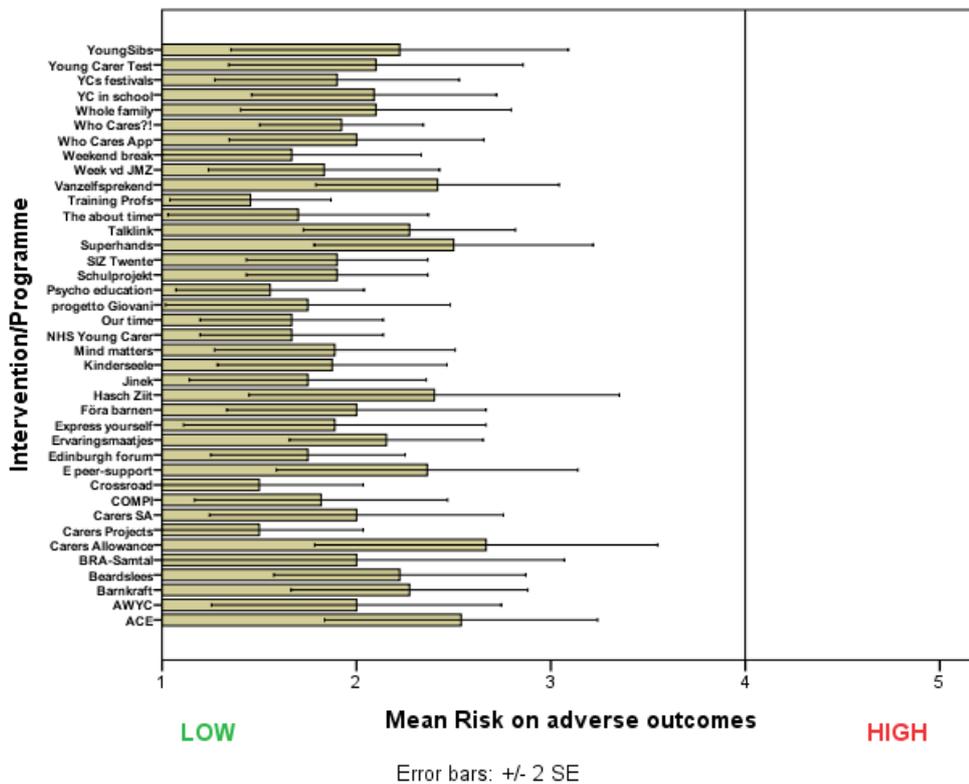
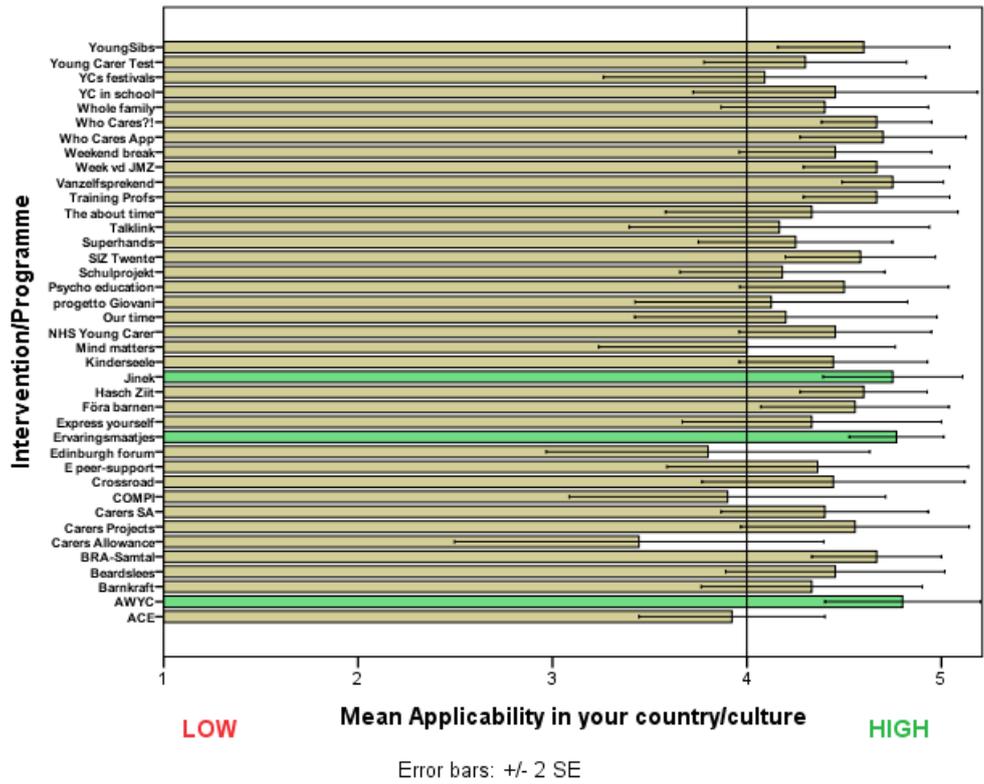
In respect to the current status, we can conclude that all interventions are rated as mature (above scale mid-point). AWYC, SIZ Twente, and Whole family score highest on the maturity of the intervention. Followed by many others, such as Our time, Mind matters, Crossroads, etc.

The openness (i.e. low costs) of the interventions were rated and ACE screening, Jinek (TV show), and the free 'Who Cares App' scored highest. It is interesting that (A)YCs festivals were rated lowest on openness.



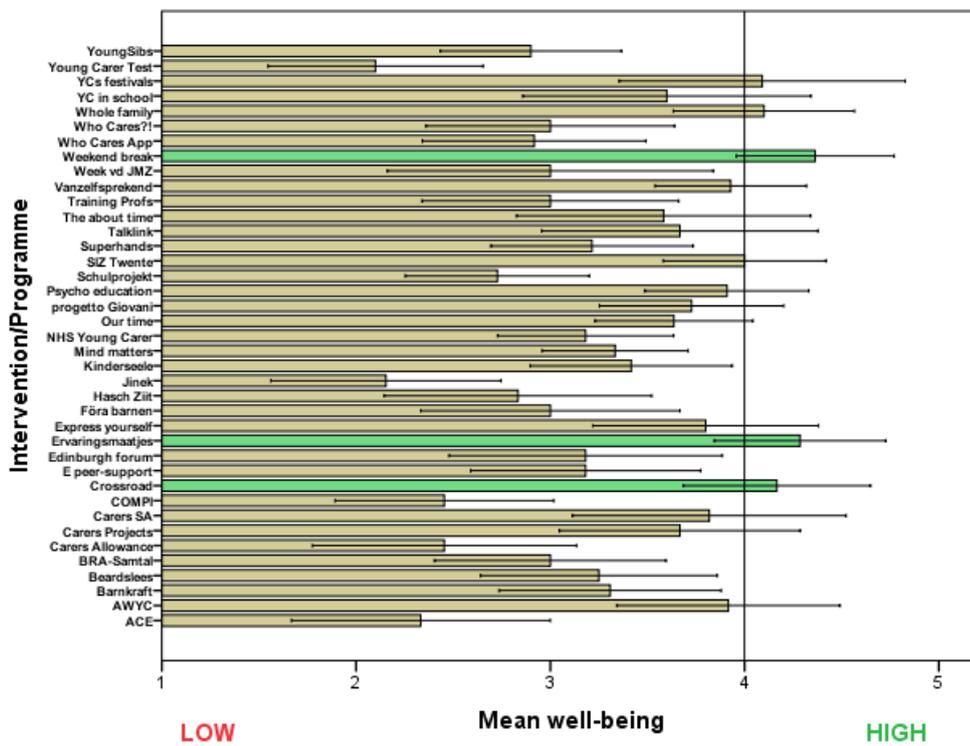
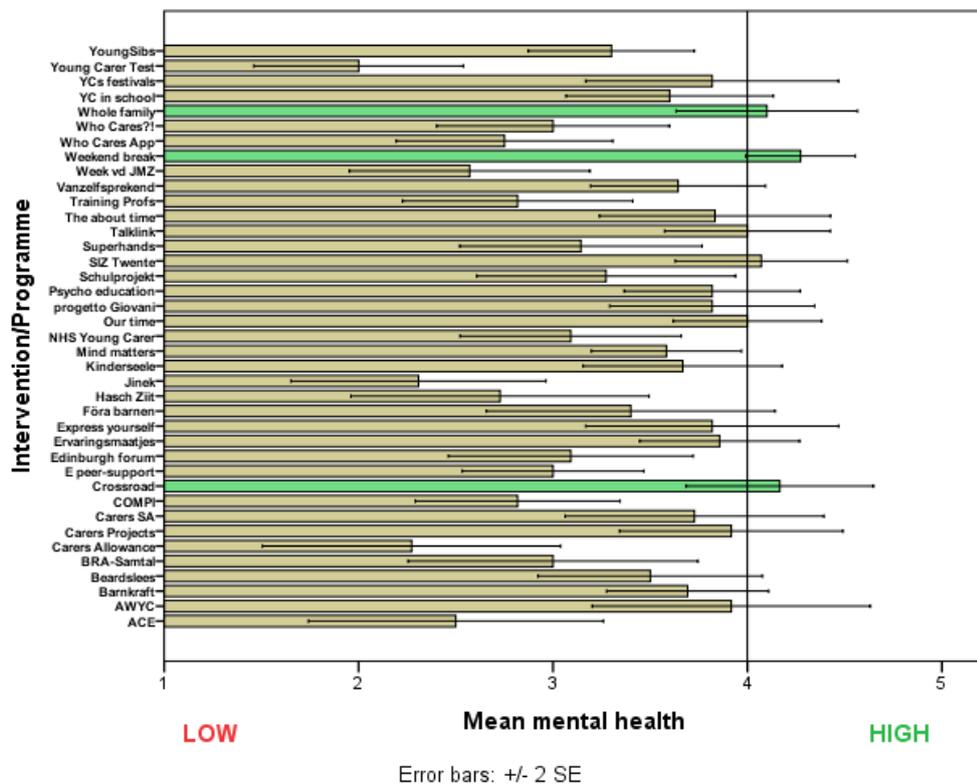
The extent to which the intervention was developed in co-creation with young carers themselves was also rated and seemed – based on the available information – relatively hard to do. However, some did score high, such as E peer-support, Jinek, and Vanzelfsprekend.

To apply an intervention across Europe, it is relevant to know to what extent the intervention is applicable in the various countries. Most interventions were, except for the English specific carers allowance and the Edinburgh forum. Jinek (TV show), Ervaringsmaatjes, and AWYC scored highest, yet, most did.



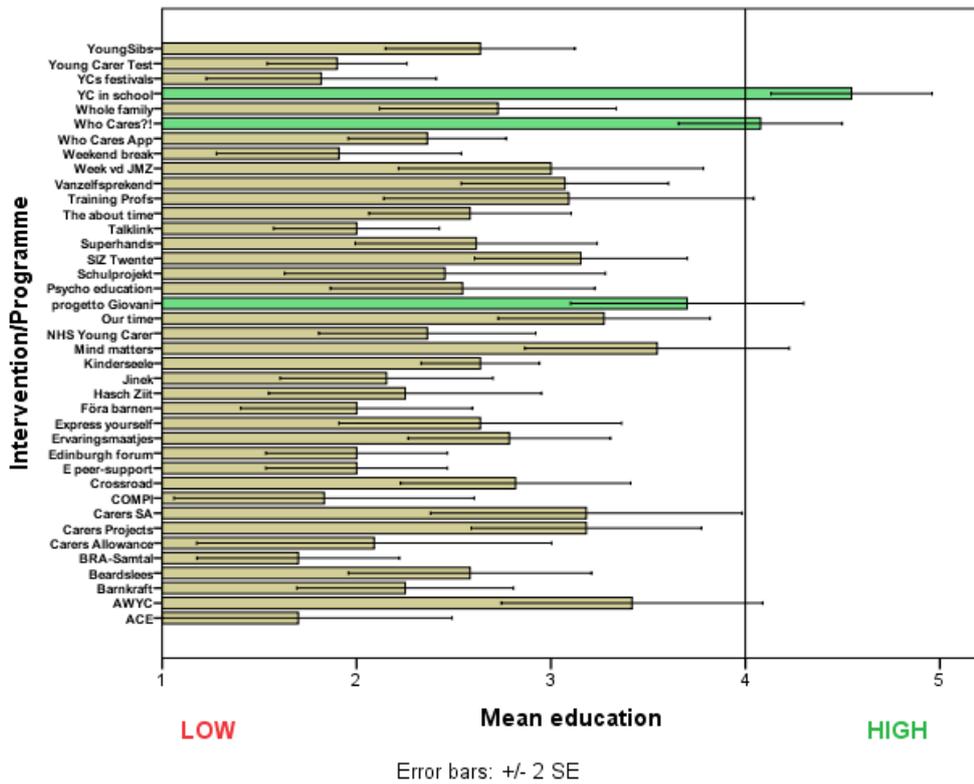
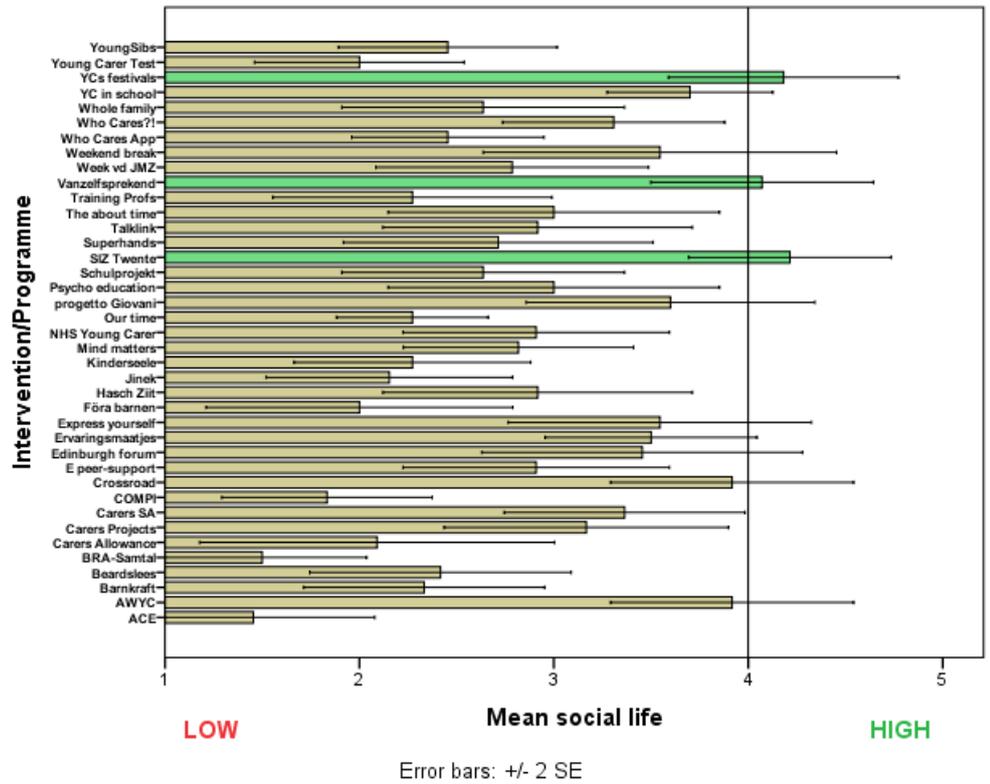
Whenever an intervention is applied, the risk on negative outcomes should be as low as possible. All interventions, and methods scored below the scale mid-point of 3. ACE screening, Carers Allowance, and Superhands scored highest.

In respect to the influence of the intervention on mental health (e.g., stress), it can be seen from the ratings that Crossroads, Weekend break, and Whole family score highest on enhancing mental health.



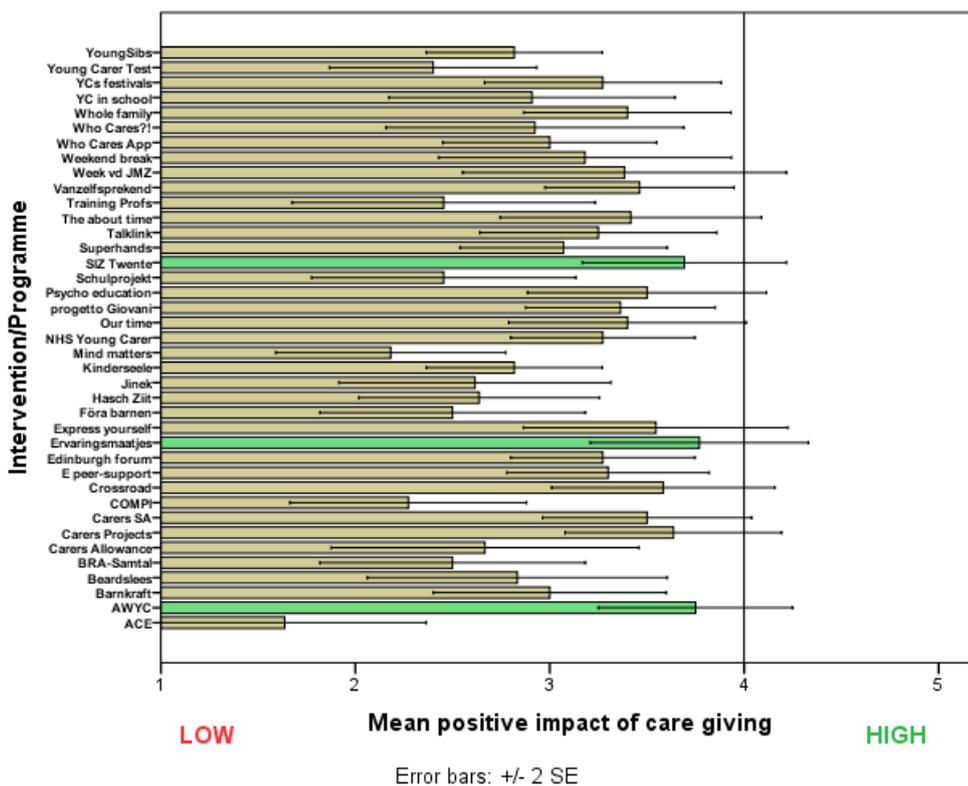
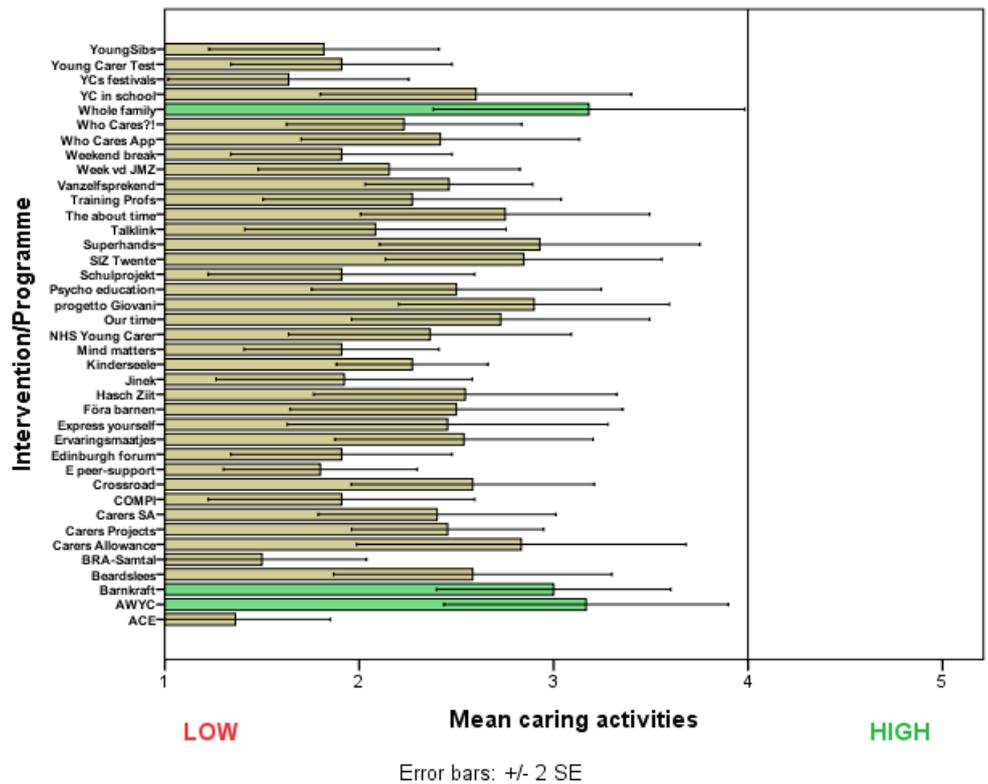
Well-being is influenced most positively – according to the raters – by Crossroads, Ervaringsmaatjes, and Weekend break. However, many score higher than the scale midpoint of 3.

The influence on the social life (e.g., contact with friends or intended stakeholders) was rated highest for SIZ Twente, Vanzelfsprekend, and the (A)YCs festivals. There is a relatively large difference between the ratings for the different interventions and as expected, ratings on tests scored low.



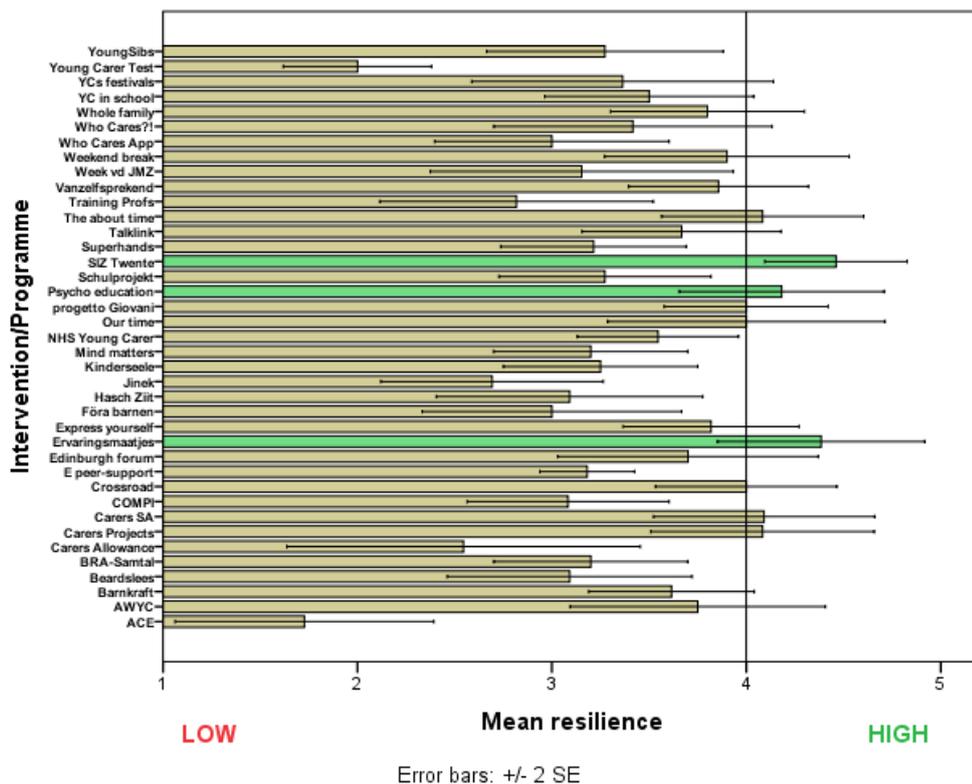
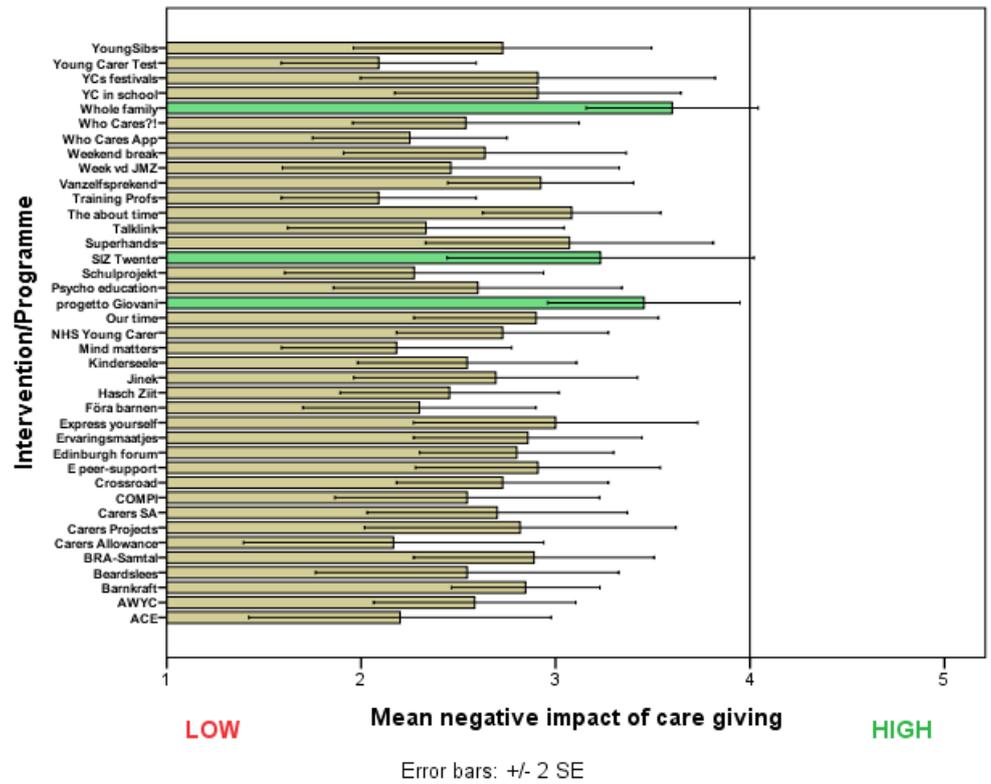
Some programmes stood out in respect to support for school progress or the ability to attend school, such as progetto Giovani Caregiver, Who Cares?!, and (A)YC in school. Followed by Mind matters, AWYC, Carers SA and Carers Projects, and SIZ Twente.

To what extent has the intervention an influence on the caring activities? (e.g., other people supporting, respite care). AWYC, Barnkraft and Whole family score highest (mean). Most programmes score relatively low on influencing the caring activities.



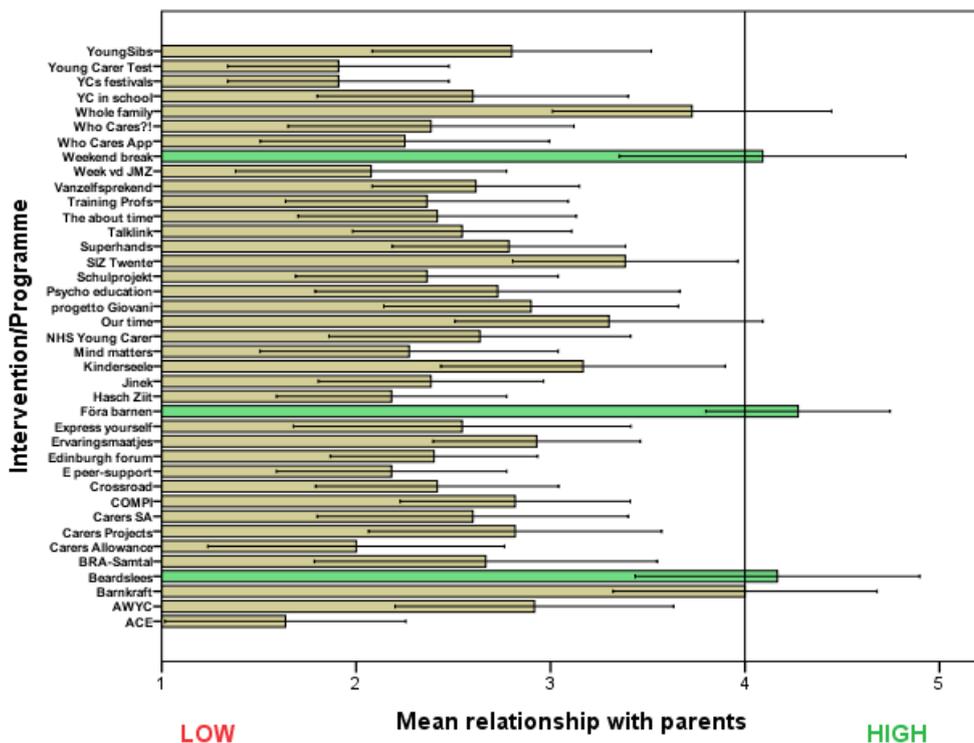
In respect to the interventions' influence on positive impact of caregiving (e.g., fulfilment), AWYC, Ervaringsmaatjes, and SIZ Twente scored highest.

Progetto Giovani, SIZ Twente, and Whole family scored highest on an influence on the negative impact of care giving (e.g., high care burden). From the results it becomes clear that raters differed considerably in their ratings and most scored below the scale mid-point. It is possible that raters were unsure how and what to rate on this criterium.



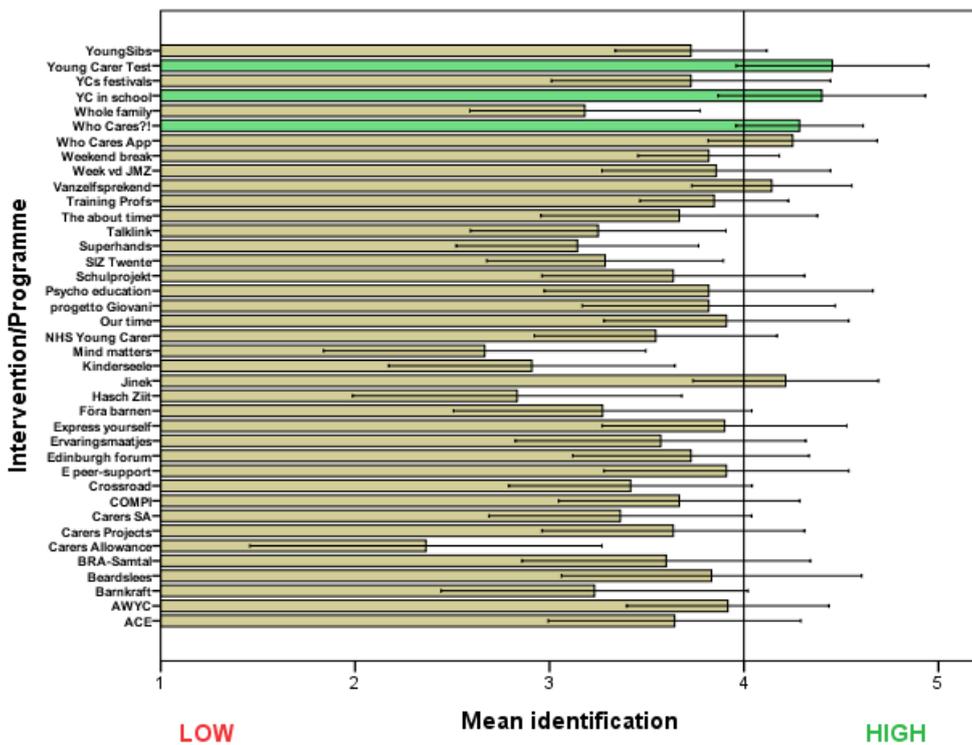
In ME-WE there is a strong focus on building resilience among (A)YCs, to deal and cope with life events. According to the raters, Ervaringsmaatjes, Pscyo education, and SIZ Twente score highest (mean) in building resilience, followed by Carers Projects, Carers SA, The about time and many others.

Some interventions or programmes influence the relationship for (A)YCs with his/her parents to a great extent. Beardslees, Förä barnen, and Weekend break have the highest mean scores, followed by AWYC and Whole family. All these interventions or programmes have a focus on the whole family approach and/or respite.

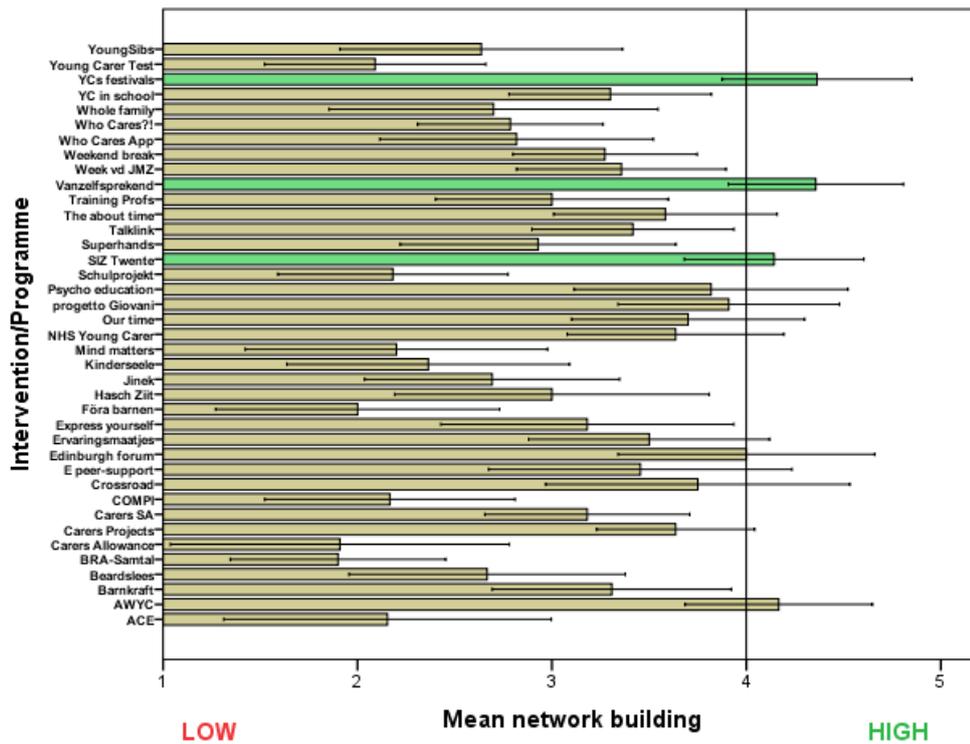


Error bars: +/- 2 SE

Interventions, programmes or methods can contribute to support strategies (i.e. ways to provide the support). Identification is important to gain knowledge about being a young carer / identity (could also be another stakeholder). Who Cares?!, (A)YC in school, and the Young Carer Test score highest (mean) to contribute to identification.



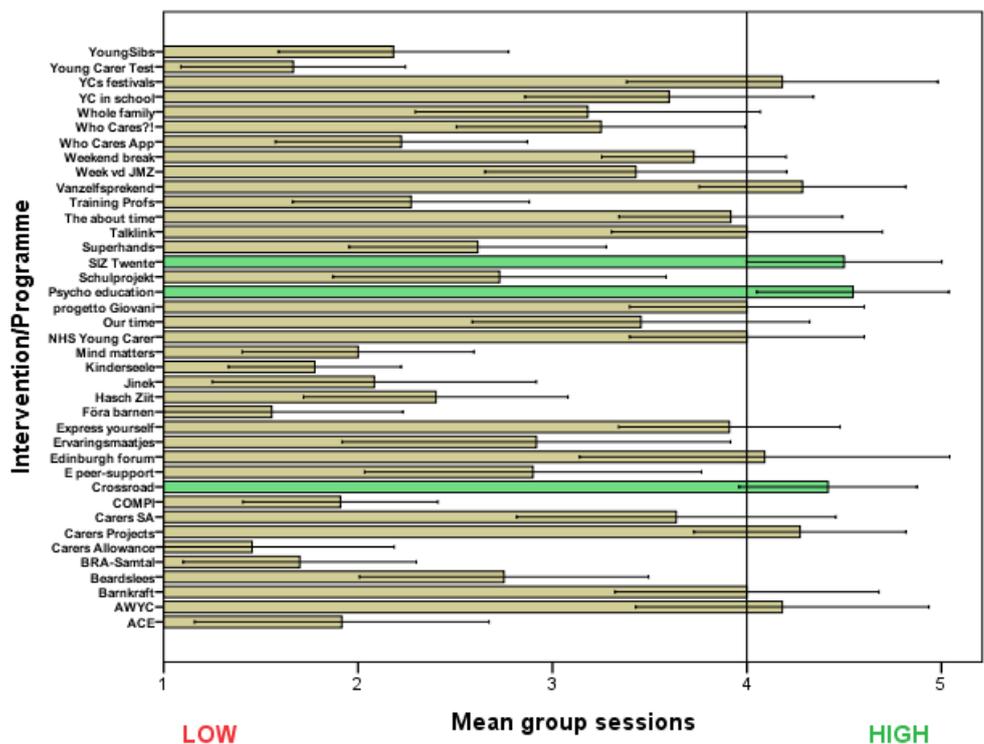
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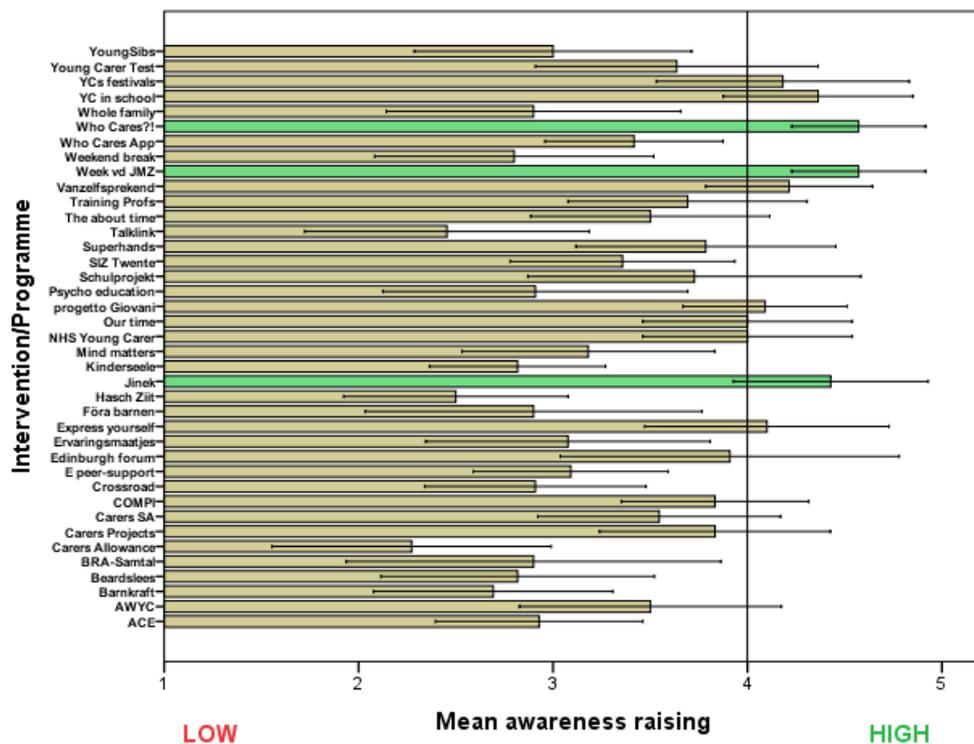
A number of interventions contribute to the support strategy network building, so the development of the network around the Young Carer. SIZ Twente, Vanzelfsprekend, (A)YCs festivals, and AWYC stood out in contributing to network building.

Error bars: +/- 2 SE

The contribution to group sessions ((A)YCs meeting other young carers or professionals in a group) was rated highest for Crossroads, Pscho education, and SIZ Twente, followed by Vanzelfsprekend, Carers Projects, AWYC, and (A)YCs festivals.

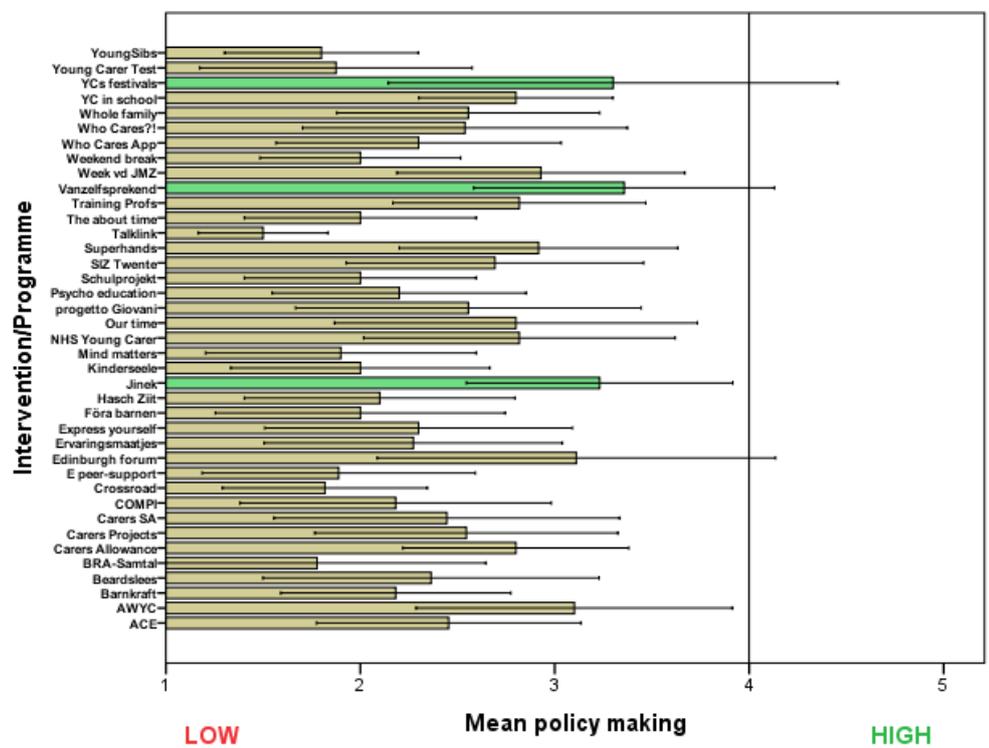


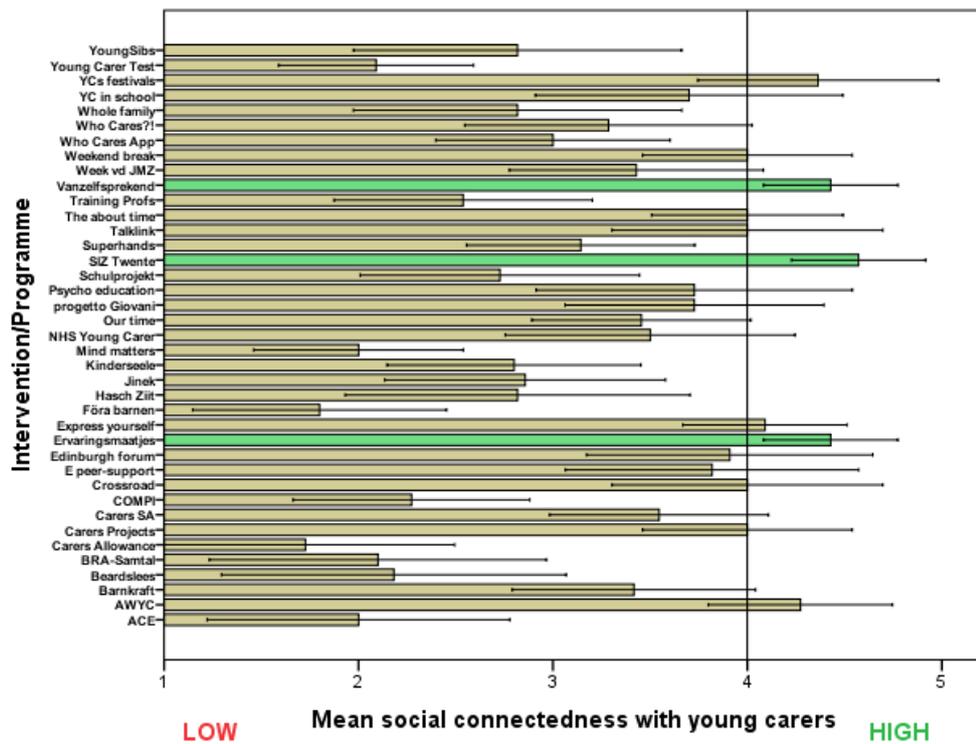
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Awareness raising consists of information and dissemination about Young Carers and their role of being an informal carer in society. Jinek (TV show), (national regional) Week vd JMZ (week of young carers), and Who Cares?! Was rated highest on awareness raising, followed by (A)YC in school, (A)YCs festivals, Vanzelfsprekend, and Express yourself.

Interventions, programmes or methods can also contribute to policy making frameworks on the topic of Young Caregiving. A relatively low amount of interventions scored higher than the scale mid-point of 3. It could be stated that it is difficult to 'predict' to what extent a method contributes, yet, experts agree that a TV show as Jinek, the Vanzelfsprekend platform, and (A)YCs festivals (indirectly) contribute to a relatively high extent to policy making.

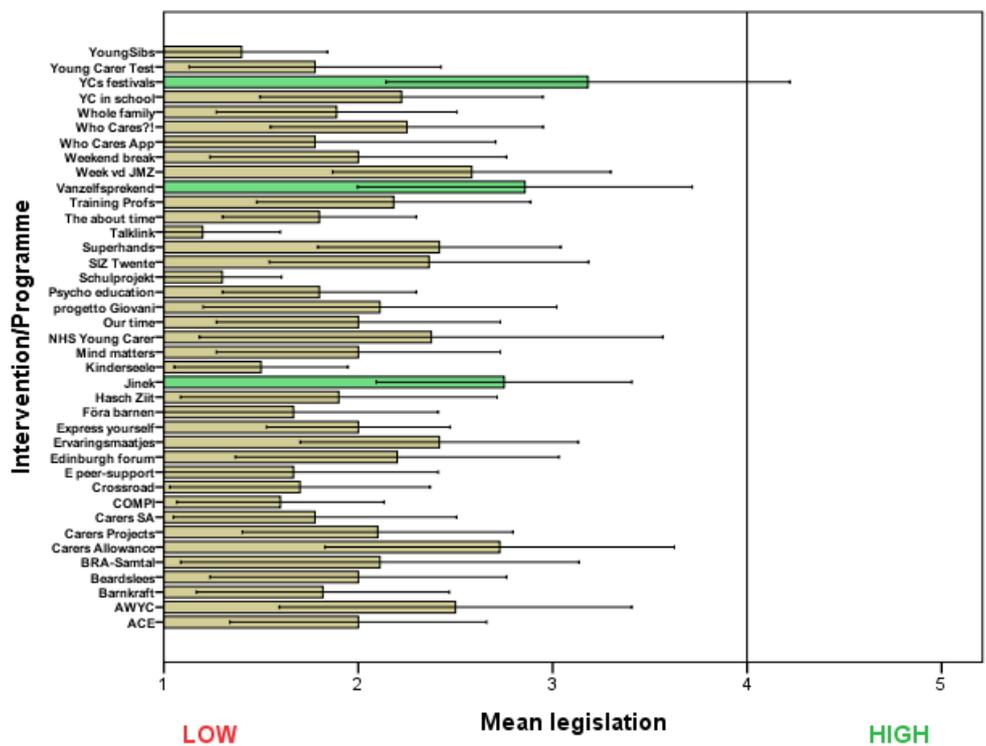




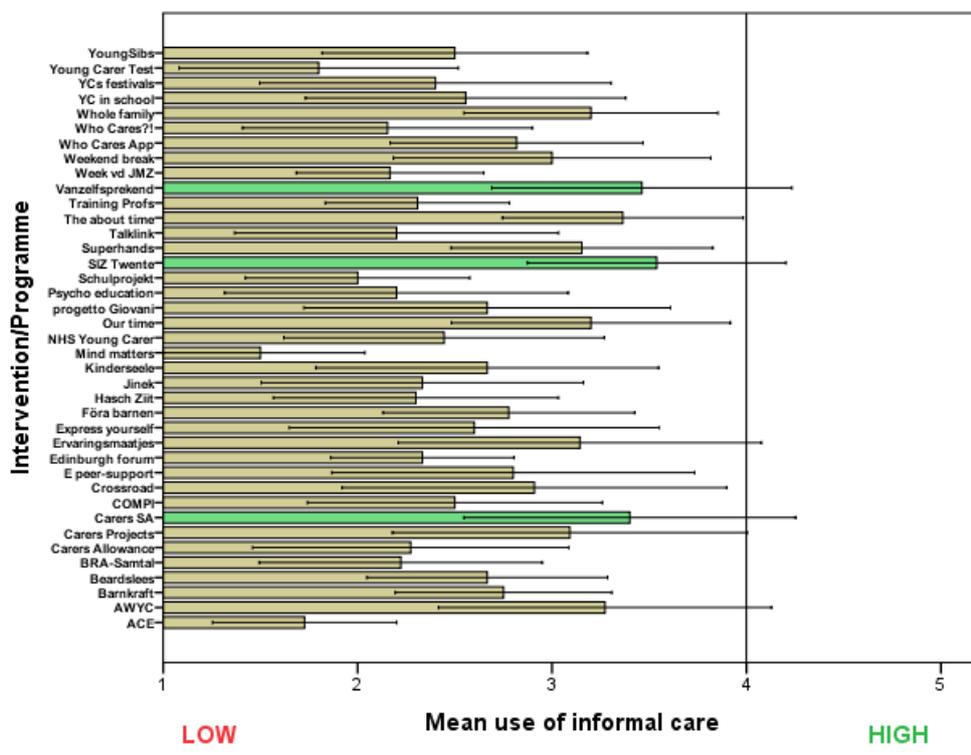
The extent to which the contact with other (A)YCs is supported by the intervention or programme was rated on social connectedness with young carers. Ervaringsmaatjes, SIZ Twente and Vanzelfsprekend scored highest, followed by ACE, Express yourself and (A)YCs festivals.

Error bars: +/- 2 SE

The raters scored the interventions also on the contribution to legislation; formal legislation on rights for Young Carers, children, and other stakeholders. Again, it seemed difficult to provide ratings on the indirect impact on legislation (possibly due to a limited amount of available information) or the interventions did have a limited impact. Nevertheless, Jinek (TV show), Vanzelfsprekend, and (A)YCs festivals scored highest on contributing to legislation (impact).

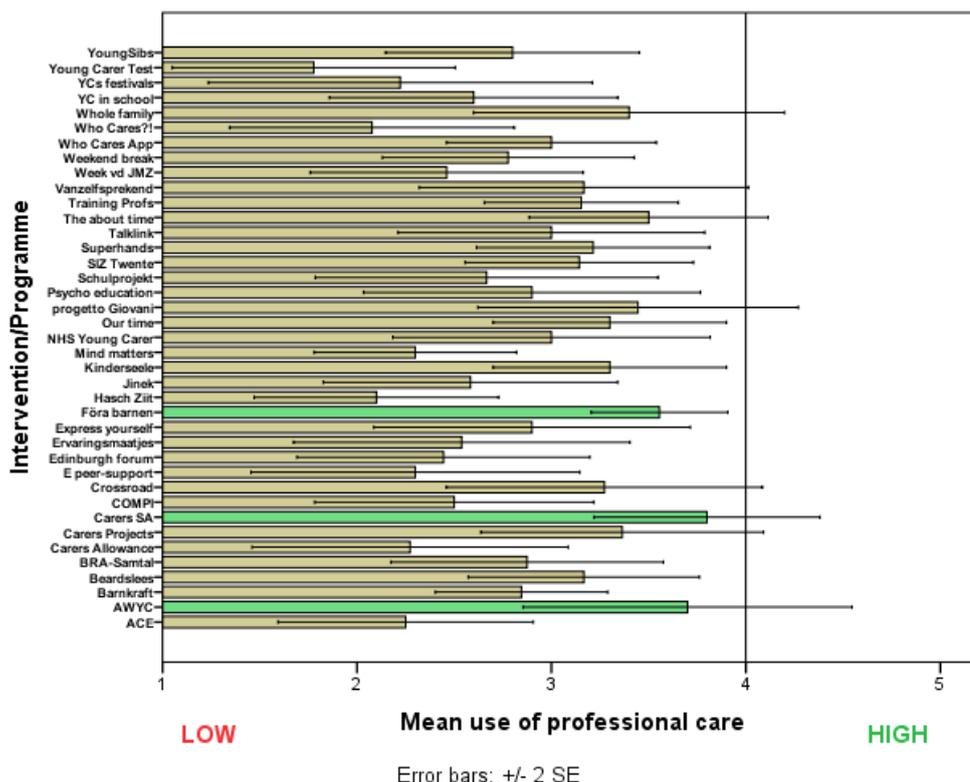


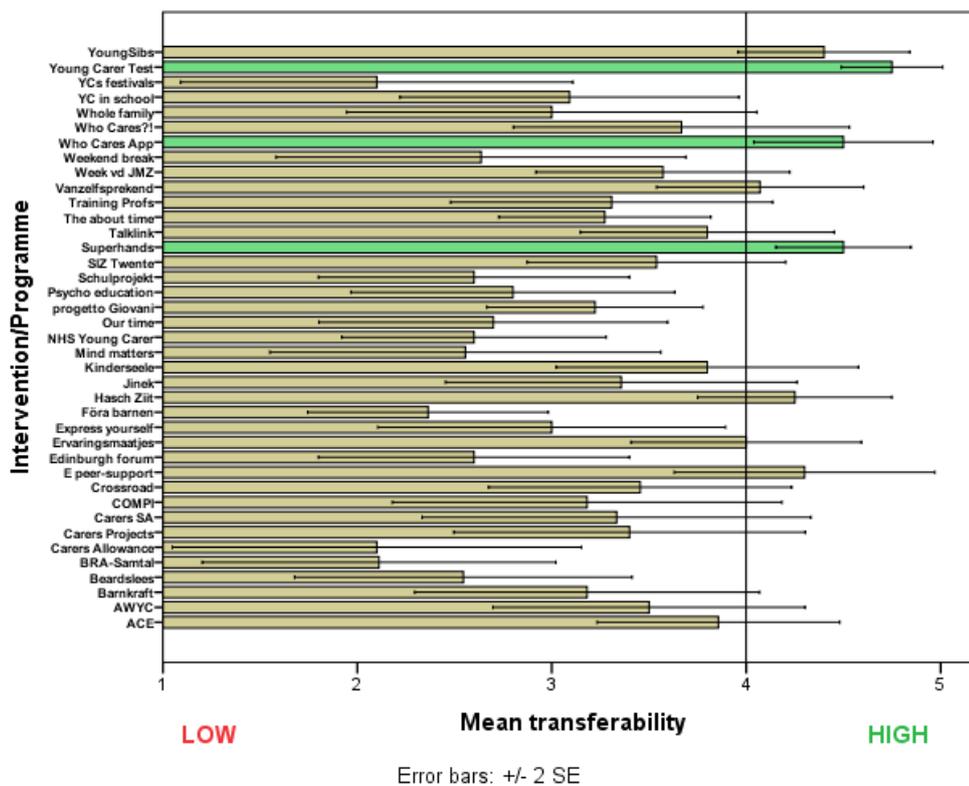
Error bars: +/- 2 SE



According to the ratings, some programmes facilitate informal respite care to some extent, although the ratings differed to a relatively large extent (see SEs). Carers SA, SIZ Twente, and Vanzelfsprekend scored highest, followed by AWYC, Our time ervaringsmaatjes, Carers Projects and others.

Just as a contribution to informal care, some programmes or interventions support the use of professional care for the (A)YC or care recipient in need of care. AWYC, Carers SA, and Föra barnen scored highest, and followed by Carers Projects, Crossroads, Kinderseele, Our time, progetto Giovani, The about time, and Whole family.





Finally, for ME-WE, it is relevant that an intervention, programme or method can be transferred to an online environment, such as an app or website. Existing online applications were rated highest, such as the Superhands website, the Who Cares App, and the Young Carer Test, followed by E peer-support, Häsch Zitt?, Vanzelfsprekend and YoungSibs.

5.4 Discussion

The rating and ranking study provided a comprehensive overview and insight into thirty-nine interventions, programmes, and methods to support Young Carers across Europe that were identified from mainly from the Delphi studies and literature reviews but also in several cases, the social media analyses and Blended Learning Networks (WP4). In particular, the rating and ranking study enabled the gathering of knowledge regarding to what extent – according to experts and (A)YCs - the interventions influenced several key criteria such as the well-being and other psychosocial factors of (A)YCs and the contribution to support strategies for (A)YCs.

In terms of the ME-WE support intervention, governmental body or NGO, to support (A)YCs according to as many criteria as possible, it is advised to draw on the work of the **Barnardo’s Action With Young Carers (AWYC) project** in Liverpool, the Italian **progetto Giovani Cargiver** of ANS (Young Carers Project) with various programs and the Dutch **Vanzelfsprekend** project, a platform for recognizing and acknowledging carers. This is because these programs score relatively high (higher than the scale mid-point) on supporting resilience. Other overall high scoring projects are the Carers Projects, Carers SA, Crossroads, Ervaringsmaatjes, Express yourself, Our time, Psycho education, The about time, Weekend break, Who Cares?!, (A)YC in school, and (A)YCs festivals.

Overall, all interventions are mature enough to be applied, and the majority are all open with little costs except for the (A)YCs festivals. It is interesting to note and supported by the Delphi studies described in chapter 1, that a relatively low number of interventions seem to have been developed in co-creation with (A)YCs (according to the raters). E peer-support, Jinek (TV show), and Vanzelfsprekend scored highest on co-creation. About all interventions have a low risk for adverse outcomes and are applicable in other countries than their origin. The influence on mental health and well-being is highest for Crossroads, Ervaringsmaatjes, Weekend break for respite and the Whole family approach, the latter also being discussed in the Delphi as an essential and relevant approach to successfully support (A)YCs and the family. The relationship with the parents is most – according to the raters – influenced by Beardslees, Föra barnen, and Weekend break, followed by AWYC and Whole family. To support the social life of (A)YC and also to possibly increase social connectedness among (A)YCs, it is advised to look into the SIZ Twente approach, Ervaringsmaatjes, Vanzelfsprekend and the (A)YCs festivals in the UK and to organize group sessions; look into Crossroads, Pscho education, and SIZ Twente. For schools to support (A)YCs in education, progetto Giovani Caregiver, Who Cares?! and (A)YC in school are relevant candidates to explore. To support caring activities, AWYC, Barnkraft and Whole family score highest and in respect to the interventions' influence on positive impact of care giving (e.g., fulfilment), AWYC, Ervaringsmaatjes, and SIZ Twente scored highest. Progetto Giovani, SIZ Twente, and Whole family scored highest on an influence on the negative impact of care giving.

Supporting and building resilience is a main focus in the ME-WE project and Ervaringsmaatjes, Pscho education, and SIZ Twente scored highest (mean) in building resilience. However, it can be argued that before you can build resilience, it is essential – as reported in the Delphi studies – to first identify (A)YCs, which is – according to the raters – to a great extent possible by Who Cares?!, (A)YC in school, and the Young Carer Test. Identification is important, just as raising awareness on the topic, which can be supported by TV shows such as Jinek in The Netherlands, a (national regional) Week vd JMZ (week of young carers), and programmes such as Who Cares?!

The extent to which the interventions, programmes, and methods contribute to policy making or legislation is difficult to conclude, except for awareness programmes such as TV shows and festivals with a relatively high impact on society. To facilitate informal respite care to some extent, Carers SA, SIZ Twente, and Vanzelfsprekend scored highest and to contribute to informal care AWYC, Carers SA, and Föra barnen scored highest.

For ME-WE it is important that an intervention and/or supportive information can also be translated to a digital platform. Online platforms or mobile applications were also reported by the Delphi experts as suitable media carriers for (A)YCs. In ME-WE it is advised to investigate the existing online applications such as the Superhands website, the Who Cares App, and the Young Carer Test. From a usability perspective this is also advised; 'do as everybody else does'. Other programmes that – according to the experts – are relatively suitable to transfer to an online app for Young Carers are E peer-support, Häscht Zitt?, Vanzelfsprekend and YoungSibs.

In the following chapter we will discuss some methodological considerations followed by an overall conclusion of the consolidated strategy and theory report.

6. Methodological considerations

When interpreting the results of WP3, some methodological considerations and limitations should be addressed. First, although the Delphi study was performed with scientific rigor and all partners received instructions and were offered a Webinar on coding and data analysis, it is clear from the country results (see Appendix 1) that the various researchers in the participating countries varied slightly in their interview methods and degree of depth of their data analysis. Nevertheless, the data from the various countries is in line with the literature, social media, and rating & ranking studies (i.e., triangulation of data). Finally, the Delphi study also had the goal to gain insight into theories on how to build resilience and theories on how to support coping among YCs. None of the experts could provide relevant information on these theories which led us to perform an additional search in the literature.

The academic systematic literature review was performed with scientific rigour and provided in-depth insights into research on interventions to support YCs. However, the academic literature review was at first not intended to gain insight into theories to support YCs. We performed an additional non-systematic search – also because of the lack of input from the experts – to gain insight into theories on stress, coping and resilience. Since the search was non-systematic, we might have missed relevant theories. The general literature added relevant data on theories and information from the grey literature. Nevertheless, the general literature review and social media analyses were performed by MSc students, which – despite relevant results – might have resulted in less reliable information. Furthermore, the general review had to be performed within 8 weeks. Due to these time constraints, the MSc students for the general review only included the first 25 hits per search engine used.

The first social media analysis focused on The Netherlands, the UK, and Australia, which resulted in a limited scope of social media usage among YCs in the EU and the platforms they use. Although various studies show limited YCs' interventions and awareness in for example Italy and Slovenia, it is unclear to what extent YCs in these countries find support online. A relatively small part of the country specific social media analysis was (deliberately) shared in this deliverable, also because within an EU project such as ME-WE it would have been insightful to show results from other countries. Overall, for a more exhaustive search on interventions in The Netherlands and across Europe, other online sources, such as other social media sites, and offline media should be included. Overall, a major restriction in finding information about YCs online, including interventions and programmes, is related to the search words used. How to search for YCs online, when they do not identify or call themselves YCs?

There are some limitations in respect to the Rating & Ranking methodology, since the ratings were dependent on the information provided in the Excel file and the raters might have missed relevant backgrounds. Furthermore, a limitation of the method is the time it took for the experts and (A)YCs to perform that ratings, covering multiple hours. The lengthiness of the rating study might have resulted in fatigue and less reliable ratings. It also resulted in several experts (e.g. from Slovenia) reporting that they did not had the time to perform the study due to high profile and demanding job obligations (e.g. in politics). We value the creativity of the UK study in which multiple (A)YCs rated a subset of the interventions. However, this could have influenced the dataset somewhat, since different (A)YCs rated one

list of interventions. Despite the limitations, raters valued the study and found it relevant and interesting, similarly to the experts whom participated in the Delphi study.

7. Consolidation & Strategies

This deliverable presents the results from three activities to provide an in-depth systematic overview of successful strategies to improve Young Carers (YCs') mental health and well-being. The results form the basis for a consolidated strategy and theory for the ME-WE intervention and app to be further developed in WP4. The Delphi study gathered insights into the visibility, awareness, interventions and future needs of YCs in six European countries and on an international level. Second, further activities consisted of a systematic literature review, a general literature review, and social media analyses. After these tasks, the rating, ranking and consolidation task was performed to iteratively build a dynamic ranked high impact list with national and international strategies and programmes that can serve as exemplars for the ME-WE intervention/s. In this chapter we will provide an overall conclusion and discussion by consolidating the strategies and theories on supporting YCs and providing requirements for the ME-WE intervention and mobile application.

Delphi Consolidation & Strategies

As already discussed, the visibility and awareness of YCs across Europe is low (see also, Leu & Becker, 2017). However, the Delphi study and the social media analyses did show that visibility and awareness can be relatively high on a local level with multiple interventions and programmes running (e.g., in The Netherlands). There is variation between and within countries, states, municipalities and schools in the interventions and programmes offered to YCs, indicating that a ranking of countries as presented by Leu & Becker (2017) is part of the picture on a national level. Nevertheless, it became clear that Italy and Slovenia are countries where hardly any activities are organized to support YCs and they still have many steps to take to identify and support YCs. An international centralized intervention and online support application – adapted to local and cultural contexts – can support in this process. In respect to identification, other countries can learn from the UK, where there already is a carers assessment, which could potentially be transferred to the ME-WE app also contributing to gaining insights into the numbers of YCs across the EU. We gained insights into the UK successes and the hundreds of programmes and interventions to support YCs. Sadly, these initiatives are mostly based on temporary funding, so now when the UK economy is less than optimal, and the Brexit might even cause more cuts in care and support, actual help and follow-up on the ground is often lacking (according to the experts). This implies that YCs' support should rather be an integral part of (social)care or welfare. For ME-WE, it is essential that the partners become aware that whatever we provide to YCs (interventions, knowledge/information, an app, etc.) it should be grounded into existing care or policy structures, and/or adopted by formal support services and/or NGOs to ensure continuation and follow-up.

The variation in support for YCs between and within countries is a major rationale for providing YCs a time, distance, culture and language independent support platform which is envisaged by the ME-WE project. The results of the social media analysis showed that most support and interventions for YCs are offline, while young adults currently live most of their lives online. An online ME-WE open access platform – website or app – is ideal to overcome physical and time barriers and ensure that all YCs can receive a basic level of support. In fact, the development and/or provision of an online platform or app for supporting YCs is preferred by many of the experts that participated in the Delphi study. The existing

Eurocarers Young Carers Working Group - which is actively running - could possibly be the product owner of such a platform. In addition, the Eurocarers Young Carers Working Group could also become more visible and accessible to further take up this role and become more visible across Europe. Experts across Europe also advised to create such a European or Worldwide NGO for YCs (possibly the working group) to disseminate knowledge and coach teachers/people at schools. Other important tasks to support YCs via an app are to gather an insight into actual numbers, identification support and tools, raising awareness, arranging support at schools, further strengthening the whole family approach, and ensure screening at for example GPs/ primary health care or medical centres.

We should provide YCs with activities in which they could relax and get a break from their care responsibilities to promote their individual development and get in contact with peers. An online platform can serve as an information channel with an agenda to activities in various localities. Online welfare interventions could focus on the provision of information by e.g., information flyers, children's helplines or a national information campaign. Furthermore, a considerable number of experts expressed the need for YCs' specific laws and regulations to formalize the rights of YCs on a national or European level, however, other experts expressed that the rights for YCs are already covered in existing (non YC specific) legislations or could be included in existing legislations (see WP2 for further details).

All in all, the ME-WE platform can serve as – among others - an information platform on rights and legislations across Europe, which will also be relevant for policy makers across the EU to learn about- and exchange best practices. Professionals need to be educated about YCs, about their situation and what professionals can do to support them. Education by online learning can be part of an app or platform and Vilans (WP3 leader), other Dutch partners, the Swedish Family Care Competence Centre (linked to Linnaeus University, project coordinator) together with the Eurocarers InformCare hub (Eurocarers, WP 6 leader, dissemination & knowledge exchange) already provide platforms with e-learning modules for professionals on which an (international) e-learning module on how to identify and support YCs could be placed²⁷.

Creating flexibility for children/students at school is essential, e.g., by means of a carers' ID and a ME-WE app could provide exemplars for schools and YCs to use. Overall, culture and values define our expectations and opinions in respect to children providing care, which is relevant to cover in particular for migrant YCs. ME-WE should rather take migrants into account in the development of an intervention or app, possibly supporting the Arabic language and – if wished for - targeting migrants via personalized channels. Overall, co-creation is KEY for the success of any intervention or app, and all stakeholders and end-users (including migrants) should be part of the co-design process.

Theory Consolidation & Strategies

People should be aware that stress is not a bad thing in and of itself and positive stress supports us in our everyday activities (Ursin & Eriksen, 2004; Nap, 2008). However, whenever stress is prolonged and repetitive, people's milieu interieur experiences 'wear and tear' that can seriously harm the health situation of a person and can lead to depression or burn-outs. Internal (subjective) processes such as coping, allostasis, self-efficacy, salutogenesis and resilience can explain how YCs can deal with external stressors that are inherent when providing informal care during several years besides their schooling.

²⁷ See <https://www.free-learning.nl/>

Loneliness and poor mental health are possible outcomes when faced with care stressors among YCs. Considering the Cognitive Activation Theory of Stress (Ursin & Eriksen, 2004) it is relevant to note that the extent to which YCs can deal with external stressors depends on the individual appraisal of the situation. In addition, people who have high positive expectancies about a future event, can be highly disappointed whenever the event is experienced as negative or will not take place. People with no or lower positive expectancies are less disappointed whenever there is a discrepancy between expectancies and reality. Of course, coping mechanisms support the process of discrepancies between expectations and reality.

As discussed in the academic literature review, the level of subjective burden that caregivers experience depends on their subjective evaluation of the positive and negative effects of caregiving and their ability to cope with these effects (Koopmanschap et al., 2008; Van Exel et al., 2008). Salutogenesis depends on whether people have available resources to deal with a stressor and if they have the capacity to use the resources available, which is called a sense of coherence (SOC). The SOC consists of the comprehensibility, meaningfulness and manageability of a situation (Antonovsky, 1979). The adaptive coping concept of Green et al. (2016) is also relevant for YCs coping with their caring situation. By adaptive coping people think of ways to deal or fix a problem or ask others for help or ideas which could be easily added to the ME-WE app by means of secured and trusted chat possibilities and/or matching possibilities to find YCs to socialize with, professionals for advice, and events to go to. It is highly advised to ensure that social interactions do not only take place online but will lead to actual meet-ups and activities, since solely online contacts do not reduce loneliness *per se* (see e.g., Yao & Zhong, 2014). People with many online contacts are not alone, yet, may still perceive themselves to feel lonely. In addition, two studies focused on developing self-efficacy and reducing stress by means of introducing different coping strategies and expanding the social network (Barrera, Atenafu, Schulte, Nathan, Hancock & Saleh, 2018; Elf, Skarsater and Krevers, 2011).

Resilience has been defined as ‘a dynamic process encompassing positive adaptation within the context of significant adversity’ (Luthar, Cicchetti, & Becker, 2000). Young carers unquestionably face significant adversity and improving their resilience would strengthen them and prevent negative outcomes. At least three studies from the academic literature review (in)directly built on resilience theory and how to strengthen resilience among YCs (Richardson, Jinks & Roberts, 2009; Cunningham, Shochet, Smith & Wurfl, 2016; Fraser & Pakenham, 2008). Two studies actually evaluated a resilience based intervention for (A)YCs and positive results have been found (Cunningham, Shochet, Smith, & Wurfl, 2017; Fraser E. & Pakenham K.I., 2008). Moreover, resiliency building interventions have shown to improve depressive symptoms in young people in general (Neil & Christensen, 2007). So, improving resilience can have a positive effect on the mental health of young carers. It should be noted that resilience – as other similar processes and concepts – is not a personality trait or characteristic of the individual (Luthar & Cicchetti, 2000). As suggested by several experts in the Delphi study we should rather learn from existing programmes and interventions, instead of creating YC specific support interventions. An ME-WE based resilience training and intervention has potential to support YCs as demonstrated by a study of Cunningham, Shochet, Smith and Wurfl (2017),

In the study of Cunningham et al. (2017), a YCs resilience-building camp was organized and consisted of a total of 11 RAP-A sessions. The Resourceful Adolescent Program (RAP-A) is a universal resilience-building programme that aims to promote positive mental health and

prevent adolescent depression (Shochet et al. 1997). YCs expressed that the camp supported in self-efficacy coping consisting of affect regulation, interpersonal skills and functioning, and confidence and recognition of strengths. Furthermore, the camp supported in social benefits such as the opportunity for respite and for social engagement. RAP-A sessions supported YCs in developing – among others - relaxation techniques and interpersonal problem-solving. For the ME-WE intervention and/or mobile application, it is strongly advised to follow the RAP-A resilience building programme as support to cope with the care burden.

Next to resilience building, a whole family approach can support YCs in coping. So, when health and social care professionals have interest in the family as a whole, identify and develop strengths of the family, both the person with care needs as well as the rest of the family, including (A)YCs will benefit. In the family there are always resources and strengths which can benefit the (A)YC. Therefore, it is important to consider the family as a whole for the identification of these strengths as it can help in building resilience (Frank & Slatcher, 2009). For the ME-WE intervention which might possibly use the RAP-A interventions to support resilience, a possible further integration with a whole family approach might be beneficial for the success of the intervention.

However, experts did point out some limitations of existing interventions used in the welfare sector. These revolved around three issues:

- (1) interventions not matching the needs of young carers,
- (2) good interventions that remain underused because people are not familiar with them, and
- (3) a lack of research to substantiate the effectiveness of interventions in the welfare domain.

All these three issues can be taken into account in the following ME-WE core activities:

- (1) co-creation of the ME-WE intervention and app in WP4 & WP5,
- (2) marketing and dissemination of the ME-WE intervention and app via the ME-WE project in WP7, the Eurocarers Young Carers Working Group, ME-WE partners and EC,
- (3) a solid and rigid academic study that evaluates the ME-WE intervention planned for WP6.

Practical Consolidation & Strategies

As discussed in the Delphi study and academic literature review, several points of the literature must be taken into consideration for a successful implementation of the ME-WE intervention and mobile application. First, awareness must be raised, and the stigma must be reduced. YCs do not recognize themselves as YCs and are not likely to actively seek out help or support. Health care professionals, school teachers and social workers can play an active role in identifying YCs, reducing the stigma by means of classes on YCs and supporting the whole family. When this first step has been taken the ME-WE intervention has a higher chance of being successful.

As mentioned earlier, the ME-WE intervention and/or support app should have a component of peer-support. In almost all the evaluations of the studies this is one of the points YCs continuously mention, when they are asked what they like about the intervention; to come into contact with other YCs, notice that you're not alone, receive and give support to peers. This peer-support can take place via the web, teleconferences or face-to-face. A prerequisite for the ME-WE app is that this application is developed in co-creation, otherwise there is a high risk that YCs will not use the app. Also, there should be a form of face-to-face contact as well as YCs often want to know with whom they are having contact (Elf et al., 2011). In all

studies it became clear that YCs have a high feeling of responsibility, they are very mature, so what is important is that they also have the chance to be a child or adolescent instead of the wise adult. Therefore, the ME-WE intervention should not only contain psycho-education and psychotherapeutic training of coping strategies or resilience, but also contain fun activities, offer respite and let YCs think of something else other than their caring situation at home. By social support via the intervention or app, YCs can express their emotions and difficulties which might alleviate stressful stimuli. An intervention can show examples of other young carers succeeding in their goal and it can provide a place to voice their thoughts.

As found in the social media analysis, for a ME-WE application it is important to focus on the concept of trust and privacy for YCs, because many groups for YCs are private (Facebook and Instagram) and questions are asked anonymously (Tumblr). Functional requirements for ME-WE include a News/Events page; Asking questions to experts or other YCs; Possibility to create groups or a community; Possibility to share experiences (possibly in blog format); possibility to follow association/organisations/foundations; possibility to befriend other users; information in the form of messages, videos or photos.

Non-functional requirements include: possibility to choose for specific regions/neighbourhood; either anonymity or confidentiality (e.g. nickname); possibility to create either private or public groups based on a subject (e.g. autism, sick mother) or region; confidentiality of an account (e.g. nickname); search other YCs based on location/region or topic (e.g. autism, sick mother); possibility to filter information of a subject (e.g. a specific disorder, sick mother, brother, sister etc.).

For the ME-WE project it is advised to not re-invent to wheel and in respect to application and usability design, 'do as everybody else does'. From the rating and ranking study on 39 interventions and programmes to support YCs, at least two of the programmes were formally evaluated, namely the Crossroads young carers' project and Bernardo's Action With Young Carers (AWYC) Project (Richardson et al., 2009; Grant et al., 2008). The highest overall ranked interventions were the Barnardo's Action With Young Carers (AWYC) project in Liverpool, the Italian progetto Giovani Caregiver of ANS (Young Carers Project) with various programs and the Dutch Vanzelfsprekend project, a platform for recognizing and acknowledging carers. It is interesting to note - and supported by the Delphi, literature, and rating & ranking studies - that a relatively low number of interventions seem to have been developed in co-creation with YCs. The three highest ranked programmes should be further analysed and discussed with the intended end-user groups in ME-WE (for example in the WP4 BLNs) and possibly combined with the RAP-A and co-created to match the needs and wishes of the end-users and the goals of the ME-WE project.

To positively influence mental health and well-being by an intervention or app, ME-WE can learn from Crossroads, Ervaringsmaatjes, Weekend break for respite and the Whole family approach, the latter also being discussed in the Delphi as an essential and relevant approach to successfully support YCs and the family. Since supporting and building resilience is a main focus in ME-WE, the interventions Ervaringsmaatjes, Pscyo education, and SIZ Twente scored highest in building resilience and should be further examined in co-creation with YCs, professionals and possibly other stakeholders. Before you can build resilience, it is essential - as reported in the Delphi studies - to first identify YCs, which is - according to the raters - to a great extent made possible by Who Cares?!, YC in school, and the Young Carer Test.

From the activities in WP3 we can formulate various requirements for an (online) intervention or support app. For ME-WE, an approach that brings about mutually beneficial forms of provision for multiple parties involved, including a more family centered approach, should be strived for and an intervention programs should be aimed at supporting young carers to use adaptive coping strategies instead of maladaptive coping strategies, by helping them solving problems and asking help (Green et al., 2016). The intervention and app should support young carers building trustworthy relationships and being in a constant dialogue, either with friends and family and/or professionals, which is also important to prevent loneliness and enhance coping. For the intervention, The Resourceful Adolescent Program (RAP-A) can be adapted and used to build resilience by aiming to promote positive mental health and prevent adolescent depression.

The ME-WE app can provide (indirect) access to professionals or people who have been YCs themselves, who can provide both instrumental support (advice) and emotional support and encouragement to young carers. The ME-WE intervention should rather support respite, just as the RAP-A resilience building camp, and the ME-WE app could promote and share activities for respite such as summer camps or YC festivals to provide a temporary relief from caring responsibilities.

Overall, the ME-WE app should support identification and recognition (e.g., via a YC assessment); provide and create a strong group identity and provide the possibility to create groups yourself; support social interactions via chat and/or localisation features (which could imply just a link to WhatsApp or other communication apps) and promoting actual offline contacts; share experiences with other YCs; inform YCs about national and local events interventions and activities targeting YCs (news & events); provide (indirect) access to professionals; for interface and interaction design learn from popular social media platforms as Tumblr and ensure privacy and anonymous communication to enhance trust among members; target all YCs including migrants; support fun activities; and overall the app should be meaningful and beautiful.

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Appendix 1: Delphi qualitative results per country

Results - Italy

Summary - first & second round

Visibility and awareness raising

First Round:

In Italy there is a lack of visibility and awareness on (A)YCs at all levels (local, regional, national) which is accompanied by a lack of systematic studies and official statistical survey. One respondent said that they carried out a survey in her school finding that 2% of students were (A)YCs, and another one told about the program for supporting oncological patients in Sant' Orsola Hospital (Bologna) that is able to reach also (A)YCs. Apart from these specific cases, the visibility of (A)YCs is due to the experience of the teachers or medical professionals.

"I don't know any statistical data about (A)YCs, I also say that may be quite difficult to give a percentage, because there is little visibility of young caregivers". (E3, R1, IT)

"I have not any idea or information about the percentage of (A)YCs in Italy. I read some data that are very generic and probably not indicative because there is a whole submerged, so I do not know ..." (E8, R1, IT)

"I can speak about my experience at the Versari-Marcrelli Institute of Cesena, which lasted about two and a half years. So, as has been defined by various article, (A)YCs are an "invisible crowd", [...] Statistically, the young caregivers we discovered are about 2% of the total number of students in our school, these are the real young caregivers, those who take care of a member of their family."(E6, R1, IT)

"Here (at Sant'Orsola Hospital of Bologna) dealing with people that I follow from the time of diagnosis, at the time of surgery up to radiotherapy or other type of therapy, there is the possibility to follow the therapeutic treatment and so to contact (A)YCs and discover their characteristics." (E3, R1, IT)

Second Round (Reflection):

Experts underlined the lack of visibility and awareness about (A)YCs in Italy at all levels as well as other countries involved in the project. In Italy, the (A)YCs visibility is due to action and sensibility of teachers or medical professionals, without any type of focused programs or planned action. In order to promote the visibility of teenagers' problems, not only of the (A)YCs, one expert suggested the use of MACA scale, actually applied by ANS in a school, in the area of Carpi, involved in a project. Other experts underlined the need to improve the awareness of the teachers and health professionals and, at the same time, to avoid the risk of labeling.

"I believed that Italy was always the bottom of the pile, I actually realized that it is a common problem" (E7, R2, IT)

"About the (A)YCs visibility, I agree that it is quite lacking, because everything is always due to the individual action, to good sense of the individual or to the formation that the individual has had or to personal experience [...] This in regard to visibility."(E3, R2, IT)

"In other countries there are strategies for the (A)YCs' identification and for the need assessment, to give help, however deficient and partial, but a type of help and support. ON the contrary, in Italy, and we have a very recent example²⁸, if there is not a personal complaint, we cannot identify (A)YCs, and there are not particular strategies and programs for supporting them" (E5, R2, IT)

"I agree with the idea of implementing methods of screening for the identification of the (A)YCs... I think that MACA-YC18 is quite functional" (E7, R2, IT)

"Visibility is important but it is crucial to avoid the risk of labelling" (E6, R2, IT)

"We have to improve the awareness of teachers and health professionals and to provide support" (E9, R2, IT)

Strategies, interventions and programs to support (A)YCs

First Round:

Except for the interventions carried out by ANS in the area of Carpi, which are mentioned by three respondents, and one support action in a school in the same geographical area, no other activities specifically dedicated to (A)YCs have been described. On the other hand, participants identified other actions - currently targeting other groups - which could be applied /transferred to (A)YCs: an ICT app to share information about health and social services, peer-support, workshops in schools, reflecting teams, support to children of parents with mental illnesses, programs to prevent earlier educational system drop outs, alternative school programs,

²⁸ The expert is reporting the case of an (A)YC that has asked for help and support to local social services and association and these actors were struggling to support him.

assistance support and more generally the application of a whole family approach. This intervention should be designed starting from a co-participation methodology such as a community based practices.

"It is very useful that in our school there are tutors in the classes [...], teachers available to listen for students' problems who can go for complaining, saying "I lost things", but also "I did not make it because yesterday I helped my mother" ... [...]. Furthermore, when I talk with new students who want to attend the school, I always say them that the educational apparatus in our school is very strong and that there will be always a person they can go to in case of problems". (E7, R1, IT)

"We had good experiences of teenagers who did not know that one of their classmates was taking care of a family member, and once they found out, they supported him and became their mentors, also outside the school". (E6, R1, IT)

"From this point of view, everything that provides information about the problems that can emerge in these cases, especially for technical and practical problems, so if I have to do a certain thing for a certain type of patient, I am uncertain about what is the best way, the idea of creating a tool that can give practical information I think gives a lot of security, so an application that regards all these kinds of practical problems can be very useful". (E4, R1, IT)

"Schools could plan specific courses for (A)YCs, because some of them could need to be absent and cannot follow the school every day" (E2, R1, IT)

"I answer on the basis of a project of the Region (Emilia-Romagna) that I think has worked very well and it is a type of project that I think is very beautiful because it involved the group, the team and involved the sharing of knowledge[...]. In my opinion initiatives like this are very nice experiences because they refer on the aspects of the work on the community based practices that is perfect, because you build up a group where people can work, compare and have a support, that is not evaluative, and this is the most important thing, it's a support in which one understands, one tells and can intervene, it is never evaluative". (E2, R1, IT)

"The family needs a systemic intervention, a family intervention, that is an intervention that allows each of the members to explain both their needs and the expectations that each one has towards others, and also the limits that each one has..." (E10, R1, IT)

Second Round (Reflection):

Experts suggested flexible interventions and tailored on different (A)YCs needs, that could differ for social, economic and individual conditions. These interventions should take into account (A)YCs' families and should be supported by long-term programs that provide integrated actions. One expert suggested the need of a psychological supervision in school, in order to support (A)YCs in managing frustration, anger and all the feelings raising from caregiving activities. Furthermore, experts suggested to add programs to contrast the school dropout. At the same time it's important to improve actions aimed to promote the (A)YCs self-expression and allow them to get a break from their care responsibilities.

"(I suggest) an activity of psychological supervision, that should be flexible and tailored on (A)YCs problems in order to manage frustration, anger, fear and all the feelings raising from difficulties of caregiving (E1, R2, IT)

"[...] families must be taken into account" (E7, R2, IT)

"(I suggest) Strategies tailored on different social and economic conditions of (A)YCs, that take in account the individual situation that could be so different. Among strategies, interventions and programs for supporting (A)YCs, I think that programs to contrast school dropout could be very useful (E9, R2, IT)".

"I totally agree with the need for families to be taken into account in a systemic way and supported by long-term programs that provide integrated actions". (E9, R2, IT)

"I really like all those interventions aimed to remove the person sometimes from the "pressure cooker" in which it stays, that's why I gave you the example of the school camp [...] could be training camps, support and support camps but also of sharing certain problems, [...] but then (A)YCs always have the chance to break from a condition that often crushes them to the ground". (E2, R2, IT)

Laws and regulation:

First Round:

In order to fix the lack of a specific regulation at all levels (national, regional and local), some respondents mentioned the possibility of approving a law on informal carers as an opportunity to support young carers as well, however one of them also underlined the risk of a "cash for care" approach, aiming to support informal carers simply by providing economic support. One expert considered the local authority as the main actor able to provide adequate interventions for (A)YCs for its proximity with local needs, and suggests the creation of a national authority responsible for the evaluation and the exchange of the local practices. Another expert suggested to deliver national Guidelines in order to have a common framework for identifying (A)YCs and planning tailored interventions.

"I think it's important for helping (A)YCs to avoid to monetize the support, that is not to think that the legislator is enlightened when says [...] this is a theme of support and therefore of service (E10, R1, IT)

"Q: So, in your opinion, what are the public institutions that should take care of (A)YCs in Italy?

A: I think it is the local authority, I always believe that the most important institution that should be supported and strengthen, as well as be funded, obviously doing the necessary checks, I believe it is the local authority". (E1, R1, IT)

"Ideally would be that there was a multi-level coordination involving all these actors and that every initiative started from the national level, it is obvious that it would be the best, with the consequences at regional level, with multidisciplinary work protocols involving all the areas, both institutional and voluntary, which is a very important resource". (E3, R1, IT)

Second Round (Reflection):

The idea of a specific law is considered positive to give visibility and promote the integration of the interventions but, at the same time, it is important that it is not a rigid law and that it does not reduce to an economic support. One expert suggested a focused legislation at local level in order to plan interventions tailored on local needs, whereas a national law would be useless because in Italy there is already a national law for planning an integrated system of social interventions and services²⁹.

"I don't believe in a national legislation at all, but I believe much more in local and regional regulations. At national level, indeed, we already have the Law 328/2000 disciplining the integration of health and social services. Thus, we do not need another Law". (E1, R1, IT)

"A desirable outcome would be a legislation focused on (A)YCs, even if it is a very sensitive issue, because legislation, beyond all the various political, economic, etc. issues, would certainly give an input, because there will always be isolated interventions. On the other hand it depends what kind of legislation, because it wouldn't be rigid and, as I had read in another part of this research, avoid that it is focus only on economic support" (E3, R2, IT).

Education:

First Round:

A lot of inputs related to the role of schools and teachers in supporting (A)YCs. In terms of dedicated interventions it was mentioned: awareness rising activities targeting teachers and students, a tailor-made educational plan for (A)YCs in schools, setting up a group of teachers specifically dedicated to support (A)YCs in school, cooperation between schools and other services in order to promote integrated actions. An expert mentioned an approach (not specifically for carers but transferable to them) that includes school-tutors (psycho-educational professionals that are the contact point for academic and personal problems of students) with the following characteristics: time to talk to families, dedicated staff member to take care of social issues of the students and, whenever necessary, to cooperate and make referrals to other services and use of peer-education.

Although there was a general agreement on the importance of involving schools and educational institution in programs for identifying and supporting (A)YCs, in the second round some experts suggested not to give too much importance and responsibilities to teachers and headmasters, because the well-being of (A)YCs should be handled and solved by Health Authorities in Italy.

"A planned activity certainly worked well for the wellbeing of the boys. For example, (A)YCs that we have involved in support of the "Young Caregiver Commission" have really said they feel better ... A girl that was supported by commission said: "I found the smile" so this would already be enough. The (A)YCs felt better and their families feel the same. The (A)YCs family so has a preferential channel of listening, communication with the school... And families feel better. They really thanked us for what we are doing". (E6, R1, IT)

"In my experience, a strength was the involvement of the school environment, that we were able to put into operation to manage the educational difficulties of the (A)YCs who were tired of managing family critical issues, so we was able to plan a dedicated team work with the educational staff". (E3, R1, IT)

"The fact that in our school there is the presence of tutors in the classes. "Presence" does not mean that they are constantly there, on the contrary, the fact that they are not so frequently in the classroom is much complained because the teachers would ask for more tutors in the classroom, because they are a very important mediation between the school, the boy and the boy and the house. But the tutor actually has this very important task, so the fact that the boys recognize in the tutor a reference figure for: go to complain, go and say "I lost things", but also go saying: "I could not do my homework yesterday, because I helped my mother" (E7, R1, IT)

Second Round (Reflection):

Experts considered the school and its educational staff an important actor in planning (A)YCs support but they are aware that unfortunately they do not still play this role. Thus, they suggested integrated actions in which educational, social and health services should be involved. Furthermore, experts suggested some interventions for school and educational staff, such as a counseling point, evaluation system able to enhance (A)YCs' caregiving skills usable in the labor market. Finally, peer support group is needed.

"It could be useful promoting the (A)YCs' caregiving skills during the internship organized by the high schools. This could be a way for enhancing these attitudes that the young carers are already learning through their personal experience" (E6, R2, IT)

"I'm a bit doubtful about the attention given to the school, as on the whole part about the school, I did not understand why the school should be such an important actor, so protagonist, when in reality the theme is essentially social health". (E4, R2, IT)

"I would not only consider the teachers as possible actors, I mean this, because otherwise it would mean giving them weight ... a heavy burden. I would aim a bit more on peer help, for example". (E8, R2, IT)

"In my opinion, school and teachers has an important role in supporting (A)YCs, so it is important to provide them a counseling point, in order to avoid that teachers become the counselors of their students". (E4, R2, IT)

²⁹ The Italian reference law to rule social services is the law 328/2000 "Framework law for the implementation of the integrated system of social interventions and services".

Welfare:

First Round:

Experts emphasized development of long term programs based on a whole-family approach, which would have a positive impact on (A)YCs as well. Moreover, they suggest an integration of the different services (e.g. health, social and educational) in order to go over segmented actions. Respondents also mentioned interventions aimed to share emotions and relieve the psychological burden.

“We need to improve the sustainability of the projects, because the (A)YCs need to be supported by long term programs, because young people are growing up and they need more time to put the deep roots that can help them to avoid some problems”. (E1, R1, IT)

“I think that (A)YCs should be supported by a multidisciplinary group, that can start working together after a recommendation of the health services or while they are dealing with a specific case requiring a multidisciplinary approach.” (E3, R1, IT)

“Public and private associations must have a family based approach to the problem, not an individual approach. You can start from one but then you have to consider all family, otherwise unfortunately you often get one out, maybe help the (A)YCs to break free from his role, but it may mean aggravating the situation of another family member.” (E10, R1, IT)

Second Round (Reflection):

An economic support could be useful for (A)YCs but it should be added to other type of actions and support such as psychological, educational, relational, in order to promote an harmonious development of (A)YCs and let them to express their own abilities. Moreover, experts suggested a multi-actor involvement in order to provide different type of actions mentioned above.

“I think that social services should be responsible of interventions with an adequate support of health services” (E4, R2, IT)

“Providing an economic support is the easiest way to support, but the fact is that giving economic support does not relieve a child of his problematic condition, this is the point. On the contrary, you give economic support, but in fact you say “now you go ahead”, but from this point of view I do not consider it correct, because (A)YCs have educational needs, they have psychological needs, they need support, that is not simply economic support, and above all they have a series of shortcomings that come from caregiving. So the fact that they have to care doesn’t allow them to have a normal life like other children. So giving economic support does not resolve anything.” (E2, R2, IT)

2.2 Goals, strengths and weaknesses

Education:

First Round:

Goals are dropout prevention and identification. Evidences that works, improvement in school attainments, awareness rising towards teachers and students, community based practices, interventions using communication channels common among youngest (e. g. Whatsapp, Facebook, Instagram), integration of actors, family based approach (+); interest of school professionals still low, interventions are currently focused on high schools while to be more effective and preventive they should start in middle-school (-).

Strengths

“(There is a need) of a really taking in charge, of a structure that is able to take charge of the problems of the whole family, then of the problems of the family and of the individuals, with the professional skills that are necessary, so there should be a psychologist to take in charge his ((A)YCs) mother, but also a psychologist to take in charge (A)YCs.” (E5, R1, IT)

“It is easier to build a community based practices in the school environment, because here students already have their own interaction tools, like whatsapp, they already have a well-defined “modus operandi”. Whereas if you have to build a community from people who do not know each other and who have to use communication tools that they do not know and that usually they do not use, such as a platform, or a forum, it is very difficult to build a sense of community with these digital tools [...] This is a point on which we must pay attention.” (E2, R1, IT)

“It is important the involvement of the health services, of the social services (such as social assistance), of the figures that are dedicated to the psychological assistance, and the educational sector. The ideal would be that there was a multi-level coordination involving all these figures.” (E3, R1, IT)

Weaknesses

“In my opinion today the school does not have the time and the tools to realize what the lives of the boys are like, and the educational services also struggle to fulfill their task and do not have the spaces, intended in a concrete and figurative sense, to know the lives of the boys and know what happens inside their families.” (E5, R1, IT).

“I carried out a project on this thematic in the school where I teach. In my experience the awareness campaign did not work: I expected many more enrollments to the course I promoted but teachers were less sensitive to the theme than expected.” (E6, R1, IT)

“Sometimes, someone starts being a young carer at the Primary school and the choice of the High School depends on the role played within the household. It would be useful and necessary designing intervention at the Secondary School for the identification of the young carers and their orientation to the next school order.” (E6, R1, IT)

Second Round (Reflection):

In light of round 1, experts reiterated that one of the main weaknesses of the Italian educational system in managing (A)YCs is the lack of awareness and knowledge among school professionals, in particular school teachers and the absence of a multidisciplinary team in the school embedding psychologists. Moreover, it would be useful that this multidisciplinary group works with the class group for enhancing solidarity. Another one suggested to involve a working group with (A)YCs in order to plan interventions more tailored to their needs. One expert underlined the importance of exploiting the experience of past young carers, today adults, for coaching and mentoring today young carers. So that the latest may take advantage from the experience of the first. In experts' opinions, supporting (A)YCs means also helping them recognize their own attitudes and competences and give them the chance for enhancing them.

“What are the strategies on which a school must work? First of all, create a teacher staff meeting in which are involved professionals, who are trained on all the problems of (A)YCs, a teacher staff meeting that shares educational management, the teaching guidelines, and then work a lot on the class group... I think that many strategies from the point of view of the school with regard to (A)YCs must work on the class group, which must be self-supporting, must become a team [...] and support each other according to the everyone's needs, so for me in school you have to work now, above all, on the class group.” (E6, R2, IT)

“In my opinion, another important thing: take advantage of the experience of (A)YCs. I mean talking to (A)YCs who have finished school and with their families, I think it could be very useful, to understand as they have lived the school when they were (A)YCs, as this role influenced their choices, the choices made in the past, therefore considering the choice of high school and choices made then for the future. What could the school do? So one thing I would like to do is a working group in which to involve young caregivers who have left school, and their families too.” (E6, R2, IT)

“I suggest to enhance the attitudes, skills, knowledge of (A)YCs, so we recognize the figure, consider what may be the tools for supporting them and how they can be enhanced in order to help them to carry on their life project, which I think these guys do not have, because of their situation, they think in the short term, with consequences for life, such as the choice of school.” (E6, R2, IT)

Goals:

Teacher staff meetings to share educational plan and learning activities more focused on (A)YCs needs, involving (A)YCs in planning activities, work on class group (+)

Welfare:

First Round:

The main issues highlighted by experts are: risk of labelling - lack of time for professionals to focus on the whole household instead of on the patient - resistances from professionals to change their usual approach, not-sufficient integrated health and social services, absence of multi-disciplinary interventions (e.g. in educational, social, health realm), absence of family based approach (-).

“I think that what could be useful, if you wanted to do something from a health point of view, is taking charge of the entire family, with the possibility of speaking.” (E9, R1, IT)

“What works on the family point of view is the awareness of what is happening. So this more inclusive approach that it comes out from taking charge on the individual but you have a familiar approach. [...] The downside is that it is difficult to get out both from the institutional rigidity of the service, which is used to a very precise process, and to the personal resistance of each individual operator because it also means changing a bit a very sector oriented mentality of some operators.” (E8, R1, IT)

“(there is a need of) awareness even within the hospital or health services that deal with the various diseases, so a recognition of the need to support the family, not only the patient, making available programs and interventions.” (E3, R1, IT)

“In order to put (the taking charge of family) to the system it would be necessary that there should not be such a rigid division between health and assistance services, this would be the first thing, [...] in these cases integration should find a complete realization. The integration of the services would provide that either within the health services or vice versa within the welfare services there were all the professional skills to be involved but this does not happen”. (E5, R1, IT)

Prevention and care for children with a psychiatric / addicted parent (COPMI)

Experts stressed the need for support a positive and healthy development, break the intergenerational transmissibility of mental health disorders, providing information, psycho-education, self-recognition.

“We work on Semola project, which is a project for the prevention of psychopathological risk in the children of psychiatric patients, but it is not directly addressed to caregivers because not all of these children become so. But the meaning is: let's help them to have a healthy development, to interrupt the intergenerational chain of transmissibility. So I see it quite close to a project that wants to help the (A)YCs.” (E8, R1, IT)

“We carry out psycho-educational interventions for parents and also for children if they want. We are in the preventive sphere in our case and therefore have their own space of speech, they can express as well as they can listen to their

parents. Our function is to improve communication within this family. And then this improves family relationships.” (E8, R1, IT)

Goals:

According to experts' opinions the main goal of interventions for (A)YCs should be the improvement of the whole family, not only on the (A)YC (+)

“I start from an assumption that the young caregivers, rather than the young people or the children we focus on, tend to be invisible and do not have a recognized role. So the concept is to promote a more inclusive approach and including in the help programs not only on the person who bears the disease, the disorder, but also he those who are next to him/her and are suffering too. This I believe is fundamental”. (E8, R1, IT)

Second Round (Reflection):

The experts reiterated that “in cash” support are not sufficient and do not help the young person to handle the assistance and the consequence of this on his/her own life.

“Providing an economic support is the easiest way to support, but the fact is that giving economic support does not relieve a child of his problematic condition, this is the point. On the contrary, you give economic support, but in fact you say “now you go ahead”, but from this point of view I do not consider it correct, because (A)YCs have educational needs, they have psychological needs, they need support, that is not simply economic support, and above all, they have a series of shortcomings that come from caregiving, so the fact that they have to care doesn't allow them to have a normal life like other children. So giving economic support does not solve anything.” (E2, R2, IT)

Goals:

Multi actor programs, economic support added to psychological, educational and social support (+)

“There is the need of an integral approach and therefore the involvement of different actors.” (E6, R2, IT)

“I would not to plan too specific interventions in order to avoid freezing their role and functioning, it would be better to promote their education instead of giving an economic support”. (E4, R2, IT)

Relaxing activities / supportive groups

First Round:

Goals

Sharing emotion and experiences with people in similar situation, helping them to release from the household (moving on and living their own lives while keeping an affective bond with their families) (+)

“I think that should be implemented family based interventions limiting the care burden and bettering the condition of the fragile person. [...] Then my experience says that the self help group (or those that are called “voice groups³⁰” for children) can be useful. In my experience group intervention can be effective for young people.” (E10, R1, IT)

“What worked well was, first of all, sharing emotions, the possibility of feeling understood by someone who knows the often invisible discomfort of caregiving and sharing the stress, anxiety, isolation and loneliness, then sharing these problems, and this in my experience was the aspect that worked the most, to feel part of a whole in which to be understood and supported.” (E3, R1, IT)

Second Round (Reflection):

Experts suggest activities in which (A)YCs could relax and break from their care responsibility in order to promote their individual development and to contrast their life conditions are take for granted. At this aim they suggest summer camp, peer support group.

“It is important that there are dedicated support groups in which the children are free to share their experience with other children who live similar experiences but at the same time , also to take a distance from their fatigue.” (E3, R2, IT)

“I really like all those interventions aimed to remove the person sometimes from the “pressure cooker” in which it is located, that's why I gave you the example of the school camp [...] could be training camps, support and support camps but

³⁰ The “voice group” is a short term intervention that aims to support children and their families during the reorganization of daily life after critic phases, such as a divorce . This methodology was designed in Canada and allows exchange and support between children aged six to twelve, that are sharing the same critic experience.

also of sharing certain problems, [...] but then (A)YCs always have the chance to break from a condition that often crushes them to the ground.” (E2, R2, IT)

Goals:

Peer support group, summer camp (+)

Individual support

First Round:

Goals:

Assistance support, voluntary peer support program (+)

“Besides to individual space, since often caregivers said “those who do not live this experience, cannot understand!”, I thought to make groups of sharing [...] Sharing helps to lighten stress and find strategies in the comparison with others, with their example, [...] there is sharing and there is sharing the effort and not feeling so isolated and alone.” (E3, R1, IT)

Goals:

Interventions tailored to different (A)YCs needs, that could involve: counseling point in school, relaxing activities, peer support group (+)

“A counseling point, offering a service that once every fifteen days, once a month, a space for listening, supervision, how to manage frustration, anger, suffering, the sadness.” (E1, R2, IT)

“I am thinking that sometimes it may be important to involve (A)YCs in relaxing activities, but sometimes it may be more important to have support; this is related to what the person is called to do, to the situation for which one sometimes needs to understand, to be helped from a psychological point of view, other times to have more group experiences or just a little more relief.” (E9, R2, IT)

Training for professionals

First Round:

Goals:

The interviewees suggest training for teachers in order to improve the (A)YCs awareness, training for medical and health professionals, in order to promote an adequate communication with (A)YCs (+)

“The school would probably need the presence of some training courses for teachers focused on the problems of their students in these situations [...] of the small training courses on the modalities first of all to identify the cases and then on how to manage them. And how to support them, so as to build a network not only in the family or voluntary sector but also in the school [...] and maybe a little more exchanges and contacts with those directly involved with patients, who advise the teachers of the critical issues of patients that concerned also their children.” (E3, R1, IT)

“In my opinion medical and health professional would need courses aimed to improve communication, because when you talk to an adolescent you need to be very aware of the person you are talking to, and the person you are talking to is a person who is building an identity, has a very difficult experience, does not yet accept certain things. What is happening to him is probably bigger than him or her albeit he/she will have to face anyway.” (E2, R1, IT)

Second Round (Reflection):

Experts consider information and training very important for school professionals in order to understand the behavior of their (A)YCs student and help them to resolve problems concerned school attendance or difficulties to manage homework. School professionals training can help (A)YCs to carry on their school careers and to cope difficulties raising from caregiving more easily. This training should cover not only the educational sector but also the health professionals in order to share awareness and knowledge about (A)YCs problems.

“Information and training about all the subjects that concern emotional sphere of these children are very important. We are still very, very, far behind.” (E6, R2, IT)

“Here there must be awareness of the health workers, of the Social Service, of the school and of the families in which where there is a problem, we can support all the family members.. More than visibility, I think about knowledge and awareness.”(E9, R2, IT)

Goals:

Training for all sectors (health, educational, social); training for teacher in order to understand the situation and feelings of (A)YCs, training for health professional, statutory training, training for schools of all types and level, information and training for students in order to improve dialogue and support (+)

“So I imagine the involvement of the school, which is not to be left alone, to think of both teacher training programs so as to be able to decode some indicators [...] so there are some indicators that may be excessive aggression, excessive rage, or on the contrary, excessive passivity and disinterest, rather than labeling it as a misfit child and thus further complicate life, teachers should be able to have or must have the tools to decrypt messages and also have spaces.” (E1, R2, IT)

“It would be advisable to use the European funds for schools to plan statutory training on the (A)YCs for teachers. Furthermore, it would be advisable to provide training for students in order to promote dialogue and support in the classroom” (E1, R2, IT)

“The school, in an inclusive sense, not only Primary and Secondary school, I refer to basic training in all levels of training, also obviously when training for professional, especially the social-health professional which are those most immediately involved in problem.” (E1, R2, IT)

“Training courses for teachers, for health workers and, as I said before, for peers and put everything together, in my opinion is very important”. (E3, R2, IT)

3. Future needs to support the well-being and health situation of (A)YCs

Main findings

First Round:

There is consensus among respondents on the need of information and training for all professionals and policy makers; in particular, training for teachers to promote the awareness of (A)YCs, training for health professionals to spread adequate communication strategy for a correct dialogue with (A)YCs, statistical studies useful for policy makers to quantify the (A)YCs. Moreover, experts emphasize the need for families to be taken into account in a systemic way and to be listened to in long term programs providing integrated actions (education, health, social activities and support).

“The school would probably need the presence of some training courses for teachers in relation to the problems of their students in these situations [...] of the small training courses on the modalities first of all to identify the cases and then on how to manage them. And how to support them, so as to build a network not only in the family or voluntary sector but also in the school [...] and maybe a little more exchanges and contacts between health professional and teachers, because the first should advise the second about the criticalities of patients’ children that can affect the latest’ educational path.” (E3, R1, IT)

“In my opinion medical and health professional would need courses aimed to improve communication, because when you talk to an adolescent you need to be very aware of the person you are talking to, and the person you are talking to is a person who is building an identity, has a very difficult experience, does not yet accept certain things. What is happening to him is probably bigger than him or her albeit he/she will have to face anyway.” (E2, R1, IT)

“It is easier to build a community based practices in the school environment, because here students already have their own interaction tools, like whatsapp, they already have a well-defined “modus operandi”. Whereas if you have to build a community from people who do not know each other and who have to use communication tools that they do not know and that usually they do not use, such as a platform, or a forum, it is very difficult to build a sense of community with these digital tools [...] This is a point on which we must pay attention.” (E2, R1, IT)

“Public and private associations must have a family based approach to the problem, not an individual approach. You can start from one but then you have to consider all family.” (E10, R1, IT)

Second Round (Reflection):

Experts reiterate the need of information and training for all professionals and of non standard and flexible interventions tailored on different (A)YCs needs, in order to improve their well-being. At this purpose, experts suggest programs to contrast school dropout and support point in school, as basic interventions that could be improved by further actions suitable to different (A)YCs needs. Furthermore, they suggest an inclusion of the topic on (A)YCs into the European project design for promoting best practices exchange and awareness in all European countries.

“Here there must be awareness of the health workers, of the Social Service, of the school and of the families in which where there is a problem, we can support all the family members. More than visibility, I think about knowledge and awareness.” (E9, R2, IT)

“I suggest strategies tailored on different social and economic conditions of (A)YCs, that take in account the individual situation, that could be so different. Among strategies, interventions and programs for supporting (A)YCs, I think that programs to contrast school dropout could be very useful.” (E9, R2, IT)

“(In my opinion) it is difficult to plan structured interventions, but I imagine a sort of support available in the school, like a point of support where (A)YCs can go and talk about their problems when they cannot do it anymore, in social service a support point from which I can acquire what I need to manage this problem and the health service that manages strictly health aspects, so a sort of reference group for problems of this kind” (E4, R2, IT)

"I suggest one of these calls of the European Union must consider the (A)YCs. Because by doing this you identify them as subjects, place the relevance of the theme, activate research on the subject, activate a network of European sharing on the subject, and so everything change! Above all, the European project allows to identify and share best practices among the various countries. This is essential." (E2, R2, IT)

3.1 Future needs to support well-being / health situation

First Round:

Long term and multi-actor programs, based on appropriate tools for (A)YCs age, such as an ICT app, aimed to listen (A)YCs needs and promote their self-awareness. Moreover, these programs must be able to consider the whole family in order to improve families well being, not only (A)YCs individual well-being, and to include: different school programs able to reach the (A)YCs educational needs, assistance support in order to improve the (A)YCs free time and get them free to spend it in hobbies and sports, support group with others (A)YCs.

"We need to improve the sustainability of the projects, which is now compulsory, [...] because the (A)YCs need to be supported by long term programs, because young people are growing up and they need more time to put the deep roots that can help them to avoid some problems." (E1, R1, IT)

"From this point of view, everything that provides information about the problems that can emerge in these cases, especially for technical-practical problems, so if I have to do a certain thing for a certain type of patient, I am uncertain about what is the best way, the idea of creating a tool that can give practical information I think gives a lot of security, so an application that reach all these kinds of practical problems can be very useful" (E4, R1, IT)

"Schools could plan specific courses for (A)YCs, because some of them could need to be absent and cannot follow the school every day"(E2, R1, IT)

"Public and private associations must have a family based approach to the problem, not an individual approach. You can start from one but then you have to consider all family" (E10, R1, IT)

Second Round (Reflection):

Experts reiterate the need for integration of the different sectors related with (A)YCs (educational, health, social) in order to build up flexible and family based interventions, tailored on (A)YCs needs and age. They suggest playful activities, peer support group and a contact point in the different services where (A)YCs could share their difficulties and needs.

"Then school, with the multidisciplinary interaction between school and social workers if it is the case, health workers and some interventions, maybe even playful, which also involves the peers in order to do not isolate the (A)YCs with something only for them, that someone can feel as something that gives a particular target, but just something that allows to share with peers who do not have the same problem, then of course programs for individual boys, which are interventions that can be dedicated to them but that allow them to share with peers". (E3, R2, IT)

"In my opinion future needs are covered by different sectors, and I think we should promote a family approach but, at the same time, also improve the involvement of the different professionals of different sectors" (E3, R2, IT)

"There is the need for an integral approach that involves multiple actors. It would really need a connection between the general practitioner and the teacher without overloading either of these but it would take a direct line for, between these two actors always in the context of professional secrecy." (E6, R2, IT)

3.2 (A)YC needs

First Round:

Multi-actor programs should be implemented to improve the professionals' attention towards the (A)YCs and their capability of listening their needs in different life realms (e.g. educational, emotional, relational, healthy dimensions) and to rise their self-awareness. Moreover, (A)YCs have a specific need for adequate information, contact with fellow (A)YCs to reduce the sense of loneliness and isolation, resilience training and space for their own needs.

"Ideally would be a multi-level coordination involving all these actors and if everything started from something national, it is obvious that it would be the best, with the consequences at regional level, with multidisciplinary work protocols that they can involve all the areas, both institutional and voluntary, which is a very important resource." (E3, R1, IT).

"In my experience, there is the need for sharing difficulties and having the possibility of feeling understood by someone who knows the often invisible discomfort of having to take care of a family and the sharing of fatigue, anxiety, isolation and of solitude." (E3, R1, IT).

"The other aspect concerns the question of information, so on the one hand the app certainly, but the app according to me must have multiple interlocutors, multiple channels." (E2, R1, IT)

Second Round (Reflection):

Experts suggest interventions tailored to the different (A)YCs needs that can vary depending on the individual case. Some experts suggest to relieve the (A)YCs of the task of caring and to allow them to live more freely their youthfulness. (A)YCs psychological wellness could be improved by interventions aimed to share emotions and feelings added to relaxing activities. Furthermore, one expert suggests the need to be informed not only about the services but also about the illness of the assisted families member as a way to reduce the caregiving stress.

"The young caregiver doesn't go on, sometimes he should take a break from the task of caregiving, what can we do to help him to have a break?" (E2, R2, IT)

"In my opinion are important interventions aimed at sharing the emotions and relieving the psychological burden, this is perhaps a specific sub-aspect that when it comes to integration of services is often overlooked and that it should be very important to maintain or at school or in any case level of services." (E4, R2, IT)

"I am thinking that sometimes may be important to involve (A)YCs in relaxing activities, but sometimes it may be more important to have support, but this is related to what the person is called to do, to the situation for which one sometimes needs to understand, to be helped from a psychological point of view, other times to have more group experiences or just a little more relief." (E9, R2, IT)

"Situations can be difficult and even when talking about caregivers, it is important to keep in mind that there is no category, there are many different situations and different needs: they are only kids who are tied up by having problems and not being able to not be deeply affected." (E8, R2, IT)

"In my opinion, an important need to address is to be well aware of the pathology the assisted person is affected by, because the knowledge gives you the idea of being able to control the situation, which you can manage better when you attribute certain manifestations of the patient to the disease and not to the patient himself, this becomes fundamental." (E2, R2, IT)

3.3 Professional and family needs

First Round:

Information and training for teachers and all educational sector operators are needed, in order to improve awareness about the conditions and the problems of (A)YCs also their specific needs. Moreover, for families: assistance support, professional support to understand the problems of the (A)YCs, interventions to support families difficulties in a systemic way, providing a place to share experiences and to reflect on themselves. There is the need of additional studies and survey to quantify the (A)YCs in Italy and training for health professionals for an adequate communication with (A)YCs.

"In my opinion, all youth organizations and groups should have a particular sensitivity to discover and support these children. The school does not have only sensitivity, it has a moral and professional duty and there must be a specific training to support these children. So as organizations I would say all organizations, all educating communities should be sensitized on this issue. But the school in particular." (E6, R1, IT)

"I think that what could be useful, if you wanted to do something from a health point of view, is the fact that there may be more space to improve the taking charge of families, with the possibility of speaking. Or otherwise a space to be able to find in the field of support at school, because a school that understands, that devotes spaces, is seen in a less pathological situation, less different and may be more to the point. So I would really support the school." (E9, R1, IT)

"In my opinion medical and health professional would need courses aimed to improve communication, because when you talk to an adolescent you need to be very aware of the person you are talking to, and the person you are talking to is a person who is building an identity, has a very difficult experience, does not yet accept certain things. What is happening to him is probably bigger than him or her albeit he/she will have to face anyway." (E2, R1, IT)

"Politicians first of all would need a nice report that tells them the weight of the young caregivers in Italy, because they do not know it." (E2, R1, IT)

Second Round (Reflection):

Experts reiterate the need of information and training for all professionals involved in (A)YCs support and the implementation of a family based approach in order to provide adequate interventions. At this aimed one suggest to provide guidelines for professionals in (A)YCs support. Furthermore, they suggest collaboration between school and general practitioner.

"In my opinion there is the need for an approach that involves the family too, so a global approach." (E6, R2, IT)

"Perhaps more than working with the (A)YCs, I would try to work more on the professionals' sectors, on those that can be updated, raise awareness on pediatricians, on general practitioners, on teachers because I believe very much that the help should be given here and now from, starting from the context. The teachers must know, must keep in mind, the general practitioner must think about these situations, or be helped to think." (E9, R2, IT)

"We could start from professionals giving the specialist or the general practitioner the guidelines, explaining what to think about some things, what it means to have a family living that situation, in order to avoid get to have people who are symptomatic even before we become account their needs." (E9, R2, IT)

"The first need for professionals is to increase awareness of teachers and health workers and give answers. Keep in mind that we are dealing with categories of people to whom compulsory training courses are always offered, in the context of these training courses start to introduce these issues." (E9, R2, IT)

"There is the need for an integral approach that involves multiple actors. I read here that the general practitioners and teachers are fundamental actors in ... I think this too, it would really need a connection between the general practitioner and the teacher without overloading either of these but it would take a direct line for, between these two actors always in the context of professional secrecy." (E6, R2, IT)

3.5 Working concepts to reach (A)YCs

First Round:

One expert suggests to reach the (A)YCs by the way of cared for people once they access the health and social services. Social workers should ask which is the caring network in order to identify the presence of a (A)YC.

“(as regards health workers) Moreover, another important point is trying to understand how the family is structured, in cases where there is a patient, and if there is a teenager try to understand what is involved in the process of care and assistance and understand if it goes to school, what it does, in order to alert and prevent some situations of suffering or discomfort.” (E2, R1, IT)

Second Round (Reflection):

Other working concepts discussed by experts are family based approach, long term actions, multi- actor programs and flexible interventions tailored on different (A)YCs needs.

“I totally agree with the need for families to be taken into account in a systemic way and supported by long-term programs that provide integrated actions.” (E9, R2, IT)

“Sometimes may be important to involve (A)YCs in relaxing activities, but sometimes it may be more important to have support, but this is related to what the person is called to do, to the situation for which one sometimes needs to understand, to be helped from a psychological point of view, other times to have more group experiences or just a little more relief.” (E9, R2, IT)

3.6 Responsibility

First Round:

At national and regional level the Ministries of Education, Welfare and Health. Schools and the Regional School Offices are mentioned as public bodies responsible for the promotion of initiatives and services at support of (A)YCs. In addition, even all public and private community based services that, for different reasons, have the chance to work with families, are identified as organizations to involve a respondent says that the well-being of (A)YCs should be a collective responsibility of all members of the community while another stresses the importance of a case-manager profile. Local authority, for its knowledge of the local needs, is the main actor responsible to plan and realize the (A)YCs programs support.

“The public institutions that should take care of (A)YCs in Italy is the local authority, I believe that the most important institution that should be supported and strengthen, as well as funded, obviously doing the necessary checks, I believe it is the local authority.” (E1, R1, IT)

“Ideally would be better that there was a multi-level coordination involving all these actors and if everything started from something national, it is obvious that it would be the best, with the consequences at regional level, with multidisciplinary work protocols that they can involve all the areas, both institutional and voluntary, which is a very important resource.” (E3, R1, IT)

“In my opinion, municipalities (i.e. Welfare Departments, Social Policies Department, Education Department etc...) should be responsible of services targeting (A)YCs, and also the world of social assistance, the Family Centers.” (E6, R1, IT)

“I would say at national level Ministry of the Health or that regards familiar affair. At local levels I would say the various socio-health workers, where for social and health professionals I mean a wide range. Both in the hospitals and in the social service. The school is another important interlocutor ...” (E8, R1, IT)

Second Round (Reflection):

Experts reaffirm the role of local authority as the main actor for its knowledge of the local needs and stress the role of the third sector in order to promote awareness and actions by politicians. Furthermore, it is desirable to have an involvement on a national level in order to define a clear proxy and political acknowledge, and a European institution that gives the same inputs to different countries in the (A)YCs supporting. For one expert regional authority should plan interventions in according with local authority.

“Absolutely important is the fact that the local authority, due to its knowledge of local needs, should be the main actor responsible for planning and implementing support for programs for young caregivers.” (E9, R2, IT)

“It should be the third sector that gives inputs to local authorities and makes it planning in the social area to do research activities through daily work, to provide the social worker with a basic education, educators, who work with front-office in order to understand (A)YCs conditions.” (E1, R2, IT)

“Within European Union, a body that deals specifically with giving directives, inputs to member countries, specifically on this aspect, as there is the body that deals with gender equality and that every year gives the directives, makes the strategy on equality at the level of four years, as there is on the issue of genital mutilation, on all forms of violence against women.” (E1, R2, IT)

“I think that the regions must be responsible for making regional plans that respond to the needs of that territory, but they must first have an analysis of the context of the needs that should then start from individuals, that is the organization in social territorial areas.” (E1, R2, IT)

3.8 Funding

First Round:

The program should be financed largely by public funds with the collaboration of the private and no-profit sector. Opportunities for funding are identified in funding for schools to prevent drop-out, the National Operational Programme for Education (European Funds through the ESF), resources that schools dedicate to the training of teachers. One respondent also mentions the fact that currently the funding available for health and social care is mostly dedicated to older persons and their carers while there is not much left for other target groups.

“Initially I think it must be the local authority, then there may be private funding that can be involved later.” (E2, R1, IT)

“As regards the training of teachers (but it is aimed only at teachers last year) there is the Three-Year Teacher Training Plan which gives the possibility to organize training units on various topics ... teachers express training needs and organize training units on these issues.” (E6, R1, IT)

Second Round (Reflection):

Public funding is the main channel to promote interventions targeting (A)YCs: for the national level, institution could be involved are the Ministry of Education and the Ministry of Welfare and Health, whereas at European level is desirable that (A)YCs become a topic in the European project design.

“In my opinion there are funds that must be coordinated between the Ministry of education and the Ministry of welfare and health, on this there is no doubt, within the social and health system.” (E4, R2, IT)

“In my opinion the European Union has to take this theme into consideration; I'll give you an example: when they define the topic, define thematic line from year to year, the theme (A)YCs have never considered it, if in the part of funding for projects that concern for example public health they put this too, there we should act at the level of the European Union and ensure that when we define the themes, because it can be done in some respects, this topic is very important, because it is growing, it is a topic that is spoken in all countries.” (E2, R2, IT)

General results

(section 1 of 2nd round)

Visibility and awareness raising

Second Round (reflection)

Experts agreed that visibility and awareness about (A)YCs are unexpected quite low in all the countries involved in the study, not only in Italy. Furthermore, experts are surprised that in country that has a legislation, such as England and Sweden, the interventions for identifying and supporting (A)YCs are little developed. One expert suggest to plan an European project aimed to improve (A)YCs visibility and promote shared actions for supporting this teenagers. Overall, an integrated approach is needed in which welfare, healthcare, and governments work together to identify young carers as early as possible, create awareness, and support them.

“About visibility, I agree a lot with the opinion of other expert that concerned the lack of visibility at all levels.” (E3, R2, IT)

“From what I have read the situation is quite common all over Europe, there is little attention, little visibility, it seems to me, even almost nothing.” (E1, R2, IT)

“In my opinion the situation is similar in all countries and one of the main shortcomings is the lack of visibility of young caregivers.” (E6, R2, IT)

“A European project that does not have great ambitions but increases the visibility of (A)YCs that is quite invisible, in my opinion, maybe an information project starting from this and that is Europe to propose it and to bring it forward in various European countries. It is obvious that the greater visibility would perhaps also give greater impetus to local authorities to invent something, something that reduces the non-uniformity in the various European states, so a common project to increase visibility and to highlight the criticality of (A)YCs.” (E3, R2, IT).

“Therefore, to increase ATCs' visibility it is necessary to adopt a multidisciplinary approach involving mainly the educational sector, the medical and health sector, but also the institutional one, trying to fit all the various competences with specific training.” (E3, R2, IT)

Strategies, interventions and programs to support (A)YCs

Second Round (reflection)

Experts reported that health services can play an important role to identify (A)YCs for their contact with the families disease. Overall, an integrated approach is needed in which welfare, healthcare, and governments work together to identify young carers as early as possible, create awareness, and support them and, in particular, their families to minimize the care burden and promote (A)YCs' wellbeing. Considering interventions developed by the countries, experts appreciate peer support group, that could include counselling activities, support group for families as well as family centred approach in order to allow an harmonious (A)YCs' development.

“I also really like the idea of the peer group [...] or the support group, not as a group of mutual help, I imagine it more as an activity in which these guys, these girls can have some sort of supervision on the they lived and then decode [...] So on the one hand a constant supervision that should be guaranteed by the services that should plan more tailored interventions, and don't give standard services.” (E1, R2, IT)

“The action that I think should not be missing is that supporting the development of these children, especially the support groups and the training for families.” (E2, R2, IT)

“It is crucial identifying the young caregiver when the family access to health or social services.” (E3, R2, IT)

Future needs to support well-being / health situation

Second Round (reflection)

Experts agree on the need of actions, such as guidelines, that promote integrated approach at European level, able to consider the different legislation and culture and, at the same time, to avoid isolated actions. Furthermore, an integrated approach is needed in order to develop adequate strategy for identifying (A)YCs and tailored interventions aimed to promote (A)YCs wellbeing, giving them the chance to build adequate life project. For this purpose experts recommended information and training for teachers as well as for other professionals.

“The thing on which I have to reflect is the need for interdisciplinary that involves various sectors in order to identify the young caregiver and from there plan support actions. Because as far as in Europe there is something, it seems to me always something sporadic not so institutionalized.” (E3, R2, IT)

“In my opinion the thing on which we should really aim is the school, and therefore the fact that, in few European areas, there are training and support programs starting with teacher, but also training for health workers. This could be the starting point for carrying out dedicated actions that are not exclusive.” (E3, R2, IT)

“In my opinion should be made European guidelines, also because by studying with experience, (A)YCs often have common characteristics that must be channeled into a project of life, that is to say, help to build ... the young caregivers to build a life project.” (E6, R2, IT)

“Overall I see a uniformity of shortcomings and even goals, the need of multidisciplinary approach comes out and, above all, a dedicated legislation that then stimulate training on various levels is needed.” (E3, R2, IT)

Visibility and awareness raising - country specific results

Second Round (reflection)

Experts agree on the unexpected lacking visibility and awareness of (A)YCs in the countries involved in the project. The condition of (A)YCs in UK and Sweden is discussed by the experts as cases of unexpected lack of awareness and visibility, although there are laws about it. For one expert the legislation in UK is not focused on (A)YCs but more generally on child and childhood. Furthermore, the same expert considers that countries in which culture allows that the youngest take care of parents, such as Slovenia and Italy, are more sensible to the (A)YCs condition. Whereas, other expert consider that visibility is different in the different countries involved in the project, thus there isn't a uniformity of intent among European countries. In order to overcome this situation, is suggested the implementation of an European organization. The television programs in UK added to social network campaigns are considered by an expert as good way for improving awareness.

“Experts of other European countries complain about the lack of visibility of (A)YCs, for example. Now, that's not what I had in my mind. Above all compared to the United Kingdom, for example.” (E8, R2, IT)

“I am struck by this invisibility that is quite common, even in countries where I thought there was greater sensibility, such as in the United Kingdom and Sweden, which is the realm of social politics, and even here seems that (A)YCs do not exist, even in Switzerland, paradoxically it would seem that we are not so bad, it would seem!” (E1, R2, IT)

“It is true that there have been various legislative acts about (A)YCs, as in United Kingdom for example, but it is also true that they are more general legislative acts, do not go specifically, while regarding children more generally, do not go into the specific problem of identifying and appropriately supporting these young caregivers, so the point that seemed to me quite relevant was a lack of coherence at the level of the countries and consequently perhaps also the need to be able to build something even more homogeneous, obviously at European level given the differences in the legislation of the various countries.” (E2, R2, IT)

“On the other hand, it seems to me that countries like Slovenia, for example, but also Italy, are the countries [...] with a culture in which it is quite normal that children take care of their parents.” (E2, R2, IT)

“We realize that other countries have already developed more important things on the specific topic, such as the United Kingdom or the countries of northern Europe, Sweden in particular, even the Netherlands in reality, and so what seems to me to emerge is above all this great differentiation between the various countries and a lack of homogeneity of that entity which is called Europe”. (E4, R2, IT)

“I'm surprised by the fact that in Sweden young caregivers have small visibility and are not mentioned in the legislation because one expects something more in Sweden. Worth mentioning that the visibility of (A)YCs is not much better in countries with welfare systems traditionally deemed better than Italy, such as Sweden.” (E9, R2, IT)

Strategies, interventions and programs to support (A)YCs

Second Round (reflection)

Experts appreciate interventions based on families approach, aimed to supporting (A)YCs and, at the same time, to minimizing the care burden; for this purpose training and information for school professionals and other professionals are needed. In particular, one expert suggest to improve training for teachers and to provide practical, economic and, at the same time, psychological support, such as peer support group or summer camp, as it happen in Switzerland, where (A)YCs could share emotions and relaxing. Strategy for an early recognition implemented by Slovenia is considered very important by one expert. The information about one parents' illness that is provided by Sweden is needed by two experts as a way to cope caregiving's difficulties. For one expert dedicated legislation is a starting point for improving awareness but is needed an European shared approach and a uniformity of intent.

"(In my opinion is needed) therefore training for teachers that in some states there is but also here a little developed, and this can allow a scholastic support but, above all, a family support, which also involve them, it seems to me there is something of this kind in some countries, now I do not remember, but it's important that is not only a practical support, which is important, but also that there are dedicated support groups in which the boys are free to share with other children who live similar experiences." (E3, R2, IT)

"I appreciate the courage of some countries, I refer in particular to Sweden and UK that delivered specific laws. It seems to me courageous to do things and see that these then work, then the ability to intervene and to legislate in this sense is undoubtedly to be emphasized and put as a stimulus to other countries and Europe." (E4, R2, IT)

"For example, Switzerland, a focus on the relief of relatives. In my opinion a support system for both the family and young caregivers should be implemented. For example, as regards Switzerland, there are summer camps. It would be really something to be implemented both to reduce the responsibility of young caregivers and to make them distract from this role, even to relax them." (E6, R2, IT)

"I appreciate what happened in Sweden, it seems very interesting to me, even though I need to clarify it, but explaining to children, that is, to give children information about the illness of their parents," (E1, R2, IT)

"People with disabilities have the right to help" (Sweden), support here is economic, but, why not! I repeat I don't believe only in economic support, however, it could also be a motivation to know "ok! I cannot work fully but I have a support!." (E1, R2, IT)

"In my opinion the aspect of early recognition highlighted for Slovenia is important." (E7, R2, IT)

Second Round (reflection)

Experts agree on the importance for (A)YCs to express freely their feelings and to have someone able to listen to their story, as has been emphasized by Sweden. Furthermore, the need for digital solutions to provide help and support is considered by the expert as a smart way to reach (A)YCs needs. One expert emphasized the role of the whole society, that is responsible of (A)YCs support, and the need of a cultural change, as is underlined in Switzerland. Finally, one expert emphasized the need of information and training for all professionals involved in long term programs in which multi-actors takes part in a coordinated approach. Of course more fundings are needed.

"In my opinion, is important what mentioned by the experts from Sweden, i.e. "to give children the opportunity to talk about their situation, meet and ask for support", as I said before, "opportunity to relax together", I consider supervision as a tool that could also include the game." (E1, R2, IT)

"For example Sweden, where experts underlined a future need for digital solutions to provide help. I think this is desirable. So since the new technologies are still the preferential channels for young people, I think that thinking of APP, however, something that includes digital solutions is a very good idea." (E6, R2, IT)

"Then for example as is underlined by Switzerland, when it is said that society in general is responsible and needs a cultural change, I think this is fundamental, because the problem of young caregivers must remain culturally in society." (E6, R2, IT)

"I agree with what has been underlined for Italy, in particular the need for training for all professionals (political decision-makers, teachers and health workers), because they are undoubtedly engaged with (A)YCs and the specific problem related to the people who take care of parents. Moreover, multi-actor programs for long-term care are needed. Furthermore, I would like to stress the need for public funding." (E4, R2, IT)

Results - Sweden

Visibility and awareness raising

Main findings - Low visibility and awareness

First Round:

The concept of “YCs” is unknown for most Swedish citizens. The term “children as next of kin” has been used during the latest decade, but when it comes to the issue of YCs, the experts perceived the visibility and awareness as low or even very low, at local as well as at regional and national levels. The Swedish welfare systems are supposed to take full responsibility for care. Thus, no children should have to assume a caring role. The common Swedish view is that childhood should be free from such burdens. This approach contributes to the invisibility of YCs.

“They are not visible in Swedish laws, because we believe that our welfare legislation will prevent children and adolescents from becoming young caregivers [...] underaged persons are not supposed to have that kind of responsibility. Thus, we disregard the existence of young caregivers” (E1, R1, SE).

“... in some way, it is like we do not want to... see them, that is, there is an idea that it is the society’s responsibility to take care of adults, and children should not be caregivers. And from that point of view, I think that we have made them invisible” (E4_R1_SE).

“We don’t want it to occur in Sweden, I would say. So, we actually do not see, and there is not so much support for them, which means that they often live in a very vulnerable situation” (E7_R1_SE).

Second Round (Reflection):

After reading the preliminary results of round 1, the Swedish experts commented on the lack of research in this field. They also commented on the low level of visibility and awareness in participating countries. These results were expected by some of the experts, while others were a bit surprised, since they had expected, or hoped for, a higher level of visibility and awareness in at least one or two of the countries. Furthermore, there were some reflections on national laws as well as national economics in relation to existing efforts for supporting YCs. When it comes to awareness raising events, one of the experts argued that Sweden could learn from other countries.

“It is an invisible group, and there is a lack of systematic studies. There is also a lack of follow-ups, not only on their existence and what’s happening to them, but also on available support programs” (E7_R2_SE).

“It becomes quite clear that there is a lack of some kind of basic assessment of young carers’ needs. This makes it difficult to know what kind of support we should develop and offer [...] we don’t really know how many they are and what needs they have” (E3_R2_SE).

“What I’m thinking about [...] is that it’s general [in the round 1 results] that it is an invisible group [...] You could almost believe that [...] some countries would have a little more, but... but it’s very obvious that this is how it is in general” (E5_R2_SE).

“Although, of course, it varies between countries, it wasn’t so very impressive results, unfortunately” (E4_R2_SE).

“I have been thinking a little bit about Britain... they talk about something called The Care Act [...] This is in many ways similar to our Swedish social support model. But then we talk about indirect family support, and that’s good... in some way... that the sick family member gets support, but still, I don’t think there is any support targeted to those young ones” (E3_R2_SE).

“In some of the countries they use media and TV for dissemination [...] That’s interesting to read about [...] We don’t do that in Sweden in that way” (E3_R2_SE).

Local and regional level Visibility and awareness

First Round:

Social workers and health care staff do not usually ask adult patients if they have any children, and they do not usually involve children and adolescents when planning care for parents or siblings. Exceptions are specialist care, where children as next of kin usually get attention, and social workers who are used to being aware that children of parents with substance abuse often take great responsibilities.

It may be perceived as difficult to talk to the children, when the parents have problems, and Swedish confidentiality laws cause dubiousness about how much staff are allowed to talk to the children/adolescents about the family situation. However, in a regional and local level there may be some variations. It all depends on the people who work in the caring fields.

In schools, the awareness of (A)YCs situation is low. School staff may notice that some children take great responsibilities at home, but it is not sure that the staff realize what this means for the individual child/adolescent.

"Those in healthcare and social care, who meet adults with problems, have not identified that the children have problems or have a caring responsibility burden. When they start doing something... beyond what they are used to do, it's very hard to motivate them, because they don't usually meet children and they don't see what changes it can lead to, if they start to give attention to the children" (E1_R1_SE).

"The specialist care is quite good... in giving attention to children as next of kin. But when you inform primary care staff about children as next of kin... they are usually not so familiar with the term" (E8_R1_SE).

"... very often, in psychiatric care, despite legislation since 2010 and so on, they don't investigate if there are children at all. And then... the next step then if there are children, to find out how the parent's illness affects the children, that's really a very rare way to go, I think" (E4_R1_SE).

"You generally know that children perform different caring tasks. If you have a parent with addictions, for example, social care staff know that several of these children are carrying great responsibilities. They have known this for a long time, even if they don't call them 'caregivers'." (E2_R1_SE).

"I remember when I heard teachers in a school saying 'yes, he is so capable, every lunch he goes home and cooks food for his parents, and he always goes straight home after school to take care of his parents'... with admiration and no kind of critical perspective concerning if this is good for this child, does the child really like this, and what is the costs for this child to do this, compared to other children at the same age, or compared to children's rights [...] I think that you have often seen them, but haven't thought one step further" (E10, R1, SE).

Second Round (Reflection):

The experts reflected on visibility and awareness in Sweden. Sometimes it may be obvious that a child has a high level of caring responsibility, but adults in the surroundings are not aware of what this really means and how it affects the child.

"there are probably a lot of people who [...] see this around, but they haven't reflected what it is. For example, the Midsummer party, where Pelle's mother is getting more and more garrulous and unpleasant, and people tell Pelle to follow his mother home [...] Thus, people use the child's caring responsibility, but haven't reflected on what this is [...] Thus, in a way I don't think people are unaware, but they are not aware about the phenomenon, haven't thought about what this means for the child" (E10_R2_SE).

Awareness raising events

Round 1

In fall 2016, one region had a seminar day, with Saul Becker, for about 200 health care professionals. The day is described as highly appreciated. In some regions, social workers organize network meetings for diverse professionals such as health care staff, school staff, and children's agents. During these meetings, they watch films about children as next of kin, and discuss fictional cases. In addition, they have invited police and ambulance staff to share their experiences of meeting children who suddenly and unexpectedly have lost a family member. One region has started the work of implementing the method 'Föra barn på tal'³¹ in the health care for patients with somatic illnesses. The method is often used in psychiatric care. In another region, there is a primary care project, aiming to get health care professionals to include the issue of children in their conversations with adult patients. In their work with education and information, health strategists and regional developers use the term '(A)YCs' related to the more well-known term 'Children as next of kin'.

"...when we organize these network sessions we have... we always try to have the children and youth perspective. We watch films, we discuss cases, and we always have family group conversations" (E6_R1_SE).

"... we had invited ambulance staff and police, and they shared their experiences of coming to a home where someone has died, and there are children in the family, and the frustration in not knowing what happens in the family afterwards" (E6_R1_SE).

³¹ 'Föra barnen på tal' (Talk about the children) is a manual based method in which the professional meets the parent(s) on two occasions and together with the parents talk about the children and their situation. During the meetings they use a structured logbook as support.

"... that this family intervention 'Föra barnen på tal' now is going to be spread to the somatic care" (E6_R1_SE).

"...if I look at regional developers' work, we have chosen to include young carers in our educations, as an information and knowledge to bring back to the health care" (E8_R1_SE).

"The term young carers has not been so frequent, and it's still quite unknown [...] I use the term in our education [...] I think it's a useful term for pondering, that's why I have chosen to include it" (E8_R1_SE).

"And some other project I have, where... when we talk about mental illness in primary care [...] where everyone gets information about the importance of raising the issue of children as next of kins... to raise that when you face mental illness, in order to see: In what way does this affect... your parenthood today and what does this mean for the children?" (E8_R1_SE)

Round 2 (reflections)

Young people's individual stories, in form of young adults' lectures, or in films where children and adolescents share their experiences of being (A)YCs, are described as important tools in the work of awareness raising.

"... films can help to make the children's and youth perspective more clear, because it affects you. That's why we usually watch films in our meetings for children's agents. There are films on the Swedish Family Care Competence Centre's website, where children and youngsters tell their stories, making it lifelike and clear" (E6_R2_SE).

"they had had a sibling who had lectured [...] in the psychiatric care [...] she told about her situation, how she had been treated, and how she had been seen, or not been seen in the care [...] with the aim to bring this perspective. To see her situation" (E6_R2_SE).

Policy notes

Round 1

One of the experts argues that an increased awareness on a national level has increased the financial opportunities for the regions to meet (A)YCs' needs.

"Nationally... there is currently knowledge enough for governmental funds for encouraging work to meet those children's needs and... and regionally, it's in the same way I think but it varies of course, in different regions" (E2_R1_SE).

Round 2 (reflections)

According to the Social Care Act, municipalities are responsible for ensuring a safe and secure childhood for all children in Sweden. The responsibility for hospital care is on the regions, while the municipalities are responsible for primary care and home care. Both areas are covered by the Health Care Act, which was updated in 2010 with an addition that health care should provide advice and support for children as next of kin.

"Still, we have social care services, which gives municipalities the responsibility for a safe childhood for all children" (E1_R2_SE).

"We got this reinforcement, 2010, in the Healthcare Act. That we should give advice and support to children as next of kin, and then it became a clear mission [...] This was very much needed. Even though we have worked with children as next of kin since 1996, it was actually 2010, when this reinforcement came, we could take one more step. We also got the assignment in a clearer way, from the county council" (E6_R2_SE).

Increasing attention

Round 1

The experts argued that the attention of children as next of kin, and (A)YCs has increased in recent years, and still is increasing. However, there are regional and local divergences.

"It has happened a lot in recent years, I think [...] they have been the forgotten children [...] But now we are talking about children as next of kin [...] colleagues know about it, we have children agents since fifteen years ago [...] But we haven't used the term 'young carers', which is very new for us [...] But we have talked about children as next of kin, and their situation. There we have quite a lot of knowledge" (E5_R1_SE).

"I think it looks relatively alike across the country. But as far as I can see... in bigger cities, there are group activities, often several of them, and this means that there may be some people who have greater knowledge and can give more. It's a quite more difficult in smaller places, to be able to have... [...] On the other hand, in smaller places, you might have more opportunities to know the whole family... which means that you have more opportunities to see the youths, but this doesn't mean that you have more knowledge about what to do" (E7_R1_SE).

"There are, of course, people who raise the question [...] I can see that people get affected, when this issue is addressed, and it becomes a new aspect they haven't really thought of, in that way, and as a concept. Therefore, I think that young carers, as a concept, is a useful concept, because... you have to think about what this means [...] the issue is received as something more to be aware of. 'Here is something that I actually should bring back and think about'" (E8_R1_SE).

Round 2 (reflections)

The experts agreed on an increasing attention, on a local level, often due to individual professionals with a burning interest of the issue of children as next of kin and/or (A)YCs. The awareness among people in general is described as limited. A lot of people may see what is going on, but do not reflect on the consequences for the children. Seeing and being aware is not the same thing.

"There are big differences locally and regionally... I thought it was quite exciting to see that a lot of experts said that it is happening a lot locally, but perhaps not so much at regional level" (E3_R2_SE).

"And when you can see [...] in the different countries, that the visibility is increasing thanks to local individuals who are burning for this issue, there are a few individuals who are running the issue of these children. And it hasn't happened so much in organizations or in new directives or regulations, it's more about individuals' struggle" (E3_R2_SE).

"There are those who mostly help the family with various things that means some kind of relief, but it's not indisputable that this covers the children's responsibilities and situation" (E1_R2_SE).

National level

Visibility and awareness

Round 1

The Swedish idea, that children/adolescents are not supposed to have caring responsibilities, contributes to the invisibility of (A)YCs. We sometimes talk about children's positions in the family and/or about children's problems, but we seldom talk about the caring tasks that children actually perform.

"In some way, it's like we don't want to... see them, since there is an idea that, in the welfare system we have built... it's the society's responsibility to take care of adults, and children shouldn't be caregivers. And from that point of view, I believe they have become invisible" (E4_R1_SE).

"They are not mentioned in the law, because we believe that our welfare legislation will prevent them from becoming young carers" (E1_R1_SE)

"I believe, in general there is this view that you want to give a functional support for the parents. And this is also apparent in our legislation, since you are not reckoned as a next of kin until you are eighteen years old" (E9_R1_SE).

"Since we have our focus on the support to the parents, and on family functioning... I believe it's a common opinion that children should have the right to a childhood without worries [...] we are trying to solve the problems in other ways, and it hits me that if you are fifteen to seventeen years old, you may be regarded, in the family, as someone who should help and support" (E9_R1_SE).

"Internationally, the discussions often concern children as carers, and they actually emphasize children who do work at home, due to family situation, while the discussions in Sweden mainly focuses on policy notes, the children's position in relation to parents and authorities, and on what problems the children may have. We have to a much lesser extent actually focused on the fact that children often do a lot of work and take a lot of responsibility in these situations" (E10_R1_SE).

"If you are born in Sweden and have your family here, and there are some kind of problems in the family, you still have another situation compared to newly arrived young migrants. When their families arrive to Sweden, they become kids who take responsibility for the whole family. And in this area, we don't currently have the knowledge of how to meet these groups, or how to identify them in an early stage" (E7_R1_SE).

Round 2 (reflections)

In Sweden the term (A)YC is still not widely used to any extent

"...we seem to agree that the term 'young carer' isn't commonly used in Sweden" (E7_R2_SE).

"I think it matches my opinion, that this is unknown to most Swedish citizens. It's like no one knows what 'young carer' is" (E5_R2_SE).

"It's also interesting that 'young carers' is quite unknown, but 'children as next of kin' is a more familiar term" (E9_R2_SE).

Awareness raising events

Round 1

The Swedish government has instructed the Swedish National Board of Health and Welfare to raise the issue of (A)YCs. Researchers are raising the issue of (A)YCs in their lectures about children as next of kin.

"We have got the mission from the government... to raise this issue [...] from 2015 [...] We have performed a survey about to what extent fifteen-year old youngsters are taking caring responsibilities [...] The study aimed to bring this issue on the agenda but, unfortunately it didn't get much attention" (E1_R1_SE).

"I've been very active and lectured about my research. I'm trying to disseminate it, both in education and to a wider public, as I think society doesn't give these children enough support. I've also written more theoretically about this issue, since this is a relatively new way of thinking in Sweden" (E10_R1_SE).

Round 2 (reflections)

The interventions in Swiss schools were met by curiosity, and there is a wish to know more about these interventions.

“Switzerland seems to have successful interventions in schools. This sounds very exciting and would be great to know more about” (E5_R2_SE).

Policy notes

Round 1

According to the Swedish Health Care Act, health care professionals must ensure that patients' children receive information, advice and support. The Social Care Act doesn't stress this issue with the same clarity. However, a new proposition suggests that social care professionals should work on a more preventive level, especially concerning children who are exposed to violence at home.

“The Health Care Act states that we are obliged to consider children's need for information, advice and support [...] The text in the Social Care Act is more unclear, like ‘the best for the children’ and so on [...] the more blurred it is, the harder it is to follow... somehow” (E5_R1_SE).

“Our legislation is designed in a way that it doesn't contribute to make young carers visible [...] In the Social Care Act you can read about next of kin caring for relatives, but children are not mentioned” (E1_R1_SE).

“It came a government proposition yesterday, about social care [...] about children who are exposed to violence at home, and how they act as caregivers [...] This is the first time young carers are mentioned in official governmental documents. And they also write about [...] development of possibilities for social care services to perform preventive work, and that this is a very important step. Because, until now they have mostly performed investigation work when they have received warning signals about children who may need extra support. Thus, this is important, even if the proposition isn't directly targeted at young carers, it's at least the first time I have seen a tendency in a text from the governmental office” (E9_R1_SE).

Round 2 (reflections)

Even though the term '(A)YC' doesn't exist in Swedish legislation, there are some legislation texts that could be used in order to promote (A)YCs health and well-being. The Swedish National Board of Health and Welfare uses the term 'Children as next of kin'. The interpretation of the Swedish Social Care Act is discussed, as well as the fact that the Convention of the Rights of the Child is going to be incorporated into Swedish law, from January 1, 2020.

“We have a different welfare system, which, to some extent, provides opportunities for adults with difficulties to receive help in other ways [...] If you don't have that kind of legislation, you don't have the same possibilities to get support in case of severe disabilities, and it falls heavily on the kids in those families” (E1_R2_SE).

“Someone said that it's apparent in our legislation that you are not considered as a next of kin until you are eighteen [...] it says nowhere that it is from eighteen years” (E5_R2_SE).

“Someone says that, according to our legislation... you are not considered as a next of kin until you are eighteen [...] But you need to read the entire Social Care Act... which gives a sufficient ground actually [...] There is really a legal basis both through the responsibility to give children a safe childhood, and through the responsibility for preventive actions. This whole group of children as next of kin, is of course included in the responsibilities of Social Councils [...] If a youngster cares for a relative [...] then, of course you are included as a next of kin [...] even if the legislature of the Social Care Act haven't thought in that way” (E1_R2_SE).

“We already have the Convention on the Rights of the Child, and we have ratified it in various ways, and we also have committed ourselves to use it... and we don't... Making it legislation will probably not make such a difference in practice” (E7_R2_SE).

“We are talking about children's rights and we are trying to highlight the positions, but still, parents can say 'no, you mustn't tell my children about the treatment or therapy I get from you', and then the children don't get any information” (E10_R2_SE).

Social media

Round 1

According to the experts, there are currently no social media channels, specifically targeted at (A)YCs. However, (A)YCs may use general youth forums and chat rooms to seek support from others.

“chat forums [...] about subjects like... well, not just about children as next of kin, but where children as next of kin may find support” (E5_R1_SE).

Television

Round 1

One of the experts recently participated in a television interview about Children as next of kin.

"Last week I was interviewed on the radio, in the morning news, about children as next of kin" (E6_R1_SE).

Round 2 (reflections)

One of the experts reflected on the UK information dissemination through TV.

"Britain, for example, seems to have used TV shows to disseminate information about young carers. I think they seem to stand out a bit by this" (E5_R2_SE).

Increasing attention

Round 1

The term 'Children as next of kin' has reached increased dissemination during the last years, and social media has given opportunities for next of kin in general to make their voices heard.

"At the beginning, many people were wondering about the concept 'children as next of kin' [...] It has been raised in many ways, both nationally and internationally, in a completely different way now... compared to... yes, seven to eight years ago" (E1_R1_SE).

"now, with social media [...] well, you talk a lot more about it today [...] next of kin have got their voices heard a little bit more, and you talk about the Convention on the Rights of the Child more" (E5_R1_SE).

Round 2 (reflections)

The preliminary results from Round 1 gave a picture of a slow progress. When it comes to implementation of the term '(A)YCs', UK is seen as a good example. In terms of visibility and awareness, as well as strategies and interventions, the Swedish approach is 'Children as next of kin' rather than '(A)YCs'.

"... you get the feeling that it moves forward slowly [...] it's about changing people's understanding, and this takes time" (E2_R2_SE).

"... it's Britain who stands out a bit [...] they are a bit ahead of us, when it comes to the concept" (E5_R2_SE).

"Still, in Sweden, we don't see children as next of kin or young carers, as a kind of client group or patient group" (E3_R2_SE).

Percentages of (A)YCs

Round 1

The experts make an effort to estimate the percentages. Some of them refer to surveys. The estimates range from seven to ten per cent of all Swedish children/adolescents.

"I would guess that there are a lot more than we know about" (E3_R1_SE).

"I would say at least ten percent of the children, or something like that" (E4_R1_SE).

"In a survey [...] performed by the University of Gothenburg [...] they came to the conclusion that among the fifteen-year-olds who completed the questionnaire [...] seven percent gave comprehensive care. But it's always a question of interpretation, what you put into the concepts of 'care' and 'comprehensive care' [...] Three percent stay home from school due to their caring for a relative" (E1_R1_SE).

"When we have been asking... in psychiatric care, as many as around ten percent of those with schizophrenia have children. And we believe that these children take a lot of responsibility [...] If we look at the group with anxiety or depression, then the numbers are probably higher, so lots of psychiatric patients have children, or young adult children... who I believe are doing great efforts" (E7_R1_SE).

The responsibility for identifying (A)YCs

Round 1

The experts claim that it is a national responsibility to make the group (A)YCs visible, while on an individual level, the entire adult world is responsible for identifying (A)YCs.

"I think we need to talk about it on several levels, because I think there is [...] a national responsibility for society to make them visible and make it clear that these children exist [...] and that it's about quite many children" (E4_R1_SE).

"In general, it's the state's responsibility to spread knowledge to schools, social care, health care, and whatever it may be, that this group exists, and then, on an individual level, it's individual institutions, health care, and schools, who have the responsibility" (E2_R1_SE).

"Everyone who meets children and young people in their profession has a responsibility" (E2_R1_SE).

"It's hard to point out only one part. Because the child exists in so many different contexts during the awake time, just as we all do. Thus, I think it's really hard to say who is the one who could see and identify this child. There are a lot of people" (E3_R1_SE).

Educational organizations

Round 1

Nursery schools and schools are mentioned as important organizations in identifying (A)YCs.

"I think the school has a very big responsibility. All children from six, seven years, are in school five days a week" (E3_R1_SE).

"School is a great area for discovering this [...] Health care can inform their patients, but in school, you can see if a child is tired or absent" (E8_R1_SE).

"I believe that student health is also a very important instance for identifying" (E7_R1_SE).

"nursery school, and school [...] it's important that they have an attention to children's home situation and what their needs may be. At the same time they are not supposed to... take responsibility for solving the problems, but they should take responsibility for discovering and ensuring that there is a cooperation concerning the home situation, and to make clear what their own role is" (E1_R1_SE).

Round 2 (reflections)

Reflections about the level of schools' responsibilities, and why it is so important that nursery schools and schools take responsibilities for identifying (A)YCs.

"I'm not sure that you have to give support in schools, since they already have so much pressure on them, to do this and that. But this general issue, to ensure that there is knowledge about young carers' existence, that you can get support and help if you need it, where you can get it, and to pay attention to children in that situation" (E4_R2_SE).

"nursery school and school [...] to start where the children and youngsters already are, because now we start where the adults are, the ones who the young carers care for [...] In that way, I think, we miss a lot of... children who are not visible, so to say" (E4_R2_SE).

Healthcare and welfare organizations

Round 1

Every organization within health care and social care are, according to the experts, responsible for identifying (A)YCs.

"child care centers should pay attention to this" (E10_R1_SE).

"There is a very clear responsibility in the health care sector when... you have... patients who... have under-aged children... Patients with addiction, disability, or a serious illness, or when a parent dies. It's very clear that the child's need for information, advice and support should be taken into consideration. And in this context you will surely find if a child has a caring role in... relation to the adult patient [...] so... you need to identify their needs for support. This means that you need to think about how they can be relieved from responsibility and what kind of support the family needs" (E1_R1_SE).

"Social care, Child and adolescent psychiatric care, but also adult psychiatric care and... drug addiction care, and somatic care, and... every context where you can imagine there are vulnerable children, I think there is a specific responsibility to find out if there are children and how they are affected by... the parent's addiction, disability or... illness. How could it affect the child and what kind of responsibility does the child take in all this" (E4_R1_SE).

"Both the Social Care Act and the Health Care Act say that you have to, for example, provide information to children if they have parents who are ill [...] And then, when you are providing information and support, this means that you also identify if they need more help" (E7_R1_SE).

Parents

Round 1

One of the experts states that if one of the parents is healthy, this parent has the main responsibility for identifying the child as an (A)YC.

"of course, first of all it's the healthy parent's responsibility [...] if there is one..." (E3_R1_SE).

Other adults

Round 1

Two of the experts state that all adults who meet the child/adolescent have a responsibility.

"All adults who are around the children, in any part of their everyday lives, we all have a responsibility" (E3_R1_SE).

"The public has a general responsibility to pay attention and report when finding a child who is in a risk situation" (E10_R1_SE).

Ways to identify (A)YCs

Round 1

Professionals can identify (A)YCs whose parents are known within health care or social care. This can be done by asking patients/clients if they have children, follow-up questions about the children's situation, and if it may be possible for the professionals to see the children. Three methods are suggested to be used for this purpose: 'Föra barnen på tal'³², 'BRA-samtal'³³ and Beardslee's family intervention³⁴.

"A minimum level should be to help those children whose parents are already known. There is a considerable amount of children that can be identified in that way" (E1_R1_SE).

"it's really not so hard, as I said, if their parents need help... then the children's needs should be noted, it's as simple as that" (E1_R1_SE).

"We have linked family forms to our regional medical guidelines" (E8_R1_SE).

"We have been working with the method 'Föra barnen på tal' [...] to talk to the parents about the children. And now we are educating and implementing 'BRA-samtal', which means talking to the children and ask them about their perspective on their situation" (E5_R1_SE).

"Beardslee's family intervention is about meeting the children in their home. And then, after this, have a conversation with the whole family, in order to gain knowledge about the children's situation in the family" (E6_R1_SE).

Round 2 (reflections)

One of the experts reflects about the psychiatric care professionals opportunities to identify (A)YCs, while other experts reflect about the methods' usefulness in identifying (A)YCs and their needs.

"I called a psychiatric nurse, since I believe that psychiatric care staff must meet young carers quite often. She agreed that children are easily forgotten, since the main focus is on the patient, although we nowadays work very actively with children as next of kin. And she thought it's important to be very clear when you meet children and youngsters, who in various ways show signals about not feeling well. To be clear, and to ask them about the home situation, and to try to figure out what burdens they are carrying" (E6_R2_SE).

Reflections about the method 'Föra barnen på tal':

"We use 'Föra barnen på tal' with all parents who receive support from the disability care centre. We perform conversations about their children once in the six months, when we write their individual support plan. We do this because the children grow so fast and you need to ask for different things due to the children's ages. And we sometimes talk to each individual child [...] there the parent also has an opportunity... or you together with the parent, have the opportunity to see if the child's responsibilities are acceptable in relation to the child's age" (E5_R2_SE).

Reflections about 'BRA-samtal':

"You have to have the parents' consent" (E5_R2_SE).

"It may take between ten minutes and half an hour. It depends on how much the children wants to talk. You have to adjust it a bit in relation to age and maturity" (E5_R2_SE).

(A)YCs characteristics

³² 'Föra barnen på tal' (Talk about the children) is a manual based method in which the professional meets the parent(s) on two occasions and together with the parents talk about the children and their situation. During the meetings they use a structured logbook as support.

³³ BRA= Barns Rätt som Anhöriga (Children's Rights as Next of kin). BRA-samtal is a model for talking with children as next of kin, in order to ensure that the children gets opportunities to talk about their situation, be involved, and be aware of their rights. BRA-samtal are structured conversations with a child, with the aim to investigate the child's current life situation, followed by one conversation which has a more supportive form.

³⁴ Beardslee's family intervention is a family-based approach for the prevention of depressive symptoms among children at risk.

One of the experts stressed the importance of not considering (A)YCs as a heterogeneous group. They are, each of them, unique individuals in unique life situations.

“if you talk about the individuals, it’s very important... like anything else, in fact, they are not one group. There are many different groups. And completely depending on what situation you are living in” (E7_R1_SE).

Family composition

Round 1

Examples of complicated family compositions are raised, such as when a family member suffers from somatic illness, mental illness, or substance abuse; has a cognitive disability; is deaf or blind; is abusive; or is in prison. In addition to the above mentioned family compositions, migrant families are mentioned. There may be several reasons why a child’s caring burden is not visible, for example parents may want to hide the problems.

“Abuse for example, or mental illness, when the parents would like to hide the problems, and during the course of time, the children also realize that this is something you shouldn’t talk about” (E10_R1_SE)

Round 2 (reflections)

The results from round 1 led to reflections on migrant families and children who have been moved from their families and placed in foster homes.

“Migrant families [...] children are used instead of professional interpreters [...] when parents or other relatives can’t speak or understand Swedish” (E1_R2_SE).

“Children who, due to severe circumstances at home have been moved to foster homes, continue to worry about the parents at home” (E1_R2_SE).

Type of relative (A)YC cares for

Parent

Round 1

The experts describe parents who need support, help or care, and sometimes receive this care from their children. It may be a parent with chronic somatic disease, mental illness, cognitive disability, or movement disability. The parent might need interpretation assistance since the parent is blind or deaf, or because the parent is not familiar with the Swedish language. Finally, the parent may have addiction problems, be abusive, be in prison, or in a SiS institution³⁵. The other parent is in a difficult situation and may need support because of this. The same applies when one of the parents dies. Of course, it also happens that two parents in the same family need support, help, and care, for different reasons.

“it’s about parents with addiction problems, it’s about parents with mental illness, it’s about parents with cognitive difficulties, and it’s about parents with violence problems” (E10_R1_SE).

“There are families where the parent, who, after all, have been the most reliable one, suddenly is taken to prison. S/he may be a criminal, but still quite skillful at home. And the other parent is weak, and suddenly the child is alone at home with the weak parent, while the strong one is in prison” (E7_R1_SE).

“asylum seekers, newly arrived migrants... Unfortunately, we use children as interpreters [...] in health care centres [...] changed power relations in the family [...] I believe that it’s difficult to be the adult, wise parent, while at the same time being completely dependent on this child’s translations and understandings” (E7_R1_SE).

Round 2 (reflections)

The experts broadened the view of the recipients of (A)YCs care.

“It may also be [...] a foster dad, or it may be another important adult in the child’s life, so to speak” (E6_R2_SE).

“parents with mental illness [...] really functional impairment, for the parents, but maybe not diagnosed in that way. You are not psychotic so you don’t end up in psychiatric care, and you don’t get in touch with a child agent, or something like that, but still [...] you have reductions in social functioning and other things that make life difficult. And the children have to take care of their parents” (E4_R2_SE).

Siblings

Round 1

³⁵ The National Board of Institutional Care (*Statens institutionsstyrelse*, or SiS) is an independent Swedish government agency that delivers individually tailored compulsory care for young people with psychosocial problems and for adults with substance abuse.

The experts describe siblings with mental or physical disabilities, mental illness, chronic somatic diseases, and siblings who die. They also mention siblings who are in an SiS institution³⁶, and the situation when a sibling returns from an SiS institution.

"siblings with mental illness, and what it means to be next to them" (E6_R1_SE).

"And then we have children with neuropsychiatric difficulties [...] where their siblings adapt to the situation, and maybe protect their sibling in school or other contexts, and perhaps even at home" (E4_R1_SE).

"there was a sister who described... her big sister had always been ill [...] as she remembered, the sister's well-being always came first, and all plans were made related to her current health condition" (E7_R1_SE).

"it might not be unusual that a sibling ends up in an SiS institution. And then suddenly, the sibling comes home again, and you should be the one who helps and fixes among friends to get your sibling back on track again" (E7_R1_SE).

Round 2 (reflections)

The experts reflect on factors that may affect the sibling roles in the family. Mental illness is such a factor. New foster children moving in to the family is also a factor that affect the sibling roles.

"When you have a sibling within psychiatric care, the siblings might be close to each other and... you may feel that you have a great responsibility, and perhaps your sibling feels that you are the one who is most easy to talk to, because you are more on the same level, compared to adults. This means a lot of responsibility" (E6_R2_SE).

"a project, and this was in the early 2000s, about foster parents' own children's experiences of having a new foster sibling. And several of the children took a quite big responsibility for their foster siblings" (E2_R2_SE).

Defining problem (A)YCs

Round 1

It was a bit hard for the experts to reflect on defining problems, since they perceived this as almost the same issue as 'Ways to identify (A)YCs'. But there were two comments about defining problems.

"in my earlier practical work, I have worked a lot from a family perspective, in order to see what's happening, what do the children know, what can they do, and how are the circumstances for the children in this current situation" (E8_R1_SE).

"in a Somalian group... there we saw that... the children are doing a lot of things that we usually say that the society should take care of" (E9_R1_SE).

Round 2 (reflections)

During round 2, the methods 'Föra barnen på tal' and 'BRA-samtal', were discussed based on their usefulness for defining problems in different contexts.

"We use 'Föra barnen på tal' with all parents who receive support from the disability care centre" (E5_R2_SE).

"it can be mental, physical, intellectual, all these different disabilities, it can be cancer, it can be unexpected death, it can be anything [...] 'Föra barnen på tal' is made for psychiatry. But it can be used in various ways" (E5_R2_SE).

"In fact, we are going to test it [to use 'Föra barnen på tal' for siblings]. We have to adjust it, but parents who have a child with an illness, while the sibling is healthy, it may be good to talk about each child and reflect about [...] what is good, what works for the children and what doesn't work [...] bringing the focus on the healthy child as well [...] and not just focus on the sick child, or the child with difficulties. We believe that, with some adjustments or maybe another approach, we could use it" (E5_R2_SE).

" 'BRA-samtal' is made for children as next of kin. You could also adapt it in order to include siblings as next of kin [...] it's a tool for those who are not used to talk with children" (E5_R2_SE).

Caring for vs. caring about

Round 1

In the first round, only one expert commented on 'caring for versus caring about'.

"One can assume that, in every class there are some children who actually takes more responsibility than they should. And I think that it can be both practical but also mental responsibilities [...] if I'm sitting and worrying about it [...] if it fills my mind to that extent that I'm not present... in school for example" (E8_R1_SE).

³⁶ The National Board of Institutional Care (*Statens institutionsstyrelse*, or SiS) is an independent Swedish government agency that delivers individually tailored compulsory care for young people with psychosocial problems and for adults with substance abuse.

Round 2 (reflections)

In round 2, the experts reflected on the term '(A)YCs' vs the term 'Children as next of kin', what we mean by 'long lasting needs', and finally, whether children and adolescents are supposed to be caregivers or not.

"Children as next of kin [...] I think this is quite... a good term [...] you can never get away from being a next of kin, and you want to be a next of kin, but you don't always want to be a caregiver [...] a child [...] not to be too much of a caregiver, but to be allowed to be a child or adolescent" (E7_R2_SE).

"long lasting needs [...] what do you mean by long lasting? It could be a long lasting responsibility, even though the efforts are not something you do on a daily basis. I think of children whose parent have some kind of mental problems, with periods... suddenly Dad goes psychotic or Mum has taken an overdose, and the child needs to take urgent actions... they're on their toes all the time, even though they might not actually do a job all the time [...] I think this is just as important, because this affect concentration possibilities in school" (E10_R2_SE).

"One thing that I think is remarkable, from a Swedish perspective, is that in some countries they really seem to think that children are supposed to be caregivers, and that this is the way forward [...] it's an ambivalence with me there, how to really deal with these youngsters who become caregivers [...] In Sweden we assume that we can relieve the children from responsibility by having a network of adult people around them" (E9_R2_SE).

Perceptions responsibility burdens during childhood/adolescent

Round 2 (reflections)

In round 2, the Swedish view versus other countries' views concerning responsibility burdens during childhood/adolescent, were discussed. How do the different views affect the childrens' /adolescents' situations? And what do we mean when we state that it is important that the (A)YCs caring tasks are voluntary?

"It's characteristic for all this, I think, that the children are supposed to continue to be caregivers. There is no clear question about this... no one is talking about protections needs, on the contrary, someone says that you should not problematize these children [...] but... I think you should problematize their situation. No one talks about the work the children actually do, with all the risks it can be for a child to have responsibility for sometimes very heavy problems, physically heavy problems and mentally stressful situations" (E10_R2_SE).

"There is nothing about the children being used as free labor... or about laying a burden on them in a situation where they really have very few options to get rid of this if they want to [...] The critical reasoning doesn't exist at all in this and I think... [...] you have to be norm-critical [...] and not just accept all this and think it's okay, if we only help them and support them, and give them some relief every now and then. So yes, I... am basically critical of the whole approach found in many of these countries' descriptions" (E10_R2_SE).

"This thinking, that children should have the possibility to be just next of kin, and not caregivers, I think it's quite special for Sweden. We have come so far in this as well as in the individualistic thinking. In many other countries, it's obvious that there is the family first, and if the family have needs, they take care of these needs by themselves" (E7_R2_SE).

"We also put quite a lot of responsibility on the children... If we don't involve them in being active and getting involved, they will be put in a situation where they just have to act [...] when we call a meeting, we don't call the children, because we don't want to burden them [...] But then we haven't realized what's it all about... most of the day, these persons aren't with us, they are with their children [...] When we say 'we don't put any responsibility on the children', that's a denial of the reality, because we want it to be in that way [...] We should involve them in the planning process, in order to ensure that they don't have to take too much responsibility" (E7_R2_SE).

"What is coercion? If I feel that someone needs something and I do it because I see the need, it doesn't have to be compulsive [...] If I am forced to do it because nobody else can do it, it can be a coercion. But how do I know that it is voluntary? [...] is it linked to shame or is it silence culture that makes me feel forced? [...] These are really difficult questions, it's quite complex, it's very complex" (E8_R2_SE).

"I think there is a tendency in this work, that you don't want to raise the negative effects, you just want to highlight their need for support. And I think... we need to talk about the children's need for protection [...] there is a general tendency, when talking about social work with children, to avoid words that put parents in a guilt situation [...] But sometimes they are guilty of things that aren't good for their children" (E10_R2_SE).

Examples of YCs

Round 1

A lot of examples of YCs were presented, such as children/adolescents caring for their siblings, or for their parents. The following quotations illustrate the examples.

"a little sister who always brought her big brother to activities [...] which was very practical for the family, and very good for the big brother, who had a rather severe disability. But it wasn't the best for the sister, because she never had possibilities to do activities on her own [...] This daughter took a lot of responsibility for the activities to be good for the brother. She prepared a lot and [...] explained the activity, and was very close to him all the time" (E3_R1_SE).

"And then we have children with neuropsychiatric difficulties [...] where their siblings adapt to the situation, and maybe protect their sibling in school or other contexts, and perhaps even at home" (E4_R1_SE).

"being a sibling of... a sibling who has mental problems and what it means [...] the feeling of loneliness, not to be seen, and to be forgotten" (E6_R1_SE).

"as she remembered, the sister's well-being always came first, and all plans were made related to her current health condition. In a way she felt sadness about this, but still, she could bear it [...] She helped to make her sister feel as good as possible and that things went smoothly and so on. But when she got her own children, she said 'I can forgive my parents for not having the time to be parents for me, but they don't have the time to be grandparents for my children' that was hard for her to bear [...] You got less of your parents' time, but you also have to adapt a lot to someone else" (E7_R1_SE).

"children who have parents with [...] chronic illness, a somatic disease" (E8_R1_SE).

"children who acts as interpreters" (E9_R1_SE).

Round 2 (reflections)

The reflections in round 2 concerned (A)YCs' worries for their parents and/or siblings; children/adolescents who take responsibility for new foster siblings; Children in migrant families often have a heavy and complicated responsibility burden.

"when children need to take care of a mentally ill parent, constantly need to keep an eye on them [...] go home earlier from school, constantly worried that the parent isn't able to take care of things [...] it doesn't have to include washing or bathing or things like that" (E2_R2_SE).

"a project, and this was in the early 2000s, about foster parents' own children's experiences of having a new foster sibling. And several of the children took a quite big responsibility for their foster siblings, and no one had noticed this, or even asked about this. On the one hand, the social workers think 'oh, that's good, there are children in the same age, or older, in the family, but they never talked to the children about it or discussed 'how much are you supposed to do?' or 'what do you want to do?' or 'what should you not do?' and so on" (E2_R2_SE).

"Migrant families [...] children are used instead of professional interpreters [...] when parents or other relatives can't speak or understand Swedish, but you, as a child, have learned Swedish, then there is a risk of [...] being used to accompany to healthcare and social care and other authorities, and spending a lot of time translating various written documents, fill in forms [...] employment services, Insurance Agencies, the Swedish Tax Agency [...] they have to take the adult responsibility in the family [...] try to understand what authorities want and how to answer [...] as they themselves describe this... they develop a tactical thinking of what might be best in this situation in order to bring the adults what they need or what they want" (E1_R2_SE).

"What you think is, this isn't good, but we make an exception [...] just for this time [...] And what we don't see then is that for the child it is no exception, it's something that takes a lot of their time and also means that they have to take leave of school [...] Thus, this can really have consequences [...] Because everyone, in all areas, make those exceptions. Thus, for the child this happens very often" (E1_R2_SE).

Strategies, interventions and programs to support (A)YCs

General reflections

Round 1

The experts do not describe strategies, interventions or programs that are specifically targeted to (A)YCs. On the other hand, they describe a variety of supporting efforts aimed at children/adolescents as next of kin, and where (A)YCs are most likely included. The supporting efforts described, are mainly activities for children whose parents have cancer, suffer from mental illness or abuse, as well as children who witnessed violence in close relationships. However, there is no overall function that ensures that these support groups exist in all regions and municipalities in the country.

In addition, the support functions that are regulated in Swedish law and give people with chronic somatic / mental illness or disability, the right to get support and help in daily life are described. This means, according to experts, that children and young people should not have to provide comprehensive support and care responsibilities for their relatives.

"So I think there are a number of examples of things that we know would work and can support this kind of group and so, but it's not systematically [...] provided in all places"(E7_R1_SE).

"I have been working in development work since 2013, where we had the task of developing quality in support for children as next of kin, children living with parents with mental illness, addiction problems, or where violence occurred in the families [...] Our authority [the Public Health Authority] was tasked with driving eighteen

development projects that would develop in different ways the support for these children as relatives and the age group was slightly broader than the subject of this interview, it was zero to eighteen years" (E9_R1_SE).

"We do not have the same as in England, where they are actively building up support for the children. We do not really have that perspective, that we should support them and relieve them, because we don't think that children should have this kind of responsibility. The public health and social care should do this. We have built a welfare apparatus, a welfare state, where there are professional groups... and authorities who are supposed to take care of these tasks, which the children otherwise easily get in these families. So... the idea, from the Swedish authorities, is not to primarily support the children in being caregivers, but relieving the children from their caring responsibilities"(E10_R1_EN).

"For example, we have the LSS [the Law regulating Support and Service to persons with certain functional disabilities] which make... if you have serious disabilities then... you have the right to receive help" (E1_R1_SE).

Round 2 (reflections)

The experts' reactions, after taking part in the international outcome of Round 1, varied from doubt and questioning, to a delight that after all, there are many good efforts. The doubt and questioning regards whether or not to accept that children and young people are taking a caring role, and to support them in their caring work. The Swedish experts assume that society should take responsibility for people who need care, support and help in their daily lives. Children and adolescents should not need to take this responsibility. Some of the Swedish experts perceive the support strategies, presented in the preliminary outcome of Round 1, as a way to support (A)YCs to continue their caring responsibilities. This, they mean, contradicts the Swedish point of view that you should allow children to be children.

"It was very different support, so it is very noticeable, it looks very, very different, and you do different efforts, but in different areas and in very different... ways [...] it looks very... different"(E8_R2_SE).

"as I said, a lot of these efforts are made to help and support the children in doing this work" (E10_R2_SE).

"Yes, I really find it amazing that there is so much. That we do such... such a job, even though we hardly talk about their existence"(E5_R2_SE).

Relaxation activities

Round 1

Maskrosbarn's³⁷ summer camp is described as an appreciated form of relaxation for children whose parents suffer from mental illness or substance abuse problems. In a Swedish region, relaxing weekend breaks are organized for children whose parents suffer from cancer.

"And ... and there was someone else too, who said, said that it's been amazing to go away... like this, when Maskrosbarn had trips [...] and been able to go to a summer camp" (E7_R1_SE).

"Then we have also ... initiated meetings for children with a severely sick parent with cancer, and this is possible thanks to a contribution from the regional cancer centre north. Families from all over northern Sweden get invited to [...] for a weekend. They meet on Friday, and the children get to do nice things together, play and play games, and the healthy parent is there too. And then you have dinner and then you stay at a hotel and then you go to the swimming pool, and this is completely free of charge"(E6_R1_SE).

Individual (A)YC support

Round 1

There are no examples of individual support specific to (A)YCs. Instead, there is a more general discussion about individual and flexible support. Within the school's framework, both support for schoolwork and general support on a more personal level, are discussed. In a few projects, school and social care services have collaborated to increase opportunities to support children and young people in vulnerable situations. One expert believes that within the palliative care there is a habit of talking with children and young people about difficult life situations. In addition, the support phone lines for Swedish children and young people, are mentioned (eg BRIS³⁸).

"What I have seen is that, for example, in student health, where they discover these children, they can provide support interviews and extra supportive efforts in the educational work, and teachers can sometimes make exceptionally far-reaching efforts" (E10_R1_SE).

"There are projects where you work together, social care services and school, and where... social care staff visit school much more than... as generally done" (E2_R1_SE).

³⁷ Maskrosbarn = Dandelion Children

³⁸ BRIS, Barnens Rätt i Samhället = Children's Rights in Society, is one of Sweden's leading child rights organizations.

"If you don't show up in school, then it is also good if you have an extra resource at school that can find out where you are [...] We also worked with this in a project, a collaborative project between school and social care services, specially trained staff" (E9_R1_SE).

"In palliative care, it's not strange to talk to children, but they have such a specific situation, it isn't a situation that lasts for all... very many years, it's more 'here and now'" (E8_R1_SE).

"There are a lot of different support phones" (E7_R1_SE).

Family support

Round 1

The experts describe a range of support initiatives aimed at the whole family. The purpose is to facilitate for the family so that the children do not need to have caring responsibilities. In some regions, Beardlee's family intervention is being used. Regional child rehabilitation centers offer support for children and adults who have a family member with disabilities. There is a collaboration between five municipalities who, together with the Swedish municipalities and county councils, investigate which family-oriented innovative efforts may be needed in families where there is abuse problems. Municipal efforts for families where abuse occurs, often also includes support for close relatives.

Parents with neuropsychiatric disabilities can get support in their parenting through sms reminders about times to keep, daily tasks to be performed, etc. They can also get practical support at certain times of the day, for example, someone can come home to them every weekday morning and help get the kids to pre-school and school. Through a questionnaire, developed by Karolinska Institutet, one can investigate which parental skills are not fully functioning, and parents are given the opportunity and assistance to train these skills.

"What we do is parental support, to provide support to the parents, which in turn can be a help for the children. Yes, ease for the family, so that the child does not need to take this responsibility" (E5_R1_SE).

"There are examples of social care services... [...] when it comes to parents with neuropsychiatric difficulties, that you have an eh... they use sms reminders, or in some cases they make sure someone comes home in the morning and helps to get children to preschool and school" (E1_R1_SE).

"A collaboration [...] where five municipalities' social care services are discussing the question of which innovative efforts may be needed in families where there is an adult with addiction... efforts which are more family oriented than those we currently have in the social care service" (E1_R1_SE).

"On March 23, we launched a new work routine for 'children as next of kin' in connection with unexpected deaths outside hospitals or emergency receptions [...] the family are offered check-ins by their health centre within seventy-two hours to hear how children are doing, and a continued contact for one year. We have developed a checklist that we have just sent to health care centres and this checklist is available in ambulances and police cars throughout the county. And we had a conference where we launched this work routine. In connection with that, we also made business cards stating that the family is entitled to receive information and support from their health care centre, and also informative links." (E6_R1_SE).

"Then we started support group activities for families in grief. We did this in 2010 [...] together with [...] the county council [...] 'Save the Children', the Swedish Church [...] and Umeå Municipality [...] We invite the families to... participate, and then, each semester, we start a group like this. We meet and have a simple dinner and then we divide the family into a children's group, a youth group and a parent group, and then we work with themes and use creative materials" (E6_R1_SE).

One of the experts describes the background to why a healthcare centre introduced family interviews:

"They had a patient there, in many years, and then suddenly it appeared a teenager who did not feel so psychologically good [...] and then realized 'no, but ... here we have lost something' [...] and after that, family conversations were introduced" (E8_R1_SE).

Round 2 (reflections)

The review of the preliminary results from Round 1 have led to new reflections and a few experts are recalling experiences they have not shared in Round 1. Finally, parental support is compared with the Swedish model of home/housing support.

"And when I think about the model of work we have developed regarding children as next of kin, then we have... there are... headlines 'to identify', 'to inform', 'to see needs', 'to act' and 'to document'. And when it comes to acting, then yes, first, the need is to be seen, what are the family's needs [...] when it comes to action then we can help and send on [...] Based on the need that comes up [...] So there's some sort of thinking in our model, about these steps" (E6_R2_SE).

"Support groups called 'Barnkraft' (childpower) [...] parallel groups, then you have a child group and you have a parent group [...] you work with different themes [...] how to think about mental illness [...] it could be abuse too

[...] it is about making the disease talkable in the family [...], among other things, the children may ask questions to the parents. We had a question box [where the children could put their questions], ask why mother so often was sad, why she slept so much. And then the parents were asked to answer the children's questions, and then they had to enter the children's group and, in front of the children, and answer these questions [...] recognizing that you were not alone who experienced this and [...] making it easier to communicate [...] see the children's needs"(E6_R2_SE).

"about practical support for parents in their parenting [...] I think it's similar to our 'housing support' [...] but... you adapt the support to the parent's difficulties [...] it often works very well when you receive a reminder of the time at the dentist and... and when to visit the doctor or cut your hair [...] it can be enough help for managing everyday life"(E5_R2_SE).

Online (A)YC support

Round 2 (reflections)

An expert tells about a support group for young people who have a brother or sister who is ill. In addition to meetings, where young people meet to talk about their family situation, they use a chat room:

"where we talked about what it's like to have a sibling who is sick and close to you, and then they also were chatting and exchanged experiences in that way" (E6_R2_SE).

Support groups for (A)YCs

Round 1

Various support groups for children as next of kin, are described. For example, support groups for; children whose parents suffer from mental illness; children in families with addiction problems; children who have witnessed violence in close relationships or themselves been exposed to violence; children in sorrow

"Different group activities for children and young people with parents with substance abuse or mental illness" (E2_R1_SE).

"Specifically for young carers, I don't know what kind of support is available and what programs are available. On the other hand, there are so-called family groups for different activities, such as children of parents with addiction [...] children for parents with mental illness, etc. But it's not sure that those children are young carers "(E4_R1_SE).

"Children who have... been exposed to violence in close relationships [...] and sometimes been exposed themselves" (E4_R1_SE).

"Support group activities for families in grief [...] a child group, a youth group, and a parent group" (E6_R1_SE).

Round 2 (reflections)

In addition to the previously described family interventions, with parallel support groups for children and parents, support groups for siblings to children with disabilities were also mentioned, as well as support groups for children whose family member is in prison:

"Children with disabilities and children with developmental disorder [...] a project... that was about to make it talkable, what happens in the family [...] where they could talk about what it's like to have, and to be close to a sick sibling [...] The non-spoken issues between children and parents. It's about thoughts and feelings that are not said [...] thoughts that we may not always are able to tell about"(E6_R2_SE).

"An activity that [...] is aimed at children and young people whose family member is in prison [...] support group talks for these children [...] It's a project that... it's time-limited"(E6_R2_SE).

One of the experts is wondering about a result from the Netherlands:

"The need for specific policies, and support by scheduling the subject [...] And they had... thoughts about theatre sets in schools, and programs to support leisure activities, resilience training, and support groups [...] I just wonder [...] if it was special to this particular group, or was it general to all children? [...] Or was it really specific for young carers?"(E7_R2_SE).

Awareness raising events

Round 1

Collaboration between different municipalities can increase the ability to carry out awareness raising events

"Our organizational membership in social care services, has moved from one department to another, and is now belonging to 'the prevention unit', and then we got colleagues, two years ago, who work in the field, which has been great. There we have also been able to start an interaction with our four social field workers. They meet youngsters in their leisure time... at youth centres, out in the city... well, everywhere [...] We have also... been out [...] and met all the staff at the youth centres [...] in collaboration days"(E3_R1_SE).

"we collaborate with the social workers in the hospitals [...] we have ... regular meetings, at least four times a year" (E3_R1_SE).

Round 2 (reflections)

After taking note of the preliminary results from Round 1, one of the experts could recall further awareness raising events in Sweden: A networking meeting for family members, and an ongoing survey of what is needed to prevent the use of children as interpreters. Another expert reflects on Swiss awareness raising events in schools.

"We organized together with the Swedish Family Care Competence Centre, in March, a networking meeting for family counselors and family coordinators in municipalities. [...] There were about thirty municipalities there" (E1_R2_SE).

"A survey going on in Sweden now, which has the task of reviewing the availability of interpreters, but they also have the task of reviewing what may be needed for children not to be used as interpreters. And that report will be ready in December" (E1_R2_SE).

"And then Switzerland had different programs that were conducted at schools to raise awareness, and then I wondered what schools? Do they mean ordinary schools for all children? Or do they mean there are training programs for those who are going to work with this issue? [...] It would also be exciting to see how such a program looks [...] Do they have any material, general, for teachers to talk about? Is it the student health, or who is talking about it in school?" (E7_R2_SE).

Trainings for professionals

Round 1

Professional training can be performed in several different ways. You could have training days, or you could form networks that meet regularly and work with various themes.

"We had a training for children's agents last Autumn, where we talked about young carers" (E8_R1_SE).

"We have, among other things, a network 'children as next of kin', including twenty-three different activities, both in psychiatry and somatics, primary care, student health, hospital church, hospice... hospital library. And we have now worked... to highlight 'children as next of kin's' needs. And when there were new reinforcements in the 2010 Health Care Act, we developed a new routine for the county council, which deals with: identifying the existence of children as next of kin in families; informing children as next of kin; investing needs; acting; and documenting" (E6_R1_SE).

"Then we have developed various tools in the form of brochures that deal with talking with children as next of kin, with a severe ill parent, and also business cards with informative links so children and young people themselves can search for knowledge. And we have... a librarian within our network [...] who has developed a book called 'Sorrow, Missing, Consistency', where she compiled books about children in difficult life situations, and from that we have also developed literature lists that are updated" (E6_R1_SE).

"A year ago, psychiatry became a county clinic, so we had a meeting with the new head of operations, to raise the child's perspective in psychiatry [...] And we also work with family intervention, Beardslee's family intervention, and 'Föra barnen på tal'. And we felt it was important to emphasize how we can continue this work and that we find key people who can work with this. And then it turned out that this would be addressed in the psychiatric management group and that a working group would be formed to proceed with the work of 'children as next of kin' (E6_R1_SE).

Aims

Being able to talk

Round 2 (reflections)

In the parallel support groups for children and parents, the purpose is to facilitate family members to talk to each other about the disease or abuse

"You work with different themes and... [...] what you think about mental illness [...] it can be abuse too, but this was mental illness, then it's about making the disease talkable in the family" (E6_R2_SE).

Visibility

Round 1

The purpose of the awareness raising events mentioned, is of course to make (A)YCs visible.

"To give these children attention and make them visible" (E3_R1_SE).

Round 2 (reflections)

By making (A)YCs visible, one can influence political decisions. For example, the networking meeting organized for local family counselors and family coordinators had a ripple effect. Municipal representatives have raised the issue at home.

"A network meeting for family counselors and family coordinators in municipalities [...] As a result of the network meeting, several of the municipalities that did not do this before, have raised the issue in their municipality and, at least one municipality has signaled that we have now gotten the ok to work with this group of children "(E1_R2_SE).

Support

Round 1

The purpose of the individual support efforts and the support groups is mainly to provide emotional support.

"Most of the support is more about the emotional support, that you can get as a child and young [...] It's not about any practical support" (E2_R1_EN).

The efforts aimed at the family as a whole, however, often have the primary purpose of providing practical support. However, the purpose of family efforts can also be to provide emotional support.

"Support for the family, or children and adults, around a disabled family member, children or youths" (E3_R1_EN).

Round 2 (reflections)

In order to achieve the purpose of supporting the child / youth, professionals in a municipal or regional activity, must sometimes provide information about the situation of the child / youth to the social care services.

"One is sensitive to the children's wellbeing and can catch up, if there is something that makes them feel bad [...] if there is a sign of this we have to report this" (E6_R2_SE).

Awareness

Round 1

The purpose is to make as many people as possible aware that (A)YCs exist, how their life situation looks and how this can affect their lives now and in the future. Family supporters may need to alert school staff to what they see and hear in their role as supporters and vice versa. The social field workers who meet young people in the city and at youth centers can disseminate information. The purpose is, of course, also to make the children / young people themselves, and their families, aware of their situation and of available support. Support efforts may also aim at increasing the child's / youth's skills.

"We can be a part of making the school aware of what we see and what we think [...] But it may not be so easy that we can sit down with teachers or educational staff, but maybe we could find a way through student health in order to raise awareness in another way than we currently do"(E3_R1_SE).

"Collaboration with our four social field workers [...] They meet the young people [...] in youth centres, out in the city... well, everywhere" (E3_R1_SE).

"Then we meet other social workers at their workplace meetings or, if they have a collaboration day, we may be allowed to come and report a little about the situation about... children they meet, where parents or siblings have had contact with healthcare [...] and the social workers make the parents or family aware that there is family support in the municipality "(E3_R1_SE).

"Beardslees [...] important that both children and adults got both information about the illness, but also understand what is happening to the other. Thus, when you are not doing well yourself, you may not really see how much you are stressing your children, or what's stressful to them. And to be able to talk about it, to think about [...] what can you help me with... that no other person can do [...] but still is acceptable that you do [...] and what could someone else do [...] And that both the adult and the child can discuss this"(E7_R1_SE).

"An educational goal, to enhance the child's skills" (E10_R1_SE).

Recognition

Round 1

To work for recognition of (A)YCs may mean to get the children / adolescents to feel that they are good as they are, and to free them from guilt and shame.

"Make them feel that they are good enough [...] And that it's not their fault [...] that the children should understand that they are not guilty of what's happening in the family" (E3_R1_SE).

"To relieve the child's feelings of guilt and shame so that... I would say that the goal is to make the child better prepared to continue to live in this life situation" (E10_R1_SE).

Inform

Round 1

The main purpose for some of the efforts that are made, is that children / adolescents and their parents should get information about a relative's disability, illness and / or death, a family member's changed behavior, how to react as a child / youth, as well as where a child / youth can search for more information.

"both children and adults were given information about the illness, but also understand what's happening to the other one" (E7_R1_SE).

"Get information about what's happening, a little bit about how you... as a child take responsibility for the situation [...] Maybe blame yourself" (E4_R1_SE).

"Business cards that inform about the family's rights to receive information and support from the health centre and also informative links [...] two brochures dealing with... that addresses the children [...] about children whose parent, or another close relative, has died [...] and the children's reactions in connection with death" (E6_R1_SE).

Relaxation

Round 1

Some efforts have as their main purpose to give children / young people opportunities to relax for a while, and just be children / youngsters who meet and have fun together.

"this afternoon is the children's afternoon, and it's not a therapeutic activity, it's about spontaneous play and spontaneous conversation" (E6_R1_SE).

"That children get the opportunity to have fun with other children" (E6_R1_SE).

Exchange with fellow (A)YCs

Round 1

Activities undertaken in a group can also aim at giving children / young people opportunities to exchange experiences with other children / adolescents who are in similar situations.

"Where children can share their experiences, meet others and know they are not alone" (E4_R1_SE).

"That you can get an arena and a room for yourself [...] And where you can... talk about things as they are, because you know that the others know how it is. You don't need to explain, you don't have to be afraid that they are wondering, or that you expose your parents. Thus, you can create... some kind of respite for these youngsters and children, I think" (E7_R1_SE).

Putting (A)YCs on policy agenda

Round 1

Currently, a survey aimed at finding how many interpreters there are, is in progress in Sweden. One part of this survey is to investigate what is necessary to prevent the use of children as interpreters.

"Review what may be needed for children not to be used as an interpreter" (E1_R2_SE).

Relieving the burden of responsibility

Round 1

Several of the experts agree that the primary purpose of society's efforts to support (A)YCs is (and should be) to liberate them from the care burden, as far as possible. We should not support them in continuing to be caregivers. Children should be allowed to be children. Children and adolescents should not have to be caregivers.

"We should not support young carers to be that, but we have to see how society can go in and relieve them from this... this care, the care burden. And it's very much about practical help in the families" (E1_R1_SE).

"They need to see that there is someone else who takes responsibility, instead of them" (E1_R1_SE).

"Give the parent more support [...] so the child does not need to take this responsibility" (E5_R1_SE).

"... giving parents support with their problem, but also support them in parenthood" (E9_R1_EN).

Strengths

Contact with fellow (A)YCs

Round 1

According to the experts' experiences, an important strength of group activities is that it becomes apparent to the children / adolescents that there are a lot of children / adolescents who are living in a similar situation. Another important strength is that the children / young people have the opportunity to converse with others who are in a similar situation, and that they in the group can talk freely without having to consider the family member they help / support. The third important strength is the opportunity to relax and do fun things together with the other children / adolescents. The group can act as a kind of breathing space for the children / adolescents.

"It's a great relief to... to know that I'm not alone" (E4_R1_SE).

"These meetings for children who have parents with cancer, where they have asked the healthy parent and the children how they have experienced it. They have experienced it as incredibly rewarding [...] that the children have got the opportunity to do fun things with other children, to talk about these difficult things and realize that you're not alone, but there are more people who have these troubles [...] being able to speak undisturbed, without the sick parent"(E6_R1_SE).

"I think if you think of this kind of group activities for children and youth in this situation, it's really important to feel that you are not alone [...] to get help to find other young people in the same situation, but also to get help to find other adults [...] To get an arena and a room, just for one's own sake"(E7_R1_SE).

Round 2 (reflections)

One of the experts emphasizes the importance of finding out that there are more people living in similar situations.

"Yes, it was a recognition in that, that you were not alone who experienced this" (E6_R2_SE).

Takes place several times

Round 1

All group activities described are regularly recurring, which can be seen as a strength. The children / adolescents get to know each other and group leaders more and more for each time they are seen each other. Activities that are regularly recurring and ongoing year after year increase the possibility that parents, who are initially doubtful, may eventually see the benefits of allowing the children / adolescents to participate. The experts also mention that the professionals' collaborative groups are also regularly recurring.

"It's the fourth year with our child group and we have offered a parental group for those children who participate [...] and what has been very good is that we are able to follow up the children and the parents"(E3_R1_SE).

"I think they are called 'Trappan' and 'Källan' [...] group activities for children and young people with parents with either abuse problems or have mental illness [...] And I have heard that young people have had positive experiences of this [...] And that, parents who have... not wanted first, but then let their children join, and also experienced it as good "(E7_R1_SE).

"A collaboration with the social workers' groups [in the hospitals in the region] And there are two rather large units [...] And there we have... regular meetings, at least four times a year" (E3_R1_SE).

Round 2 (reflections)

Several experts described the benefits of having recurring activities repeatedly, since it provides possibilities for follow-up. Families appreciate recurring activities and would like them to continue even after the predetermined period of time.

" 'Family and grief' have between eight to ten meetings, and 'Barnkraft', they have ten meetings [...] they meet once a week [...] Then you have a follow-up meeting, in 'Families in grief' [...] after maybe one or two months"(E6_R2_SE).

"We've had families who have said 'oh, we'd like to go once more', but then you've already met eight to ten times" (E6_R2_SE).

Combination of informing and relaxing

Round 1

Combining information with relaxation is described as a working concept

"The meetings for children who have parents with cancer, where they have asked the healthy parent and the children how they have experienced it. They have experienced it as incredibly rewarding [...] that the children get the opportunity to do fun things with other children, to talk about these difficult things "(E6_R1_SE).

"Some who have said 'it's been fantastic' [...] Maskrosbarn's trips and [...] summer camp" (E7_R1_SE).

Empowering the (A)YCs

Round 1

Individual support and support in groups can help strengthen the child / teenager by creating the conditions for talking about and understanding their own feelings and reactions, relieving guilt and shame, enhancing the child's / teenager's skills, as well as providing tools and strategies

"Just in the case of violence, there is also often a silence culture. You don't talk about this [...] at home and this is nothing you talk to others about [...] And breaking this silence culture, making things talkable, I think it's so central" (E4_R1_SE).

"Understanding your own reactions [...] intrusive emotions and thoughts, and what happens inside yourself, to understand that this can actually be normal reactions to an abnormal situation" (E4_R1_SE).

"To relieve the child's feelings of guilt and shame [...] I would say that the goal is to make the child better equipped to continue living in this life situation" (E10_R2_SE).

"Current efforts are mostly educational [...] And that's something children appreciate, I'll say, so those efforts aren't... wrong [...] the children appreciate this" (E10_R1_SE).

"That you can also help them get clean knowledge, and train various things [...] Provide information about society, their families rights, their own rights" (E7_R1_SE).

"Can also get... get tools to handle emotions, or get to know and get help with how to come forward" (E2_R1_SE).

"Strategies for their own protection, safety and security" (E4_R1_SE).

That someone listens and confirms

Round 1

If young people get opportunities to talk about their situation to someone who truly listens and confirms their thoughts and feelings, this can be perceived as a form of relief. Knowing that there is someone willing to listen can contribute to reduced worries. Conversations can also open ways to seek help and support.

"That you had someone to talk to, to relieve you from some things" (E2_R1_SE).

"That there is someone from 'outside' who knows [...] without doing anything concrete, it has led to the child's return to school for example [...] made them feel less worry and anxious, but felt relieved" (E1_R1_SE).

"The social field workers today, are a bit more... have a bit more 'eye and ear' to ask questions about how it is in the families [...] And we have had social field workers, who have taken young people in their hand, and brought them here [to family support]" (E3_R1_SE).

Round 2 (reflections)

One of the experts gives an example of a region's work to make the children / adolescents feel that they are heard and confirmed. Joint meetings are organized for families, where participants are divided into a children's group and a parent group. In the children's group, a question box is created, where the children may anonymously leave questions that they would like to ask the parents. The box is then transferred to the parent group who discusses the questions and together decide how the question should be answered. Then the parent group goes into the children's group and answers the questions to the children.

"Among other things, the children could ask questions to the parents [...] why mother often was sad, why she slept so much, and then the parents were given the task of responding to the children's questions and they got into the child group and answered these questions" (E6_R2_SE).

Systemic / family-focused approach

Round 1

Starting from a family perspective opens opportunities for: Identifying the roles and needs of all family members; Identifying (A)YCs; Visualizing family members' situations and roles to each other within the family; Providing concrete, practical and emotional support to all family members, thus relieving (A)YCs; Doing follow-ups

"In our efforts, we had in focus to support the whole family [...] To help parents with their problems, whether it is an addiction problem or a disease problem, and tell the children about the parents' changed behavior, give them information, they are entitled to receive information [...] this legislation is not so easy to follow [...] One of the projects was to follow up [...] have you registered that there are 'children as next of kin' in this family when an adult comes to the psychiatric care, for example, and have the children received information?" (E9_R1_SE).

"The mother probably didn't really understand how much responsibility the daughter took [...] Until we talked about this in the parent group [...] where the mother became very well aware of this great responsibility, but also of how she spoke to the daughter [...] the mother had one day a week off from the caring of the boy [...] She used to say 'today is my day off', and now she turned it on and said that tonight is mine and X [the name of her daughter] It's our evening. Today, it's you and me [...] began to appreciate the time with the daughter and really saw that... the daughter needed to get full attention at least one evening a week" (E3_R1_SE).

"What was very practical for the family and very beautiful for the big brother, who had a rather severe disability, wasn't the best for the daughter [...] Since she never had time to do her own leisure activities and the mother became very well aware during this year, that this sister, or the daughter took very much responsibility for the activity to be good for the brother [...] a wake-up for the mother who had never previously considered this, since the daughter had never expressed any complaints [...] the mother understood that this couldn't go on. Of course, she should have her own activities. And be with her peers and not always have to speak for her brother"(E3_R1_SE).

"We can give the parent more support [...] so the child does not need to take this responsibility" (E5_R1_SE).

"And what has been very good is that we... we can follow up with both the children and the parents and also pick up on things we see [...] Not expose the children [...] the children need to be sure that what they do and say here, stays here. But that we can talk about it in a general way, so that parents are aware of what we see and hear when we are together with the"(E3_R1_SE).

Round 2 (reflections)

Experts compare the Swedish welfare system with other countries' systems, reflecting on housing support as a resource for families, as well as how to find information about what efforts and activities are available to the families.

"We have another... welfare system here for some groups [...] in Sweden compared to Britain [...] when your physically ill [...] I have the impression that here we have better care for parents [...] home care and such things"(E2_R2_SE).

About housing support:

"If you have a disease that sometimes causes difficulties, for example, to accompany your child to school, then you can get extra support there [...] the housing supporter can help you with this. But if that's always the case, we try to find other strategies, maybe SMS reminders or someone gets there to ensure they get started and get out the door [...] so it looks a bit different, but there's really no efforts targeted to the children, but it's to the parents... you get help to shop, make sure they have laundry time. This helps the children indirectly, you may say [...] Likewise try to steer or structure the day so that that they are not completely exhausted when the children come home from school [...] The housing support can accompany to [...] meetings for the children, if they need it, but also to meetings for parent support [...] the efforts is for the whole family, directly or indirectly" (E5_R2_SE).

"In holidays [...] tips and ideas about available activities, what to do and so on, we always send out to the children's agents so they can bring this to the parents"(E5_R2_SE).

Weaknesses

Lack of cooperation

Round 1

The lack of cooperation between different regional and local organizations is described as an obstacle in various contexts. Lack of resources, but also a fear of breaking confidentiality laws, often constitute obstacles to cooperation and collaboration. The lack of cooperation between different municipalities and / or regions is also raised as a concern. In order to achieve equal opportunities across the country, cooperation across municipal boundaries / regional boundaries is needed. The existing support phone lines, that are valuable to children and adolescents in vulnerable situations are driven primarily by NGOs with limited resources. They are not able to answer every call and there is no coordinating function that can forward unanswered calls.

"A difficulty in making an interaction between the different organizations that may need to interact when discovering a problem in the family" (E9_R1_SE).

"we are not getting this cooperation to function, and we are afraid of all this about privacy and everything [...] And with the school and... [...] we all have a hard time with resources [...] It's difficult with such a question, because... in some way it's no one's responsibility, but everyone's responsibility"(E5_R1_SE).

"Talking about equal conditions [...] there is no possibility for small county councils, or maybe small municipalities, to have the same resources that a large one has... And you are too much exposed too... to the ones who happen to work there, to the idealists who works in the area"(E7_R1_SE).

"There are a lot of different support phones. It's a jungle of support phones, but there's... no cohesion. It should be a phone number that you call, and if the one you would prefer isn't available, you'll be forwarded to someone else. Now all of these phones are saying ... that unfortunately, you do not get through [...] All of them are currently fighting for finding funding. Thus, there will be no cooperation, because they need to try to find their own funding. This is stupid, I think"(E7_R1_SE).

Round 2 (reflections)

Having taken part of the results in Round 1, one of the experts draws a parallel to completed surveys of available parent support. The mapping showed that there was a lot of support available, but the municipalities had not managed to disseminate the information about available support.

"We have done some studies about parental support, universal parent support in general [...] we did surveys in some municipalities about what's available and what do parents know and ask for [...] the big concern there was perhaps not lack of available support, there was more than I thought, but nobody knew about it [...] If you do not have any overall coordination [...] or a kind of communication plan, how can you inform, how do you get out [...] to those concerned? I do not think you should underestimate the dilemma there [...] in some of the areas [...] parents requested for some support [...] four to seven percent knew that the support actually existed"(E4_R2_SE).

(A)YCs hard to reach

Round 1

One expert said that the difficulty of reaching out to (A)YCs may be because they themselves do not want to seek help because of fear of not being allowed to stay with their family and / or for the parents to be subjected to scrutiny.

"One might imagine that... there are groups [...] who may not want to report, because they do not want to be taken care of and that the parents are to be exposed to trial and criticism" (E10_R1_SE).

Programs are underdeveloped

Round 1

The support efforts today for children and adolescents in vulnerable life situations are mainly psychosocial and psychoeducative support, but lack concrete and practical support in everyday life. Furthermore, it is not sure that the issue of caring responsibility is raised in children's groups, youth groups and parent groups,

"What they haven't been satisfied with [...] is that the support may have been mainly to inform about the disability" (E3_R1_SE).

"There has also been a lot of focus on the abuse, the disease, explanations or information about... about that [...] and then you haven't had so much more" (E3_R1_SE).

"There is a risk of staying at this kind of efforts [...] now they have a group and now they are able to talk about it. But in this group there are also children with the greatest need for support and help"(E4_R1_SE).

"Those development projects we had were... Well, many of them are trying to give parents support with their problems, but also to support their parenthood. And I'm not so sure that you'll see the children's needs then, since you don't really talk about the care provision for the children's part. And I'm not so sure that if you have child groups, support groups, where the children sit and talk about being a child of a parent who has this and that problem, that this issue will be raised, how it is to be a caregiver"(E9_R1_SE).

Round 2 (reflections)

The different types of support efforts and target groups are discussed. There is an impressive amount of efforts being performed, but the question is whether they are really targeted at (A)YCs or if they are targeted at 'Children as next of kin'. Another issue that the experts reflect on is whether the issue of caring responsibility is given space in the group conversations.

"All these support groups, well, they are for children as next of kin [...] there is a small part, focusing on what you do and such things, but it's probably... very very small"(E2_R2_SE).

"When I read this... these programs that exist, I think yes, there are many and there are many good ones, and so to say important programs, but [...] is it really here you catch up young carers, or is it rather that in these programs, there are children who are young carers? And then nothing more happens concerning this"(E4_R2_SE).

Lack of follow-up after program

Round 1

Firstly, follow-up support measures are often lacking, for example following a completed support program, with a number of group meetings. Secondly, follow-up studies do not show the impact of support efforts for the individual, in the immediate future or in the longer term.

"I have a few examples, when the society has known that it has been quite... quite a serious situation where children have been left to themselves and to take care of parents and yet nothing has happened"(E2_R1_SE).

"There are very few of such activities that are really followed up by comparing, seeing a result for the children [...] just asking 'are you satisfied with this, was this good for you?' But nothing about the impact on their development or their strength later on, or on reducing problems in the future, we do not really know anything about that"(E7_R1_SE).

"This parental support program or this program with Beardslees, there has been some research, but it is also [...] done in a short term, did it help you right now [...] Long-term studies that really are what you would like to know about, there is a lack"(E7_R1_SE).

Round 2 (reflections)

Follow-up efforts after completed support programs are discussed. If necessary, there are opportunities to forward children / adolescents to, for example, child psychiatry. There may be reasons to believe that engaged individuals, who work locally with support for children and young people, actually have a lot of knowledge about what happens to the children / adolescents after they have completed a support program. But that knowledge and experience isn't visible to others. The lack of follow-up studies, both nationally and internationally, is discussed. It also appears that a systematic follow-up of the 'Family and grief' program has begun.

"If you need additional support, maybe this is something for child psychiatry or you can forward the child, but... the work in support groups is limited, you know that there is a beginning and there is an end, that is quite clear "(E6_R2_SE).

"Where can these engaged people share their... their experiences [...] I believe there is a lot [...] Both nationally and in the rest of the world, but perhaps they have the knowledge in their own drawer"(E3_R2_SE).

"There have been a lot of well-known projects in Britain, and I know that [...] we have [...] looked very much at Britain and thought they were ambitious. On the other hand [...] not many of these have been followed up and evaluated"(E3_R2_SE).

"I wonder how many of these known projects in Britain have been made permanent. This is also interesting to know. Projects are good, but do they lead to real actions in the future?(E3_R2_SE).

"Those efforts that have been made in Sweden [...] there are no systematic follow-ups [...] We don't collect it in a way that makes us able to compare" (E7_R2_SE).

"There is relatively little about what works well for whom" (E7_R2_SE).

"We have started to work with systematic follow-up on" Family and grief ". Then we had an offer from the National Board of Health and Swedish Family Care Competence Centre, two people who came here and presented how to work with systematic follow-up. We have just begun to produce questionnaires and follow up how... the results, how it has worked with the 'Family and grief' effort."(E6_R2_SE).

Short-term offer

Round 2 (reflections)

There are examples of families who feel that there are too few meetings, they would like to continue meeting the other families even after the pre-set end time.

"We have had families who have said oh, we would like to go once more, but then you have already met eight to ten times [...] But ... with support groups, it's limited, you know there's a beginning and there is an end, that is quite clear "(E6_R2_SE).

Lack of resources to provide practical help and support

Round 1

Several of the Swedish experts emphasized the lack of practical help and support. They say that in Sweden we are good at providing psychosocial and psychoeducative support, but that these forms of support need to be supplemented with practical support and help to the family, which currently is performed to a quite limited extent. The reasons for this may be lack of resources, lack of knowledge about available resources, or the parents do not want to receive practical support.

"Practical support, we are not good at all at practical support in Sweden" (E2_R1_SE).

"The most important actions are the efforts of the educational battle [...] the children appreciates this and think it's nice, but [...] one has to deal with the parents' problems as well [...] it may still be that the children then... still takes great responsibility and bears a heavy burden. And that the children may continue to be exposed to neglect and abuse, so this doesn't solve the risks in these children's lives really [...] this the idea that the child should continue and be in the situation, doesn't help the child to scream loudly that the family needs more help "(E10_R1_SE).

"Expectations being graveled, expectations that maybe you could get more support once you've told about... how it looks at home"(E2_R1_SE).

"I've heard young people say [...] 'I could only get the help they had in their package. And I needed other things'. And I think that's constant. You have this group activity, but you have no tools for it later if you find someone who needs much more, when they say that 'now I really need help here with my parent who feels bad' [...] you just say 'yes, hope it resolves, we will talk about the next time' [...] But they wanted practical help "(E7_R1_SE).

"Maskrosbarn have had trips and so, 'Yes, they offered me that, but that wasn't what I wanted because I... I could not leave my... my mother alone, I would have needed a timing with a relief system, something for my Mum. And this... and it was not compatible, because I had to go to the summer camp one week and then my Mum got an activity next week' [...] We are not able to coordinate our efforts" (E7_R1_SE).

"You are afraid that if you ask the child, you are afraid that the child... needs something that can not be satisfied [...] We do not know which resources are available"(E5_R1_SE).

"It is an integrity question [...] We cannot force families to receive that kind of help, but we can take care of the children. That's the compulsive measure we have the possibility to do, and it is very high demands to move a child from their home, so they may be in a bad state for many years before it comes to that, if the parents refuse to get help and support (E10_R1_SE).

Round 2 (reflections)

An expert reflects on a statement that there are no financial resources to introduce practical help and support.

"I think financial issues are also visible... in some countries and that it's a lot about money, but at the same time... it was a bit exciting, I read somewhere about Switzerland... I imagine Switzerland is no low-budget country in any way, but there are very few supportive efforts for... for young relatives or young carers [...] So it's not really connecting, this reasoning about how the country's economy [...] It's perhaps not about economy in this case, but it's something else they've invested in" (E3_R2_SE).

Individual approach

Round 1

The Swedish welfare system is described as 'rigid' with a clearly defined individual approach. Decisions on assistance or support only concern the individual and not the rest of the family. Housing supporters should only support the adult, and is therefore not allowed to talk with the children about their needs. Information that may be given to the children focuses entirely on the family member who has a disease / disability, but often the children get no information at all. The focus is on the family member who has a disease / disability and there is an uncertainty in talking with children about their situation.

"It is very rigid, for example, we have a system that means that it's the adult who receives a decision on support associated with the adult individual, which means that if the children in the same family have needs of this adult as a parent, in a way that the adult does not manage, it is still not included in the decision to give children support"(E1_R1_SE).

"I hear examples of being strictly forbidden as... for example, housing supporters to [...] talk with the children about their needs" (E1_R1_SE).

"The focus has been on the person with the disability. And of course, it is the responsibility of the healthcare or the region, to provide that information [...] But there is a bit missing [...] to see what... or ask what the child / adolescent wants to have more of"(E3_R1_SE).

"It has also been a very strong focus on the abuse, the disease, explanations or information... about that" (E3_R1_SE).

"Talking about children... it must start there. If the parent gets a disease or something happens, then the healthcare will offer the children a conversation or a meeting where you get the information about what this means [...] But we know we are missing this to a great extent. One is so focused on the patient. But at the same time it is a responsibility, the health care has to pay attention to the children [...] And there I can say that there are still too many shortcomings"(E3_R1_SE).

"But this is difficult for us, because we are very focused on our efforts to the adult [...] in general, so we are a bit... yes, careful, a little afraid of this with the children" (E5_R1_SE).

Round 2 (reflections)

The consequences of an individualistic approach are further discussed.

"It is indeed this individualistic way, or individualism, which has led us to think that the health care is responsible for treating this sick parent. Point. But perhaps a part of the treatment... if you consider quality... is that this Dad or Mum shouldn't worry about their children being overloaded. And having feelings of guilt for this" (E7_R2_SE).

Mentally stressed healthy parent needs support and relief - which indirectly means a relief for (A)YC:

"When there is a very sick person in the family, then you should think a little bit bigger in Sweden, sure, you can have home care, but the mental burden on the healthy parent should perhaps be more in focus, to be able to support the young carers who need calm adults around them [...] You do not talk so much about this, or I don't think we see the family perspective in this way"(E3_R2_SE).

Housing support in relation to the children in the family can vary in different municipalities. An expert reflected on the claim that housing supporters are not allowed to talk with the children about their needs:

"We had this fifteen or twenty years ago. Then you shouldn't talk to the children, because it's not your job. But today it doesn't look that way. Today we have 'Föra barnen på tal' we are talking to the parents about their parenthood and we offer the children a conversation about their situation. If there is any effort the child needs then you have to help them search for it [...] and also to tell who you are, to talk about things, so the children know that their parents receive housing support [...] But the effort is, as I said, not addressed to the children [...] you need somehow consent... to talk to the children"(E5_R2_SE).

Ways to mitigate negative influences - psychosocial/environmental factors

Round 1

Most of the experts had difficulties in formulating a response to the issue of actions that could help mitigate negative impacts. But what emerged was the importance of flexibility and individualization.

"It looks very different for these children, what responsibility they're taking [...] And therefore it is difficult, I think, to say that there is a particular effort [...] If we ask them, and become aware of their situation [...] it's not an effort, but it can be something that relieves responsibility, that someone is telling them that this may not be a responsibility as a children should have "(E5_R1_SE).

Round 2 (reflections)

It was not easier to discuss this issue after having read the preliminary results from Round 1. One of the experts reflected on Britain's proposal to review the legal rights for children and families. The expert believed that although laws are reformulated, there is a risk that this will have a very small actual significance for the individual.

"The risk is that young carers still will become a low-priority group in every decision for... children and families [...] the one who needs most help is the one for which the law text is written, and [...] I'm afraid that you get a sentence that may not have any effect"(E3_R2_SE).

Coping strategies

(A)YCs not asking attention

Round 1

Two experts say that it is characteristic for, at least some (A)YCs, that they do not require much attention.

"These are children and youths who... don't make a lot of noise, may not require much attention or ask for help" (E3_R1_SE).

"One might imagine that... there are groups of... especially those older children who are used to be caregivers, and who may not want to report, because they do not want to be taken care of and they don't want the parents to be exposed for trial and criticism" (E10_R1_SE).

Round 2 (reflections)

Three of the Swedish experts responded to a statement in the international results. According to the statement, (A)YCs don't usually want to have attention, as they are not the ones who are most in need of help and support.

"That's the only thing I do not agree with throughout the study. Because that's not what we see here [...] our children love to get attention [...] to get plenty of attention and full focus on their own person [...] Or perhaps... perhaps the one who had answered in that way, means that they don't want to get attention for being a caregiver, maybe that was what they meant "(E3_R2_SE).

"It would be interesting to know [...] where that statement came from and how common it is [...] and why they don't like to get attention if it's about thinking there's someone else who needs the support, or if they really don't want to have attention. Otherwise, I think that many of the adults who have grown up [...] on the contrary, they say no one asked, no one noticed us, or me in my situation"(E5_R2_SE).

"How do you know this and how common is this? [...] is it the most common line or thought [...] or is it the one that has been expressed, but also common to want to get attention? [...] I can somehow... recognize these thoughts, but I do not know if it's so common [...] I believe both are common" (E4_R2_SE).

Adjusted behavior

Round 1

One of the experts described (A)YCs as adaptive, responsive, attentive and well-functioning.

"Maybe even more well-functioning than many other children of that age" (E3_R1_SE).

"They... are attentive in a way that other children and adolescents of their own age might not be in the same way" (E3_R1_SE).

"At school [...] they are also very adaptable and well functioning and therefore they don't really receive much attention or questions about how they feel" (E3_R1_SE).

Striving for control

Round 1

Two of the experts described (A)YC's strive for control:

"Taking care of, is also to feel that you can control a situation, which is important because... gaining control and feeling that you are not completely powerless is also a way to... to feel better" (E2_R1_SE).

"They make sure things work, maybe primarily at home [...] They enforce and they... prepare" (E3_R1_SE).

"They have somehow a sixth sense for how things are going to be done, to make it as good as possible, they've developed this, I think" (E3_R1_SE).

Future needs to support the wellbeing / health situation of (A)YCs

The Swedish view of childhood and adolescence, as well as the fact that there is a clear lack of support efforts, that are specifically targeted (A)YCs, is the basis for the experts' descriptions of the future needs they see in this area. In this discussion many important key elements for optimal support are identified.

Ideas /key elements for optimal support

General key elements

Round 1

In the discussions about 'ideas/key elements for optimal support', five of the experts choose to highlight the points they consider to be important in the work of developing optimal support for (A)YCs. In order to be able to provide optimal support, there is a need for consensus across professional boundaries, about the importance of supporting (A)YCs. The issue of support for (A)YCs should be seen from a public health perspective, and the overall responsibility should be on public health instead of social care and healthcare. Other basic prerequisites for being able to provide optimal support are: taking the child's/ teenager's perspective; early identification; early and cohesive interventions.

"Perhaps we also need to work a lot [...] in designing the support and deciding that we should really work to support young carers who are still minors. I think there may be a conflict there too, between professions, whether or not they want to work in that way. I might be wrong, but [...] this ideology that children... children shouldn't be caregivers" (E9_R1_SE).

"It feels crucial not to... how should I say... declare young carers as sick, that is, end in a view that there is something wrong with them, since they are young carers [...] it can actually be a positive experience too [...] I can see a problem there, if you think this is a task for healthcare, or social care. Thus I am thinking, perhaps you... should think about it from a public health perspective. Young carers are so many in society so... this general level could fit in the framework of public health work" (E4_R2_SE).

"I think it is important that we ask children about their needs [...] the child's perspective [...] Not from our adult perspective, but identifying the children and actually ask them what they think they need [...] I think that could... give us more opportunities to be able to support them in the way they actually need" (E5_R1_SE).

"If we really want to relieve children and youngsters, we must be ready to meet their needs" (E7_R1_SE).

"I think one has to work a lot earlier, with establishing relationships" (E10_R1_SE).

"If I may dream a little, you should identify... what should I call it... fragile families, early" (E7_R1_SE).

"Early interventions and it should be coherent" (E7_R1_SE).

Round 2 (reflections)

The question about general key elements has involved all ten experts in Sweden. In the reflections the term (A)YC is discussed, based on the following points:

- How useful is the term (A)YC and how well is it recognized among the public?
- What words would the public use to describe a young person who takes extensive responsibility for the care of a family member?
- What distinguishes a (A)YC from another young person who helps at home?
- The term (A)YCs is compared with the term *Children as next of kin*.

In addition, they emphasized the importance of the following:

- A resolute ambition for reaching equal support, all over the country.
- To start from a public health perspective, based on the terms *selective prevention* and *indicated prevention*.
- To start with the interventions that already exist for children/ young people in general. To revise and strengthen these efforts so they can be specifically targeted to (A)YCs.
- Flexibility and individual adaption.
- To be attentive to children's / young people's needs for protection.

- To be attentive to the children's/ young people's rights to receive support.

Below there is a sample of quotations that illustrate some of the above points:

About the term (A)YC:

"How would the average Swede describe this [...] what terms would we have then? [...] Because, this is a term that comes 'from above', somehow [...] Thus, if we should ask the question in another way [...] if we want to know something about awareness or attention... would we get another answer then? [...] I would like to know more about this, if people don't think it's a problem at all, that it's not a social responsibility, or do they have other ways of expressing it?" (E9_R2_SE).

"I think about the term 'parentification' [...] There has been a discussion about how you should separate this from children helping at home in general, and it has been said that it must be based on some kind of culturally-adapted concept for the situation when children are doing something, which in their culture isn't normal for children to do. But that's problematic too, because there are cultures where they use children in hard labor... even if it is normal in that culture, it maybe not so good for the children and it can affect, for example, their opportunities to go to school and so on." (E10_R2_SE).

About the term 'Children as next of kin':

"It's a view of children as victims, children as exposed, children as vulnerable. That's the focus, while young carers is more focused on children who actually do something, who is an actor [...] We have to combine these two, I think. It's not one or the other, it's both together" (E2_R2_SE).

Other reflections:

"There should be less inequalities within and between countries [...] in Sweden it is not the same everywhere and it is one thing to tackle [...] it really depends on where I live and how the work is conducted there [...] So that... I think, is an important part here, for us to... work with" (E8_R2_SE).

"You can invest a little in order to strengthen those interventions you already have. You start with what you have and reinforce it a bit more" (E5_R2_SE).

"There must be access to flexible interventions and efforts [...] not only one method straight off. If we should be able to do individualized efforts, we cannot have only five choosable interventions. You have to be prepared within, for example, healthcare and social care, to fix special solutions for just this case" (E7_R2_SE).

"How to balance the child's participation and the recognition of the child's work [...] with attention to their needs for protection, and the risks [...] I think there is a tendency in this work, that you don't want to write about the negative effects, but you only want to emphasize that they need help. And I think... we need to talk a little more clear about what the children need to be protected from. This must also be included. Because I think there is a general tendency, when you talk about social work with children... you avoid those words that make parents suddenly end up in some kind of guilt situation. You don't want that. But sometimes they are guilty of things that are not good for the children" (E10_R2_SE).

"Maybe we should be more attentive to the rights for support. We should talk much more about the children's or youngster's rights to receive support, instead of problematizing" (E3_R2_SE).

Further research and follow-up studies

Round 2 (reflections)

The experts agree that more research is needed in the following areas:

- How well do authorities comply with the obligation to inform the children of patients in Swedish healthcare?
- How do people in general define the terms 'care' and 'carers'?
- The percentage distribution of (A)YCs among children and young people
- (A)YCs' needs
- Development, testing and revision of interventions in order to meet (A)YCs' needs
- Systematic follow-ups of existing support programs.

"Some kind of continuous follow-up of how well you try, how well you comply with the law, on providing information, for example [...] surveys of how people are complying with this information obligation" (E9_R2_SE).

"There might well be a need for cultural adaption, I think, when it comes to what people consider to be 'care'..." (E9_R2_SE).

“In some way, we end up in this all the time, that we do not really know, we do not really know with how many they are and we do not really know their needs. So I think, when I read this, that many more pilot studies are needed [...] in all countries” (E3_R2_SE).

“How small children is this about? How do you think about the really young children who also do these tasks? It is very easy to think of a teenager who stands up and takes responsibility and is capable and feels capable, but there are a lot of small children who also do these tasks, and there it becomes more obvious that this is problematic” (E10_R2_SE).

“These performed programs, which are not always targeted to this group, do they benefit? We would need studies to ensure that for this particular group, this type of intervention works” (E7_R2_SE).

“We need to know what’s good and if there are any efforts that might be a bit harmful, have side-effects, that you need to keep an eye on” (E7_R2_SE).

“There might be a need of control of how well it turns out, when young carers meet, because I know, I have read some results showing that sometimes there might become a negative spiral, when people with very hard experiences meet. They might help each other to manifest a hopelessness and a situation that feels quite burdensome” (E9_R2_SE).

Support at an early stage

Round 2 (reflections)

The tendency to wait until the problems are facts, is discussed. According to the experts, Swedes are not so good when it comes to preventive efforts. The children’s time perspective versus the adults’ time perspective is raised.

“We tend to not face the problems until they are already there [...] then we do something... but in this whole range of prevention, we are much, much worse” (E8_R2_SE).

“For children the time perspective is somewhat different than it is for adults [...] it is about reaching the child at an early stage, rather than [...] long-term perspective on support. I think the choice of method is not as critical as the accessibility [...] We should not be so afraid of starting and offering something, because for the child it is about needing help now or support now [...] a child might be eleven years on that occasion and the next time... three years later the child is suddenly a teenager on the way out, into the adult world” (E3_R2_SE).

“You need to discover these kind of tendencies in families much earlier, before the children have been socialized into that this is what they are going to do in their lives [...] The ones who have the healthcare responsibility for the family member, should have the awareness and follow-up responsibility when it comes to the functioning at home [...] And you also have to be aware that this might happen to a five-year-old too” (E10_R2_SE).

Practical support

Round 1

The need for developing more practical support efforts is emphasized, which has been stated previously in the presentation of results. A form of practical support could be that (A)YCs have their own case manager or assistant.

“Practical support, we do poorly when it comes to practical support in Sweden” (E2_R1_SE).

“And we don’t have the capability to coordinate our interventions [...] And some of them, I think they have such a difficult problem that they would need to have some type of case manager or assistant [...] someone who could be there for them, for many years... someone they could have as their own one” (E7_R1_SE).

Round 2 (reflections)

Practical support to (A)YCs, as well as to the family as a whole, may exist locally in some places. Practical support may, for example, involve the healthcare, social care, and other community services, working together and resolute, in order to get professional interpreters instead of using children as interpreters in various situations.

“What is needed are various solutions from healthcare and social care and so on, so that everything works with professional interpreters” (E1_R2_SE).

“To get practical help, which I believe exists already today in some places” (E8_R2_SE).

Development of technology /apps supporting (A)YCs

Round 1

Development of digital support functions could help bridge the current inequality, across the country.

“Today perhaps in a small municipality you couldn’t have such a group activity, because there is no more than one or two at a time [...] or you might have to have mixed groups with very different ages [...] I think many youngsters would like to have meetings on Skype [...] just as well” (E7_R1_SE).

“And in the same way you could have... which could also be perceived as a little less dramatic, a kind of support function, support chat [...] where you could talk with a competent adult who can give support and advice in various ways [...] and together you can find out what’s available in the municipality where you live [...] This would be [...] economically feasible” (E7_R1_SE).

“And all the individuals in society should be able to find it through 1177³⁹ [...] And then you can connect [...] to various kinds of... help functions [...] chat rooms for young people [...] information services [...] apps [...] mental health support” (E7_R1_SE).

Round 2 (reflections)

Two of the experts reflected on the advantages and disadvantages of digital support functions.

“The function needs to be available on the phone and chat and mail, so you have the opportunity to choose. Sometimes you want to have an immediate answer, sometimes you want to send a question and have the opportunity to open the answer when you feel ready for it [...] And sometimes you just want to chat” (E7_R2_SE).

“If the adult community arrange this for children, then the adult community also has a responsibility to keep an eye on what happens in these meetings and chat rooms [...] There may also emerge things that can be destructive [...] You cannot leave children and youngsters with the whole responsibility for what happens and so on... They have their social channels anyway. If the society arranges something like this, then the society also has a responsibility for control, so it doesn’t emerge things like encouraging suicide, supporting taking one’s life. Such things may occur, you know” (E10_R2_SE).

(A)YCs’ needs

Round 1

The experts agree that there is a need for long-term, individualized interventions.

“The most important thing is that... we create... support efforts [...] for these children and youngsters, that may be long-term [...] that may follow them for a long time [...] So you don’t need to start all over again all the time, but... can have a long-term support... and that the support they get can be individually adapted” (E7_R1_SE).

“Well, it’s the whole range, from these educational interventions, to professional trauma therapy, which some children need” (E10_R1_SE).

Round 2 (reflections)

In the reflections during Round 1, the experts return to the need for flexibility, individual adaption, and need of protection. One expert reflected on what is meant by ‘formal support’ while another discussed how universal the needs are that we are talking about.

“Individual solutions [...] to be able to combine having a holistic view of the entire situation, and also providing them the support they need” (E7_R2_SE).

“There must be access to flexible efforts and interventions” (E7_R2_SE).

“To see their protection needs and the risks that exist” (E10_R2_SE).

“Britain [...] they want opportunities for young people to get formal support, and this varies from region to region. And then I’m very interested in how they provide formal support and what they put into the term ‘care’ in Britain” (E9_R2_SE).

“Very much of what we are talking about, there are groups, and you should listen to the children, and you should arrange opportunities for children with problems at home, to talk with each other, exchange experiences, and they should be able to get away from home... be relieved and have common activities without feeling responsible for this situation. All of these are things... that children need even if they do not have a caring responsibility, but have a parent with a mental problem or a parent with an addiction problem” (E10_R2_SE).

Adaptions at school

Round 1

Flexibility and individual solutions are also necessary in schools.

³⁹ 1177 is an official telephone- and online-based healthcare guide in Sweden

“If there... are periods when life is awkward, and it’s difficult... To have the opportunity to do a test at a later date, you may need help with homework [...] It is about being open to solutions within the school framework” (E1_R1_SE).

Round 2 (reflections)

Two experts discussed if adaptations in school are the primary need, or if having opportunities for unrestricted participation in school is the greater and more important need.

“This need to provide flexibility in school for the group. From my point of view [...] this means that the school makes it possible for the young people to provide care [...] I think that you should make it possible for the young people to be in school [...] But of course, you cannot be too narrow [...] But if I think of the families that we have had, worked with, it has been parents with really serious drug problems. And then, it’s these who need efforts [...] so the child is given opportunities to attend school” (E9_R2_SE).

“Then you also talk about the school’s flexibility, that the school must be flexible when you have identified these children in school. And I say again that [...] you just see one side of the case, that the school should adapt and be flexible so these children can continue to be carers. But can’t you see that as children they have a right to a normal schooling too? [...] we are satisfied if they just reach passing grades, and they don’t need to go to this activity, and this. Those children lose what other children receive” (E10_R2_SE).

“Of course the school should always be flexible, in order to see to each pupil’s individual needs [...] but it mustn’t be doubted that these children have a right to reach their full potential. That’s where the school flexibility comes in, finding ways so that even children with problems at home have the possibility to develop all their abilities in the best way [...] This must not mean that you have to lower the standards for these children” (E10_R2_SE).

Being able to be yourself

Round 2 (reflections)

The ideas about theatre plays in school and support for leisure-time activities are appreciated by an expert.

“I like this, with theatre plays in schools and programs for supporting leisure-time activities, resilience and support groups. This is something I believe in very much [...] But I do not know if it is because... it would be especially good in Sweden, but it is providing the opportunity for the individual to continue to be the individual s/he is. That the focus isn’t only on you expanding your capability and to be a carer, and I think that’s the right way to go” (E9_R2_SE).

Being able to relax

Round 2 (reflections)

There are great needs for relief, according to the experts. Getting away from home and participating in summer camps and other activities together with children/ young people in similar situations, but also being given the opportunity to be involved in completely ordinary activities with children / young people who don’t have similar experiences.

“To relieve [...] summer camps and such things [...] you can do more of, I think [...] because there are still quite many who need this” (E9_R2_SE).

“To get away from... be relieved and get to, yes, common activities without feeling responsibility for this situation” (E10_R2_SE).

“Perhaps it is not always the most strengthening that you have the same situation, but maybe it is also being able to choose to do things that you think are fun and enriching [...] with completely different persons and youngsters” (E9_R2_SE).

Notice that you’re not alone

Round 1

Recognizing that you are not alone in taking an extensive caring responsibility, also means opportunities to reflect on your situation in a new way.

“Many children have grown up and it has always been like this, as long as they have... they began when they were very young and this is included in their understanding of how life is constructed [...] And they may actually need to reflect on this. Yes, this is our life, but it could be in another way too” (E4_R1_SE).

Recognition for (A)YCs’ situation

Round 1

The experts agree that every individual (A)YC’s life situation needs attention, that children and young people need to be recognized as full-fledged next of kin who need a functioning daily life.

“That there is someone that is aware of this as an unsustainable situation” (E2_R1_SE).

“To change focus. To actually see the child as a next of kin, and see his/her needs [...] And regardless if it is a parent or a teacher, or one... whom the child is meeting, we hope that this person wears those glasses [...] And identifies what it means for this child to have this sibling or this parent, or whoever we are talking about, at home” (E3_R1_SE).

“What each unique child needs in the family situation right here and now [...] Of course it changes over time, too [...] what their situation look like” (E5_R1_SE).

“Seeing children’s needs for a functioning school, leisure-time and everyday life” (E1_R1_SE).

Round 2 (reflections)

A recognition of (A)YCs and their needs for support is discussed in relation to the point of view that children and adolescents should not have a caring responsibility.

“Here it becomes... a bit paradoxical in some ways, because I also think that it’s important that although you avoid the heaviest... that children are heavily burdened, children also need to be recognized for having done something good” (E2_R2_SE).

“If we always have the approach to see children as vulnerable, and victims, and those who have suffered in some way, then we easily miss the other part [...] With children... and young people who actually contribute a lot and learn something and... as they say... this becomes an experience for life and so on. So you have to see those parts, too. It is not good or bad, or only bad, or only good” E2_R2_SE).

“That it is not only bad, it is... Of course you can improve your skills by being... that is, learning about life [...] in reasonable doses, it can also provide skills [...] for the future ” (E8_R2_SE).

“Understanding and confirmation [...] but it must not lead the child to take more responsibility, so it becomes even more of a burden that I am expected to do this [...] So... it’s a bit double-edged” (E6_R2_SE).

“But... then... yes, the opposite, to blame, that feels wrong too, to say ‘It is terrible that you need to do this’. We do know, at the same time, that the young person is aware that ‘if I don’t do this, no one else will do it, and what does that mean to my parent’ [...] this is a balancing act in some ways, I think [...] It’s not easy” (E6_R2_SE).

Connection with fellow (A)YCs

Round 2 (reflections)

The experts believe there is need for support groups that are specifically targeted to (A)YCs. They also say we need to be aware and observant of the risks with support groups, for example, that participants in the group influence each other negatively.

“Programs that are more clearly focused on being young carers” (E4_R2_SE).

“To be able to meet others in the same situation and not be so alone and [...] a forum where you can share” (E6_R2_SE).

“Opportunities for children who have these problems at home, to get to talk with others, exchange experiences” (E10_R2_SE).

“Quite acceptable that in a group meeting if it is with other children experiencing this, sit and talk about guilt and shame and fear and worry and so on, that you can easily join in such discussion [...] But if you are going to talk about how you... tell each other about how you can best do your homework in the evenings, how to be able to wheel mum to the store and shop and then take care of everything, then for me this becomes... [...] This would be interesting to do an analysis, to compare the countries, if there are differences, in what you put in there” (E9_R2_SE).

“getting in touch with others who will help one to... to accept and feel... get good self-esteem in their role, in the family you are in. You may need to look at how you should work with this [...] That these group meetings with persons with similar experiences might be designed differently to avoid there being a negative group recognition” (E9_R2_SE).

Empowering (A)YCs

Round 1

Children’s and adolescents’ rights need attention.

“The Parents Code comes in here, because I have also seen examples when... you have identified children who need help and then, when you are trying to get a little closer then the parents move [...] They have the power to do that, and then... then the society lets go, if it wasn’t so serious that it was possible to take care of the child, then you let go [...] And then I think that there should be some kind of... children’s rights to keep a contact person whom, for example, the parents cannot terminate” (E7_R1_SE).

Round 2 (reflections)

In order to be able to explain what they need and want, (A)YCs first need help reflecting on their situation, their perceptions, experiences, thoughts and feelings. They need to receive information about their rights. Furthermore, they need access to tools and support to find useful coping strategies.

“To get help with reflecting, that is what you might really need to put the emphasis or energy on. Getting to know about the children’s need for support, might first begin with helping them to reflect on their role and on what they actually want [...] We are a little too quick there, I think, we sometimes have our adult believe, that children will be able to express this after a straight question. But I think we are not there yet, or... we have to begin with finding good models for helping children in reflecting” (E3_R2_SE).

“Tell the children about available relief possibilities and about their rights” (E3_R2_SE).

“To see how it looks at the local level, in their surroundings and pay attention to their rights. This could be a common way for all countries” (E9_R2_SE).

“And resilience training, that’s it’s an acceptance of their situation and how to manage it in the best way” (E9_R2_SE).

“Tools to be able to deal with both their own situation and those whom they give... who they are taking care of [...] coping strategies both for dealing with the problem itself, and with the system. You need coping strategies to withstand the healthcare system!” (E7_R2_SE).

“Children do the same thing as adults do sometimes to support a sick adult person [...] and they may feel extremely vulnerable in this, and feel that they would have needed another support but they don’t get it. But the child is completely disadvantaged, and cannot even request their rights, they do not even know them [...] Here we could do some more work [...] to strengthen this side” (E8_R2_SE).

Talk ‘with’ instead of talk ‘about’ (A)YCs

Round 1

Conversations with patients’ children may be easier to accomplish within hospital care than within primary care. Experts give suggestions on how conversations with (A)YCs can be arranged and emphasize the importance of the child/ adolescent getting to speak.

“It is much easier within hospitals, because if a patient is admitted, you can ask the family to come, and the family comes to visit, and then you can inform them of what happens at the hospital and children can get information. In primary care it’s usual... usually there is just the patient and you never see the family [...] And you are short of time, and so on” (E8_R1_SE).

“The professions need to be good at talking about this question [...] ‘Is there anything you do that we could do instead?’ [...] ‘What kind of help could we provide, instead of you having to do it, so that you can attend school instead?’ ” (E9_R1_SE).

“What’s really absolutely most important is that the children get to speak” (E10_R1_SE).

“If you don’t get the children to tell their story, then you cannot find out what the children are actually exposed to, their stresses and their needs for help, both themselves and how they experience parenting and parents’ needs for help and support [...] Children can provide very concrete situational descriptions that clarify what they are exposed to” (E10_R1_SE).

Round 2 (reflections)

The reflections concern conversing with children, talking about anxiety, talking about being voluntary, letting the children/ adolescents be part of the team, and discussing society issues with children and young people.

“Children have told us that ‘Well, they looked in when we sat in our room and asked us ‘How are you?’ And we said ‘Good’ we said, and then they went away’ [...] One doesn’t take conversations with children seriously, and the parent perspective becomes very dominating” (E10_R2_SE).

“You have to see that the individual child, also the younger child, may need to have a special individual attention to their needs and their perspective on the situation” (E10_R2_SE).

“It is not only that I bathe someone or that I run home after school, but that I actually spend a lot of energy wondering how my parent is doing now, or how my siblings feel and what should I do about it [...] That part can take a lot of energy [...] that you also get help in sorting your feelings and actually finding ways” (E2_R2_SE).

“It’s when you talk about possible help from outside, it’s not until then you can talk about voluntariness [...] And you can begin to talk about what help it could be and... what help would be okay [...] Then you can start to figure out [...] their choice [...] But you do not know that until you talk with the children” (E8_R2_SE).

“Really ask how they are doing and be interested in their whole life situation [...] What does your life look like? How does your day look? What does your week look like? What do your weekdays look like compared to your weekends? [...] What do your days and nights look like? This, in order to get a good picture [...] Do not just ask what do you help your Mum with [...] Give them time to talk” (E7_R2_SE).

“We do not allow them to join the team and when we allow them to... to speak... then we take the right to interpret [...] we need to find formalized ways to really discuss with young people [...] invite them to participate and to change and influence [...] There is a common question: Are we allowed to invite them? Then we have to ask parents for permission [...] And there I think that... of course if it's about small children, then you must ask the parents, but when they are almost adults [...] why do you have to get permission to invite them if they want to participate and influence the care system? [...] There doesn't need to be an eighteen-year-old age limit for them to decide for themselves if they want to participate [...] The youth health clinic prescribes contraceptive pills to young girls without the parents having to know this... when they have turned fifteen [...] Then we must be able to invite young people to join discussion forums” (E7_R2_SE).

“The child has already established the picture of how things should be done and if it isn't done well by this professional who comes, then they will not want the help [...] So it is also about [...] listening to how they do this [...] what do they do and how do they do it, to discuss and show respect to the methods and strategies they have developed themselves, so that you can end up in a dialogue with them about it and not just come in and take over” (E10_R2_SE)

“We have to go out and be there in the schools and... together with the young people and teachers, and collaborate in a work about future care [...] We must go out to leisure-time activities [...] ask the football team about their thoughts [...] We cannot just sit in our institutions and invite them to come there and discuss how we want the society to be. We must get out there, where they are, and talk with them about the society... about community support and help and so on...” (E7_R2_SE).

Someone who listens to their story

Round 1

The need for someone to listen can be met in both individual and group meetings. In some cases the individual dialogue may be preferred. It is important that the child /adolescent feels confident in the relationship with the listener.

“And listening to the children with respect, and be prepared to talk and establish such good relationships with the children that they feel comfortable to tell their story” (E10_R1_SE).

“Maybe you need to meet the children separately in order to find out if they are carers” (E9_R1_SE).

Round 2 (reflections)

It is never wrong to listen. The experts emphasize the importance of listening ‘with open ears’ and taking the children’s stories seriously.

“One such general rule that is actually easy to follow, is to listen. To their stories, ask them to tell about their life situation and ask about it [...] That's the prerequisite for being able to do individual interventions later” (E7_R2_SE).

“Individual children, including small children, may need special individual attention to their needs and their perspectives of the situation” (E10_R2_SE).

“Attentiveness for children's signals, so to say, to believe in children's stories” (E10_R2_SE).

“I really believe in encouraging staff to listen with open ears [...] I meet this in general discussions with children and young people, when they say they want to participate and design the system that will take care of us. And then, later on, they say ‘you didn't listen to what we really had to say’ [...] and this is both in groups and individual conversations... we may hear, but we still do a re-interpretation [...] Instead of beginning with what did you say, was this what you meant, was it this that you wanted to say, we have already decided what it was [...] from our adult perspective” (E7_R2_SE).

“How do you want me to listen? Should I ask questions and... or should you talk freely? How should we do and how do we check that I have understood correctly? How should we do to make you feel sure, when you leave, that I have listened. I think it is not harder than this” (E7_R2_SE).

To be relieved from responsibility

Round 1

The experts agreed about the great needs for relief, and that it is a duty of society to ensure that children and young people do not need to take on a caring responsibility. One dilemma that may arise, however, is if the parents do not want to receive help and support from the community. It may be necessary to prioritize the children's rights before the parents' rights.

“You must make sure there is an alternative that works, where they can get away and feel that now there is someone else who is taking care of this. Now I can let go” (E1_R1_SE).

“If you see there is a caring responsibility that the child cannot or doesn’t dare to hand over to someone else, then you must make sure there is cooperation with social care services in order to find solutions” (E1_R1_SE).

“If you can motivate parents to accept, or actually force them to accept support for the family, in order to be able to tackle the situation. I don’t think you can take responsibility for allowing children to be in this environment with these problems, just because parents don’t want [...] So there are lawful measures that deal with parental rights versus children’s rights” (E10_R1_SE).

Round 2 (reflections)

There are a lot of reflections about the needs for relief. The experts discussed how this relief could be achieved and if (A)YCs will receive support in their caring role, or if the support should be that someone else is taking over the care responsibility completely. Finally, children who have been taken care of, and placed in foster care, may still feel a continuous, heavy burden of responsibility.

“The primary thing is really that the public should be there and provide the needed support and help, so the children do not need to be involved in it” (E10_R2_SE).

“The effort should not be to... provide them with support in the role, but rather give them support that allows them to get out of that role [...] And provide other support they might need” (E1_R2_SE).

“to be there, and to help individual children to find an acceptable level” (E2_R2_SE).

“If you know that someone else is looking after the parent, then you can let go, to some extent [...] I suppose all children worry about their parents sometimes, but if you have a parent, for example with an addiction problem, or who is very physically ill... then the anxiety is greater in those periods [...] and there they need support in different ways, of course” (E2_R2_SE).

“Support the healthy parent, then we have come a long way” (E3_R2_SE).

“Practical help for parents in their parenting role” (E10_R2_SE).

“You also have to look at... how this type of parental support works from a child’s perspective and not just from a parent’s perspective. What do the children need that the parent gets support with, or when the parent fails that someone else actually do this” (E10_R2_SE).

“It becomes almost harder for them when they are placed [in foster care] than when they live at home, because living at home they at least know how it is. Thus, they need to get a very clear feeling of ‘now someone else is taking over this responsibility’...” (E1_R2_SE).

Talking with (A)YCs’ families

Round 1

Conversations with the parents can serve as a form of support in their parenting. The conversations can be used to make parents aware of the children’s needs and the roles the different family members currently have in the family. In the conversations, you should also determine what care capability the parents have, what obstacles there are and what kind of support may eventually be needed for the parents to be able to function fully in their parenting.

“It is a lot about support in parenting, so parents can see their children’s needs and not burden them with too much” (E1_R1_SE).

“A lot depends on... the parents’ awareness, too [...] sometimes parents need to be made aware of how... it actually looks, which roles the children have at home” (E3_R1_SE).

“That you... find out what... caring capacity there is among those who are actually the care-persons, the ones you suppose to be the adults [...] And that you make sure that you can support that when it is lacking, in a way that you can get the roles... back to their initial places again in the family” (E4_R1_SE).

“Supporting the parent in giving the child the space to be a child, to be a provocative teenager for a while and then maybe take on an enormous responsibility the next moment, but you still open up the possibility to get the [...] normal development [...] And I think you may need help with that if you are the one who needs care” (E7_R1_SE).

(A)YCs being able to talk

Round 1

All experts agreed about the importance of giving the children/ young people opportunities to speak. For this to be possible, attentiveness and flexibility are required. If the children/ young people feel a responsibility to protect their parents, they probably don’t tell about all their thoughts and feelings when the parents are present. Nor are all children/ young people comfortable opening up in a group with other children/ young people. Therefore, it may be suitable to have individual conversations with the child/ adolescent.

“What really is absolutely most important is that the children themselves get to speak” (E10_R1_SE).

“Maybe you need to meet the children individually to find out if they act as carers. They probably don’t tell about this if their parents are present [...] at least not freely [...] and it is not so sure they will if there are some young people around them either [...] It depends a lot on how they perceive it, but if they feel burdened then I don’t really believe they tell about it” (E9_R1_SE).

Round 2 (reflections)

In round 2, the experts emphasized the importance of the children/ young people getting to speak.

“Be supportive and make it talkable for the children” (E6_R2_SE).

“These support groups can be incredibly important [...] that there is a forum where you can share” (E6_R2_SE).

“To be allowed to talk about it” (E2_R2_SE).

“It is always important when working with support groups that you have safe boundaries. To set rules, for example if you don’t want to speak then you just say, ‘Pass’ [...] that there is confidentiality between groups if you work with parallel groups” (E6_R2_SE).

Organizations supporting (A)YCs’ needs

Round 2 (reflections)

One of the experts reflected on proposed changes or additions to legislation. The Swedish Social Care Act is perceived as sufficient in its present form. Changes at the municipal level, to improve the situation for (A)YCs, are perceived as fully enforceable according to the current legislation.

“We have had discussions with our lawyers earlier that we would like the Social Care Act to indicate clearly the group of children as next of kin, but the more groups that are pointed out the greater risk there is of some group falling outside protection [...] Our current legislation covers young carers, because it speaks about children’s safe childhood and environment, health and development, and that social care services should work preventively. So I believe it’s more about using it, in order to highlight this group, instead of requiring some specific legislation” (E1_R2_SE).

“It is more on an organizational level... it is... We have legislations that are sufficient, but then you perhaps have some municipalities organized in a way that doesn’t... that makes young carers be left out. But through political and organizational changes, you can deal with that [...] This responsibility is already extremely clear” (E1_R2_SE).

“If young carers actually... care for a family member as stated in the Social Care Act regarding the care of family members, then of course, they are principally included, even if the legislator, initially didn’t think in that way. Because it’s not supposed to be like that. But in practice... if you care for a family member, there is nothing that prevents you from using it, even if it is a minor, but the aim should be, of course, that minors shouldn’t have that role” (E1_R2_SE).

Staff / professionals needs

Resources

Round 1

In recent years the situation in social care services has become increasingly busy, with high workloads and lack of time. The need for a solution to this is great. School nurses would need more time for each individual pupil. They are currently responsible for very large groups of pupils and often have their working time divided across several schools. School social workers would need to spend time with all pupils to reduce the stigma for pupils who visit the school social worker. School social workers would need to be included as a natural person in the school day, for all pupils and at a very early stage, preferably starting with nursery school. However, nursery schools, today, don’t have their own student health, unless this has been decided locally.

“Lately it has been a little chaotic in social care services, so to say... Yes, within children and family units, it has been very busy in many places [...] for some years... or, for very many years” (E2_R2_SE).

“Strengthening the school nurse’s role and giving more time so you don’t have so many children and perhaps not so scattered at several schools [...] I think you get... that would be the most effective” (E10_R1_SE).

“Then the school social worker’s role needs to be strengthened [...] The social worker meets the teenagers who have problems at school, but the social worker is the person who knows everything in this social field, where these problems exist. So the social worker should really already be linked to the elementary school and be there as someone children naturally... all children meet and talk to regularly [...] That you establish a social worker’s contact from the beginning and she is there as a natural contact person, because now it is... [...] it is a little embarrassing [...] to go to the counselor, then you have a problem” (E10_R1_SE).

“The nursery school should actually have a student health. Which they do not have today [...] but it depends on local decisions” (E10_R1_SE).

Round 2 (reflections)

One expert reflected on the need for increased resources. For example, more time for work tasks; possibilities to schedule working time outside of office hours, in order to be available to (A)YCs during times when they need support; and finally, guidance for staff.

“In order to reach a change there needs to be some... you need to have enough resources to be able to do it, too. That is an important part here, being able to find those resources” (E9_R2_SE).

“Make sure that you can be available as a professional at times when these young carers need this [...] We don’t do that [...] we work during office hours. But in these cases, with families that are fairly difficult sometimes to get in contact with... what do you do then? Maybe you need to re-consider that also. Are you available during the times they need [you]?” (E9_R2_SE).

“Have opportunities to get guidance and to be strengthened” (E9_R2_SE).

Education about YCs

Round 1

According to the experts there is a great need for knowledge about (A)YCs and their situation, but also a need to exchange thoughts and experiences with other professionals in order to be strengthened in their role. Furthermore, there is a need to clarify the difference between helping at home and taking over the responsibility. Informational films and (A)YC stories are emphasized as effective aids in this work.

“Much more information is needed about these issues, to the various professional groups that meet these children” (E10_R1_SE).

“If you have knowledge about this, then you also dare to ask” (E2_R1_SE).

“More knowledge so perhaps you could ask more, about what the children actually do. We... should try to be a bit more attentive to this, when the roles become reversed, or where the child becomes more of a parent to his parents” (E4_R1_SE).

“Continuous updates, with information and knowledge [...] to meet others for exchanging thoughts and experiences in order to be strengthened in the role” (E6_R1_SE).

“Information films, I think, stories [...] so you can get a picture of what we are talking about [...] This difference between helping and taking too much responsibility, it is... difficult, I think. Where is the limit? But also why is there a limit, why is there a border between helping and becoming the one who bears the responsibility?” (E8_R1_SE).

“This picture of children who help, and that this is a part of the upbringing. It’s included also, so if you, as a staff, don’t have the picture of what it means to be a young carer, then you may not perceive this as an important issue” (E8_R1_SE).

Round 2 (reflections)

Education about (A)YCs, their situation and what you, as a professional, can do to support them, should be included in the professionals’ basic education programs. However, currently there is no space for this, so it has to be a shorter course, in that case. Education about (A)YCs should also be included in Master programs and in training for working professionals.

“An early establishment of the knowledge, for the persons who are going to meet these children [...] Schedule some parts in education programs, such as teachers’ programs and social workers’ programs [...] Making ‘young carers’ become a concept in the university world and perhaps even earlier than that, in the secondary schools [...] emergency personnel also, of course” (E3_R2_SE).

“Getting this into education programs where it belongs, both in teacher education as a short course, and of course, social workers, psychologists, doctors, nurses, all who work in social care and healthcare, making them familiar with this. I think Italy had education for teachers [...] and they had also gathered information for all professionals [...] But I believe, getting this into the basic education programs is very important” (E7_R2_SE).

“I am involved in the children’s agents’ program [...] I lecture there and then I work at the university. And we should be able to do this better too. What we talk about here and teach about is our view of children [...] and this fits there too” (E2_R2_SE).

“The sociology program is a general education. We cannot really educate for working specifically with difficult child cases and such things, but there is a need for employers to see the value of further education for professionals” (E2_R2_SE).

“I think the films on the Swedish Family Care Competence Centre’s website are really good and they are not too long, but short and strong [...] And that’s also a tool to use, for example, at workplace meetings. You can show one such short film and then start a conversation and discussion around this” (E6_R2_SE).

Education and guidelines

Round 1

The issue about the need for education and guidelines engages all the experts. There is a need for a common knowledge base containing: how to meet children, young people and parents; how to identify (A)YCs; how to continue once you have identified an (A)YC; available support efforts. One expert suggests introducing a requirement of a minimum level regarding what municipalities should offer. Primary care is mentioned as an important area to prioritize in terms of education and guidelines. One suggestion is to include questions about children, in the primary care journal template (i.e., a patient/client questionnaire). School staff need, in addition to training, also some form of support in their work with issues of (A)YCs.

“Knowing how to ask, what to ask and, I think, if you have knowledge about this, then you also dare to ask. But then, something must happen after you have asked and got to know about it. You must know what you should do and what support efforts are available” (E2_R1_SE).

“I wish we could have some kind of common knowledge base, and education for all those who work with children and young people. About how to identify them and available support. And some kind of... mini-kit [...] this is what we are obliged to offer. This has to be available. And then, how you do it, may look different depending on if it’s a large city, countryside and so on. Possibility to do it in various ways” (E7_R1_SE).

“A lot is placed in primary care. Here, I would like to see a huge effort from many sides. Information about children as next of kin as well as this area. Because here are the parents [...] who are chronically ill, who have primary care as their place, but the children are not there [...] Here I see a development area” (E8_R1_SE).

“A question in the journal template about children [...] For example, you must ask some questions and fill in the answers, otherwise you can’t go on [...] in the template [...] Are there any children and when were they born and... so on” (E8_R1_SE).

“To train staff who work in schools so they... feel sure about addressing the issue and also developing some kind of support to offer” (E9_R1_SE).

Round 2 (reflections)

The issue of education and guidelines continues to hold attention. There is need for support and guidance for staff who meet (A)YCs. Furthermore, there is a need to gather research results so that they can be effectively disseminated. A common interpretation of the Social Care Act is needed. The checklist introduced for emergency personnel in one Swedish region, is suggested to be introduced in all of Sweden and expanded beyond unexpected death to include other dramatic situations, such as acute illness or serious accident. There is a need for guidelines on how to include the children’s needs when doing a caring plan for a parent or a sibling. An introduction of family interventions in somatic care is proposed.

“Making use of research results or studies that... have been done. What is effective, what has been seen to be effective support strategies or support programs? And how do you communicate this? [...] I cannot see that it is so very easy to find... find what has emerged” (E3_R2_SE).

“I have actually read a bit more in the Social Care Act now, and I sat and looked at what it actually says [...] Maybe we should begin reading the law text and interpret it and try to find a common interpretation” (E3_R2_SE).

“The places where there is available help and support today, in this issue... it is because there is someone who sees the issue, someone who thinks that this is important [...] It is due to individual persons [...] I think enthusiasts are great, but I see the vulnerability in this [...] It must be based on [...] routines” (E8_R2_SE).

“There was a county [...] that had introduced a new work routine, for children, concerning unexpected death. They had a checklist for ambulance personnel and police, and I thought that sounded rather appealing. If you could use more of this in Sweden [...] and perhaps not necessarily just death, but it can even be a serious accident, or when something dramatic happens with people with an illness” (E3_R2_SE).

“Guidelines how you include the children’s needs when you make a care plan for a parent or a sibling. That I think sounds very... very important in getting the child to be a part” (E5_R2_SE).

“‘Föra barnen på tal’ is an easier family intervention [...] used mostly in psychiatry [...] It would be useful in somatic care too, to go further and train in family interventions” (E6_R2_SE).

Overall needs

Dissemination of knowledge about (A)YCs

Round 1

There is a need to inform and talk about these issues, in public, in compulsory school (as early as the first years), in secondary school, in higher education programs and among professionals who work with people.

“Working nationally with dissemination of knowledge [...] in both municipal and county organizations, about these groups” (E2_R1_SE).

“We need to be informed, in general in society, about these problems, so that we know they exist and that it’s okay to talk about them. That opens up at least for young children to talk about this early, before they have been sucked into this hiding and concealing [...] And then you can identify these children early” (E10_R1_SE).

“Generally talk about these issues, make them open, talk about them in school, let children read texts about this early and hear about these issues. That’s also what the children say ‘Why don’t we use this knowledge early, that these families exist?’ One problem is, as the children say, they feel alone, they do not know what the problem is and they do not know there are many other children who have similar problems” (E10_R1_SE).

Round 2 (reflections)

Channels that could be used for dissemination of knowledge are reports, brochures, films, social media, and mass media such as TV, radio and the press. Globally knowledge could be disseminated at international conferences. The information should include a definition of the term (A)YC, (A)YCs’ life situations, what are (A)YCs’ rights, their families’ rights, available support, etc. An introduction of a national/ international day for (A)YCs is proposed.

“TV programs contributing to increased awareness at a national level, so that it, for the general public, is something you realize, that life can look like this [...] know that this exists” (E8_R2_SE).

“I believe that first comes the attitude and cultural change and then it’s necessary that you are ready to do it. Knowledge is also needed, and they partly enhance each other, that is, knowledge can also change the attitude” (E7_R2_SE).

“On a global level [...] more Delphi studies [...] international conferences on... about young carers. Because you need ... you need to read about it, you need to meet others about it, you need to find forums to find common terms and also, yes, to share experiences [...] Something happens when you participate in a study and when you consider other’s results” (E3_R2_SE).

“To be able to find strategies and support programs on a global level, you must also [...] recognize the term ‘young carers’ and also that we... mean the same thing [...] So that we agree on the concept” (E3_R2_SE).

“We talk a lot about ‘children as next of kin’ in the country and have done so for a long time [...] but this ‘young carers’ becomes... like a new twist of the concept [...] You need to spread... the term too, what it means” (E5_R2_SE).

“We have a ‘national carers day’ in Sweden and it feels, I don’t think it feels exciting for the children. Maybe we should either raise the children’s issues more that day, or maybe they should get their own day, I think, a ‘national carers day for young carers’ [...] to give much, much more attention to the children, nationally and perhaps... internationally too” (E3_R2_SE).

Acceptance that (A)YCs exist

Round 1

The view of the Swedish welfare society as fully responsible for all forms of healthcare and social care, has brought some resistance to the acceptance that there are children and young people who take responsibility for care. The Swedish experts’ reflections clearly show this when they discuss support for (A)YCs. There is a concern that if we accept that (A)YCs exist, and give them support in their role as (A)YCs, then we betray them, since we let them continue carrying a heavy burden of responsibility, instead of relieving them from that burden.

“I have worked with children, in various projects, who take responsibility in different ways, but not until I got the assignment, from the National Board of Health and Welfare, to work with the project on young carers where we did a survey... I have thought in terms of young carers. And when I first saw how they work in the UK, I thought, Oh no, they accept that... they accept in some way that young carers exist. And that cannot be good! [...] But there I have changed and more... as I said earlier, we have to admit that this... it exists and we must help and support in different ways, and set limits for what is acceptable for each individual [...] They exist and it’s not only bad” (E2_R1_SE).

“We have young carers and we need to discuss how we look at this. Should we support them or are we going to make sure that they are allowed to be children and not carers. Because in other countries it’s very clear that they have taken that direction, to support young carers. Regardless if you are a minor or not.”

Interviewer: “And you want to raise that discussion in Sweden?”

Expert: “Yes, I think it is important to do that, so we could come to an agreement on how to support them” (E9_R1_SE).

“There is a problem in this [...] especially when some of the children at an early age perform work that is very heavy. And if you define that as work more than just a responsibility, then you realize all the classic work environment issues, that it can be physically heavy, that it can involve risks, that it is stressful both mentally and physically for the children in some cases. So I think we have to raise that perspective” (E10_R1_SE).

Round 2 (reflections)

The reflections on the acceptance of children and young people taking responsibility for care continues with the same enthusiasm as in round 1.

“No child should have a caring role [...] That’s of course an utopia, I think, that is ... Well, how can we achieve that, if we on the other hand not... well, we make it invisible [...] Children become... they don’t dare to say anything, and not adults either. They don’t dare to seek for help because they are afraid of what’s going to happen [...] So it becomes a paradox [...] If we have this zero tolerance [...] then we will not see them until it is too late. And this is how it is today, I think, when the threshold to social care services, for example, is so high [...] There we have a lot of work to do in Sweden [...] Of course we should help children not to have a responsibility that is harmful, but we will never be able to prevent children from taking some kind of responsibility in different ways, at different levels” (E2_R2_SE).

“To see children as persons who are active and take responsibility [...] being a young carer, there are positive sides too” (E2_R2_SE).

“I think, coming from a Swedish society [...] that there should not be any care performed by a minor person. I still think that the society should take care of that in some way. So there is... yes, a reflection. How do you relate to that among countries? There are several who have answered... who have discussed this in the way I do now, and I feel this is a discussion you want to have, how do we proceed?” (E9_R2_SE).

“I think you should... you have to admit... they exist. But... that this isn’t only bad, but it’s not desirable either. That is how I would express it” (E10_R2_SE).

Reducing the stigma

Round 1

There is a strong need to reduce the stigma, since stigma makes it more difficult for (A)YCs to tell about their situation.

“It is so encircled, being a young carer, having a parent who is ill, and then perhaps not physically ill which is not as stigmatizing as a parent with mental illness or addiction [...] You must reduce this stigma in some way, and that applies also to being a young carer, because that is also something you do not talk about. Because we know that in Sweden, children should not perform care [...] That also becomes a further burden and counteracts in some way... children’s wellbeing [...] if we can reduce the stigma and see that these children also contribute, and that this is something natural, that the majority of children and young people would do this if they ended up in such a situation [...] Then we should support so that it doesn’t become... so children are not harmed by this” (E2_R1_SE).

“That we also think about it not only as a problem, but in fact some children may be... yes, very proud of their capacity or their ability, or they may also feel proud of their family, even if it’s not similar to how you think other families are. That you still may feel that, this is how we do it, and in some areas we have good times and in other areas we have hard times [...] not get stuck in an either-or thinking, that it’s only problems” (E4_R1_SE).

“First, this must be... there are a lot of taboos about this [...] Within the qualified professions, but also in general, we don’t want to moralize over the parents and we protect them in various ways [...] Somehow, we have to raise these issues in society and talk about parents with serious substance-abuse problems, and that these substance-abuse problems affect the children. We have to talk about mental illness... We allow children to live with parents who occasionally become psychotic, yes, that should be something generally known and that we can talk about it as a problem without it causing guilt to parents. We need to understand that parents end up in this without having actually thought that they should expose their children to this” (E10_R1_SE).

Round 2 (reflections)

The experts reflect on statements about the ‘silent culture’ and stigmatization of the role of (A)YC, and also the stigmatization existing about mental illness and addiction. Do we contribute to the stigmatization when we create separate support groups for children of parents with mental illness and/ or addiction? Attention is again drawn to the discussion about acceptance of the responsibility (A)YCs take.

“Then I wonder the stigmatization of what? In my experience from the children we have met, it is the stigmatization of the parent’s problem that causes the parent’s problem not to be visible. And you cannot see and talk about the parents... if the parents are the ones with the problem, that they need... yes, addiction, for example, mental illness, all of this. It is that stigmatization which is the problem for these children. I don’t really see the stigmatization of children helping at home. I get the opposite picture, when children do these tasks, the outside world sees that as something positive and even makes use of it and expects the children to continue and do what they are already doing in the family. So I wonder what is it you want to... de-stigmatize?” (E10_R2_SE).

“This ‘silent culture’ [...] that something is a bit secretive [...] of course this embarrasses the children [...] ashamed of their situation [...] But it is by beginning to talk about it you can understand that this is not my fault and it’s not my shame [...] The circumstances are no one’s fault. We have an illness in our family, but it is no one’s fault. This is what you need to talk about. Parents who feel ashamed because they need help or children feeling ashamed because... and cannot bring children home, other children, because they feel that... they don’t want to show how it is [...] The shame is devastating” (E8_R2_SE).

“It is a bit more legitimate to talk about the difficulties at home when you have a seriously ill parent, with a somatic illness, while it may be harder to talk about it publically when they have mental illness or addiction. There are often family secrets, and you cannot get help from a network in the same way to make it talkable in the family” (E6_R2_SE).

“When we have the groups who are targeted for... physical disabilities and illnesses, then the meetings with the parents in the door, are very happy and positive, compared to the group that comes and visits us to join the group of children within addiction and mental illness, then it is a completely other... Here they come in quietly [...] They don't give eye contact with us in the same way. You just drop off your children and disappear rather quickly through the door [...] There is a big difference [...] You need to really pay attention [...] Here comes a unique person and it's important for him/her to be in focus [...] But perhaps not... not so much focus on the caring itself, but more focus on the individual, talking about rights, providing accurate information and letting the child grow” (E3_R2_SE).

“Is it important to have groups distinguishing that I come from a family with addiction or mental illness, when we don't divide other forms of impairments and disabilities, illnesses, with the other children? [...] Is it we who maintain... who stigmatize?” (E3_R2_SE).

“Accepting the existence of young carers and reducing the stigmatization becomes a bit problematic for me, because I do not know how to relate to this. Of course, accepting and identifying that a young person becomes a carer to a large extent, but reducing the stigma... then I wonder, is it because they should be able to continue to be young carers? I do not think they should [...] Instead we should try to organize support by adults who can provide care to these dysfunctional parents. Here, I get interested in how other countries have organized this, and reasoned” (E9_R2_SE).

A family perspective

Round 1

The experts agree there is a need for a family perspective in legislation, as well as in practice, within healthcare, social care and criminal care. However, introducing a family perspective in the current individualized and specialized Swedish systems could not be done without complications. There are also thoughts that a family perspective perhaps should not be introduced everywhere.

“Within care, social care services, and psychiatry, and so on... I think overall, you would need more of a family perspective [...] whether you are a child or an adult, you live in a context... with other persons. And we cannot just watch, even if it's the individual who is in our treatment, we must also find out a little about the surrounding context” (E4_R1_SE).

“We have many different chronic illnesses where we know they are going to get worse [...] Then you would like to have a support who helps this young person cope with the process [...] and the system to be a little prepared for a plausible greater load on the child later on. And I think it can reduce the risk that the parent refuse this kind of contact if they are introduced in a calm phase rather than in a more stressful phase” (E7_R1_SE).

“It should be possible to include the adult's parental responsibilities in the framework of a support decision, and in that way the children in the family would get the needed help which the adult normally would have given as a parent but is hindered due to disability” (E1_R1_SE).

“Families where suddenly the parent who, despite everything, maybe has been the most stable ends up in prison. The parent might be a criminal, but still quite helpful at home. And the other parent is incapable and weak, and suddenly the child is at home alone with the weak parent and the strong one in criminal care. And how staff in criminal care can help this parent to support the child” (E7_R1_SE).

“A family perspective that involves working with adults, both parents, even if the other parent does not have any problems of this kind, there may be a problem to [...] manage the other parent's problems. And the children need help and you need to work with the relationships in the whole family [...] The children need support, even if they have one parent that doesn't have this sort of problem. Because it is not enough, that parent cannot compensate fully for the problems, and you need to help the children even if they have been separated from this parent with problems, even if they do not live together with him, even if they have not been together once, but they have completely cut the contact. Still that parent is in the child's mind and the child has experiences of this parent that need to be processed” (E10_R1_SE).

“We have very much, both in our legislation and in practice, that is individually-oriented... It is not completely without complications to start paying attention to the family... Within healthcare, for example... it is not clear how you should document if you, for example, have a conversation with children and notice they have needs of various kinds... Our systems are built around individuals and not around families and relatives, which makes it more complicated to bring a family perspective in many contexts. So we have to find systems for bridging this” (E1_R1_SE).

“I do not think you should let that perspective take over, for example, in the social childcare, because that means suddenly that we emphasize the parents' problems, and then there is a risk, theoretically anyway, that we do not really see that children must have their own support, and they are vulnerable and can be harmed. As a next of kin you are there for someone who has a problem, and certainly, when we talk about adults, we see that it can also be heavy for them... But children can, of course, be harmed very, very badly and we cannot drop the old childcare perspective where the child's needs for protection are central” (E10_R1_SE).

Round 2 (reflections)

The experts reflect on why the family perspective is needed and what it means to have a family focused approach.

“As long as there is no automatic family perspective in everything that is done in healthcare and social care services, we will need to continue reminding that these are parents of children who have needs in connection with this illness, or other kind of difficulty, the adult have [...] those who work with children are... have to focus on what the children need. But those who work with adults don’t have that focus, so it doesn’t happen naturally. Therefore we need to continue reminding” (E1_R2_SE).

“It’s... interesting to note that you... it is so often you do not involve children and young people, so to say, when you plan for parents or siblings and care and so on [...] Some sort of family-centered or family perspective. I can still wonder a bit about this [...] But maybe it’s because I am an old family therapist that I think that when something happens in one part of the system then it affects all the other parts too [...] Because I recognize these descriptions and at the same time I think... well, haven’t we got any further than this” (E4_R2_SE).

“a family-centered [...] approach: how is it in the family? Find out if there are children and youngsters, their tasks and... There is in fact a responsibility to go beyond the individual, the client or the patient [...] seeing also the surrounding context. So there I think, there is need for both knowledge and that you clarify the professionals’ tasks” (E4_R2_SE).

“If you have someone in the family who is seriously ill with cancer or something, the other parent could be helped by getting a few extra reminders during a period and a little extra support. SMS, could help getting the day to function a bit better [...] at small costs [...] It’s a fairly cheap support effort” (E5_R2_SE).

“It is important to see when you talk about family perspective that... you must give the same importance to each individual person in the family. You cannot just think of the family as a whole, because then it becomes easily an adult perspective, a parent perspective. But you must see that the individual children, even the small children, may need to receive special individual attention to their needs and their perspective of this situation [...] The relationships must be made clear from all sides [...] The individuals, the relationships and the whole, all those levels, so to speak, must be there in a family perspective. And you must have a systematic model when you work with this” (E10_R2_SE).

“There are several who emphasize this tension between having to see the whole family and the individuals’ needs [...] I think we... well, our big problem right now, is rather that we... do neither of this, we don’t do enough... of anything” (E7_R2_SE).

Working concepts to reach (A)YCs

Round 1

Since many (A)YCs do not identify themselves as (A)YCs, you need to go out to all children and young people with information about what it means to have a caring responsibility. In going out with this information, there can be opportunities to get in contact with children and young people who recognize themselves in the description.

“We have to go out wide and we have to go to them [...] We must reach them out in their arenas. And then I think a lot about this technology and social... [social media] where I think we need to reach out. And where the children are and, of course, also where the parents are [...] That this becomes something that... is talked about [...] that it’s not something strange” (E5_R1_SE).

Round 2 (reflections)

The experts reflect on how we express ourselves when we try to reach (A)YCs. Do we make use of the right expressions and manners of speaking? How easy/ difficult is it to find information about available support efforts on the municipality websites? Would ‘next of kin support’ by prescription be useful within healthcare?

“If we say that this is an invisible group and it is difficult for us to find them. Yes, but how have we addressed them and in what way have we... What purpose have we stated for them to talk to us? [...] How do we express ourselves and in what... ways do we try to find these needs and these children?” (E3_R2_SE).

“The Netherlands is also focusing on young carers’ strengths and not problems, and I thought that was good. I related this to... rights” (E3_R2_SE).

“If we think of ‘parental support’, if you look at how it... the municipalities’ websites [...] It’s about fifteen clicks before you get some information about this. And I think that ‘young carers’ may be twenty-five or thirty clicks away, before you can get some information about it” (E4_R2_SE).

“Maybe we should call it... ‘early next of kin support by prescription’ [...] as a way to help the healthcare or doctors, to think a little more, perhaps it should be some kind of prescription block for children [...] when you see these children in families where some ill family member appears” (E3_R2_SE).

Responsible organizations

Round 1

The responsibility should, according to the experts, be at all levels and with all organizations that work with people.

“Overall responsibility is of course on the politicians, legislators and the National Board of Health and Welfare” (E10_R1_SE).

“I think the responsibility must still be... greatest for us who... work professionally” (E5_R1_SE).

“There is still work to do to get different professions to accept an extended assignment, or discuss who should have this assignment” (E9_R1_SE).

“No one has the responsibility, and that is one of the things that I wish for, a future model where we have decided where the responsibility lies. And I think that this must be a shared responsibility, it must be first at the political level, civil servant level and down into the field. Because this child, young person, depending on the age, can be... is going to exist in various areas and their relative is going to be in other areas and get help, so it is not possible to say that there is one who will have responsibility for this. But we must put it together” (E7_R1_SE).

Cooperation

Round 1

All experts agree that cooperation is an important key to a functioning support system. This means cooperation over municipal and county borders, and cooperation among different authorities, organizations, services and professions.

“It is a very high threshold into social care services. It needs to be lowered in some way. And one way to do this, is that social care services visit schools” (E2_R1_SE).

“Collaboration [...] this is easy to say, but so hard to get [...] If we could organize our resources better around the children in these vulnerable situations, then I think it could... have made it easier for the children, because now... they don't about their rights, and what kind of support they can receive [...] If we had [...] some kind of common clinic [...] where all the competence is available, and then the child comes to that place [...] And then you can find out about this individual child's needs” (E5_R1_SE).

“When it comes to smaller municipalities, several municipalities should need to collaborate” (E7_R1_SE).

“We have heard reports from BRIS and others, these days, about how they only manage to answer a fraction of all of their calls. [...] This could be organized in a much smarter way, and it should be supported nationally [...] It should be possible for everyone who works in the field to find it easily through a knowledge guide or whatever you have, and all individuals in the society should be able to find it through 1177” (E7_R1_SE).

“The collaboration needs to be strengthened among these various efforts for adults and children services. And it's also about raising an awareness about the necessity of cooperation, creating routines, structures for this, and managing the confidentiality issues in a more sensible way than... we do today” (E10_R1_SE).

“Family centres [...] where you gather social care services, children's health clinic, preschool... so you have a natural context where parents of children, from infants and up to preschool age, establish relationships with the relevant authorities. And where you can discover these families at an early phase and begin to provide support before they end up where they perceive they are being questioned and perceived as bad parents, and the children are being harmed. There have been these kinds of attempts... where they have included someone from social care services during the obligatory home visit from the children's health clinic. And then you also make sure you have met the families several times during these early phases and [...] established good relations. And then you have something to stand on and build on further” (E10_R1_SE).

Round 2 (reflections)

The collaboration among different services is described like a chain. However, there are needs for an agreement regarding the overall responsibility for the collaboration to work. Otherwise everyone's responsibility can easily become no one's responsibility. Collaborations between the community-based services and NGOs are discussed.

“Everyone sees the need for expanded collaboration, perhaps primarily with healthcare and municipalities, when someone in the family becomes ill... and it... might not be emphasized enough really, this chain. I see it as a kind of chain that the young carers are in, or follow, that it bounces a little back and forth. And you must be a little flexible in where the support is given during different parts and with a short time-perspective too” (E3_R2_SE).

“A collaboration among healthcare, school and social care services, so that the child gets as favorable development as possible, in the current situation” (E8_R2_SE).

“Then it is this eternal problem, what is everyone's responsibility becomes no one's responsibility, so [...] someone must have a collaboration responsibility. Everyone should, of course, do their part, but to reach collaboration you must put that somewhere. And it must be on the social care services, in many cases, to have the collaboration responsibility. And that means the other professionals then must have established channels to the social care services” (E10_R2_SE).

“If, for example, non-governmental organizations arrange weekend breaks or camps for young people to get away [...] If the public welfare system takes an overall responsibility [...] makes sure there are opportunities, this can be a

way to relieve the children... The activities may be arranged by a non-governmental organization, so that you can meet others in the same situation [...] It isn't care, but it's like any summer camp [...] then we have shared the tasks wisely" (E7_R2_SE).

"I think it is completely insane that we have a whole set of help phones [...] There should be a single large telephone switchboard and there should be someone who could help with sorting. And who also always can make sure that everyone gets an answer. If you are not connected to the one most suitable, then you are at least connected to someone [...] This... to make the individual sit and call and call and call, and find a bunch of different numbers and figure out by oneself what fits best [...] It takes a lot of responsibility [...] But it's also ineffective, because it's not always for sure you use professional people [...] where they are best needed" (E7_R2_SE).

Involved stakeholders

Round 2 (reflections)

The reflections on which stakeholders need to be involved, result in the same conclusions as in the previous question about cooperation and collaboration. State, municipal and NGOs need to be involved in a collaboration around children, adolescents and their families. Structures, however, need to be clarified and created for this collaboration.

"Who are these adults we want around the children, that's what we are looking for all the time... We haven't really identified and will probably not be fully able to do it maybe... but we might need to widen our views a bit more than just school" (E3_R2_SE).

"What I missed maybe is this demand on what... on what different levels we need to do different things. Think about preventions... prevention perspective and [...] universal and selected and indicated levels, in addition to a general prevention" (E4_R2_SE).

"Not everything should be explained as illnesses, but [...] to see, it looks like this and we can catch it on different levels" (E4_R2_SE).

"And then you might also wonder, who should figure out in some way what needs this person has. Maybe it's not the social care services, but is in fact the school or someone else [...] student health or something, if the child is old enough to attend school. There are currently no structures for this in Sweden, as far as I know" (E9_R2_SE).

Social and health services

Round 1

Youth health services, primary care, and social care services, are mentioned by several as important actors in this context. These are also mentioned:

"Adult psychiatry if a parent is admitted" (E9_R1_SE).

"Children's health services must screen for this, children and youth psychiatry" (E10_R1_SE).

Round 2 (reflections)

Various aspects of the roles of social care services and healthcare services, and how they can assist supporting (A)YCs, are discussed.

"Different educational support groups [...] where you can discuss and talk about what it means to be a young carer and so on, or maybe psychological support services that are more on a selective level, directed to... groups that identify themselves as young carers. And then I think of another ... the last level here, or the indicated level, where you need to do very clear interventions with the families, with the children and so on, which then may be a more clearly task for social care services or healthcare" (E4_R2_SE).

"You are a next of kin from age zero. And you thereby have a right to... in cooperation with social care services of course, to receive the support you need [...] Healthcare has the obligation to inform about illness and to make sure you get advice and support [...] But there must be someone receiving you [...] and there we have the Social Care Act and the next of kin support [...] This needs to be developed, when you identify a new area you need to develop new strategies for it and new ways to work" (E8_R2_SE).

"The development of these children's agents [...] they need to have continued encouragement and guidance and training to... work in different ways... to conduct conversations and to... feel strong in doing these conversations [...] I processed an application last year for developing this in the southern part of the country [...] It's a considerable effort for every county to build up such an infrastructure. It was the region of Skåne that had worked very intensively, and as far as I know, the southwestern psychiatry district in Stockholm, has implemented children's agents. But I wonder, what about the rest of the country?" (E9_R2_SE).

"The social care preventive work [...] has been quite diminished for a long time, because of the resource shortage and the staff turnover [...] They have to focus primarily on the most serious cases, so the young carers [...] they are often very competent [...] Hopefully, it will be a greater... focus on preventive responsibilities, in the Social Care Act, making it easier to focus on young carers and their situation" (E1_R2_SE).

Public authorities

Round 1

Since this area is included in the responsibility of municipalities and regions, the municipal and regional authorities are involved.

“This is a responsibility for the public. It has to do with the municipalities and counties” (E1_R1_SE).

“Social care services [...] and the region has a great responsibility too, of course” (E5_R1_SE).

Round 2

The legislature needs to be involved and engaged in this area. The National Board of Health and Welfare Sweden and the Public Health Agency play important roles.

“Legislation [...] yes, it must go all the way [...] how to spread knowledge [...] both generally and specifically targeted to different groups are important aspects, and there the National Board of Health and Welfare has a responsibility” (E2_R2_SE).

“This general level could be held within the framework of public health services” (E4_R2_SE).

Schools

Round 1

The importance of school for identifying and supporting (A)YCs is discussed. In this context the role of student health services and, perhaps primarily, the role of the school nurse, is raised as significant.

“When it comes to identifying [...] expanded student health services, for example... could be of help” (E9_R1_SE).

“In many cases school has the possibility to discover problems [...] but also in many cases it may be a haven, if you at least come to school. A haven from this... extra responsibility at home. If you don’t come to school, it would be good to have an extra resource in school, who can check where you have gone” (E9_R1_SE).

“But then, of course, student health services have a key role in this. A school nurse who sees this child can become a key person, who then engages the healthcare and psychiatry, social care services, and makes sure these authorities gives the child the needed support [...] the school nurse is, I would say, the one who most often has direct contact with parents in difficulties, and who you feel confidence in both from the child’s side and from the parents’ side” (E10_R1_SE).

Round 2 (reflections)

School is described as a knowledge-conveyer for both pupils and parents. The school’s possibilities to identify and support (A)YCs are further discussed. Student health services is again raised as an important actor in this context.

“The school is, of course, a way to communicate knowledge, both to children and parents” (E10_R2_SE).

“School is an important part in identifying these children. Where you know that parents... there is a circumstance [...] from a school perspective you can be observant of this [...] Is this child given the opportunity to carry out... have a meaningful leisure time and carry out the schooling, both attend school and... to be able to do homework? Being able to participate, to have the things you need to be able to participate. There I think, school has a very important role” (E8_R2_SE).

“You should have the right, I think, to work much more with social issues. You need to strengthen the social vision of student health, so to speak, and much earlier [...] you need to have social workers starting in the elementary school [...] preschools need to have student health services” (E10_R2_SE).

“School is of course... preschool and school are important actors of course [...] the majority of children are there [...] and just as well you... meet a school nurse and have health checks and conversations and with doctors [...] it should be natural that everyone talk to a social worker, about other issues” (E2_R2_SE).

3.8.4 NGOs

Round 1

NGOs play an important role for many children and young people. NGOs can also act as good partners for giving support to (A)YCs. Therefore, people who work in these organizations need to receive information and knowledge about (A)YCs.

“Those children who manage well, I think, have found a... perhaps have joined a football club and think it is really fun to play football [...] or something else, photo or something. It is a haven there where you have a complete different life and meet other people, and no one knows how difficult it may be at home sometimes [...] just by being there, you can help young carers [...] Maybe you don’t need to talk about support in their caring role, but support in being a young person. Yes, who gives joy and positivity and [...] meaning in life” (E9_R1_SE).

“Cooperation naturally with the non-governmental organizations... or nonprofit organizations, but that is not where the responsibility should be” (E1_R1_SE).

“Nonprofit organizations [...] I think, the UK, for example [...] where you work with young carer organizations, I don’t know if that is a way forward, but it’s a way to reduce the stigma in some ways” (E2_R1_SE).

“I think there are possibilities with nongovernmental organizations and others who... absolutely have a role to play here, because... they do it already in many areas [...] both church communities of various religions and so on, but also sports clubs and others [...] in fact, they already do... in many ways a fantastic social work” (E4_R1_SE).

“Then there are always those children who don’t... whom we do not reach, and they can be reached by all these other good organizations in the country. And therefore these organizations may need information on support and so too, about... even if they have no responsibility... they need to receive more knowledge about opportunities to support these children” (E5_R1_SE).

Round 2 (reflections)

Based on the results from round 2, the discussion on the importance of NGOs for (A)YCs continues.

“Where shall we make them visible then? [...] Where is their living space and where do they stay? It’s also in their leisure-time activities and out in clubs and so, you cannot forget those parts [...] Who will bring the knowledge? Who will do the training for this? This is also an interesting question [...] If we talk about Sweden, is it the Swedish Family Care Competence Centre or the National Board of Health and Welfare, or whom should it come from and how” (E3_R2_SE).

“And about those selective levels then I think that... it should lie on... the municipality and the county [...] but maybe the nonprofit sector has a... can also have a role [...] There is a long tradition with good intentions [...] They have had group activities for children with difficulties in different ways, and can be important partners [...] foundations [...] religious... associations [...] sports clubs, could play a role in this” (E4_R2_SE).

“quite a lot is done by nongovernmental organizations. And it is good in a way, and we talk a lot about that, that we should bring in nongovernmental organizations. But we could also discuss if [...] if this is a sign that we... that things are not taken care of properly in social care, so we have to hand it over to nongovernmental organizations [...] When it comes to... to create... a good leisure-time and relief, to get away, there is a lot today that... [...] is done by nongovernmental organizations” (E7_R2_SE).

“We have to go out to the schools and... together with young people and teachers do some joint work about future care [...] We have to go out in leisure-time activities [...] to those who play football, ask the football teams how they think... So we must get out to them, we cannot just sit in our institutions and invite them to come to us” (E7_R2_SE).

“I think ‘Maskrosbarn’, if we return to the issue of relief. This has always been an idea, that it’s nice for children to get away for a while in the summer... during the summer holiday and so on. But then it depends on... if these are children who are so involved in care at home, how should they be able to get away? It isn’t enough that you invite them to come to camp or get away a bit. You must make sure there is someone who does the job they otherwise do and does the checking as they otherwise do” (E10_R2_SE).

Level

Round 1

There are needs for changes at all decision levels.

“This is something that is required on several levels” (E10_R2_SE).

“You would need to create [...] shared responsibility for all these different decision levels, over the authority boundaries” (E7_R1_SE).

Round 2 (reflections)

The reflections in round 2 are in agreement with what was found in round 1.

“It strengthens... strengthened my opinion about this, that you need to do interventions on several levels. So this idea I have that I told you about last time, that you think about this from a more general or more universal perspective and also more selective, more indicated efforts in different levels in society, this is really needed everywhere” (E4_R2_SE).

“the concept and this perspective need to be included in different regulations and legislations, to be mentioned. But this is probably not enough, it’s also necessary to connect it to what you actually are supposed to do at different levels” (E4_R2_SE).

Local and regional

Round 1

The experts’ statements is about both local and regional levels.

“And I think that this must be a shared responsibility, but it must be first at the political level, civil servant level and down into the field” (E7_R1_SE).

“And it must be a shared responsibility-taking in the municipality, county. And then you have to have decision platforms for this” (E7_R1_SE).

Round 2 (reflections)

“There are many efforts at many different levels, I think, both at the individual level regarding individual civil servants and employees in the various services, but also at the political and legislative level. So we have to work with the whole... entire package” (E2_R2_SE).

“Young carers are so many in society so [...] this general level could fit in the framework of public health services. And, when you need more selective measures, or indicated [...] then you end up in healthcare or social care services or other [...] organizations, but the basis should lie outside those systems” (E4_R2_SE).

National

Round 1

At the national level, legal texts and children’s rights versus parents’ rights are discussed.

“Legally, they can talk with the children if the parents allow it. Again we let the parents’ rights and parents’ integrity be prioritized before the children’s needs. I think this is unreasonable. If you live with a parent with mental illness, or with substance-abuse problems, you have the right to get information from the care, about this... What you do? What treatment is given to my mother or father, and how it is going? Is it going well? Can I count on her getting better? So it is unreasonable in some way that they are not informed” (E10_R1_SE).

Round 2 (reflections)

The reflections in round 2 concern: upcoming changes in the Social Care Act; implementation of the Convention on the Rights of the Child, in Swedish law; a new commission report on provision of interpreters; the concept (A)YC needing a definition and a place in legislation; and the necessity of regarding each individual as a next of kin from the moment of birth.

“The new Social Care Act that has been proposed [...] as I understand, the Social care services are going to work more preventively [...] This might make it easier to work more with this kind of support” (E9_R2_SE).

“Now when we are implementing the Children’s Convention [...] address these issues in relation to the Children’s Convention articles [...] address the children’s rights” (E10_R2_SE).

“We have an ongoing survey in Sweden, which aims to investigate the provision of interpreters, but also to investigate what may be needed to prevent children not to be used as interpreters” (E1_R2_SE).

“Somewhere in the law you need [...] to state that you have to pay attention to children as next of kins and being young carers and then a definition [...] or something overarching from the National Board of Health and Welfare that says that this term should be related to that legislation” (E8_R2_SE).

“The municipalities have a lot of self-determination in this, of course, but you also have things to follow, what do I have to fulfil in this legislation, what do we have to provide [...] And should that legislation be strengthened with that you are a next of kin from... next of kin is from zero years...” (E8_R2_SE).

Ideas about the funding of programs

Round 2 (reflections)

One thought is that changes do not always have to cost money.

“It may also, in some way be an approach, that in turn is raising awareness among colleagues about this target group, and that does not need to cost a lot of money” (E6_R2_SE).

Funds

Round 1

Supporting efforts for (A)YCs and their families should, according to the experts’ point of view, be financed by state and municipal funds. The costs for this, they say, pay for themselves in the long run if the interventions lead to fewer young people being affected by mental illness.

“We also... performed an economic analysis that shows extremely high costs if you don’t do anything [...] Perhaps there are initial costs, but you retrieve them in the long run” (E1_R1_SE).

“It depends, of course, on if it’s a municipal service or state service [...] State resources primarily, I think. To make sure skills are there and resources are there [...] But in the long run, I think that you... benefit from it” (E2_R1_SE).

“It must simply be financed by taxes, the society [...] based on both purely economic reasons and this being a responsibility for society” (E4_R1_SE).

"I am so convinced that these kind of things [...] must be nationally financed [...] The municipal self-government doesn't increase because you have... you have to do everything out there, and it would be much better if we... instead of getting those general state grants, that there was a part of the national budget that was targeted to these things [...] Everyone struggles to find money. And ... then there is no cooperation among them, because they need to try to find their own financing. It's just stupid, I think" (E7_R1_SE).

Round 2 (reflections)

Financial solutions are proposed, for an expansion of the nonprofit help and support telephone lines, which are presently insufficient to tackle the needs:

"You should receive financial support for expanding such organizations [...] there must be financial resources for staff" (E6_R2_SE).

"Some kind of... telephone switchboard that helps increase accessibility, but that also prioritizes [...] instead of the state distributing small funds here and there, you could do some kind of large investment in order to establish this function and then nongovernmental organizations may get the task of filling it with content, in various parts" (E7_R2_SE).

"We have enough money and space to do special solutions [...] I'm not at all sure that it is always cheaper if you offer these narrow standardized solutions, because often it is more effective when you make it possible to... adapt to the individual" (E7_R2_SE).

Expectations according (A)YCs in the future

Increase in informal care + Challenges reaching (A)YCs +

Increasing awareness leads to development

Round 2 (reflections)

In order to go ahead and develop functional and effective support interventions, at least in Sweden, the distinction between the terms 'children as next of kin' and '(A)YC' must be defined, clarified and spread. Furthermore, the view must be widened regarding what is included in a caring responsibility.

"About our Swedish approach being [...] more 'children as next of kin' [...] That we have this approach in Sweden, also says something about our view of 'children as next of kin' [...] children as victims, children as exposed, children as vulnerable. This our focus [...] Children as 'young carers' is more about children who actually do something, who is an actor. We have to gather these two, I think. It's not one or the other, it is both together" (E2_R2_SE).

"All these projects and organizations for supporting young carers [...] I am a little scattered [laughs] about this [...] on one hand it should not be necessary. On the other hand I know that it is necessary [...] It is important to discuss and there we can really learn from... other countries [...] need to discuss advantages and disadvantages [...] If we, the whole time, look at children as vulnerable and victim and suffering in some way, we easily miss this other part, with children... and young people who contribute a lot and who learn something [...] an experience for life" (E2_R2_SE).

"I think of theoretical approaches for how to think about 'care', and when it can be harmful and not harmful [...] It is a large part of caring and is at least as heavy as you taking care of someone in practice [...] that you reflect on how you should act and... figuring out the needs of others, and the anxiety also comes in [...] Reflecting on what I should do, because I am awfully worried now for Mum or Dad, or whoever it is. So that part must also be paid attention to, as a caring activity" (E2_R2_SE).

Results - Slovenia

Visibility and Awareness Raising

Main findings

First Round:

Experts pointed out, that YC are an overlooked subject in Slovenia and that there is a need to raise awareness about this problem, especially in social media and in educational field. YC in Slovenia are not regulated under any law, although they are not unknown to the experts, since they have experiences or have heard for young people providing care to their relatives. They emphasized the importance of developing a definition of YC and stressed that it is important to be cautious not to invent the problem by forming a too broad definition of YC. Experts pointed out that the core issue is whether care responsibility represents a burden to them and whether it is a permanent long term responsibility. They stressed that organizations in direct contact with young people should be primarily responsible for detecting the problem, especially primary schools, physicians and organizations engaged in the field of social home care.

Firstly, I would like to emphasize, that this is relatively overlooked subject, especially in Slovenia (P1, R1, Slovenia).

Raising awareness and getting in contact with YC in the social media (P7, R1, Slovenia).

There is no awareness about YC in the educational field (P9, R1, Slovenia).

We should be careful about not to invent the problem by forming a too broad definition of YC, the core issue is whether care responsibility represents a burden to them and whether it is a permanent long term responsibility, since every young person has some caring roles in their families (P9, R1, Slovenia).

Second Round (Reflection):

The majority of experts in the second round agreed that visibility is very low in Slovenia and that there is a need to work on awareness raising, however, some of them expressed their concern with the fact that raising awareness is meaningless, because YC's involvement is never voluntary. In addition, one of the experts stressed that the reason for low visibility might be in the generosity of the welfare state, while the other claimed that YC are a symptom of multi-governmental approach failure. The connection and similarities between YC and child work were expressed. In addition to Round 1 experts stressed the importance of the definition, which in their opinion, should not be focused only on specific age, but on their dependency/student status and should be as broad and flexible as possible to acknowledge a number of situations in which young carers can find themselves.

I.../ the first step is to identify young carers, while the second step is the fact that a child in this age period is never voluntarily included (into caring). It is a fact. Therefore raising awareness among children and parents is meaningless (P1, R2, Slovenia).

I.../ Young carers are a symptom that something is not working in this multi-governmental, intersectoral approach. (P5, R2, Slovenia)

To me it seemed parallel to the child work in Slovenia I.../ similarly there are young informal carers and probably there is always some degree of care work in the family, but when certain degree is starting to interfere with the normal development of a child, then it becomes a problem and only then it is also a social problem. (P8, R2, Slovenia)

No, I would not limit it neither to fifteen nor to eighteen, I would go wider. Younger as well as older, who are burdened - maybe you are a student and you have to financially support a family - therefore I would limit it to as long as they are dependent, as we already have it. (P4, R2, Slovenia)

As I understand it, in Slovenia, the definition of who is and is not young carer will, in my opinion, affect the recognition and future definitions of this problem. Therefore it seems logical to create this definition as broad as possible I.../ to acknowledge a number of situations in which young carers can find themselves in (P8, R2, Slovenia)

Firstly we should have some sort of a strategy, for example we should work on awareness raising and establishing what the number of young carers is, because one part will always stay in the family as help to a fellow man, but what is more than this (a help to a fellow man), what is considered as care, should be restricted with some additional programmes (P7, R2, Slovenia).

With regards to the results from other European countries, experts emphasized that UK stood out, because they already have programmes and services developed in this field. Additionally, Sweden is mentioned because of their belief that childhood should be free from caring roles. Experts stressed that seeing YC as a problem can be a symptom of inoperativeness of other social systems.

I think that England is recognizing it a little bit more (than other countries), they already developed some things. Otherwise I think the results are similar everywhere, the concept is not visible and it would be reasonable to think about how to support these people. Somehow I don't see any extra specifics (P4, R2, Slovenia)

I.../ I think Sweden is standing out in key findings from country specific results, as they are saying that childhood should be free from having a caring role - but I do not believe that it is the belief of all cultures/countries, what is also visible later in the case of Switzerland, where they are emphasizing the difference between migrant and their (Swiss) children. While Swiss children are keeping their caring roles for themselves, migrant children are seeing care and caring roles as something normal. Italians don't even see this problem - I do not know, maybe it is a matter of cultures and the more or less family centred welfare systems. I.../ it is possible that in the countries, where we see young carers as a problem,

they are actually the symptom of inoperativeness of other social systems or subsystems - education and health system, long-term care system, social system, etc.. (P5, R2, Slovenia).

Local level

First Round:

Mixed feelings about local level are expressed, with some experts emphasizing the importance of bottom up approach and some with critics that a local level is too low for this problem. They stressed that services and organizations in the field should be qualified to acknowledge YC, however, the home help services differ on the local level, since municipalities are responsible for their provision and price. One expert emphasized that there are more young carers in rural areas and within deprived families.

I imagine young carers could live in the settings/communities where home help is inaccessible, too expensive or if they live in economically poorly situated families (P1, R1, Slovenia).

We have to start top down. To get an insight and to proceed from the local level. Basically that the municipality shares the information about how many people there are at their disposal and how many are needed and also which programmes they finance (budget). /.../ (P4, R1, Slovenia)

For this kind of thing, a local level is too low and with a regional level we do not have any experiences, even though it is operatively (P5, R1, Slovenia).

Second Round (Reflection):

Similarly, to the first round, local level is stressed as important, but a concern is raised by some of the experts that the state would pass everything on a local level. However, some of the experts especially emphasized mezzo level. In addition to the first round, some of the experts pointed out the differences in the financial resources of municipalities, which could result in different quality of certain measures.

That we need to take a look inside and see if there is a problem and what it is and then occupy ourselves with it. Then I also think that the local level is important /.../ it is important that we work on a local level, but on the other hand, we need to be careful that the state would not leave everything to the local communities. Meaning that if it is a local level, things should not have been done in a way that the state would "wash its hands". (P3, R2, Slovenia)

*Yes, it is emphasized in a couple of bullets, that in order to detect the problem, the interventions must be successful on a local level, but in our case (Slovenian) the division of care from the national to the municipality level, would not be reasonable, due to the difference in financial power between municipalities. (P5, R2, Slovenia)
/.../ I would include the local community into planning different strategies and policies, because it is a more flexible way as if we start at the highest level, for example with acceptance of legislation (P7, R2, Slovenia).*

I think this bottom up approach or an approach, based on mezzo level is better, than if we would primarily move to the legislation level - I am speaking for Slovenia - because if the problem would be bigger, it would make sense to cover the macro level, but in our case we can plan on the experiences other countries have with schools (P8, R2, Slovenia).

Additional

First Round:

In addition to the visibility and awareness, experts stressed that a cooperation between existing systems and development of community programmes is needed in Slovenia. Again, it is stressed that there is a need to develop flexible definition of YC in order to encompass numerous situations of YC. Schools and health care institutions are emphasized as responsible for the acknowledgement of the problem.

There is no need to develop a new system, what is needed is a cooperation between existing systems and infrastructure (P6, R1, Slovenia), good prevention programmes in the community (P2, R1, Slovenia).

To develop an overarching, flexible definition of YC, which would encompass all specific situations that YC are facing (P2, R1, Slovenia).

Most interviewees see schools and health care institutions as the ones responsible for acknowledging the problem and for applying appropriate interventions (P8, R1, Slovenia).

Second Round (Reflection):

Additionally, difference in visibility between different countries was emphasized and the issue of drawing a line, where negative aspects of informal care start showing up in young people, is pointed out.

I do not know, I find it interesting that almost all countries are dealing with low visibility of the problem with exception of some countries standing out /.../ especially in a case of UK, where they have the least problems with visibility, while on the other hand Slovenia probably has the lowest visibility /.../ (P8, R2, Slovenia).

Where to draw a line between what is wanted or normal - normal informal care and where the negative aspects of informal care starts showing up at young people (P8, R2, Slovenia).

Strategies, interventions and programs to support (A)YC

First Round:

There were different strategies and interventions mentioned, from developing awareness and destigmatisation programmes, to the development of functioning relationships within the family in which YC is living. To empower YC with the needed information about caring and to provide information where he/she can find support. Experts stressed that it is important that a YC is voluntarily engaged in caring for relatives and that he/she is not under constraint. One of the important strategies mentioned was early recognition.

The most efficient and consistent helping strategies are general awareness and destigmatisation programmes. That young carers are acknowledged and that they can share their experiences with other adolescents and that they can find support not only with their parents, but also at school counsellors, in the nearest hospital, from their older relatives (P6, R1, Slovenia).

We have to establish a relationship with a family, a working relationship. This means that first of all we need an information that the family needs something and when we have this kind of information, we can offer them concrete information (P4, R1, Slovenia).

/.../ when this situation is acknowledged we have to examine it with official mechanisms /.../ and ensure that /.../ this situation is regulated, that the burden is acceptable for a child and that he can handle it and is willing to do it. (P5, R1, Slovenia)

I think the key to all these matters is early recognition and afterwards informing and acknowledging, which could not be properly carried out if there are not enough information available about who is YC, who is not a YC, what is cool (acceptable) and what is not, what it causes in an individual /.../ (P6, R1, Slovenia).

Second Round (Reflection):

In addition to Round 1, it was mentioned, that there is a need to appoint a responsible person for perceiving the problem of YC. A need for a cooperation between different sectors was also pointed out. However, some of the experts raised their concern about developing special programmes and raising awareness about YC, since in their opinion we should engage firstly on the prevention programmes, that there would be no YC.

I think so many hopes are laid to the Centres (for social work) as if they will do numerous things, but in reality they do not have either finance, or time for it (P4, R2, Slovenia)

/.../ I think that specifically for our country (Slovenia), there is a need to appoint someone responsible for perceiving this problem. Someone must coordinate the efforts on this field (P2, R2, Slovenia).

/.../ it is true that the cooperation between different systems should probably be improved /.../ to create some sort of institutional network committed to better recognize and address this system. (P8, R2, Slovenia)

I think the strategies were captured and the idea to detect them through education and health system seems important to me, what is open is the next step /.../ I would say that we need to focus on preventing that young carers would even emerge /.../ the other path of interventions is, when someone already is a young carer, to try to relieve and empower him, offer him support, etc.. (P5, R2, Slovenia).

With regards to strategies and interventions mentioned by experts from other countries, differences and similarities with other countries are pointed out by one of the Slovenian experts.

It is obvious that Scandinavian countries see it more as a problem, some sort of child protection and that UK has a lot of programmes. I found Switzerland interesting with their notes on the difference between migrant and Swiss children. Italy is probably similar to us - I think the reason for the low visibility could be that they are not seeing it as a problem, but as a part of normal family functioning (P5, R2, Slovenia).

Strategies, interventions and programs

Laws and regulation:

First Round:

Experts emphasized, that there is no policy or regulation related to YC in Slovenia.

Second Round (Reflection):

While the majority of experts agreed that there are no policies developed in connection to YC, one of the experts stressed that everything depends on the context in which we detect YC. Experts emphasized that there is no need for a creation of a new system/legislation or a new law, while some of them stressed the need to create a small body or pressure group to address the problem of YC.

/.../ to me, personally, I do not find it reasonable to create a special law about it /.../ we would probably need some sort of all-embracing framework /.../ (P4, R2, Slovenia)

Certainly, as is written here, not invention of a new system, but the invention of a small, intermediate body, some small, integrative and flexible structure, as for example pressure group or a body, which will act on already existing systems and push them into solving these (young carers') issues (P5, R2, Slovenia)

/.../ social legislation rarely addresses them. Anyway informal carers are rarely addressed, young informal carers I guess even rarely (P8, R2, Slovenia).

/.../ I do not agree that there is no policy regulation connected to ... carers, because if we put it in context, we can apply the legislation and regulations connected with the protection of child's rights and interests and in this sense it would be harmful to discuss it as a completely separate matter (P9, R2, Slovenia).

/.../ we need to place it in a context and one of the contexts could be the protection of child's rights /.../ within the concept of child's rights, the state's obligation is to protect a child from exploitation, sexual and physical abuse, labour exploitation and from negligence. /.../ we can place it (YCs) in the context of labour exploitation, because it is typical unpaid labour /.../ unpaid labour of children is problematic if it interferes with other developmental goals children have in a certain age period. However in our case the problems are connected to neglecting the child and in some way we can talk about using his/hers time for tasks, which might be inappropriate or burdening for a child (P9, R2, Slovenia).

Education:

First Round:

Schools were emphasized as the most important institution for acknowledgement of YC and the development of special procedures and programmes within schools was mentioned. In addition to schools, Centres for social work were also recognised as important actors. It was emphasized that schools should be a contact point and it is very important that the doors are always open to YC, when in need of help.

I would say that it is the responsibility of school services, to contact everyone that needs it. After all it probably is not fair to shift the responsibility on them, but it is the only contact point where all adolescents are present (P6, R1, Slovenia).

Schools should be an entry point in some way. They should be the first to acknowledge/perceive the problem, then they should also have a written protocol about how to act in these situations (P1, R1, Slovenia).

Second Round (Reflection):

In addition to the first round, some of the experts expressed their concern with too much expectations from the schools and the Centres for social work, while others emphasized them as crucial actors. The importance of developing certain protocols was additionally stressed, and it was added, that in schools there should be a screening process in place. Early detection of the problem is of crucial importance, because when children are 14-17 years old, it could be too late to "save" them. An idea was raised by some experts that YC could get a special status in schools, similar as the status of sportspersons. An expert emphasized his/hers concern that teachers are not empowered enough to recognize and help YC. Inability of schools to interfere into family matters and their lack of cooperation with Centres for social work was also stressed by experts in the second round of interviews.

Now that I am seeing it for example at school, I think it is impossible that all teachers will understand it and even implement some sort of screening afterwards. I do not think it is as simple to reach the goal through schools and teachers. I would say that Centres for social work are the better fitted institution to reach and implement this concept and to be additionally attentive. (P4, R2, Slovenia)

As far as I am familiar with the Slovenian system, getting the status of a young carer, would be the best, the easiest and the most effective way, because when a person would get the status, it (the status) would define who is a young carer, what he/she does and what special needs he/she has in connection with it (the status) (P1, R2, Slovenia).

/.../ despite everything, we need to be aware, that the school cannot interfere with the family as such. The school can point to something, but it cannot coordinate or intervene with the family

/.../. The school can help in the part that concerns schools /.../ but it cannot provide something interfering with medical area, or coordinate financial help for example. There are other services responsible for doing these things (P6, R2, Slovenia).

Yes, I was surprised by these results that they depend on schools to such an extent, because in Slovenia, I do not see them (schools) as an important actor or as having an important role. They cannot even handle special needs students or cases of abuse, let alone young carers. /.../ I mean, because I am familiar with this area and I can say that schools are not familiar with young carers' issues and I doubt that they would be keen to accept certain measures in connection with them (P7, R2, Slovenia).

I think it would be good to have some protocols about how to act /.../ when various actors detect negative aspects of informal care with a young person. So the school would be aware how to act upon it, who to contact, maybe some case management - in a sense of an individual approach to problem solving /.../ how to create a network of service providers to solve this problem. Therefore a case management approach seems important to me in this situation. (P8, R2, Slovenia)

I think that if you want to save a child, you should start saving him/her already in primary school /.../ when he is fourteen, fifteen years old, it is already too late. It is hard for me to say where the age limit is, /.../, because there is a lot of hidden burden, however I would give a child status of a young carer much earlier, /.../ (P1, R2, Slovenia).

Welfare:

First Round:

Experts stressed that welfare support should be developed for YC and their families.

I think certainly we should materially support families, I have to say that Slovenia, in this sense, has (to a certain level) relatively generous material support for families in crisis (P3, R1, Slovenia).

/.../ Centre should be a coordinator of a help network in the local community. /.../ To inform us, that there is a special situation in the family, therefore they would probably need additional help. And also raising awareness about this area of work in the media (P4, R1, Slovenia).

Second Round (Reflection):

Additionally, some experts emphasized that we should reconsider the role of the Centres for social work, while others stressed a possibility to create a list of guardians, which will be able help YC and relieve them of their caring role/duties. The need to train professionals working with children and to empower them was emphasized. In addition some experts pointed out, that there are information available about certain diseases, but are not specifically aimed for YC.

I think that we should probably re-think the role of Centres (for social work) because as I am watching them from the distance, I am noticing their powerlessness and incapability, caused by the completely financial factors. Furthermore we should rethink their role and destigmatize them - the belief that people seek their (Centre's) help only when they reach the bottom (P4, R2, Slovenia).

Maybe to create a list of possible guardians, which can cover for you and help with care, if you want to go out (P7, R2, Slovenia).

Yes, for sure, it is good that youth workers, as well as social workers are informed about it (young carers). (P4, R2, Slovenia)

/.../ obviously we need to perform some trainings (for professionals) to teach them how to acknowledge young carers and how to detect and solve more problematic aspects of this problem, because informal care is not problematic per se if it does not affect other aspects of young carer's life. (P8, R2, Slovenia)

We do not need to find completely new approaches, but to train the professionals in this field, to empower them with the information about young carer's existence /.../ (P7, R2, Slovenia).

I was surprised that they have special programmes developed in the UK, while for others I think that they, similarly to us, mix what we have and don't have - for example in Slovenia, young people can get information about the parent's disease in different associations/NGOs such as Sonček, Sožitje, etc. /.../ it already exists, but it is not specifically tied to young carers, but to a specific condition - a disease or an accident /.../ (P7, R2, Slovenia).

Goals, strengths and weaknesses

Laws and regulations:

First Round:

A need for uniform procedures was emphasized.

I think it should be more uniformed, to know that you will get exact and correct information no matter which Centre and which person you call (P9, R1, Slovenia).

Second Round (Reflection):

Experts emphasized that YC issues could be inserted or mentioned within long-term care legislation, which is currently still under discussion (in Slovenia). As they mentioned before, they do not see any need to create a special law or legislation for YC, but to insert this issue of YC into already existing legislation. One of the experts mentioned Law on marriage and family relations as sufficient enough to protect YC.

/.../ it would be good to take a look at the long-term care law and there would be no harm if we would, now as we do not know anything concrete, insert something simple in the Long-term care law /.../ because it does not make sense to me, that we would have a special legislation about it, considering the fact that over regulation can be dangerous. I don't know, some special rights or maybe even some money (financing). It is all just strengthening their status (YC), because as soon as it becomes a legal status, the people will take it for granted and will formalise some of their statuses and it is dangerous (P3, R2, Slovenia)

/.../ there is no need for a special law for young carers. They can be mentioned within the Family Code (P7, R2, Slovenia).

For the future, these kinds of things as no policy or regulations, is not going to stick, because we are not going to write a special legislation and special policies about it and there will not be special institutions, etc. (P9, R2, Slovenia)

For now article 119 of the Law on marriage and family relations in which it is stated that "the Centre for social work is obliged to take necessary measures, required for the protection of child's interests", gives us the right to act accordingly. It is a general article and should be sufficient for everything - we do not need special law (P7, R2, Slovenia).

Education:

First Round:

Screening in schools was mentioned as important measure in the first round of interviews. Additionally, experts stressed the need to have some tools or procedures for acknowledging YC and contacting Centre for social work to support and help him/her. It is necessary to empower them and to convince them to seek help. It is of crucial importance to have qualified professional always available for talking with them and helping them in these situations.

Probably there should be some sort of a form or a questionnaire, some sort of screening, through which they could detect if something is happening to a child, as for we have it for violence detection. /.../ to have some regular channels, where it could start an alarm if a child takes over too much care (P8, R1, Slovenia).

A child would need information about where to seek help, when he can not handle it anymore. /.../ We should support them with information and enable them to spend quality leisure time and to participate in extracurricular activities (P4, R1, Slovenia).

Second Round (Reflection):

Some experts stressed their concern with schools not being competent enough to efficiently screen for YC and especially to coordinate different processes, especially due to the lack of authorization.

/.../ but as you know, the school doesn't even take care for these learning things, and it happens with girls, which you can see are intelligent and that it (their intelligence) is not the problem. They said to both of them that they should attend remedial classes and if they do not show up there, nobody deals with them. And here we are expecting that school would occupy itself with young carers (P4, R2, Slovenia).

I think the school is an important institution regarding the identification or a place, where young people struggling can find help. But school as a coordinator of everything else and not school as an institution solving their situation, because they (schools) do not have professional staff nor is their purpose to solve their (YC) problems /.../ I felt (in the results) as if it's the school's responsibility to solve their (YC) problems. They are laying too much hopes on the school in a sense of solving their situation (P6, R2, Slovenia).

Welfare:

First Round:

Emphasis should be on the prevention, awareness and destigmatisation as well as cooperation of different systems. Interventions in a form of self-organization and informing interventions were stressed by experts. Almost all experts mentioned self-help groups as an ideal solution. The crucial goal is the support for all individuals involved in the caring process - the whole family, person in need of care and young carer.

The support of individual without supporting his family is like watering the sand in the desert (P3, R1, Slovenia).

What is helping YC is to hear others with similar problems and courses from psychology or interpersonal relationships and it is important that organizations include someone with personal experience into programmes/support groups (P7, R2, Slovenia).

Second Round (Reflection):

Experts agreed that the programmes should be designed with and for them. Additionally the complexity and the need to solve this problem interdisciplinary was mentioned.

I absolutely agree that the programmes should be designed in cooperation with them (YC), so we would be able to really originate from their needs (P7, R2, Slovenia).

/.../ I would emphasize two things, which are important to me and about which we have already spoken - the cooperation between different stakeholders, between different sectors, meaning social, health, education sector and civil society. /.../ it is a complex problem, probably derived from the fact that some people's needs are not satisfied /.../ and that it is truly important to solve this problem interdisciplinary. /.../ the next important thing is the proposition for co-creation groups, for the re-involvement, meaning that all the stakeholders, especially young carers and probably their parents, families /.../ need to be involved into the decision making process, because we are seeking the solutions for them, therefore they need to be involved (P5, R2, Slovenia).

Regarding results from other countries, the influence of the welfare cuts on the situation of YC in the UK was stressed and that early recognition (which was mentioned by Sweden) is of crucial importance.

I find it very important, what the English are finding out, that the welfare cuts are influencing the situation /.../ that if the state passes it (care) to the private sphere, than we have to count on children not having support. The state has to acknowledge its responsibilities for social reproduction or care work /.../ early recognition, some of the countries also mention early identification, for example Sweden /.../ shortly there is a need to detect it as soon as possible. I think it is important /.../ to develop interdisciplinary training programs (P3, R2, Slovenia).

Coping strategies and support groups

First Round:

Experts emphasized that children, caring for a family member, grow up too fast, which results in adult functioning as a coping strategy and has important developmental consequences. They shared mixed feelings about coping strategies and support groups, with ones emphasizing support groups as coping strategy, while others stressed that coping strategies are not suitable for children.

I think probably this manner and this hyper adult functioning is a strategy, which develops /.../ however this, in a sense, has consequences for his/her development (P3, R1, Slovenia).

Therefore, we have to be very careful when talking about coping strategies. We can not teach people or agree that basically still children (those younger than eighteen years old) provide a big amount of care for their parents and then offer them only coping strategies, etc (P8, R1, Slovenia).

I advocate for organized user/support groups, to which professionals do not have a direct access, however there has to be some level of responsibility. There has to be an individual to whom potential complaints can be addressed to and there has to be a record (P6, R1, Slovenia).

Certainly these support groups are very good for people in distress, people with special needs or some additional burdens. /.../ But I am sceptical about this identity ascription - "okay so I am a young carer and there is a website for me", I think it is double-edged. I think it is very double-edged (P3, R1, Slovenia).

Second Round (Reflection):

Experts agreed that coping strategies are not an appropriate solution, since the goal should be not to have YC and not to teach them how to cope.

That every child needs to cope with it, but we do not need to teach him how - because coping strategies means that you teach people how to adapt to their status and how to accept it. Obviously you have to learn handling your own situation, but to overly emphasize it would mean, that they would have to accept their situation the way it is (P3, R2, Slovenia)

/.../ coping strategies are definitely not a reasonable thing, especially for this target group. If we are talking about young people, for them coping is definitely not the right thing, because it mainly speaks about burden and stress, and burn outs are not prevented with coping, but with withdrawing from the situation/.../ ultimately in the end coping strategies do not present a good direction for this research (P2, R2, Slovenia).

Additional

First Round:

Experts stressed the role of youth organisations, and that the informal care of YC should be acknowledged - certificate of young carer as a future reference for finding work in the labour market. On the other side, some of the experts strongly opposed this suggestion.

Hypothetically thinking, we could have a profile of youth carer, to whom we would acknowledge some competencies, that he could enforce later on the labour market, etc (P1, R1, Slovenia).

Let's say Youth Centres /.../ where these children, anyway they are just children, do not have to take over so much responsibility (P3, R1, Slovenia).

Second Round (Reflection):

Hesitations were expressed about the role of youth organisations, since they are politically focused (in Slovenia), therefore they can not have a crucial role in addressing YC issues.

I am not entirely confident that youth organizations in Slovenia could be—I don't know, I think that they are occupied with completely different themes, such as political participation, therefore this one seems a bit off. It seems to me, that within the framework of long term care /.../ on the systemic level, I think it would better fit into the framework of long-term care (P8, R2, Slovenia)

/.../ if youth organizations would recognize these activities of young people or as everybody is stating that we could formalize the accumulation of various skills so they can be taken into consideration later on the labour market as some sort of training and actually used on the labour market (in the future) - that makes sense to me (P8, R2, Slovenia)

/.../ non-governmental organizations and youth organizations could have a role, but not a crucial one (P3, R2, Slovenia)

Future needs to support the well-being and health situation of (A)YCs

Main findings

First Round:

Experts emphasized that there is a need to detect, recognize, acknowledge and support YC. The development of integral approach is mentioned with cooperation between different ministries (Ministry of labour, family, social affairs and equal opportunities and Ministry of health), schools and other institutions connected with children and their wellbeing.

This means acknowledge, evaluate the amount of it (YC) and research which already existing programmes could cover a part of their needs and what else would we need. /.../ There are a lot of programmes, we just have to connect them and recognize what the family needs and what we can offer them (P4, R1, Slovenia).

Principally I think the key element is to recognize peculiarities of every situation. /.../ And accordingly to the recognition of these individuals, the long term plan should be based on more coordinated activities and cooperation of social and health pillar (P2, R1, Slovenia).

Second Round (Reflection):

Experts agreed with the need for cooperation between different actors. A need to establish specific programs in the future is emphasized, as one of the experts stressed that the problem will probably increase in the future.

Basically this network of different actors should be well connected - if we imagine a young person with troubles at school, caused by his absence as a consequence of him caring for example for his parents - the professional at school should know who to notify in the Centre for social work and then this professional at the Centre for social work should have his/her own protocol who to call and how to act, how to communicate with such person (YC), because these are young people and probably their problems differs from the problems of older informal carers. (P8, R2, Slovenia)

It is true, if we speculate a bit, that this problem could increase in the future. I think it might happen, because some of the survival strategies in Slovenia are going in the direction, that if a family or a household cannot provide certain services on the market, that the person being cared for needs, then they rely on informal care. And we see it with "normal" informal carers, and will probably also see it with the young ones, therefore we should not underestimate the problem /.../ (P8, R2, Slovenia)

At first we need to acknowledge a need and establish some programmes, then we should create a working environment, also for the relief of young carers, financial means, and in the end the regulation of the legislation of this field (P7, R2, Slovenia).

Future needs to support well-being / health situation

First Round:

The experts mentioned necessity for the development of integral (all-in-one-place) organizations and some sort of continuity and exchange of information among the experts was emphasized, that a child would not need to tell a story from a scratch.

First we have to evaluate how spread is the problem in Slovenia, and then apply measures (P5, R1, Slovenia)

There should be a flow of information about YC, so that the professionals working with him/her could see his/her history and to build on that and not to have to start from a scratch every time the person comes to another professional/institution (P9, R1, Slovenia)

In this sense they have to be very flexible, they have to know how to reach young people and they need to be available when young people need them to be. This is in a sense of accessibility, then they have to be educated in youth work and how to approach young people, in a sense of plural approaches. We have some organizations in Slovenia, that lack that plural approach (P8, R1, Slovenia).

Second Round (Reflection):

In general, experts agreed with the development of an integral approach. They emphasized that the integration should occur on a systemic level, and that the approach needs to be flexible. Furthermore, the majority of experts stressed the importance of getting the overall picture of the whole situation in order to reach a reasonable and informed decision. It is mentioned that the Institute for home help should be included into different programs. One of the experts stressed that many times there is no need for protocols, if we use common sense.

/.../ because flexible approach is appropriate from this point of view. (P8, R2, Slovenia)

Probably some sort of integration, which needs to be on the systemic level making sure that there is the flow of information or that it is informative. Here (in Slovenia) I think we are thousand years behind anything and what we are talking about seems utopian or some sort of an ideal /.../ (P4, R2, Slovenia)

We need to get the overall picture of the whole situation in order to reach an informed and reasonable decision - if a social worker has an information from the health centre in which the person is currently located, an information from school about the level of education of this involved child, and if he/she (social worker) has an information of the Centre for social work about the home situation. But if the decision of the social worker or a medical personnel is one-sided, then this decision can be very invasive, and there would be more incorrect than correct decisions (P2, R2, Slovenia).

/.../ but the programmes should include The Institute for home care (in Slovenia) so the adults would provide the majority of care to the person in need, so the young carers would rarely be burdened with it, because it does not suit to their age, or to their needs. It is truly a completely grey area, /.../ (P7, R2, Slovenia).

You know /.../ everything cannot be done just with protocols, there is a need for a certain framework and so on /.../. Sometimes /.../ we should use common sense if we see a tired child or a child in need and simply ask him/her "how can I help". /.../ just to regulate something with protocols does not always work. I am realising that since we have all these protocols, about abuse for example, but there is even less reporting, because there are formulas to be filled out, and so on /.../ (P7, R2, Slovenia).

(A)YC needs

First Round:

Experts stressed that support for the YC is of crucial importance and that services supporting YC need to be integral and flexible, while the goal needs to be that the YC is not alone in the situation.

It is absolutely hard to imagine that this issue could be solved isolated. It did not appear isolated, because this child did not suddenly start taking care for something that appeared yesterday (P5, R1, Slovenia). In this sense they have to be very flexible, they have to know how to reach young people and they need to be available when young people need them to be. This is in a sense of accessibility, then they have to be educated in youth work and how to approach young people, in a sense of plural approaches. We have some organizations in Slovenia, that lack that plural approach (P8, R1, Slovenia).

Second Round (Reflection):

Generally, experts agreed that we cannot discuss and solve this problem isolated. Additionally, they mentioned a psychiatric check-up, which, they believe, should be added to the already existing health screening in schools. Social conditions of a child should be screened when enrolling to kindergarten/school.

/.../ mainly I would like to see some regular interview or a psychiatric check-up added to the already successfully performed basic medical examination in schools (P2, R2, Slovenia).

/.../ it is important, here under "additional" - "that we should not examine the problem isolated, because it did not appear isolated" /.../ it would be reasonable to have a broad perspective towards this problem - why it is appearing, how it manifests and afterwards, what influence it has on a young person. However, it is a social phenomenon of a kind, because we can perceive it in different shapes in different countries

/.../ in our case (Slovenian) we should perceive it as some sort of systemic problem, in a sense that if it will become a social problem it will be because our system has failed. (P8, R2, Slovenia)

The social conditions of a child, coming to the Centre or in a school or in a kindergarten should be systematically investigated, because in this way we will get the information about family needs (P7, R2, Slovenia).

Professional and family needs

First Round:

Concerning professional and family needs experts emphasized the importance of cooperation between different stakeholders and institutions. They also stressed the need for home help and other services, which would help not only YC, but also their families.

/.../ it is compulsory to provide parents with certain services, when we find out that a young person is a carer. Absolutely. I think there could not even be a situation in which children would provide care for their parents (P8, R1, Slovenia).

In this sense they have to be very flexible, they have to know how to reach young people and they need to be available when young people need them. This is in a sense of accessibility, then they have to be educated in youth work and how to approach young people, in a sense of plural approaches. We have some organizations in Slovenia, that lack that plural approach (P8, R1, Slovenia).

Principally, I think the key element is to recognize peculiarities of every situation. /.../ And accordingly to the recognition of these individuals, the long term plan should be based on more coordinated activities and cooperation of social and health pillar (P2, R1, Slovenia).

Second Round (Reflection):

In general experts agreed with the findings of first round interviews. Majority of them agreed that we need to work with a family and to empower them, so that YC would not need to be burdened with care work. Additionally, some of them emphasized the problem of privatisation of care work, which is believed to contribute to the increase in the number of YC in the future. In terms of professional needs, acknowledgement of a context and social embeddedness of a YC was emphasized. With regards to the results from the first round, a concern was raised that we over psychologized the problem of YC.

/.../ this long-term care law is very risky, to say at least, there is a lot of risk connected to it, due to the fact that it leaves a lot of care privatised in the family sphere /.../ so there are certainly a lot of risks in more care being passed on to the children. The more the care is privatised and reduced to the private sphere, the more possibility there is to get even more young carers. /.../ however there is nothing helpful here. Once we get to this point, we cannot solve the fundamental inequality, caused by us and by the state, with individual programmes, because we are pushing the family into it and then offering support and support groups for the children (P3, R2, Slovenia)

As long as the care is privatized, the family is organized in that way and you cannot reduce it with an individual programme (P3, R2, Slovenia)

Otherwise the burden and the role of young carers could be decreased with empowerment of families and patients in need of care. If chronic patients would be supported on the systemic level, it would considerably decrease young carers' burdens. Therefore the problem should be addressed in its roots, not with the coping strategies and applications for young carers enabling their survival (P5, R2, Slovenia).

It has been proven repeatedly that if you do not understand the context in which a person is living, you can't understand his/her problem and you certainly can't solve them (P3, R2, Slovenia).

The only thing I think is that we should not over psychologize it /.../ it is also important to understand the social embeddedness of this child. Not only what he experiences, but also his embeddedness into the (social) environment - what is happening to him/her, what networks he forms - social networks - outside the psychology (P3, R2, Slovenia).

Then I think there is a little too much emphasis on psychology (I am not sure in which country report I have seen it) - as if it is just the matter of psychology, that you have to know the psychologic profile, and so on, but it is not true. There are

also sociology and other sciences and it is crucial to embed it into the social context, that it is important to understand not only what the young carer is experiencing, but also his or hers social position. /.../ (P3, R2, Slovenia).

Working concepts to reach (A)YCs

First Round:

It is possible to reach (A)YCs through social and health care. When adults seek for care, help, or support, their “children’s situation and needs should be investigated”. In addition, we can reach (A)YCs through their leisure activities and social media.

It has to be investigated what are the family needs, what they actually need, what type of help do adults, for which young carer is caring for, need and also what are young carer’s needs (P4, R1, Slovenia).

Second Round (Reflection):

In general experts agreed that family needs must be investigated and added that in order to provide efficient support, we need to develop broad, supportive and counselling approach and a well-functioning healthcare system, which would be closely connected with other services. Some of the experts stressed, that the first round results are too generalized. Some other emphasized that we need to be careful that the qualifications for working with YC are not too narrowly defined to exclude relevant experts.

Broad, supportive, counselling approach /.../ and that those young people would know where to seek help or if they acknowledge them (YC) to offer them support and support-groups /.../ that there would be more integrated institutions, which would be able to direct them. And really some wider forms of support (P4, R2, Slovenia).

It means all together - a well-functioning health system and orientation toward prevention in connection with other stakeholders in the community. We can prevent it if we are looking the bigger/broader/complex picture. What to do when someone already is young carer and has a stressful situation? - I think we already have services, such as psychologists in schools, personal doctors, and then when it escalates there are CSDs (Centres for social work) to solve really critical cases of an individual child. We also have some security systems, which would probably also be able to tell how many cases connected to family care they had had (P5, R2, Slovenia).

/.../ that all these things I have read /.../ I think they are too generalized, in a sense, that there are so many tricky perspectives as to just give them a sticker, or to define them as a special group, because many times we have some lame campaigns and flyers and we would play the destigmatization card and with such things, we often shoot in the dark with these things (P4, R2, Slovenia).

If I was conducting this research, and would read this, I would say that it is all garbage, that it is all completely useless. Because everything is general, nothing concrete, cooperation - I mean, there is nothing in it for me (P1, R2, Slovenia).

I would emphasize that in Slovenia we should be really careful, because it can quickly happen that the qualifications needed to work with young carers could either become very specific, or they could close the doors for some experts /.../. I would say that a broad network of professionals, able to help young carers, needs to be established (P2, R2, Slovenia).

Responsibility

First Round:

Most of the interviewees argued that the primary responsibility to acknowledge YC and to address the issue is on the state. In the field of identifying the YC the primary responsibility is on the school system while the responsibility for developing programmes and strategies is primarily on the state, to support and develop laws and regulations, considering YC, and to provide them with information, additional help in order to relieve YC. Some experts stressed the importance of Centres for social work.

I think the responsibility is on the state, from two different points of view. Firstly, to provide a systemic, a systemic approach toward the problem, where the major emphasis would be on public and non-governmental services, thorough which families could be palliated. That enables defamiliarization, right /.../. Secondly on the field, it is clear that we have to establish some measures, programmes, which could be financed via some tenders through Ministry for labour, family and social affairs and Ministry for health (P1, R1, Slovenia).

/.../ in my opinion these Centres for social work should probably have a network of such people or a group of people /.../ qualified. Which means social educators, social workers, maybe psychologists, I mean psychologists with additional training (P3, R1, Slovenia).

/.../ the state should, via its mechanisms, take the responsibility over this kind of family. The state has to be the crucial coordinator and has to lay the foundations everyone can connect to, and basically to give a status of a volunteer to a young carer. Volunteer, so to say, that he is doing it voluntarily. He should not have to do it as a forced labour and to his detriment (P5, R1, Slovenia).

I would say that it is the responsibility of school services, to contact everyone that needs it. Afterall it probably is not fair to shift the responsibility on them, but it is the only contact point where all adolescents are present (P6, R1, Slovenia).

Second Round (Reflection):

In general, experts agreed that Centres for social work are the responsible actors, while for school system, some of the experts took a step back from the first round, saying that schools are not appropriate facilitators and that teachers and school counsellors are already overburdened. Additionally, they pointed out, that schools do not have appropriate authorisations and while everything is being passed schools, we forget on other services. Majority of experts agreed that it is the responsibility of the state and its welfare system to establish and develop programmes and connect all ministries and institutions into a good working system.

It is all right that it is a school matter, that school should acknowledge it, but what seems lost in these findings are the responsibilities of other services /.../ (P3, R2, Slovenia).

/.../ the biggest deficiency, as far as I know the health and social system /.../ is weak cooperation, lack of consistent activities, but probably the government is responsible to connect all the ministries into a good-working system (P5, R2, Slovenia).

The schools are not the appropriate facilitators, because when a child is incorporated into an educational process, it does not matter who he talks with - if it's a principle or a psychologist - everybody is connected and a child does not feel safe to discuss his/hers problems there - at least for me, school was not a secure environment. Therefore, either it is a Centre for social work or counselling centres (P1, R2, Slovenia).

/.../ it would be reasonable to pass this responsibility to teachers or psychologists in schools, even though this would be a big expectation from them, since they are already overburdened /.../ (P2, R2, Slovenia).

My personal opinion is, that the state should take the responsibility for the development of programmes for the young carers (P7, R2, Slovenia).

I think that Centres for social work should be responsible for the formal establishment of the mechanism for the family protection and also for the protection of the carer as well as the person being cared for. It should not exceed the capabilities and possibilities of the child, it should not harm him in any other area, but I would not go as far as to say that children cannot do it (care). However it is a question of to which extent /.../ it has to have a nature of voluntary cooperation within the family /.../ because you want to help, but it cannot be to the detriment of YC development (P9, R2, Slovenia).

Funding

First Round:

Majority of the interviewees stated that the responsibility to fund the programmes is on the state, while some of them mentioned that it can be funded from the long-term care budget. Some experts stressed that financing could also come from EU projects and that finances needed to support YC are often exaggerated. Programmes should be financed by different ministries. This should be the responsibility of the state and not municipalities, since if the financing is left to municipalities, there would be significant differences among the larger and smaller as well as from the richer and the poorer municipalities.

/.../ I think it can be a part of a general system, because if you provide care, it is connected to a long term care, isn't it? Okay, it could happen that it is a short term care, if a mother goes to operation and would need fourteen days of care after it, they can agree on it and it is probably not even acknowledged in the system and it does not need to be. But if these are people with a long term need for care, then we have already existing long term care systems (P8, R1, Slovenia).

I think from the side of ministries or state, from the states' side /.../ Yes, the state should be the one responsible for taking care that the things would not be left for municipalities to handle, because then it would all depend on the development of the municipality, on the number of citizens and on the percentage of caregivers (P9, R1, Slovenia).

If we discover that it is a new matter, something additional, we would need additional resources. But if we discover that it is something that already exist, something that should be or is already covered within programmes of social and health policy, prevention or education policy, then we should cover it with existing resources (P2, R1, Slovenia).

Second Round (Reflection):

Concerning funding, experts generally agreed with the results from the first round. Additionally, they pointed out the problem of public tenders, causing NGOs to adjust their activities to the requirements from public tenders posted by different ministries in order to receive funding. Furthermore, some of the experts emphasized that in order to get funding, something must be perceived as a social problem and if it is not relevant enough, it is hard to obtain funding. One of the experts stressed that the additional funding of YC, can be a step into the wrong direction, since it could lead to more YC. Furthermore, the short duration of project based funding was emphasized as an issue.

The Ministry for social affairs gives out the public tenders and all of a sudden all NGOs start researching and working in this areas /.../ and because there is funding available everyone adjusts their activities to it. So I would not over emphasize it /.../ because then, they start to exploit some areas and what happens is that the state loses its interest, and these residual policies, or policies which are based only on programmes and not on the prevention of some fundamental—I don't know what, they lose - and it happens regularly, that the state loses its interest after a couple of tenders or they find another area more interesting (P3, R2, Slovenia).

The problem in Slovenia is, that it will soon lead to people saying it is not a problem /.../. And as long as something is not recognized as a social problem, it would not get any funding. Maybe it would be reasonable to emphasize the prevention of the problem, so the strategy for Slovenia would not be that it is a big social problem and we should address it through public tenders and financing, but that it should not become a big social problem, therefore we have to act preventative and in order to do it, we need some funding (P8, R2, Slovenia).

Resources should be given to some non-governmental organizations by the Ministry of labour, family and social affairs (P8, R2, Slovenia).

So much money probably won't be available for young carers specifically, therefore the most interesting target group for us will have to be saturated (P2, R2, Slovenia).

Regarding the future needs connected to funding, I think the most important thing is where to get funding. If we put the burden on the state and emphasize it as a big enough problem, then getting it (the funding) should not be problematic. If not, we would need to connect all relevant projects and interested people and establish things in such a way, that they would be able to continue permanently in the future. The "cancer" of all these projects is that they are set for a limited time period and after the project comes to an end everything being established is abandoned (P2, R2, Slovenia).

It is a question of how it will be designed, how will it function, from where it will be funded and there can also be some additional risks, for example that the families and groups dealing with young carers, are the most vulnerable groups per se and if this is be something they would need additional funding for, it can only be a step in the wrong direction. There will be even more people deciding to care for a family member inside the family and not spending the money on long-term care insurance. Therefore these new forms represent some risks. Probably these endeavours for health strengthening in the communities and now developing Centres for health strengthening in the communities are reasonable and it would also be reasonable to present the problem to them, as something that can be solved with cooperation of different stakeholders, for example civil sphere, municipalities, state, health systems, social work (P5, R2, Slovenia).

Results - Switzerland

General View from Experts (2nd round)

Second Round (Reflection):

There was general agreement of the results from the first round:

E: I mean you know I know most people probably that you interviewed from Switzerland there aren't many of us these topics and I think we all kind of agree so actually most things that are in here I would support (E3, R2, Switzerland (CH)

In general there is an academic discussion about the percentage of adolescents who are affected by caring. E1 is referring to this number and thinks that the number is probably higher:

E: Um I think that the current results I statistics of child carers we have 5, 8% in practice my practice, I think there is a little more, young carers, I think there is a little more. Because the problems are currently wide among children and teenagers and teachers are not forms for many problems and returns to me or the school psychologist and in each problem there is a part of young carers.

I: OK so it the problem is bigger than we think perhaps:

E: Yeah (E1, R2, CH)

Visibility and awareness raising

Main findings:

First Round:

In Switzerland, the visibility, awareness and understanding of Adolescent Young Carers ((A)YCs) is low or invisible at the local, regional and national level. The term young carer is generally not known. The idea that a child takes over care for their parents, siblings, etc. is practically not recognised. Few people talk about this topic and stigma remains. Caring by (A)YCs is generally not seen as an important issue by professionals. Research on the topic has raised awareness with some organisations.

E: I think that in Switzerland it is not much visibility at this moment. I think that it is a topic that no one talks about. I think the people that know this topic they talk about it. But all other they don't know that this is a topic in Switzerland because it is invisible. I think it is invisible. Yes. (E4, R1, CH)

Second Round (Reflection):

Research is raising attention of (A)YCs:

I think the awareness it has risen because there is some research that has been done on the topic but as we've discussed before it's on the topic, it's within the mental health sector it's for parents with mental health problems and not with somatic problems. (E2, R2, CH)

I would argue actually as academics we have to look at this a bit more it's more complex than that, so on the one hand actually quite good collaboration I would say in the individual case but more problems in the, or not a lot of interaction for in the professional discussion (E2, R2, CH)

E: OK so, so maybe but [inaudible] working, they could be the same you have at the head of child protection unit at Children's University Hospital Zurich, is a practitioner and in practice he works quite well with the [HES Zurich etc. : DP] but [HES Zurich : DP] and child protection unit um at Children's University Hospital and they [inaudible] at different conferences they don't this might be actually the same people who do know each other from practice but to participate in a in very different professional debate so I would I'm fighting for more, for more interdisciplinary debate in [inaudible] and around child protection. (E2, R2, CH)

E: I think we are at the beginning but I think in the last 2-3 years we developed I think together with Careum because our school is part of the actual quantitative study and together with Careum we always have contact. They come to our presentations or we are part of their study and this for me it's very important because I can use the results of the Careum and research for my lessons and for my students and I can show to my students the films and the interviews from the congresses from Neuchâtel for example and this for me it's a great beginning. I think we have to go on in this way and I think like this is okay for the moment I think in the whole Switzerland there is more to do but step by step I think it increases (E4, R2, CH)

Local level

First Round:

Some interventions at local level have started to raise awareness of the topic of young carers. E.g. In one municipality, some programs that aim to support (A)YCs have been started in schools.

if you are lucky and you live in an area where there is a little bit more (E3, R1, CH)

Regional level

First Round:

At regional (cantonal) level, the visibility and awareness of (A)YCs is still low. Most of the cantons are not aware of the issue, but there are differences between linguistic regions: In the German-speaking part there is a little bit more awareness than in the French and in the Italian part.

E: (inaudible) in the Swiss German part there are a little bit more in the Swiss French part (inaudible) in the Italian part... there they have even less so it would completely depend on the location of (E3, R1, CH)

E: No. No. It is a good abstract about it. Yes. Something I recognized. You asked the difference between young carers at first. I think there is a difference if young carers live rural, also in ländlichen Umgebungen, oder cities, or in multigeneration families where multi generation are in the same house I think there it is more normal to help each other than in little families in cities. I think there may be a difference between the young carers but also between the support of the young carers. (E4, R1, CH).

Second Round (Reflection):

E9 is surprised about the low visibility in the Italian and French speaking part of Switzerland because the “social services” are more developed in these parts than in the German speaking part.

E: And that the cantons are not even aware of this, that is exactly what it is. Awareness of this is also lacking. (...) Yes. (...) Then what surprises me a little is that in the, (...), in the Ticino part, it is really hardly present. (...). I am surprised that in the French and Italian part in particular it is so weak, because they actually do much more social work. (E9, R2, CH)

National level

First Round:

There is no visibility of (A)YCs at a national level. This might be due to the fact that young carers are not a major group and that Swiss families tend not to speak about these issues because they fear interference from the social services. There is some awareness of the issue in the mental health sector, but adolescent carers of people with a physical illness are not a topic at all. The national media usually portrays younger children (4-9 years).

E: Yes then... at a national level I think visibility does not exist (E1, R1, CH)

E: But visibility in Switzerland is still very low that is a topic that is not much talked about it isn't talked about it's actually mainly the area of mental health problems adolescent carers of people with [a chronic illness; EG] is not a topic at all (E3, R1, CH)

Second Round (Reflection):

Agreement with no visibility

we have low, low low visibility in Switzerland. (E1, R2, CH)

Additional

First Round:

(A)YCs are a `difficult-to-reach group` because they are between systems. They typically don't see paediatricians anymore and they do not communicate their situation to their GPs. They have finished the regular nine school years and then typically start an apprenticeship or further schooling.

E: They are typically not identified in Switzerland which also have to do ehm it's a difficult to reach group because there they typically don't see paediatricians anymore they don't ask their GPs... they finished the regular 9 school years here in Switzerland then typically start an apprenticeship or further schooling so they are really in between systems so they a difficult to reach group and as I said there is very little awareness (E3, R1, CH)

Health professionals come across (A)YCs regularly but do not realise they are a specific group of children, different from other children. Other issues are seen as more serious problems (e.g. violence, obesity, chronic illness).

It doesn't exist it's a shame...it's a shame uh when I talk to my colleagues... paediatricians or when I talk to psychologists and from helping child sociologists, now because now I know him a little bit... they say; EG] ah no but it's not serious ah no no and then what's important for them is the violent children it's the children... uh obese it's the hyperactive children it's the chronically ill children but the helping children... are not visible [then; EG] for them it's not a problem it's not a problem (E1, R1, CH,)

Health professionals are aware that there are children who take over some responsibilities for their family but they do not know the terms `young carer` or `adolescent young carers`.

E: Yes. So how shall I put this? We do not use terminology. We don't call them `Young Carers`. We don't label them, they are children who have a mentally ill parent. And we take care of them, advise them, support them. We don't call them `Young Carers`, but we call them, well, by their name, (laughs) see what support they need. Like this. (E10, R1, CH)

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

E: Ehm there's very little... I'm actually not aware of any significant media coverage of young carers in that age group (E3, R1, CH)

In Swiss families, children tend not to talk about their caring roles. It is something private and hidden. They fear that the school and the authorities will find it out. For foreign children, it is a normal thing to care for family members in their culture and they are more open to talk about this.

E: Take care of my dad... the children in Switzerland Chaux-de-Fonniers uh they are in La Chaux-de-Fonds and the families can't say it, they don't say it... don't say it because we have a system here in Switzerland when the child is... is safe (...), the protection of the child who comes and who poses problems... for the psychologists, the social workers this remains something hidden: in the Swiss family... and in the foreign family. It is spoken about, but it is normal [the expert probably means that it is normal in foreign families to care about their relatives, they speak about it and do not hide the fact, that they are caring for their family members, FB]. (E1, R1, CH)

Support systems are often not seen as supportive, but as intrusive. The result is that children carry their burden for an extremely long time before seeking help.

E: Both. I think both. The one is stigma because when other people or other students know, you have a mother who drinks alcohol, I think there could be mobbing and so on. I think this is the one. Or to say, we have a family that is not functioning. Who wants to tell that the family is not good? That the family not works. And the other in a little jüngere, younger children, I think it is the fear, they take my mother away. They take my mother and they do her in a clinic and I don't want that anyone take my mother even she is ill. And I think that is a great fear. Or they take me away and they take me as child in another institution. I think that is also a fear by the younger children. When they are eighteen they are adult but when they are younger this problem may be. Yes. (E4, R1, CH)

Awareness rising in the field of psychiatry; conference about children of parents with mental health issues.

What we have done, I think we support the Mental Health Network, and they had a psychiatry congress in Basel two years ago, so they have the Mental Health Network, combined with an international psychiatry congress in Basel, which took place there and they have taken in mental health across the generations, and they have really paid special attention to these children of those who are mentally ill. (E9, R1, CH)

Low research on the topic of children as YC of parents with mental health problems in comparison to the amount of caring undertaken by children.

E: Well, now on young carers in general, I can't say that, no. That's why we do this, I think the data situation in Switzerland is low in this respect. So we can already say that due to the information we have in the field of mental health about children of mentally ill parents, the proportion of those affected is actually quite high. But that's actually a problem. Well, that's fair to say. But of course we cannot say really how far they have an active role as young carers, so it is not, they have not been questioned about their active role. (E9, R1, CH,)

Visibility might also have a negative effect. Visibility means recognising the issue as a problem, which could be in contrast to the idea of a family where it is viewed as natural for family members to help and support one another.

E: (...) I believe that this is so contradictory, so making it visible would mean naming and naming could possibly have negative connotations and might violate the concept of the family itself. So family means being there for each other and looking after each other. Labelling the caring role as a 'problem area' might contradict this. (...) (E8, R1, CH)

Second Round (Reflection):

The stigma is higher in the field of psychiatric diseases

in psychiatry there is also the shame that no one who is somatically ill is more ashamed of it, I think so. (E6, R2, CH:)

Health professional just do not see the problem- they often do not want to because of the time lacking, etc.:

E: (...) Many of my colleagues [E10 means medical staff, FB] are so one-dimensional. They'll be working straight away with their clients. And to think that he has another hat, that he still has a parent, that he has children, many just can't do that... (E10, R2, CH)

Agreement about lack of awareness; especially on the field of professionals:

E: Teachers and... The one thing that was lacking I think awareness is not just an issue with teachers and adolescent young carers, but it is also an issue about healthcare providers of the parent I think there is also a complete lack of awareness (E3, R2, CH)

Often research is guided by an approach to "solve problems" - so there is the danger that the term `Young Carer` has a negative connotation and becomes a label. There are also differences between the three areas of Switzerland (German part, French part and Italian part).

(...) the term young carers is illuminated rather deficiently, thus the target group young carers does not. So one would probably not describe them subsumed as capable young people who make a very important contribution to the success of family life, but one would describe them rather than young people who are forced (...) to take on tasks that are not adapted. Do you understand what I'm trying to describe? It is like that young carers describes as a brand, as a notion rather a maladministration than a positive state. (E8, R2, CH).

E: And I wonder whether the statement does not now reflect what is so long-standing cliché that the concept of family, cohesion is already totally different in Ticino than in German-speaking Switzerland. In general, then. And whether what

young carers describes as a concern is perhaps still perceived as problematic in German-speaking countries rather than in Latin-speaking Switzerland or the Latin-speaking environment (E8, R2, CH).

Disagreement: E8 is not sure whether foreign children are more open - and besides if the term `Young Carer` becomes viewed in a negative light, they are not open anymore to speak about their caring tasks.

E: (...) "Additional Findings" "For foreign children, it is a normal thing to care for family members in their culture and they are more open to talk about this." I'm not sure if they're more open. (...) That is as long as it is positively connotated. But when they fall into the negative, I think they are often not very willing? xx for reasons of loyalty. What I want to address is that from my point of view it is important that young carers do not become a problem concept, i.e. children who are so overtaxed. (...) (E8, R2, CH).

What should the German translation of Young Carers be?

And the other thing is...I was wondering how you would translate the term...in the third bullet point you say `Health professionals do not know the terms young carer or adolescent young carers`. What would be your translation in German? I was wondering ...to really assess if they know it, I would have to know it in German. (E2, R2, CH)

Strategies, interventions and programs to support (A)YC

Goals

First Round:

To avoid children taking on too many caring responsibilities (reduce the burden). To increase the awareness with teachers and (A)YCs themselves. To train professionals, and to provide individual support: to provide informal respite care; to help and support young people in their caring activities; to improve (A)YCs well-being; to strengthen self-efficacy of YC, especially children of parents with mental health problems.

Second Round (Reflection):

Disagreement of the goal "children taking on too many caring responsibilities". Expert knows (A)YCs who thinks that being a (A)YCs was a good experience. It is good when someone supports them, but only when the (A)YCs want the support.

I know some young carers that say it's not a problem I was a young carer but it was never a problem it was good it was good for my family it was good for the relationship between our family it was good for me to grow up for me to learn for me to get... autonomy I think for me that's important young carer to be a young carer is not just bad to be a young carer can also be really good I think there are 2 sides of this and because of that I think also young carers with [health ill; EG] can do it and can take responsibility and can be proud about this responsibility and not have to be bad you know what I want to say? (E4, R2, CH)

I think they need support but we don't have to get to take all away from them I think it would be good when they have a person who is there and who can give support but just so much support as this child wants I think the need of the child is important and maybe the child doesn't want support maybe it's okay maybe he says ok you are here and when I have a problem I can come to you but for the moment it's okay and then I think it's enough to know that there is a person I can go when my burden is overloaded as you said I think it's important to have a person to know where I can go that's important then I'm not alone but when this is okay I can do it at home without support or with less support as I need (E4, R2, CH)

Main findings

First Round:

Switzerland in general is still near the beginning of this topic (P4). In general there are no dedicated interventions for (A)YCs but support for (A)YCs comes through child protection routes and some more general interventions. There are a few new, mainly local programs, aimed specifically at supporting (A)YCs. Services vary depending on the region where (A)YCs live (German part offers more than the French and Italian parts).

In Switzerland there's a huge gap between the healthcare system, the schools, the educational system and the social system, those are all very different entities with little inter-connections. (E3, R1, CH)

Round (Reflection):

There is a discussion in the area of child empowerment; should we empower children generally, or should we focus on children with particular burdens, like (A)YCs have?

And, um, I think the discussion that you have to think more specifically about what you need for stressed children and how you can strengthen them, that would probably serve the young carers in my opinion. (E7, R2, CH).

There are more interventions & programs than we already have listed here:

Well, I think these offers that are listed are certainly good offers, but there are actually many more, if you look at them as offers for young carers and judge you should actually have a whole bunch more for children and the young people there is still on it. It's like a bit, there's a bit of one, just a selection of certain things, but there are so many projects and measures for children and young people. If you want to look at it openly, I mean. (E7, R2, CH)

It is important not to create new programs and interventions just for (A)YCs; it would be better to include this topic in already existing interventions and programs:

Yes, I think if you specifically demand measures for individual target groups, your own sensitization campaign, your own projects, then you simply end up paying the costs of the things that already exist. Where they are intended for similar goals. (E7, R2, CH)

Laws and Regulations

First Round:

Legislative framework: If a young person is under the age of 18 there's a legislative framework protecting them. The law focuses on children who do not get the care they need. The goal is to prevent children from coming to any harm and not to take unnecessary interventions. On the other hand, child protection does not aim to empower children - as it would be in 'prevention'. E5 also mentions the strength of the YC approach looking at the strength of (A)YCs and the positive value of their carrying; and not just on the "protective approach" of the child protection law.

E: It's and it does not it has to balance the protection of the child against the intervention into the families so that's not... legislation has to avoid unnecessary intervention into families so it's always a balance a dilemma between should I go in should I stay out so this has to be... does it meet the threshold to intervene but there's one thing all the intervention... intervention setting or the child protective services and the whole system but of course... we do have prevention programme who are looking at strengthening but... (E2, R1, CH)

Some other points :

- There is nothing about supporting or recognising YCs or (A)YCs
- The legislative framework needs thresholds to provide support and services (balancing privacy and protection)
- The legislative framework/child protection does not consider all the factors

Second Round (Reflection):

Disagreement about changing the legislative framework since it is extremely difficult in Switzerland because of the specific policy and political structure.

E: I mean legislative framework is extremely difficult to change in Switzerland and I'm not sure if that's the realistic way to approach this... there are very big topics that we lack a legislative framework and that's very difficult on the current climate to change that so I'm not sure that that should be the main focus and if so it would be on a Canton level which again which means you would have to address 26 different Cantons and work on legislative frameworks there so that's very difficult... then visibility and awareness I think that's being done in a good way but it's just way too small... and for that you need more private funding (E3, R2, CH)

What would be needed?

E: You would need that in every region of Switzerland... So you know it's again it's extremely difficult for things to migrate from region to region in Switzerland it's very much dependent of kind of key people that see after this topic and so I think as a first step that's what you would need... I would be probing an additional thing you know we have a similar topic children of parents with a mental health problem we have a national meeting and then we started to organise meetings in the Cantons and those travels from region to region where each area of different regions needs to organise that and then you have a natural collaboration of the different of the healthcare field the education field the social services and that model also would work for the topic of young carers you really need to bring the important people in one region together to look at what they want to do in the region... But the problem you find if you just go to the schools you know where do the young carers turn to then after they discussed it in their schools you also need to support the social services and the medical care system (E3, R2, CH)

Visibility and Awareness

First Round:

In respect to school programs, one foundation runs a programme in schools talking about mental health issues. A carer, a professional and someone with a mental health condition delivers sessions together:

E: As a foundation we have a big project where we go into schools with people who have a mental illness [so they] experience of that mental health problem...(E3, R1, CH)

E: But that has been very successful and a good way to reach teachers... It's done all over Switzerland but not in a significant enough number that actually every teacher will benefit from such a programme or that every student would have once during the school times such there are regions like my own region where I'm responsible for the services we do reach every single student and that is a good way to reach them (E1, R1, CH)

Overall, programmes are a useful way of meeting and talking about (A)YCs who care for parents. A good way of reaching students and teachers. Yet, all across Switzerland but not in significant numbers.

Educative films: a small association creates short films about different topics, including children of mentally-ill parents and siblings:

So, the films actually intend to bring up topics that are, just about family health and that are not very visible but very often are actually somewhere in the background, (...). The main aim of the films is to make experts aware that when they work with families, they should also look at such topics. (E5, R1, CH; translated from German to English)

It is valuable that the films can be used for training purposes, yet it is difficult to evaluate the effects

Foundation for the promotion of children's mental health has the goal to create understanding about mental illnesses and to educate the children in order that they do not feel guilty. It is positive that they use methods convenient for children; enabling effects and it supports children of parents with mental health problems. On a negative note, it focusses only on children of parents with mental health problems detected by health support system.

Then this institute is Kinderseele Schweiz, actually one has to say it is such an isolated institute, it does not have a national effect but more such organizations, it does not have to be an institute every time, but more such organizations into the care system purely where one treats not only the adults but also the children, the situation of the children very well and gives the children a framework to express themselves (E9, R1, CH,)

Approaches in mental healthcare

First Round:

The Open Dialogue Approach is one approach to mental health care, where professionals work directly with the entire family (Family Approach). This approach identifies adolescents at home and what responsibilities they have, with the aim of reducing the burden. Support is organised to support individual issues for family: parenting issues, health problems and school issues.

E: And that also cannot... it made me change how to think about young carers and really also the importance of it that would be the same here in Switzerland... I do of course young carers on a daily base whenever I treat adults with a mental health problem and we talk about them having children or adolescents... where I'm... I don't know if you are aware what open dialogue it's an approach to mental health care where you work from the with the entire family. (E3, R1, CH)

Quotes for family Approach:

And after the fourth phase that we will do in March... next year is to organize weekends with helping parents and children... with the Red Cross to spend a weekend in a chalet in La Chaux-de-Fonds and show that we can help them and the child and the child the teenager will do nothing this weekend and is busy [or he goes; EG] he will play with other children and parents will be busy with other professionals why because the caregiving children tell us I want to be a quiet weekend I can play I can see my friends and we will offer them this moment there with their parents but without them taking care of their parents (E1, R1, CH,)

Quotes for Family Group Conference:

(...) And I don't even think about it anymore. What is, for example, something that is there as a strategy, but that is unfortunately far too little executed, is the application of Family Group Conference. This is a very very simple !!?? Means of support. (E8, R1, CH)

E: Family Group Conference. There's a German expression for that. He calls himself the Family Council. But that's like, that's like, that's not comprehensive. This is an idea where, for example, implementation is much better in Holland than in Switzerland. And in Germany, for example in Stuttgart, very well implemented as a municipal offer. And that would be a very effective answer to the question. (E8, R1, CH)

Positive supporting quotes:

- This is done at home so professionals are automatically aware of other adolescents at home and their responsibilities, what they think about the mental health problem of their parent and how they cope

- Professionals are aware about the home situation from first contact; who helps and supports the children, how much caring do they have to do
- Work is done with the whole family network
- The family approach also encourages adolescents to talk about their situation at home and ask questions.
- (A)YCs are also encouraged to have a break from their situation.
- Every mental health trust in Switzerland will do things very differently which means they can be very innovative with good ideas.
- (A)YCs know who is caring for their parents and who they can call if they feel overwhelmed
- Easy way to support
- The problem is recognised and the family has to find a solution, if needed with other people
- Strong relation with the specific situation
- The care responsibility will be distributed among different people and not imposed on the child

Less positive quotes:

- Every mental health trust in Switzerland will do things very differently which makes it difficult to spread ideas.
- The system is too slow; health care providers involved in the open dialogue approach might not be able to enable the adolescents to cope better with their situation
- Underdeveloped in Switzerland; not accepted enough; no structures to implement it; funding coming from authorities (not voluntary anymore) and a sense of shame and of duty has been triggered; lack of a systemic perspective (too individualised).

Working on the stigma of mental health problems: One foundation works with adolescents on reducing the stigma of mental health problems. It also addresses the issue of young carers.

But that they also have this frame as, so that they do not yet[incomprehensible], so in the sense that a bit like expanded think, child soul Switzerland, because there they are very strong in this victim role anyway, they are picked up, but it is not everywhere then the case. But they have[incomprehensible] and burdens and they have to have a negative effect[incomprehensible] but how can one relieve them then rather.(E9, R1, CH)

Positive points are that the organisation is well connected and that they get in really good feedback on social media. Negative points are related to the small size of the foundation and it not sufficiently funded. Funding is for projects not regular services. Prevention of mental health problems is not funded.

Other Approached(s)

First Round:

In the French speaking part of Switzerland an organisation exists that provides interventions carried out by social workers (home visits)

E: State-funded eh when there is a problem in the family... if there is; EG] by the school by the doctors by the social... these people go into the families and try to understand what is going on... and unfortunately... appointments are 8 months a year appointments the appointment(E1, R1, CH)

It is positive that the organisation organizes additional help in neighbourhood. Yet, visits are only 8 to 10 months and need to be every one or two months. It is not YC specific. Neighbourhood assistance (e.g. quartier solidaire).

E: (...)therefore Quartier solidarity solidarity is an interesting approach because it goes very much to neighbourhood aid and also municipal support.(E9, R1, CH)

Early detection in day-nursery: attention not just of children with specific differences, but also of children who are quiet. Professionals learn concepts/tools/interventions to enable them to take action

E: (...) a KITA (day care) expert, how can one address that, and then there are also mothers where one has noticed, they are suddenly no longer well, they are, They have changed so much, and the child is also different in KITA (day care), that one has given them tools to address this and there were partly such topics that someone, (...).(E7, R1, CH)

Second Round (Reflection):

Neighbourhood assistance (e.g. quartier solidaire): problematic because the people might only help if they are affected by the topic of (A)YCs

“then those would say yes who are somehow connected with the (name) in such a way that they have the feeling that the problem concerns them. And those who are not, are not emotionally connected or are not affected by the grievance” (E8, R2, CH)

Education

First Round:

Different programmes have been carried out in schools in Switzerland. Professionals and people with an experience of young carers discuss the issue of young carers with students.

'I think that there are also students that have been young carers, but they don't tell it, because it is a taboo topic. It is a topic not everyone wants to talk about, I think.' (E4, R1, CH)

'I know that we have many children in the schools but I don't know how... I don't know how to get to those children' (E1, R1, CH)

There are some discussions about young carers. In one school, a discussion programme has been established consisting of 4 stages:

Stage 1: One staff member discusses the topic of young carers, explaining who they are with pupils aged 13 to 15.

Stage 2: Pupils identifying themselves as young carers.

Stage 3: Invitation to discuss further with staff and then also their parents.

Stage 4: Respite weekends with the aim to run a weekend break for (A)YCs and parents. Supported by an NGO. The young people will have respite from their caring roles and take part in activities. Both parents and (A)YCs will receive education to support their situation from educators. A further aim is to find alternative support for the families.

E: Yeah the children are doing some activities without (E1, R1, CH)

It is positive that (A)YCs have respite from their caring role. A quiet, fun weekend with friends and parents (without having to care for their parents). Parents are assisted by health professionals.

E: And then the parents the parents... there will be nurses there will be educators for the parents (E1, R1, CH)

Mind matters is also a support programme with the goal to talk about mental health problems with students. It is possible that it is evaluated and used all over the world and young people can decide what to talk about.

A platform (group) for young carers is supportive where young carers can regularly meet and share their experiences and talk with peers about their lives. It is positive that peers can better understand the situation than adults (P1). They can share their experiences and worries (P3), realising that they are not alone (P5), support can be given early (when there are low-level needs) (P5)

Peers might have difficulties in handling some difficult situations (P5)

... I think the only disadvantage, because that is an offer only those who really want to make use of it, the only disadvantage I could imagine is for the advisory peers. That perhaps young people calling who are in a very difficult position and because these peers who do counselling there can be overwhelmed. That's the only thing I think I wouldn't know what that looks like now... (E5, R1, CH)

Teaching the topic of 'caregivers' and family: in one Higher Education Nursing School, the topic of 'caregivers' and family is taught which includes young carers. Students were not aware of the topic before the lesson. But they think that it is a very important topic (P4). What is positive is that it increases awareness of topics among teachers and (A)YCs. In each class, students realised they are young carers and they are not alone in what they do. Students who are identified as (A)YCs can be referred to the school counselling (see below).

Students who learn about the topic can then spread this knowledge throughout their places of work.

E: Yes. Ok. Thank you. As you know I in Higher Education Nursing School and there I teach some topics and one of the topics I teach is about care givers and family. And during these lessons I tell about young carers. I tell the students about what is going on in Switzerland, about the actual project in Switzerland. And I tell them, what are young carers, how it is defined and I tell some stories about young carers, show some interviews and films. (E4, R1, CH)

School Counselling is also a method to support (A)YCs, which is offered to students who identify themselves as an (A)YC. Students can get support. It is positive that the school counselling works with the young carer to look at what could be the next step. The young person feels valued and not alone. People who are responsible for the (A)YC and that the (A)YC trusts can be contacted. The (A)YCs can be linked to psychological and social services for young people. Young carers get the respect for what they are doing. They get the feeling that is ok and that it is a good job and that they do not have to feel ashamed about it. On a less positive note, there are few school counselling services and it is often difficult to identify and to approach this target group. Students can be really fearful about what will happen (that they will be taken away from their parent especially when there is a psychiatric illness, like depression, addiction, alcohol, drugs); they do not talk about it.

'And my experience is that for them, often it is easier because they have the opportunity to tell about it. I think much of the burden goes, is a little bit easier when they know someone knows about (it) and someone is there.' (E4, R1, CH)

'He (student) said, 'But Madam when I get out of school, I have to pick up my little brother at school, arrive home at noon I have to cook because Mommy is sick she can't, she's at home.' (E1, R1, CH)

Second Round (Reflection):

In the second round there was disagreement; there are enough school counselling, at least in the canton of E3, but it differs from canton to canton:

E: With the school counselling I don't know if it is there it says that there's not enough school counselling... at least here's again it probably depends on the Canton but actually most schools I work with do have school counsellors and they are key players in this area and they are also the natural person that a child will go to with this kind of topic (E3, R2, CH)

One experts mentioned 'Mindmatters', which is a good approach or programme:

mind matters, "to talk about mental health problems with students". That is something I think is an extremely important point. There are so many good ideas. For example, it is our turn with Promente Sana to think about the implementation of "mental health first aid" in schools, where it is all about "awareness rising" for "take yours" and "try to differentiate, what are positive and negative feelings, and how can you adequately express them". (E8, R2, CH)

According to one of the experts, the program "Mind Matters" is described wrongly. It is more than just to talk about mental health. It also includes creating a healthy environment.

E: Yes, in part I don't think it's quite correct, so yes. If I would be a bit different, (...) at Mind Matters the goal is to talk about mental health problems. So that is not the goal of mind matters. The goal of mind matter is, hmm, to see in the school from the school management over the teacher up to the children that beneficial measures are implemented and that the mental health is strengthened over the life competence over the resource reinforcement, and then it has in there also most diverse products, (...) (E7, R2, CH).

First Round

In respect to child protection, there is a whole legislative framework for Children under 18 including an assessment of the situation. Children are referred or reported to child protective services when they develop problems. Child protection services provide tools to address the problems (e.g. neglect or child maltreatment, so a child might get assistance). What is positive is that school teachers are good at reporting if a child is a child in need as a result of behavioural issues and therefore identify young carers. On a downside, the child protection services only become aware when children are already noticeable and difficulties arise, e.g. at school and reported by other professionals.

E: School problems...ehm behavioural problems etc. some of them because they have to care for... for other persons because it's just too much for them and if such a child or young person is reported referred to child protective services so then they get a whole they get a whole toolkit to meet this problem but that's not... it's the general toolkits... tools not toolkits tools they have to encounter neglect or child maltreatment...well these [kids; EG] probably most the neglect so... but it's not... so a child might get an assistant which is the German in German is Beistandschaft (E2, R1, CH)

Assessment, screening, early detection is not done consistently in Switzerland:

E: So this but this is a big issue in child protection anyway assessment ehm one of the many problems that it's... assessment screening early detection that's all been so far that's often been done quite idiosyncratically in in Switzerland or not just Switzerland (E2, R1, CH)

The child protection services have a legal mandate so adolescent carers are terrified of child protection becoming involved.

E: Compared to other countries we have a difficulty with our social services because that's part of the legal system so they really I mean... the child protection services they have a legal mandate... so most adolescent carers are terrified of... child protective service I mean (inaudible) are terrified of them becoming involved they're the only one funding so this is really the difficulty... ehm that's a difficult problem how to change that how to get the funding even if there's mandate that the adolescents be taken away from the home... there will be the solution (E3, R1, CH)

You can't usually improve the situation of families with economic, socio-economic problems'. Instead structural problems in families need addressing. An 'offender-victim dichotomy' was often used in the past, but it is not applicable to (A)YCs.

So it's the view of the child is burdened so the burden has to go away, or that's actually the approach where you don't just do that, so not just the child protection, and I think the young carers approach has just, that's a little like child labour in the third world (E5, R1, CH)

According to the experts, child protective services have scarce resources.

funding so this is really the difficulty... ehm that's a difficult problem how to change that how to get the funding even if there's mandate that the adolescents be taken away from the home... there will be the solution (E3, R1, CH)

E: Well it depends the problem is... child protective services do always have to they usually have scarce resources (E2, R1, CH)

Second Round (Reflection):

There was disagreement that child protection services have got scarce resources:

And 'scarce resources' yeah, that's what, what the child protection services are complaining a lot but maybe this is within the Swiss context compared to other nations are resources are probably not that scarce actually (E2, R2, CH)

In addition, there was disagreement that the children are terrified of child protection services, and found this too strong wording:

I do yeah 'The child protection services have a legal mandate so adolescent carers are terrified' Um I don't know if terrified is really. Terrified is maybe too strong and I would I don't know of any study who ask young people if they are actually terrified of [inaudible] or child protective services. Not so sure if this is just an expert assumption. I can't tell it as I don't have the empirical findings for it but I would somewhat doubt that this is really if the [german word: DP] child protective services are really viewed this bad by adolescents themselves. (E2, R2, CH)

Furthermore, there was disagreement that teachers are good at reporting children if they are in need.

E: And this says 'school teachers are good at reporting if a child is in need as a result of behavioural issues and therefore identify young carers. That one I definitely not agree. A recent study [inaudible] study on the incidence of reported um on reported incidence of child maltreatment in Switzerland gives the, has report from school at a very low level. So maybe they see themselves as good reporters but also internationally school report only few cases. There we have empirical findings this is just not ..empirical findings don't base this statement. (E2, R2, CH)

One of the experts reported that child protection services address this topic, even when they do not call the children (A)YCs.

And um and I would also argue that in in um field workers in child protection, they do sometimes...they will address, sometime address is the issue if they see oh there's an older sibling taking care with a of his younger siblings or even his mother if she's drug using. I think this is sometimes [inaudible] would say this is regularly addressed in child protection practice but not it does so far not been a topic at conferences, meetings er it's not been much of an issue in the professional or um or public debate except for a little bit of visibility on children of mentally ill parents. (E2, R2, CH)

There was agreement among experts that children and their parents are afraid of being taken away by legal services of child protection

E: Mhm I think one specific Swiss topic which is mentioned here also under additional planning at the end about the Swiss authorities there we do have a big problem child services that's a legal service where a sort of threshold needs to be reached before they can do something but at that point they also have to do something and that it really increases the threshold for young people or their parents to seek help before they are all afraid that I mean children are afraid that they will be taken away from their home by social services.. (E3, R2, CH)

According to experts, there is a need for changing the law with regard to the legal duties of child protection, to a more preventative approach, so that the parents and children do not have to be afraid to get support:

E: I think there actually we would need to change the law (E3, R2, CH)

E: I think for young carers it would be extremely important that they can seek help where they don't have to fear that any [step; EG] will be taken where they can talk to people about their situation where they can or the family can ask for support also for the child without having any fear of an intervention that takes...(E3, R2, CH)

It was reported that early detection is not the way; instead of screening for problematic groups (which is a problem oriented approach - family of YC are a vulnerable group). It would be better to get concrete support for YC and empower them:

E: The problem is early detection always comes down to something where people are extremely vulnerable in it. When you look in a family where a child or teenager or young adult looks for a sick mother, when you go in and say ah oh, that's in case a problem that's not good, that's not good for that child, then you create pressure and guilt and it results in a refusal to cooperate with the help system, (...) (E5, R2, CH)

It was mentioned that Mind Matters involves teachers - and they are not educated for such topics - maybe it can overload them in general - and a school social worker could do this probably better but there is no social worker at every school in Switzerland:

Teachers can be strengthened. Networking can be increased, but entrusting them with the responsibility or giving them substantial responsibility to become active in this area now will at least not correspond at all to the idea here in Switzerland, nor to the training content of the teachers. And there, I believe, one must also be careful not to overload the cart with task portfolio. I've looked at this in the context of Mind Matters, if yes. I think you soon reach your limits. (E10, R2, CH)

E: But it is important that it enters the classroom and not that this is seen again as a task of the teachers, but that they could only be informed that this young group exists. (E9, R2, CH).

Training for professionals

First Round:

According to an expert, there is one health service in the French speaking part of Switzerland, in collaboration with a university that is being established to train professionals who work closely with (A)YCs.

we are working with the University of Neuchâtel... science of education... with the HES-SO of Neuchâtel for a training program for adults who... are close to caregivers to help caregivers (E1, R1, CH; translated from German to English)

Second Round (Reflection):

According to the experts there is room for improvement to train nurses so that they could take primary responsibility for a person with chronic medical problems.

E: They have national meetings and again go into the [training; EG]... The nursing school that's an excellent partner in the UK where nurses will be the primary responsible people for people with chronic medical problems in Switzerland those are harder to reach (E3, R2, CH)

If it is part of the curriculum in schools where professionals are trained, the students will pay attention to the topic of (A)YCs and might write their thesis about it.

and some of our students write their Diplomarbeit [e.g. bachelor thesis, etc., FB] about this theme and this are the little goals I get with my students and our school of higher education that are little steps but I think that they are many important steps about these students they multiply the topic in the institutions in the hospitals in the clinics (E4, R2, CH)

Possible Additional Support

First Round:

Experts mentioned telephone lines because they are anonymous, however they are not specific for young carers.

E: Yes, actual I think there are some telephone lines, die dargebotene Hand or also... No. I don't know much. I think they have to go to an expert. They have to go to a Child Psychiatrist or Child Psychologist, social services. I think these are the places they can go. And the telephone, die dargebotene Hand and others, I think there are some places but not much (E4, R1, CH)

Furthermore, case management to organise care and support was also mentioned.

E: From this case management? Yes, it is at different levels, it is also here in the Vocational Training Office, or is it. And that is besides the career counselling, this is a part of it, which takes place here or, here also with underage youths, one must of course also have the agreement of the parents who accompany them or. Maybe to find solutions that can, how can you offer them support, be it from a university of applied sciences or for a profession, or which profession they want to choose, I think it's more at this level that they do that. (E6, R1, CH)

In addition, the national action plan for family caregivers was reported as additional support. Yet again, young carers are not specifically taken into consideration. Financial support was also discussed, however, this is often not applicable to young carers, because they are not in a situation of unemployment.

E: Well, I think it's basically good to make visible what family members, so there are a lot of women in particular, but in the way I take over this act of care in the families... so I don't know this one so well but I have the feeling that it's mainly about the legal aspect of absences from the work of continued pay, from entitlements to holidays, and of course that doesn't concern young people at all, so it's about completely different, (...). (E5, R1, CH)

According to the experts, there are some differences between rural and urban (A)YCs. Rural (A)YCs come - in general - from multi-generational families & possibly receive less support from services, while urban (A)YCs can have family members who might live far away & might receive more support from services.

That these are always very small groups, because they are also thematically designed, and then some of the way is too far, that's why in the city, in the Bernese Oberland, there was something at some point, in Thun, which is also a city again. (E7, R1, CH)

It was mentioned that psychiatrists and psychotherapists supporting adults sometimes think of children as a resource for the treatment of the parents.

E: So adult psychiatrists often think of children as resource for (...5) for the treatment... or so because they love their children and... it's what they say sometimes he's the only good thing in my life and whatever... But we child protection researchers is looking it a bit differently and say well even... if a... if the child loves... his parent his mentally ill parent and even if he or she does provide good care for her that's... that might be problematic for the child because... the child is... has a role or task which are not a beneficial for the development (E2, R1, CH)

Coping strategies

First Round:

According to experts, young carers wish to have some relaxing moments and time to see their friends. Swiss children and families hide their caring roles because they consider it something private.

(...), the young people don't go to anyone they don't know and tell them how it is at home, they just don't do that. (5, R1, CH)

Future needs to support the well-being and health situation of (A)YCs

Main findings:

First Round:

According to the experts, changes need to take place at a policy and strategic level to underpin developments. All society should be involved in supporting (A)YCs and many professionals and organisations can be involved. Media and social media should increase the

awareness and visibility among young people, the public and professionals. Professionals themselves need training and tools to support them. A range of support measures should be employed to support the individual needs of (A)YCs and families and a family approach employed to meet the range of needs and reduce the burden on (A)YCs.

E: I think it would be nice if the Swiss population is aware that there are young carers and that it's the reality of life... and the job of society is not to protect them but (inaudible) (E3, R1, CH)

But generally at least for minors for... kids under the age of 18, it should, we should try to avoid that they have to take over too many responsibilities. (E2, R1, CH)

Policy and Strategy

First Round:

A culture change is needed: with more time to support the young person as an individual and move from a traditional view of the family to a perspective considering diversity of family models.

Adolescents are not very well supported by our society (E1, R1, CH)

According to one of the experts there should be a change law for funding for prevention e.g. using health insurance money.

E: Ehm then one of the project actually that have been done is of your health insurance payment is actually been used for prevention and that funding has just been increased so there's gonna be a pot of money available there and so that's a way to address the issue to apply for that kind of money (E3, R1, CH)

The topic is often discussed in the area of child protection, according to an expert. Should aim to improve the early detection of young carers.

I think the first step is to determine in the actual quantitative study the facts. It is important to collect data. After this I think it is important to increase the visibility and awareness. And the next step is to develop strategies and programs. (E4, R1, CH)

It was also mentioned to create a young carer network like in other countries (e.g. UK and Germany).

E: And they also have, for example, there are countries that have such networks. And to my knowledge there are young carers network also in Germany and also at different places in England. And I think that something like that could be done, and that would make sense. (E5, R1, CH)

Second Round (Reflection):

There was disagreement of the statement that adolescents are not very well supported by our society.

And I would also add if we go on to policy and strategy, adolescents are not very well supported by our society. This is really for me, this is too absolute. That's it ...it's a statement by a politician, but not by an academic so ...I don't ... the system is actually there is a, we have quite a variety of services and organisations who take care for adolescents. And there's a lot of a lot of help offered, so um in this absoluteness I disagree with that one so at least there is a... if they always address ...I'm not sure if they always address the ones they should meet, the ones most in need but at least the variety of services that offer help for adolescents is quite respectable and the numbers too. (E2, R2, CH)

According to an expert, it would be great to create YC network in Switzerland - The NGO Pro Juventute does this at the moment.

E: There is also the young carers network and I think part of it is peer support. But I'm not quite sure you know that better [laughs]. (...)And I think it would be there so I mean there are so many platforms for young people and I think the young people also inform themselves there, so especially with the Pro Juventute I believe that, so if you can just put the subject somewhere else or that there are burdensome situations in the family, (...) (E5, R2, CH)

Visibility

First Round:

According to the experts it is important to remove taboo (P4, P9), make issues visible (P1). Seen as reality of life, without stigma:

I think the most is for me the visibility in the public is the important thing. When it is normal in public, then I think it would solve much. (E4, R1, CH)

I think that in the future the dialogue must be transparent and accessible for all the families. (E1, R1, CH)

According to an expert it is supportive to raise public awareness; like a yearly national mental health campaign.

E: So in concrete terms (...) there should be (...) a campaign work in the sense of for example "How are you?", the campaign of Pro Mente Sana, Health Promotion Switzerland, where it explains that (...) it can happen that you yourself as a person no longer simply //... functions lovelessly, that this can simply happen to anyone. Because this ultimately results in the task where Young Carers carry. (E8, R1, CH)

Furthermore, the topic should be taught in the school curriculum and social and traditional media channels will be very important in the future.

And I think also it needs something online tools because the young carers are in an Alter where computer and online forums are very important. I think it can be. Online forum, peer support, information platforms, anonymous platforms where they can ask questions like this. I think this is important because these young people, computer platforms are centre of their lives. And I also think that they can go to a computer when they are at home and when they are carrying at home. And it is more difficult to go out to a group in a room because they have no time to go out for this group, because they have at home to look to their parents. But go for computer in a minute that is free I think that is possible. And I think the social media channels are very important are very important in the future. (E4, R1, CH)

Second Round (Reflection):

From the second round there was disagreement; it is not sure whether a campaign would be useful or would have any effect regarding visibility and awareness rising.

But generally I have to say I am just very 'critical' as a scientist, so I don't necessarily believe in the effect of campaigns, because they are also just incredibly hard to prove. So if you were going evidence-based, you'd just have to keep your hands off it. So from the general campaign for awareness raising. I mean, do you remember the FOPH campaign on health promotion against obesity? (...) So, and it is yes, I do not know if they know these studies so effect of such campaigns, the effects are virtually invisible. (E5, R2, CH)

According to an expert, a better way to try and change the policy is by a campaign, instead of mass media communication.

E: So I find a gender setting something else again, so I think that this is then also on the political level, that is certainly necessary, and I think these young carers who have been forgotten in this national program, is very important that you also look again. And says it's okay in the case, it's women doing the job, it's also young adults. I think that is important, but it is on a different level, it is not at the level of the public, but of policy making and yes, I think it is important to point out that. (E5, R2, CH)

Responsibility

First Round:

In respect to responsibility, the experts reported that the whole society is responsible for supporting Adolescent Young Carers. The politics and policy can play a role, as well as schools and job trainers, the healthcare and the social system. NGOs are too tiny in Switzerland and therefore they have difficulties in supporting (A)YCs, but they can raise awareness of the topic, together with research.

And if really want/can help young carers... in this level we don't need to have a lot of money or a or big strategy or big intervention. If each person can help... in this level I see everybody, you me, and any others, we can help the children... (E1, R1, CH)

An expert noted that a new company similar to existings NGOs like Krebsliga or Alzheimervereinigung or Pro Senectute or Pro Infirmis, Institut Kinderseele Schweiz, ProJuventute or a big foundations (e.g. Health Promotion Switzerland) with experts on young carers should focus on the issue.

E: Ehm that's actually I mean the Pro Mente Sana is one of the initiators of that a couple of different foundations that work together (E3, R1, CH)

It was reported that many people can support these children through case management. Social services, school psychology services, child/adolescent psychiatric services, GPs.

E: Who has to be responsible for supporting? That is a good question. For me it would be great if there is a new company like Krebsliga [Swiss Cancer League, FB] or Alzheimervereinigung [Swiss Alzheimer's Association, FB] or Pro Senectute or Pro Infirmis. I think it is such a great and important topic that for me it has to get a new company with experts for young carers. It would be great when the teachers or the Sozialdienst can get the children to these experts of this topic. And there are many people who can support these children in form of a case management. (E4, R1, CH)

The whole society was also mentioned by an expert.

E: All the society because... eh... the young carer is [in; EG] the society society... in Switzerland for example and in the society you have schools you have sport you have education you have... mother father you have family you have friends (E1, R1, CH)

Second Round (Reflection):

There was agreement that the responsibility lies with the whole society educational, health and social system and NGOs.

E: I think the whole society that's very broad I think it's the key players in this area that have the main responsibility so social systems education system healthcare system. (...). And NGO again would be good not to have the responsibility but to kind of be the watchdog that something does happen and kind of bring strengths from abroad into Switzerland so that would be good to have that (E3, R2, CH)

Again, there was agreement about a vision of a new organisation which focuses on (A)YCs

Something I also said at the first round I think there are Krebsliga Alzheimervereinigung palliative care Vereinigung my... vision is that there is also young carers Vereinigung a centralised organisation about this topic I think that would be great and that there are summarised results and films (E4, R2, CH)

(A)YC needs

First Round:

(A)YCs need interventions based on their individual needs, i.e. personalized support, according to the experts. Opportunities to share their caring experiences with other young people will be helpful as well as support groups, workshops and respite from their caring roles. There is the need for dedicated support services for (A)YCs.

The interventions must be very individual...because each child has their own story (E1, R1, CH)

Another expert stressed that YCs should be strengthened in coping with their difficult situations.

E: It's also having a place to share but it's also about getting knowledge about you know how can we be learning from others how did they deal with the situation... in a workshop (E3, R1, CH)

Show (A)YCs what they are doing is valued, they can be proud about it, according to an expert.

The second is that I believe it is important that there can be a normalisation process for the Young Carers themselves, so that they themselves know that I am not an isolated case and I do not have to hide it, I can talk about it. There are people with such experiences. (E8, R1, CH)

In addition, respite is needed and carers need a form of "Entlastungsangebote" they can have free time and "do hobbies (replacement care that gives respite)

And what I forgot what the young carers need it is in a form Entlastungsangebote. People who come for one or two hours at home that the young carer can go to a hobby. I think something like Entlastung for short times it can be also important for the young carer to make hobbies, to go to a birthday party, something like this. (E4, R1, CH)

In respect to booklets and information, there are some gaps between "to inform myself as YC" and "to take real action" for getting support according to the experts.

And I think that is also important that the young carers know more about the illness of their mother or their father. I think information about the illness is also very important because when a child knows what this illness is and what is the prognosis of this illness and what is the normal therapy of this illness. When they know this illness I think it is easier for them. I think it is hard when they don't know what illness has my mother. (...) And because of this I think information material about the different illnesses in easy understanding way are important. And I know Krebsliga [Swiss Cancer League, FB], Alzheimervereinigung [Swiss Alzheimer's Association, FB] there are some documents like this and I think that could be an important thing also other illnesses describe in Broschüre [brochure, FB], information materials, films that the young carer know what is this illness my mother has. I think this is important also.(E4, R1, CH)

Materials and films that inform young carers about specific illnesses was also reported by an expert.

And that actually the way I, if I have understood it now, is actually better if you look at low-threshold offers on the Internet, online information, (...). (E5, R1, CH)

Furthermore, support e.g. like patient congress groups workshops, online discussion forum, online tools, peer support, information platforms, anonymous platforms where (A)YCs can ask questions could be difficult whenever they consist of 'physical' platforms and meetings for YCs in rural areas to get sufficient YCs together. There are some gaps between "to inform myself as YC" and "to take real action" for getting support regarding information platforms; that means that an information platform does not mean, that the (A)YCs automatically will ask for help.

we have what it's called patient congresses it's a 2-day meeting where adult to have a mental health problem and they have workshops they have social I think something like that would be wonderful for adolescent carers. (E3, R1, CH)

In addition, creating flexibility for students was also mentioned.

E: And what we did what this teacher did is that she told this child ok the 15[last] minutes is not good so... when there is the 9.30 break you stay with me alone in the class to help you move forward if you need... and those 15 minutes... this teenager left 15 minutes before the end of school (E1, R1, CH).

Regular support groups for (A)YCs are helpful to YCs according to one of the experts.

E: I think what are you doing in the UK would work very well here... I think having groups that meet you know once a month where the adolescent young carers meet each other and have an afternoon of social time that's also a bonding time that would work pretty well here in Switzerland... Because that is what the adolescent carers also online there are current (inaudible) and so there are (E3, R1, CH)

I was suggested that a young carer could have a confidential person to support them and that they are not seen as victims.

Young carers are not seen or treated as victims, their work is respected, help is available and organized if needed (E5, R1, CH)

Self-help groups were reported as a method to support, e.g. for children of addicted parents. An example is a project where children create an avatar and a story. This is a good way of processing their experiences.

By means of these groups, young carers realise that they are not alone, their feeling of guilt is reduced, and it is a "protected place" where they can talk about their experiences.

E: Institute Children's Soul Switzerland. So this in a part of Integrated Psychiatry Winterthur. That is something I know explicitly, for example, where I do very good work in this area. ?xxx some educational work has been done in the sense of what does it mean for you as a child when a parent is mentally impaired..., and how can you be supported in this. The same can be found in self-help groups for children of addicted people, for example. (E8, R1, CH)

Second Round (Reflection):

It was reported that the approach should support (A)YCs in an appreciative way.

E: Or, not, in addition to what they do themselves and relieving where it is needed but not, just that one tells the children that it is good that you do it, it is ok. And don't say oh dear it's bad that you have to do that, I mean clearly it's also bad but it's also nice, it's norm, so I think it's normal that you look for those you like it's not just coercion and somehow suffering (E5, R2, CH)

Furthermore, peer support was reported as a good way by one of the experts.

E: Yes. Well, I'm very fond of the stuff that's all about being a platform for young carers, for example. So the peer things work well, too. This is extremely important. Young people who are accustomed from the ground up due to social media and and and that they do not primarily turn to adult experts but look for answers or support in their environment. (E8, R2, CH).

Family needs

First Round:

It was reported that (A)YCs will be helped through supporting the family; in different ways. For example by strengthening the resources, if poverty is a particular issue. If the socio-economical level of families is increased, families have more resources to gain additional help. (Family approach)

E: (...), and I find that family as a whole and not simply young carers have to, because that is somehow, (...) , it is always funny when you pick up this target group, this vulnerable target group only alone because that is stigmatizing. But that one actually creates a framework and that in the family and for everyone in the family, what kind of challenges there are, (...), there are so many, one has to focus on something and I think school is certainly an important field but it is important that families are taken up differently as a topic, so you can't just say, there are the others, now they are there with their children and there they are, and they are affected by poverty and they are not, but simply how is the family situation, and then what are things like in the family and what are the challenges that the children face, you have to be very careful in Switzerland, because family is very private. Well, that's why it's so taboo. So we are not in Sweden now, for example, where family also has a very strong public character. But in Switzerland, the family is an extremely protected space, not talked about, which is accordingly tabooed. (E9, R1, CH)

Second Round (Reflection):

It was stressed that we need to focus on the family approach instead of an individual approach.

E: I mean if I look at the health field that's really where we need the focus away from the individual to the family... model unfortunately tendencies are going the other way the old primary care adult system there often the family doctor would treat the whole family so he would naturally see the situation for the children that's not the case anymore now care is more professional so the children will see a paediatrician and primary care doctors change now all the time you don't see the same doctor so that's lessen that... and we really need to be able to change that system and then force the idea that health problems always affect the whole family and not just the individual and it's the medical field responsibility to look at the whole family (E3, R2, CH)

Family Policy

First Round:

Family policy is really important... is to have a family policy... if we help the parents, we help the children. If we help the children, we help the parents. I think it is really important. (E1, R1, CH)

The families are different the problems are different in each family. So we must adapt to each family...we must offer help adapted for each family`. (E1, R1, CH)

According to an expert, it is important that family integrity is safeguarded.

E: [laughs] So, young carers are supported in achieving their educational goals in accordance with the conventions of the rights of the child, so that is the child right, the right to education, and without just taking the responsibility from them, so you can't tell them you have to do an education now and at the same time you can't do the care at home anymore because then they will decide against that education, in many cases (E5, R1, CH).

Second Round (Reflection)

According to the experts, the problem is how to integrate YCs into existing legislation. It would be better to create a new national policy firstly. It would be helpful to integrate the topic of (A)YCs into the national care policy of the BAG (Health Federal Department of Switzerland)

E: And I don't know if that's the main finding. "The legislative framework needs thresholds to provide support and services." Now you have to see. They are now, as I said, there is no law for children and young people on which we could also influence the other laws such as. If there is a children and youth law, then one would have to adapt the regulations in all the other laws. There's no such thing. (...) But that actually means that there is a (...)(...), the question is which law, which law could be used to regulate this at all? There's a health insurance law. (...) But this is not a social law. But you'd have to see that again. And then there's an invalidity insurance law. And (...) then a social security law when you become unemployed. (...). Yes. And if, so you notice, there are so many then these different laws, one would rather have to have such a "policy. (E9, R2, CH)

Or on the side of the BAG on the side of the Bundesamt für Gesundheit there are also topics where I think young carers that it's not written there or it's not a topic of this side because this side also is a good homepage of the BAG and what's going on in Switzerland for palliative care for dementia for other topics and there it would be great this young carers also get an own topic not only caregivers but especially young carers young caregivers I think that would be great (E4, R2, CH)

Professionals Needs

First Round:

According to the experts, professionals need to be more aware of (A)YCs and understand issues in order to support (A)YCs better. Information centres, counselling experts need information, documents, literature, and films.

E: In the future I think it is needed experts who know this topic. There are needed Beratungsstellen, counseling experts with information, documents, literature, films. This is one thing. (E4, R1, CH)

In addition, training for professionals could be offered especially staff in education in all school stages. This because teachers can be the first person who can recognise that there is a problem.

The other I think in education of teachers, primary school, play school, nursery school. In all school stages I think it is important to teach the teachers about this topic. And I think it is important to take it in the curricula of all schools, in the curricula [curriculum, FB] that the children are knowing this topic in play school, in primary school. I think that is an important thing because the teachers in play school, in primary school are the first person who can recognize that there is a problem. (E4, R1, CH)

Teachers can present this topic and introduce films; on online platforms, this according to one of the experts.

But I think it is important that the teacher in the play school also informs about it and gets the way to this online tools. I think that is the(...), the relation between the information I think it has to be with the teacher in school who present that this is a topic that can be seen in this films, in there online platforms.(E4, R1, CH)

Furthermore, teachers need information in the form of facts and tools to support identification (guidelines, checklists).

E: Because of this I think it needs tools to identify this that the teacher when they see that there is something wrong with this child. They have questionnaires, guidelines, checklists to look together with this child what is the problem, why are you so sad, why are you so tired and why don't have you homework and so on. I think in primary school, in play school it is important that there increases the knowledge about this theme (E4, R1, CH)

This can be followed by a school strategy to support (A)YCs.

E: Has...problems...of...of... to be well... it is up to me as a school doctor to discuss with the principals... and put in place a strategy at school to... help these children [I am having something; EG] for you... we have a teacher told me listen I believe I have a close child helping in my class (E1, R1, CH)

Second Round (Reflection):

The experts agreed that there is need for training of Professionals and an NGO could train them and initiate this.

E: Not so sure about the information centres if that are a top priority... And again one thing I find with the professionals' needs is they need to be trained together in a region you know because it is a network thing where these different agencies act together who normally do not have any interfaces, (...)

I: And who would do that training?

E: That could be an NGO so if we have an NGO young carers they could organise that or it's again also on a Canton level that the regional directors of the different fields can kind of put that together because often the question is who can be the first to initiate that... So I think it would be a good NGOs (E3, R2, CH)

Funding

First Round:

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

E: Ehm it's a difficulty with the Swiss legislation again because most of this social services or then the services of prevention for which there is no real funding... have the solution there doing my work implementing this things. (...) Well we have a public vote you know we have a very direct democracy and we had a public vote on the law prevention the public turned it down... and that was 2008 so ten years ago and so the easiest thing would be to start another referendum and the public vote again and see how they feel now there's a big risk that they will turn it down again (E3, R1, CH)

Second Round (Reflection):

According to one of the experts there is disagreement on the results from the first round, since child protection is well funded.

E: Child protective services actually... they are extremely well-funded and they have extremely good resources but they are all legal (E3, R2, CH)

Following the report of one of the experts, it will be difficult to change the law, so that money from health insurance could be used to support (A)YCs.

E: I think there you are on a very high level with that culture change... Changing the law for funding is again extremely difficult the health insurance money that has been done you know the national campaign I talked about that being done with the health insurance money but that's actually quite limited and it will be hard to get into that pool only combined with an existing campaign otherwise it's not realistic. (E3, R2, CH)

Yet, it was stressed that funding is not needed in any case (probably government funding is meant here) because Switzerland has a lot of resources.

E: I would like to say one thing about funding in Switzerland is also the biggest deterrent from doing something getting something done in Switzerland and very successful things have happened in this country but they were not being funded so... I think we need to address this topic despite not having funding for it. (...) Because we are a country that has many/extreme 'financial' resources (E3, R2, CH)

It was also mentioned that the vocational schools (Berufsschule) should not be forgotten.

E: ...think that could also be a difference to other countries, that somehow one could or would have to do something in this area at the vocational schools, so that one could also do something in the vocational schools or with the vocational trainers. (E5, R2, CH)

Finally, one of the experts questioned how we would improve funding for families. According to the expert it can be financed from the welfare budget. But it should be a general financing, not a case financing.

We know, for example, that (...) that (...) in youth and family aid, very many assistance does not come from a global budget, but from case-specific budgets. And this means that every measure, support service requires an individual cost guarantee, a separate cost guarantee. And this often hinders the use of support simply because it is stigmatising, because it involves too much effort, because it is shameful, because it is too administrative,... (E8, R2, CH)

General results

Second Round Reflection

In general one of the experts is not sure whether most of bullet points of the first round are valid.

I'm pretty sure some of the arguments, comments from experts are more [inaudible] are more opinions than actually empirically based (...)for me some of the bullet points were just a bit too, too general, too vague to get anything to get anything out of them. (E2, R2, CH)

some of the comments, arguments are not empirically based have so far not been are not so far opinions and not nothing more, nothing less. (E2, R2, CH)

Visibility and awareness raising

Second Round (reflection)

According to one of the experts, it can take a long time to change legislation - especially in Switzerland - (A)YCs do not have that time to wait.

E: legislation, why not, but it take a long time and this long time, les enfants, les adolescents are young carers. (E1, R2, CH).

In addition, schools can support identification of young carers, according to some experts.

Because of the identifying of the young carers and to make seen at schools that schools can identify young carers it's important, (...). (E4, R2, CH)

I think the other point is the teachers in schools in the pre-schools and the schools I think that they have to be trained and informed about the topic and they have to recognise young carers to know how they can recognise them with some

guidelines with some assessment instruments I think and then they can talk with them and they can support them and they can show them what are the next steps, (...). (E4, R2, CH)

E: School programmes I think. I didn't understand much, but it's important to have a school program (E1, R2, CH)

Furthermore, experts agreed to make sure that this is out in the open and that it should not be a taboo subject.

I think the most important thing is to get out of this taboo to get out of this invisibility for these young people I think that's important because they do it and they don't realise what they do and when someone comes to them the teacher comes to them and tell "what do you do at home? How is with your parents?" I think the young people or the children realise "oh that's important that's an important thing I do something that is not normal and this is seen this is... I can be proud about it and I can tell about it and I don't have to be ashamed about it" I think they have fear to have shame about it because we don't tell about those family problems in the public I think. (E4, R2, CH)

It was reported that there is not uniformity across the languages and the use of the term 'Young Carer'.

I think in the people who specialised in that field, they tend to use the English term in German and also the English term in French. That always has advantages and disadvantages whereas like the Federal Government they tend to use more the general terms of caring in general where then when most people hear that they will not think of a child or an adolescent they only think of an adult... and when they think of a child care they actually mean the child of someone with dementia who him or herself is maybe 60 years old. (E3, R2, CH)

It was mentioned that few people know about the problem. The problem is not perceived to be significant.

I find that there is little room for these children by lack of knowledge of the problems. The society in which we live is individualistic. Children's problems are also cultural and taboo...the situation remains with the family. (E1, R2, CH)

as I've said when it comes to um visibility among the general population I'm not aware that there are studies that have looked at it empirically so especially I can only tell for Switzerland but I also doubt it for other countries that there are a lot of lot of research on the visibility of programs. (E2, R2, CH)

According to experts, in general the focus is still on awareness raising. The term 'Young Carer' is not really known - the visibility is low and because of that there are also just a few supportive interventions.

E: I mean most of the examples are good ones that I think are very supportable the one thing I was thinking about strategies and interventions and programmes is I think they could be even more specific things for young carers that help them with their today's issues that they deal with you know like how to you to you know how do I talk to my friends about my mom being sick at home how do I deal with that see examples of how that's done... A lot of focus is still on you know making people aware but once they are aware what do they actually do? (E3, R2, CH)

This research by Horizon2020 is important to gain more visibility by adding new empirical research; it also will be helpful to fund new research projects.

...with such a delphi study, and I find that very important. I think on the level of getting money for research or even offers it is important that you can also empirically prove what you want to do, why you want to change something. And I think that's good. (E5, R2, CH,)

The issue needs first to be understood by society. Media and social media are needed to improve the visibility and awareness, according to one of the experts.

For me the most important point is that public information are visible in the media in the television on YouTube on social media in Internet or in doc film that comes soon I think... the publicity for the film for the topic I think is important because I think when people see films or read in magazines... come in contact with this topic then I think that's the most important thing I think it's like dementia or palliative care in the last years and for a long time that was invisible and none knew about it and now I think dementia and palliative care is [evolving; EG] because it's more in the newspapers and in television and on social media and I hope that this publicity this can increase the visibility in the public I hope. (E4, R2, CH).

There was disagreement with results from the first round, that it is problematic to create a new label of 'Young Carers'

E: (...) So, how shall I put it? In general, I have a little trouble labelling what is associated with Young Carers. (...) It's a huge taboo subject and then to call yourself so, to surround yourself with the label, I think the shyness is great. (E10, R2, CH)

Strategies, interventions and programs to support (A)YCs

Second Round (reflection)

The experts reported that in Switzerland, the only strategies or programmes are small, and are local initiatives.

Actually we have not strategy or programmes we in the Chaud de Fond we have small groups. We have four persons and we talk a lot about this problem, we try to, maybe we talk about it in a few minutes er we talk about programmes about we do what we can do, we need to understand the problem. (E1, R2, CH)

Understanding of the problem is regarded as being needed in the first place, according to one of the experts.

We need to understand the problem. The problem is large it's very large. And the strategy comes after, when we finish to understand. (E1, R2, CH)

In general regarding the creation of a "new system" the expert is concerned about "overburdening" the teachers by involving them in the support of (A)YCs.

E: I mean it sounds like a good idea not to develop a new system because you know the systems generally are overburdened I mean teachers would say you know there are so many things we should pay attention to and for every topic there is a different help or support system I need to get in contact with I feel completely overwhelmed... So that for... you know they have to focus on migrant children and they have specific support there then they have to look at children with mental health problems children of parents with HIV parents who are unemployed there are many topics that they need to focus on and they feel overwhelmed doing that. (E3, R2, CH)

Furthermore, an expert reported that support could be offered as an alternative peer approach.

And I simply believe that if a child, so now an individual child, (...), but the individual child to confide in someone it needs a relationship and the trust relationship is with these people that the child often sees, and has much contact with them, and also an individual contact. And I don't know if these are the teachers. Because teachers today have 23, 26, 30 children in classes. That you think more like that, i.e. from the young people or, what kind of trusted people do they have and to whom would they trust each other at all and then perhaps it would not rather go into such a peer story. (E5, R2, CH)

The goal is to accept the diversity of families and instead of creating one concept that fits all it is better to provide individual support.

But there are more and more children where one has to say that this is a very great diversity and one cannot meet this diversity by standardizing programs. And also not by doing an awareness raising campaign for every single life situation, but telling the people who work with them for example, hey, if you have a class, there are certainly 4,5,6 children, some are poor, others have a migrant background, the third have a parent at home they have to care for, the fourth have a disabled sibling, the fifth have an escape behind them, look at these children and look at what they need individually. (E5, R2, CH)

Following the report of one of the experts, it is difficult to "help a (A)YCs or people in general, because they often do not want to speak about it, or are afraid.

E: So right now, I would say, of the children we care for in hospital, if you like, all have highly stressed parents and the children, how shall I say, indirectly take care of it. At first they are simply burdened. Some care in some way or vice versa your needs of different ways are not taken into account. And the willingness to talk about it often simply strives towards zero. And that goes on forever until you have access to it. (E10, R2, CH)

Following the discussion of the experts, there are some good interventions and programmes but it is hard to reach (A)YCs. It would be important to improve the communication and promotion of such interventions and programmes.

E: (...) I think this is. The programs are always one thing. I really do think we are in a very good, very favourable situation in Switzerland or Central Europe in general. There are many offers, but what I notice, or what I feel is that communication or sometimes the accessibility of the one of the stakeholder group is often the biggest problem, so that it doesn't do much good if we have insanely good programs, if you don't bring them to the target group. I really think the big focus must be on communication work. (E8, R2, CH)

Second Round (reflection)

Once people are aware, the focus needs to turn to practical support for young carers, according to one of the experts.

I think they (programmes) could be even more specific things for young carers that help them with their today's issues that they deal with, you know, like how to you to you know how do I talk to my friends about my mom being sick at home how do I deal with that see examples of how that's done... A lot of focus is still on, you know, making people aware, but once they are aware what do they actually do? (E3, R2, CH)

Furthermore, modern and concrete approaches are needed to raise awareness and support young carers.

I think it can be either in the form of a booklet or of Youtube films and as you know how to... for example in another topic I deal with I do a lot of things on the mental health on the workplace and there the most common question is how do I talk to my boss about my mental health problems or how do I talk to an employee asking him or her if he or she has mental health problems and it would be the same thing here you know how do I talk with a teacher about my situation at home. How do I start such a conversation and the same for a teacher, how do I actually address a student about this difficult topic... Very hands-on kind of things with examples...(E3, R2, CH)

Following one of the experts, media and social media are needed to improve the visibility and awareness.

I think the media, television, or video or smartphone or many things like this is very important in our society. The media for me is the priority. (E1, R2, CH)

Agreement and importance of the "Coproduceddesign" of future support interventions.

E: So at Netherlands need for co-creation with young carers stands, I find that simply mega important, that's what I also said before, that you really include them and they also develop with them so don't just ask what you want and we do that

now but really also include in the sense of they are the experts for the situation and they can best say which forms of support are helpful. (E5, R2, CH)

However, to develop support systems by co-production with YCs; this is good but also takes a lot of time:

be it now in the care that one thinks of these children and young people where there are still, in which, with families where somewhere in a care are in it, I say this now simply because I think, as soon as one has the requirement really, and also wants to convert it from the participation, it does the whole simply also, a little delay or slow down. (E7, R2, CH)

According to an expert, it should be routine that professionals in health care always ask about children and whether they have any needs when a parent is ill.

E: (...) In my opinion, today there is something that is actually common both in medical training and in the nursing professions. And that they actually also check the private situation. Frequently, this is a query of the private situation, which they often learn continuously in their training and are trained on it, but are not asked of the children. And I think that would have to be more pure in the training. So basically that also means there. You ask how. Let's say it's a mother with cancer who takes off the children. Then you often ask if the mother has the support, but you don't ask: Do the children need support? (E9, R2, CH)

According to some experts, there is no need for a new legislation for YCs.

There is another point here, if I have understood it correctly, namely the need for legislation specific for the group of young carers, which I do not see for us in Switzerland. I think you just have to bring them in where strategies and programs are already on the way. (E7, R2, CH)

Furthermore, it is relevant that stigma needs to be reduced.

I think those findings show really good the actual situation in Europe because I think that are elements that are really like this in Europe and I think... The most important element I think that's question 2 the most important elements are that the young carers to their needs as I think to reduce the stigma and to... see that the young carers see what they do and they see how proud they can be about this what they do I think that's an important point (E4, R2, CH)

Young carers need places where they can relax, according to the experts.

The activities to let young people that they have a place to stay can relax that they have a place where they can more energy to go on in their job I think that are important points and I think that it's seen in this first round (E4, R2, CH)

Country specific results

Visibility and awareness raising

Second Round (reflection)

In respect to the results from Slovenia, one of the experts agrees that there is no need for a new system - also in Switzerland. It would be better to improve the cooperation between existing systems.

So I would...my, what I often argue, when I do the seminar findings on child protection, we don't need another new type of organisation or service but it's the problem is in my personal view, the problem is more how the communication and pathways and management of pathways between organisations. (E2, R2, CH)

Some experts are surprised why the topic of migrants regarding (A)YCs is not also mentioned by the Netherlands.

E: I do know from the Netherlands the [Laden : DP] people of university of [Laden: DP] [inaudible] who did Netherlands prevalence study on trauma treatment on incidents and prevalence of trauma treatment in the Netherlands they did extensive analysis on native Dutch people and immigrants and even more in detail they looked at traditional immigrants, so from the former Dutch colonies, and new immigrants so... especially from them I'm a bit surprised that I'm pretty sure there is research, the Netherlands have great researchers [inaudible] in child protection, child welfare sectors so I would think it would have looked at such things as well. (E2, R2, CH)

I would think that migrant populations, migrant adolescents in other countries as well do care more um than or more in the role of adolescent young carers than let's say natives or whatever. (E2, R2, CH)

There is an overall low visibility. One of the experts is surprised that there are no more legislative frameworks.

E: Well yeah kind of, it's what you said overall, overall visibility or low or none visibility this is this is a thing. Maybe what I'm also kind of like was surprised that I've not seen a lot about; legal frameworks. Legislative frameworks because there are, there are um in other countries as well child welfare, child protection legislation, which would include as in Switzerland, which would er um see certain or a lot of adolescent young carers' situation as neglectful situation and would include and such children or young persons could be supported or reported to child protective services and helped by them so... (E2, R2, CH)

Apart from in the UK there are few programmes specifically targeting young carers, following the discussion of one of the experts.

'these programs don't always aim for young carers in particular and then it says Italy, Switzerland, but if we go, if we move on further to country specific results er I think it's not just not Italy and Switzerland but I think I'm not so sure ..if I'm reading the findings on other countries as well the, I don't think apart from the UK, maybe apart from the UK there's not a lot hell of a lot of very aiming very particularly but this is just this is not the same as I told you before, this is another point. It's just what I've um when reading through you're findings I was not so sure if this applies, if this only applies to Italy and Switzerland in particular. (E2, R2, CH)

There is some doubt about how well known support programmes are by the general population.

I do know, I'm pretty sure the experts know a hell of a lot on which programs are available etc. but others, as I've said when it comes to um visibility among the general population I'm not aware that there are studies that have looked at it empirically so especially I can only tell for Switzerland but I also doubt it for other countries that there are a lot of lot of research on the visibility of programs. (E2, R2, CH)

Increasing the visibility is still the big issue; in comparison to the other European countries and Switzerland, the UK is quite ahead:

E: Ehm actually you know reading at most things really made sense I think you know the UK is quite ahead as far as visibility and awareness score whereas the other European countries even also the ones who did not participate I think that's the big issue still increasing visibility and awareness that the general public even knows that there is such a thing as young caring and I know that one of the difficulties there also is what kind of terminology would be used for that I think most countries have struggled with coming up what word to use. And that [kind of; EG] mention too but anything else I can completely support makes sense. (E3, R2, CH)

E: There are big cultural differences and the UK you have the advantage you had it on TV shows so you have the advantage of showing Saturday night TV drama about an emergency room where you can show the situation of a young carer and what actually is done to support that person that's extremely crucial and Switzerland doesn't programme any of its own televisions it's all imported from mainly the US so that's a big disadvantage that we have. (E3, R2, CH)

The term Young Carers or Adolescent Young Carer is not part of the policy strategy of the federal Government in Switzerland. With the definition "relative care" people think about elderly relatives who are caring according to one of the experts.

E: I think in the people who specialised in that field they tend to use the English term in German and also the English term in French. That always has advantages and disadvantages whereas like the Federal Government they tend to use more the general terms of caring in general where then when most people hear that they will not think of a child or an adolescent they only think of an adult... and when they think of a child care they actually mean the child of someone with dementia who him or herself is maybe 60 years old. (E3, R2, CH)

To improve the awareness of YCs in Switzerland it will be hard to get a specific campaign just for YCs as in the UK, because of the lack of funding. But it would be possible to add the topic of YCs into existing campaigns, e.g. the national campaign on mental health. Unfortunately, it would just focus on topics related to mental health. Other topics (e.g. diabetes) would not be taken into account according to experts.

Switzerland can do a lot with national campaigns but there again we have it's hard to... do its own campaign young carers I think funding for that would be extremely difficult to get but we do have national campaigns on visibility and we do have national campaigns on mental health and I think it would be easy to make that... you know the big mental health campaign will be running for the next 3 years so one thing we could do is do one year on the situation of young carers. (E3, R2, CH)

The issue of children of mentally ill parents has been there is research on that issue in Switzerland too and practitioners have been made somewhat aware. I would still argue visibility is low overall. (E2, R2, CH)

One of the experts was surprised that Sweden is not a pioneer in this topic of (A)YCs.

E: Yes. So, what is the first thing that I really noticed is that, contrary to the general opinion, Sweden is not a pioneer here. I think that's the way it is, and you can underline it even more. I always say, why? Because Sweden, for example, is very sensitive to family problems or the needs of children in the context of family problems. (E8, R2, CH)

An expert reported disagreement with the Swedish statement that a child should be free from having a caring role; it would be better to support them (suggested improvement by Expert).

E: I stumbled on the Swedish statement child should be free from having a caring role. (...). I personally disagree with that (...) I think illness is a normal part of life and I think it is normal that in a family everybody shares the burden and helps support that person in the same way that unemployment unfortunately is a normal part of life and losing a next of kin is a normal part of life... I think life isn't all pretty and so I don't think it makes sense to protect children too much from that and who should not be a perfect place it should be a human place and I really believe more in supporting the children who naturally care for their sick mother... But that's also where you can tell that Sweden has a both idealistically different approach but also kind of the services they provide... I'm not sure how they are gonna keep the Swedish children from worrying about their mom with cancer (E3, R2, CH)

E: It stands childhood should be free from having a caring role. That's bullshit. That's not true for me at all. I simply believe the question is how is the caring role framed, or, and how much recognition there is also, and how much one also takes into consideration the or. I have a godchild who has had cancer and who, that is clear from here with us in

university, people who somehow can learn less well for various reasons who have so-called disadvantage compensation. This gives them more time for exams, for example. (E5, R2, CH)

The experts agreed about migrants taking their caring role as normal (CH-context) but this does not remove the burden of caring.

I even believe in the Swiss Results that children from migrant families have a lot, a different, simpler relationship to that when they care for relatives, because it is simply normal to do that. That doesn't exist, it isn't even questioned, you just do that. Whether it is still a burden is another question. (E5, R2, CH)

A campaign by television programmes as one of the old ways - it would be better to use new mass media channels like Youtube

What struck me, United Kingdom, increase awareness by television programs, I find easy, brrr, who still watches television today. To put it bluntly, the people in the old people's homes. Because between 15 and no idea 45, most people I know watch Netflix and the youthful YouTube, all the kids and teenagers I know don't watch TV, except the World Cup match. But I find television programs a bit, but that's last millennium as campaigning on TV, I think, phew, so this may not quite be the right channel. But maybe the kids in England are watching more TV[laughs] I don't know. (E5, R2, CH)

In respect to a standard or regulations on a global level, the experts commented that it will be difficult to get a global standard worldwide (e.g. by the WHO).

E: (...), of course it's hard for the WHO for example to do a programme that will address issues in Uganda at the same time as in Sweden... So they are really straggled because in a lot of countries like Uganda you know parents do not have access to mental health care... so then you know doing something for young carers becomes extremely difficult. (E3, R2, CH)

E: On a global level um? Well, I think um, I think it's also that it's to address the global level is just goes too far. I think that er the answer for the African continent er or the subsaharan african Africa, certainly have to be much different than maybe in western Europe er the situation is (E2, R2, CH)

One expert commented to discuss the topic with UNICEF.

So I think that UNICEF should at least include things like this, because that is also part of the children's development, (...) (E9, R2, CH)

Strategies, interventions and programs to support (A)YCs

Second Round (reflection)

One of the experts commented on possible differences between Switzerland and other countries regarding the legal duties of child protection.

E: Mhm I think one specific Swiss topic which is mentioned here also under additional planning at the end about the Swiss authorities there we do have a big problem child services that's a legal service where a sort of threshold needs to be reached before they can do something but at that point they also have to do something and that it really increases the threshold for young people or their parents to seek help before they are all afraid that I mean children are afraid that they will be taken away from their home by social services... I'm not aware that that's exactly like that in other countries so that makes it more difficult here (E3, R2, CH)

There was disagreement with the first round that a new legislation is needed. It would be better for the countries to implement the child rights better - maybe legislation regarding prevention would better address the funding problem; specific legislation just for one group is not needed.

(...), But legislation that now specifically targets this group, that I believe is over-regulation. Because actually with the Convention on the Rights of the Child there is legislation that says that every child has a right of access to education and every child has a right to have his or her opinion involved when it comes to his or her affairs in relation to how it grows up, and I think that you can use it without needing new legislation.(E5, R2, CH)

One expert noted that the Swedish Health Care Impact 2010 is really important.

The Swedes who have (...) who have apparently decided by law that the children have a right to information regarding their parents. The Norwegians have gone a bit further. They have just said that the adult sectors that look after the health of parents should definitely ask whether the children, how they are doing and whether there is support there. I think that something like this could certainly be discussed and brought forward in the other countries. I think that would be an ingenious step forward. (E10, R2, CH)

According to experts, it is problematic to involve schools/conferences. There is the danger that the parents feel betrayed if the children get an opportunity to tell their problems to a professional.

Well, I have also experienced really serious mistakes, yes what the children that there were helper conferences. Then the parents were invited. They fell out of all the clouds and said, kid, why can't you tell us? Loyalty is undermined in families. The child has been decompensated, had to be hospitalized with us and then denied everything. (E10, R2, CH)

In Switzerland the legal situation is focused on strong subsidiarity principles - the national legislation compared to England and other countries is weaker according to one of the experts.

(...), you have this better situation in England or Sweden, where there really is a "Health Care Act" or a "Care Act" and a "Children and Family Act", where you can really bring something like this into it. That is precisely the other kind of thing that is also much more nationally organised. And then, of course, much else can be done at national level. (E9, R2, CH)

Future needs to support well-being / health situation

Second Round (reflection)

According to the experts, there is a need for an individual approach which is based on self-organisation and is easy to access (e.g. information platform which is possible to access by smartphone, which indicates the need for an App).

(...), I'm generally just a fan of outreach and decentralized support and self-directed use, so that people can somehow decide for themselves how and when they want help but that if they really want them to get it. (E5, R2, CH).

According to an expert, it would be nice to have the same legislation in Switzerland like Sweden have established. But because of the weak national legislation compared to the other countries and the subsidiarity principles, it will be quite impossible to establish such a legislation on the national level

Now that's what you have in Sweden, it's interesting. "Identify fragile families at an early stage and provide support they need". That is actually very desirable. Now we need to know again that in Sweden the state is much closer to the family. So this is interesting that it's done there and that they want to do this. You can almost forget that in Switzerland. (laughs) You really always have to say that. (E9, R2, CH)

Furthermore, an expert suggested that professional training in Switzerland could be like it is done in Italy.

But what I like, I like all the other points that are written under "Switzerland". And what else I find interesting, Italy. "Need for information and training for all professionals and policy makers and also teachers". That, I think, is something you could really take up to Switzerland. (E9, R2, CH)

Finally, there was agreement to the Dutch future need: "YC should be seen as a group of informal carers" and "do not problematize the group".

I still like "young carers in the Netherlands should be seen as a specific group of informal carers". I think it is also important that they are so informal. As you also know, there is now from the Federal Office of Public Health that adults are approached in the same way as carer, but children are of course even more informal. (E9, R2, CH)

Results - UK

1. Visibility and awareness raising

Main findings:

First Round

Research by organisations such as Carers Trust have led to the increased visibility of young carers, coupled with the passage of the recent Care Act and Children and Families Act (in England, specifically). However, experts felt that we do not know enough about the actual numbers of young carers and young adult carers, nor do we have a concrete definition of young carers. Overall, it was thought that young carers remain quite hidden in UK society, especially those out of contact with a formal support service, those from Black and Minority Ethnic communities, and those with their own health issues.

“In the city that I work in they are identified by ... The list is often quite similar to young people who are at risk of significant harm. The factors that you might look for if you were to make a front door social care referral are quite similar. Things like poor attendance at school, lateness on a regular basis at school, the young person’s appearance when they attend in the school setting or other community settings. Their own personal disclosure about looking after somebody, perhaps presenting with distracted or stressed in an education setting. Those are the main initial starting points as to what a professional might notice. In terms of how that person makes that referral to us, hopefully it’s pretty well known now that we’ve got a city wide website that people can make the referrals through. They can also download a checklist from our website. They can go through that with the young person to get a bit more detail about whether or not they think they would be classified as a young carer or not. They would make a direct referral to us then in partnership with the local authority we will assess their needs and decide whether or not they are classified as a young carer or not.” (E10, R1, UK)

“I don’t think we’re that great at identifying young carers really as a community as a whole. Particular cases would include people who care for someone with a mental or substance misuse condition. If a young person has a parent in a wheelchair, for example, and you can clearly see how that person would need a young carer’s support, but it’s less visible with a mental health condition. How can you be a young carer if your Mum is depressed, for example? There’s an over-emphasis on what housework the young person does versus the emotional support that they are offering. That’s something that we should definitely improve upon. In terms of how services are delivered there’s probably an expectation from outside agencies that services like ours are essentially glorified youth clubs. It’s like, yes, just go in here and you’ll get lots of fun trips. That’s just one part of what we do. There’s a lack of recognition about the spectrum of support that young carers can get from a service like ours. These are all awareness things. How could we improve services?” (E9, R1, UK)

“I think there are particular groups of young adult carers who are perhaps less seen than others, so I think particularly young people with learning difficulties, I think there is often an assumption that young men can’t be carers. I think perhaps levels of support amongst black minority ethnic families are often overlooked as there can be a cultural assumption that caring is the norm. I think particular groups are less likely to be identified than others I would suggest.”

Second Round (Reflection)

Overall, experts agreed with the feedback from their fellow experts from Round 1. It was thought that that adolescent young carers and young adult carers are particularly hidden in comparison to young carers (children under the age of 18).

“I think they are less aware because just thinking about our database we have got about 100 young adult carers compared to about 500 young carers. And again that is probably because again through the work that we have done with schools and colleges, schools are sort of referring perhaps more to us and again the colleges are taking a bit longer perhaps to catch up. And yes just services in general you know GPs, medical centres, hospitals, yes probably don’t even think about it and think oh you know that is a young person that needs help and support with their caring role. But I think perhaps education professionals and health professionals might be a bit more aware that younger children need support and I think young adults do tend to slip through the net.” (E9, R2, UK)

Local level

First Round

Experts recognized that schools and social care professionals were responsible for the majority of identification and referrals to formal support services for young carers.

“Yes I would say they are still quite hidden. Certainly when I just talk to people generally, people that you know I am perhaps friends with they are quite shocked by the fact that young people are in these positions of having to take on like really massive caring roles. And like you say people are more familiar with adults carrying out these roles and older adults at that as well so yes I think it is very hidden. And certainly work that I have done with [name of college] College has really highlighted the fact that yes staff within the education system may well know what the expression perhaps means vaguely. But they don’t know in depth, they don’t understand what it is for a young adult carer to have all these responsibilities of perhaps taking siblings to school and that is what is making them late. And I don’t think even with a limited awareness I still don’t think they perhaps probe what is going on in their lives if they are being late, if they are missing. Yes so I think yes they are still quite hidden and I still think awareness is low, yes.” (E9, R1, UK)

“The biggest contributor to our referrals is our social workers from children’s social care. You can extrapolate from that that a number of them have other safeguarding needs as well, being young carers, but that’s probably the top one

because social workers are more aware of young carers needs perhaps more so than health professionals. The other thing to mention in that is that within those children's social care referrals we get a number from children with disabilities teams. Those would be slightly different in that they would be working with the family in the first place, not because of social care issues necessarily, but because the cared for person is a child sibling with disabilities. Overall, children's social care is the biggest referring agent." (E10, R1, UK)

Second Round (Reflection): It was expressed that the entire society must be targeted on a local level to spread awareness about young carers. The burden of spreading awareness on a local level typically involves referrals from schools or social care professionals to young carers projects.

"I do find that whole society approach is really helpful. One of the things that some of our young carers in the Health Champions Programme have done recently, we gave some funding to North Region and the young carers based in Newcastle have done a fantastic billboard and bus stop poster campaign that's just gone out this week and it's had a huge impact, so they've had a digital billboard as well as some poster billboards around the centre of Newcastle, including outside the library, so a real focal point. But they've also put posters in bus stops around identifying young carers and they were featured on the local news. So there are some things like that, that are going to start making wider groups of people start thinking about who young carers might be and what they might do and I just think that's fantastic and these are all young people between 16 and 24, so really good that they've done that and it's getting that message out there and how we start conversation starting". (E4, R2, UK)

"We don't receive a lot of referrals from GPs to be honest. We would get some maybe from health visitors and occupational therapists, people like that, rather than GPs, but I haven't had any referrals in the last two years from GPs. Most of our referrals come from social workers to be honest, once Social Services become involved, they are very quick to refer, and skills they identify, we would go into schools and give talks to raise a wee bit of awareness to try and just even [inaudible] and let the teachers know that there are services available, but I learn that family identify themselves, we'll receive referrals from them." [Belfast, NI] (E2, R2, UK)

Regional level

First Round

"So yes I think it probably it is quite low everywhere really. I don't see that it would be stronger in particular areas, I don't think. But umm yes, no I would say it is probably quite low yes." (E1, R1, UK)

Second Round (Reflection)

Experts reported that whilst it was true that the actual number of young adult carers in the UK is unknown, the census allows for accurate estimates. Despite the discrepancies in reported figures, it is understood that there may be disproportionate levels of young caring in certain locations, e.g., Northern Ireland because of its special situation involving the sectarian conflict, The Troubles.

"However, we do have something, which other countries probably don't. We do have the census, and we can get breakdowns by age group to local authority area. So, we can have a rough guide, and I think if we want to use the BBC findings and, kind of, times it by four, that gives u that really good guide. So, it's not that we've got nothing. We have got something to go by, and, yes, we absolutely do need to improve how we record young carers. I was going to say 'capture'. That sounds terrible, record the numbers of young carers, and we've got to promote to schools that they can use their systems. They can use SIMS, they can use other systems. Social care can use their systems, like the healthcare use their systems. They've all got the ability to do it, and they just need to do it. I mean, that is just one small part of the problem really. I think we can fairly say there's lots out there, and they're worthy. The numbers are worthy to require legislation, to require support and services. So, let's not get too bogged down in that, but a next good step would be to speak the census team now, to make sure we're asking the right question in the right way, to give us the best chance to identify." (E7, R2, UK)

"I find it very annoying actually that we can't agree on the numbers of young carers that are there. I find this extremely particularly so in Scotland where for a number of years we quite happily spoke about there being over a hundred thousand young carers in Scotland. And that was based on the 1/10 statistic that had come out at least one in ten it was that had come out repeatedly through survey work that we had done in many areas in Scotland in schools. And that all held together. But in terms of Scottish government actually developing legislation and I think even sorry, but even in the strategy, even in our national strategy that is a government document and that refers to the 100,000 figure. So we were quite pleased that government had accepted that and even the Children's Commissioner in Scotland who you know, he was really supporting the young carers' agenda quite heavily for quite some time, he had said you know the numbers are important because professionals especially teachers need to have an idea of it. If they have a class of say 22 or 26 how many young carers are likely to be in that class? And if you are not supporting anything then you know you are missing something maybe? But it very much annoyed me that the government referred back to the census and the Scottish Household Survey and came up with 29,000 young carers which I think dilutes the problem, you know dilutes the issue massively. And for me it is not valuing the lifestyle of them or not recognising and valuing the lifestyle of many of our young people in Scotland. So I am, and you can maybe tell by my tone that I am slightly annoyed by that. But I do think that we need to try and get together and agree what the figures are." (E5, R2, UK)

"We think it's 12,000+, yeah, I think we have the highest number per capita. I think, there's specific areas in Northern Ireland that would have a lot of mental health issues, and specifically because of our history and the troubles, I think there's a lot of people who maybe have been affected by that, and because of that there's mental health issues and...Carrying forward into the next generation. Yeah, it's a generational thing, I think." (E2, R2, UK)

National level

First Round:

“Umm, I would say it is probably low. I would say it is probably low throughout the country.” (E11, R1, UK)

Second Round (Reflection)

On a national level, awareness of young carers is piecemeal and scattered. Experts reflected that there is no standard across the nations.

“what’s come through at various points through the report was that sort of regional and local differentiation that there is no standard, if you like, that we’re all adhering to....no one’s said, “There is a particular standard that we expect and I think that again, it’s that suffering from the degree of variation that we have around the country. Where we’ve got a good piece of practice, we’re not then saying, “Right, let’s get this right for everybody.” So there are more exceptions than rules.” (E4, R2, UK)

“My only other comment was, kind of, attention in the media leads to a slow increase of visibility and awareness, and I think it does. I think, for that continue, it needs to be an important part of the jigsaw puzzle on a national level, but also on that local level.” (E9, R2, UK)

“Scotland and England are very different when it comes to awareness, and especially policies that are supporting that, so I just thought that was interesting to note.” (E5, R2, UK)

“I mean, I think we need to have a young adult carer definition. I think they need to be separated. And actually again in Scotland I’ve seen that have a massive impact. Because young adult carers have been identified in the Carers Act Scotland, I’ve seen services come in to support that transition for young adult carers to adult carers services, to exiting them onto fulltime education if that’s what they want. And I think it’s purely because - if you don’t have a name for young adult carers, it’s almost like they don’t exist” (E3, R2, UK)

“I think families in general just need more help, there just seems to be a lot more awareness of what help is available for families that have kids maybe with severe autism and that there is support for siblings that maybe wasn’t there in the past, but now because there’s more help in general for these conditions that families are becoming more aware and referring siblings...Who have diagnosis questions and maybe in the past, so there’s a diagnosis there, so they are more aware.... There’s still a lack of awareness, yeah definitely it’s getting better in schools and things, but in general I think there’s much a lack of awareness of what the young carers actually do.” [Northern Ireland] (E2, R2, UK)

Additional

First Round: From the summary interview guide:

Research by organizations such as Carers Trust have led to the increased visibility of young carers, coupled with the passage of the recent Care Act and Children and Families Act in England (P4). The Children in Need programme in the media, coupled with more press attention (e.g., “DIY SOS” project) from celebrities with a background of young caring has helped to increase the visibility of young carers (P6; P8). A focus on young adult carers has developed because of our understanding of the importance of the transition from childhood to adulthood, however we still do not know enough about the actual numbers of young adult carers (P3; P5). It can also be difficult to define young carers and thus a “harder checklist style definition” is needed (P4). The visibility of young carers may be further hindered by a lack of advertisement in public spaces about young caring; one expert remarked that if it was not for his involvement in professional research with young carers, he has never seen a notice about young carers in a public space for the general public (P4). Notably, most children in the United Kingdom would not have had contact with a young carers service (P4). In Northern Ireland specifically, the crisis in government (devolution and its recent collapse) has played a significant role into the lack of profile-raising of young carers, as young carers simply have not been seen as a political priority (P10).

The definition of young caring defined by researchers and academics from the 1980s and 1990s has caused people to focus predominately on young people caring for parents with a physical condition or disability, rather than those young people caring for parents with mental illness. Other experts pointed to other problems with the current conceptualization of young carers, specifically with the term “adolescent young carers”. It was felt that the introduction of the term was unnecessary because young people aged 15-17 years old are already included into the typical definition of “young carers” because they are legally classified as “children” (P3). Furthermore, increased categorization of young carers is unhelpful because terms such as “adolescent young carers” are not recognized in the current legislation affecting young carers (P3). What is needed is to continue to remind society of the requirements and duties already in place to recognize and support children with caring responsibilities across the health, social care, and educational sectors, particularly in light of the “Children in Need” legislation (P3). In light of the Children in Need legislation, one expert noted that adolescent young carers may in actuality be hidden within the classification of

“Children In Need” and this can serve to complicate the ability to draw out hard statistics on the numbers of young carers (P4).

There remains gaps in understanding and awareness of adolescent young carers within the educational sector; on an individual level, some teachers may feel that identifying and supporting young carers is not their responsibility, rather, it is the responsibility of social welfare (P4).

In P1’s view, the Nordic countries (namely, Norway, Sweden, Denmark, Finland, and Iceland) have done particularly well in acknowledging the children of parents with mental illness (COPMI), and comparably better than the United Kingdom. P1 believes that there is an avoidance to consider the impacts of parental mental illness on a children’s mind in the United Kingdom. P1 believes this is due to the fear of social service involvement and the child’s removal from the parental home. Thus, P1 asserts that children caring

for parents with mental illness are generally overlooked when considering the young caring experience in the United Kingdom. However, Scotland may be more forward-thinking than England in this regard (P1). P1 points to the definition of young caring promoted by early young carers researchers' did not take into account children significantly affected by parental mental illness as "young carers", and this likely influenced the hidden position of COPMI in the discussion of young carers.

P2 found it critical to remember that adolescent young carers should be firstly considered by their developmental stage and cognitive and emotional stage of development, rather than their biological age. She preferred this way of thinking because it is often thought that adolescent young carers are of the age to do "legally" and "appropriately" perform certain caring tasks, yet, their developmental maturity can vary widely.

Regarding visibility, P2 believes that there is a particular pervasive stigma for adolescent young carers because of their age; there persists an societal idea that adolescent young carers are "not working hard enough, not doing well at exams, and not working hard enough in school". This stereotype is connected to wider societal beliefs about youths and youth culture. Similar to P1, P2 believes that there is more stigma for young people caring for those with mental illness or addictions in comparison to those caring for physical disabilities. She believes that those caring for individuals with physical disabilities can receive a "hero" status, yet those caring for family members with addictions or mental illnesses do not receive that same "branding".

In Scotland, the recent passage of the new Carers Act has affected the visibility of young carers (P2). More broadly, there may be an growing awareness of the kinds of activities that young carers do, but there remains a gap in understanding about the complexities and diversity in young caring experiences (P2). Within the Scottish school system, most teachers have a reasonable awareness of young carers but do not know how to put that awareness into practice (P7). In Scottish universities, the development of a Carers Recognition Award has been helpful in helping universities identify young adult carers, but it is understood that those young people not in education remain hidden (P7). In addition to the passage of the Carers Act in Scotland, awareness of young carers in Scotland may be growing because of the history of political campaigning, coupled with the visibility of politicians speaking up about their own caring experiences, and finally the appearance of young carers in popular Hollywood movies such as the *Hunger Games* (P2). Specifically, P2 points to the level of heightened awareness in Edinburgh due to the involvement of the local young carers project into schools and its connected publicity.

Second Round (Reflection):

Strategies, interventions and programs to support (A)YC

Main findings

First Round: From the summary interview guide:

Adolescent young carers are identified through children's social services and that contact may lead to involvement with the over 300 young carer services (called "young carers projects") in the United Kingdom. Formal support for young carers appears to be concentrated in England, as there are not as many young carers projects in remote areas (P3). Young carers could also be referred to formal services through adult mental health services, if there is an "enlightened mental health team and an enlightened mental health consultant" (P1). Still others are referred by voluntary bodies and by schools (P1; P5). In schools in England, the National Young Carers in Schools programme includes resources for schools such as posters and other information for young people to self-identify as carers, whilst also allowing them to connect with a designated person in their school to speak to about their caring role (P5). The ability to access a young carers service may be less defined by rural or urban localities, and more dependent upon the allotment of funding (P3). Other hidden groups with low service access include Black and Minority Ethnic young carers and LGBT young carers (P7, P8). In Northern Ireland, professionals point to their unique situation of children caring for parents and other family members involved in intra-country armed conflict (The Troubles) (P10). How much funding a local authority receives for young carers and whether there is consistent services depends upon funding (P3; P10). Because of budget cuts, some young carers projects are not able to offer a transitional young adult carers service (P9). Young carers projects are indeed useful because of the way they can offer family support and consider the needs of the entire family (P3). Young carers projects also provide the opportunity to talk amongst other young caring peers and talk to adults who are knowledgeable about their family situation. The young carer project can also direct a young person to other avenues of support, respite care, or help facilitate communication between social care and schools (P4; P9). One expert pointed to the need for young carers services to have better "exit strategies" in place for when young carers transition into adulthood (P3).

Currently the NHS England runs a programme called the "Young Carer Health Champions programme" that involves a group of young carers working with the NHS for a year term (P6). It was suggested that GPs and GP attached nurses should play a more significant role in the identification of young carers, yet the overwhelming view is that they currently do not (P1). School nurses are ideally placed to identify young carers due to their close contact with children; however P1 points to the devolution of the school nursing services to local authorities as the reason for their decreased involvement in identification. Historically, carers were not a central focus in health training, and therefore even the concept of "carers" was absent from health professional language (P6). Furthermore, it was asserted that health care professionals are frightened to ask more questions leading to the identification of young carers because they feel incompetent in regards to how to direct young carers to services (P6). It was also thought that the lack of a "solid" duty (in reference to the Care Act and Children and Families Act, health professionals have a "duty of cooperation") for health professionals to engage with carers was one reason for the disengagement with young carers (P6).

There is also a need for more detailed training for professionals in the complexities of young caring experiences, family dynamics, and an understanding that young carers need ongoing conversations about their caring role (P2). Part of service delivery on building boundary-setting for young carers within their families (P2). One example of best practice shared from Scotland includes the ongoing young carers forum in Edinburgh, in which young carers led the forum with city commissioners and project workers present, providing an opportunity for them to share their views (P2). The young carers forum demonstrates the success of empowerment and skills building for adolescent young carers, as they have listed their participation in the forum on their CV and for college admission (P2). Additionally, Scotland has seen the development of a National Strategy that identified young adult carers as a distinct group (P7). At the Edinburgh Young Carers Project, there appears to be a growing acknowledgement of the specific needs of LGBT adolescent young carers evident by the continued engagement of LGBT-oriented workshops during young carers group and respite

activities. This project has also seen an uptick in transgender adolescent young carers identifying themselves, which P2 believes is characteristic across Scotland.

Child and adolescent psychiatrists also should play a role in identifying young carers, however, as they currently work in Child and Adolescent Mental Health Service teams (CAMHS) which are “grossly underfunded and grossly understaffed” and at a “state of crisis in the child and adolescent mental health” (P1). This is why P1 believes that child and adolescent psychiatrists can only work to support other professionals in identifying young carers. The issues of understaffing and underfunding continue in adult mental health services and therefore the transition period for young carers aging into adulthood is also fraught with troubles (P1). Adult mental health services are “very threadbare, understaffed, and over-pressed”, and further complicating matters, adult mental health services do not typically think of the social context of the family and often claim that they do not know how to talk to children (P1). P1 calls this a “cultural problem” and has been involved in the campaign to create change in this area.

“We’ve got our peer support which encompasses some pure fun respite activities for young people to enjoy themselves and enjoy their childhood. Also, within the group activities we offer some slightly more educational workshops which might focus on a particular health condition that we might get our whole cohort together that supports the sibling with autism, for example, to raise their awareness of the symptoms that they are dealing with. A certain area of our group work is around arts and self-expression. We do a number of workshops whether it might be drama or sculpture. We try to keep a young carer’s related theme involved with all of those and it allows them to share their story, but perhaps do it in a slightly detached way. They’re not sitting around in a circle telling each other about what their caring role looks like day to day, although that might come out organically anyway. The idea is that they are able to talk about some of the things that they are proud of and the challenges they face through different art mediums. That’s the group work stuff. The one to one is not therapeutic I wouldn’t say. It’s fairly practical....How to deal with a situation that’s unexpected and then also to help them to draw on existing strengths and internal resilience to recognise the good stuff they are already doing and build on it. If they are lacking in those self-awareness skills we can offer them relaxation techniques and help them to identify a wider support network, which would lead into our third and final area of support which is advocacy. That involves getting together with the young carer to draw up a statement if there’s an upcoming meeting where they’re not confident enough or old enough to attend themselves, but they want their voice heard by the professionals. Then the attendance at those meetings and making sure that their feelings are considered. It could be a safeguarding meeting. It could just be an internal school meeting. All sorts of things like that. That’s the main three areas of support that we offer.”

Second Round (Reflection):

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

“My anxiety when I read through all of that and I guess, particularly thinking about some of the differentiation we’ve got through devolved areas, so with Scotland having a different system, with Wales having a different system. How do we make sure that in the UK as a whole, our offer to children and young people is good enough, has enough ambition to do it, that we’re not setting a ceiling rather than a floor, if you see what I mean.” (E8, R2, UK)

“that was an awful lot of [young carers] project work that’s fantastic and has brilliant elements to it, but actually is still so piecemeal across the country and across the UK that we’re not actually delivering anything sustainable for those young people. And that really worries me.” (E7, R2, UK)

Strategies, interventions and programs

Laws and regulation:

Second Round (Reflection):

It was agreed that identification by service providers remains an issue for (A)YCs. However, it was also thought that legal issues of safeguarding may actually serve as a barrier to getting individualized support for an (A)YC. Experts also thought that supportive policy across the United Kingdom was scattered and this caused inequalities in the provision of formal support. Experts also expressed that the current policy in place needs to be closely monitored to see how well it is working in practice. One major takeaway from the experts in Scotland was that it was critical to acknowledge the different policies across the four nations of the UK. For example, laws supporting young carers that apply in England do not apply in Scotland.

“we’re not so good at identifying in the first place. I think that we are still very, very hung up on safeguarding and that then becomes a barrier to saying, “Actually this is a young person in need.” And then we get very hung up on what we kind of, think of as a standard offer or as an appropriate offer rather than personalising what we do and thinking about what matters to that young person.” (E10, R2, UK)

“we’ve got that difference with devolved parts of the UK we’ve got to be really careful about the inequalities and inequities that we are creating through our legislation and I don’t think that we’ve had the blinkers off for that.” (E3, R2, UK)

“I think what needs to happen is I think there needs to be better monitoring of how the legal duties are being implemented, because at the moment it’s not really monitored. So for example, how many additional young carers have been identified, or how local authorities are actively trying to identify, and on a national level it’s not being monitored well enough really as to how well these duties are being implemented and rolled out, so there’s no requirement that local authorities should be feeding back any data around, for example, if the young carers have received the assessment they are entitled to or anything like that. I think if we can strengthen the monitoring it could actually then highlight where there is still need for better implementation and where these legal rights could be strengthened within the local areas, so I would quite like to see a general recommendation nationally anyway, that there’s better monitoring of how this is actually being embedded, because it’s almost, we have the rights now and the strength and rights for young carers in

England and the UK were really welcomed and are welcome but I think the next stage is how do we ensure that they are embedded effectively and actually working out on the ground.” (E4, R2, UK)

“I think it might be useful to for instance the Care Act and the Children and Families Act don’t necessarily apply in Scotland. I think that maybe needs to be pointed out that there is legislation which is made in Westminster but that actually is for England and sometimes in Wales I am not sure about what is devolved to Wales. But certainly in Scotland nearly every aspect, every government department that would work with carers has devolved powers to Scotland.... again here we are seeing an example of not understanding that the UK is made up of four different countries. And sometimes four different countries have four different areas of legislation or pieces of legislation that would affect them.” (E5, R2, UK)

“We wouldn’t be as far ahead... No, we’re definitely lagging behind, the work that the Carers Trust, has done in England, and I think even from a policy point of view, they’re way ahead of Northern Ireland in terms of the support that they provide especially to young adult carers as well. We’re quite far behind.” (E2, R2, UK)

Education:

First Round:

Experts repeatedly expressed that there was a need for young carers to be supported in schools and colleges. A few areas of good practice were identified, including young carer ambassador programs and a student carer card.

“it is a card that will enable carers to basically show the card if they are having to be late or if they need some time to just make a phone call. Or if they need extra support for assignments, if they need a bit of an extended time to do that or they need some I don’t know, some quiet time or they need to be able to work from home. It is so they don’t have to then keep explaining to everybody, ‘This is my story.’ The hope would be that once awareness is raised with the tutors at college they will understand what the card means, recognise that this person is a carer and needs help without giving them too much of a hard time.” (E9, R1, UK)

Welfare:

First Round:

“I guess my big concern is the impact that caring has upon young people, in terms of particularly the negative impact that it can have upon their lives as they grow up as children and go through transitions during adolescence. So, you know the feelings of isolation, the health difficulties they might experience themselves, the lack of network, the difficulties engaging in education and progressing onto employment. So, I guess I would like to see a system where young people are protected from the negative impacts of caring, so that would involve really good identification, putting support in place for them quickly and sensitively. I guess it would be about taking a really holistic approach, so looking at the needs of the whole family and working out the best way of enabling a family to stay together, to support each other, but also for young people who have those caring responsibilities, to be able to reassure their own interests and aspirations and achieve their potential.” (E8, R1, UK)

Second Round (Reflection):

Experts expressed that the voluntary sector (i.e., young carers projects) have provided the most support for young carers historically. The governmental sector (i.e., statutory services in local authorities) lags behind in providing formal support.

“But actually we’ve missed out some key areas in terms of making sure that health and social care are on a par with haven’t necessarily given the right priority and the right recognition to the voluntary sector within that as well, because actually it’s the voluntary sector that have been driving support for carers it’s not the statutory services.” (E7, R2, UK)

“Across all sectors, early identification and intervention for all children in need is required. Yes, so experts identified other key stakeholders and it’s got CAMHS (Child and Adolescent Mental Health Service teams) can play a more significant role if they are trained to deliver sessions for children and their families. Additionally, educators within the school system are important stakeholders.” (E6, R2, UK)

Goals , strengths and weaknesses

Laws and regulation:

First Round:

“I think we need to see a higher profile for carers and young adult carers at national government level. So, we now have a new action plan cares and young adult carers I have specifically mentioned within that, particularly in terms of transitions. It is across government strategy, so in theory that should bring together all of the different departments and agencies to provide comprehensive support to young adult carers, but we know in practice that services often operate in isolation. So, for example, one of the things we have spoken about quite a lot is the 21-hour rule in the benefit system which prevents young adult carers from studying and claiming carer’s allowance if they are studying for 21 hours or more per week. I think that is just a real example of how government policy effectively works against each other really because not many people would disagree that young adult carers deserve the right to study and also receive small amount of benefits for supporting their families, but actually, the policy is not joined up across departments, so it is effectively education and welfare policy working against each other. I think austerity is key but if we could also break down the barriers across different government departments and different services that exist, we could see more effective joined up support for young adult carers.” (E8, R1, UK)

Goals:

Second Round (Reflection):

Whilst it was expressed that England's Care Act and Children and Families Act is significant policy, it was widely understood that the current legislation had little real benefit for young carers.

Goals: More "teeth" is needed in current national policy to give the policy "bite".

"I absolutely agree that legislation is needed, I think the issue that we've got in terms of the Children and Families Act is that although young carers are in there, they do fall through a bit of a loophole because the emphasis is on getting the care right for the person who's receiving care rather than necessarily giving them the same rights as adult carers and I just don't feel that we've closed the gap enough and I think our legislation hasn't gone far enough and our legal duties still sit primarily with local authorities and health has this duty of cooperation." (E11, R2, UK)

Education:

First Round:

"I think in terms of education and employment, one of the key national priorities is the expansion of the apprenticeship system. The government has a big target in place to achieve 3 million starts by 2020, but at the moment, apprenticeships aren't particularly flexible or inclusive. They are typically delivered on a full-time basis, Monday to Friday 09:00 to 17:00; and as we know, young adult carers often need quite high levels of flexibility in terms of their working arrangements. So, I think changes to the apprenticeship system which would provide greater flexibility, would really benefit young adult carers and also really important in terms of enabling employers to benefit from the wide range of skills that young adult carers typically develop through their caring roles. I guess that applies to all jobs, but particular as apprenticeships are high government policy priority in terms of the pathway into employment for young people, it is particularly pertinent I think." (E8, R1, UK)

"So from the work that we've been involved in over the years I think there's quite a strong evidence base to show that when children and young people have caring responsibilities it has quite a big impact upon their access to education whilst they're at school. So in a range of ways really, there's a practical impact in terms of disruption to their ability to attend school, so on occasions they may need to stay at home to provide care for their family, or the person that they care for, they may need to miss school in order to attend things like hospital appointments. There's obviously a strong emotional impact as well, so the pressure of caring can place quite a lot of pressure upon a young person which can mean they may have difficulty concentrating at school, they may be tired, they may not have time for homework, they may have feelings of anxiety or stress or often anger which can impact upon I guess their ability to engage fully in schooling. There's also obviously an impact upon their wider experiences, so the extent to which they're able to build relationships with their peers, take part in social activities. They might often feel quite isolated, all of which can effect I guess their confidence and their capacity to engage fully in learning and develop skills and experiences that can contribute towards their future employment." (E6, R1, UK)

Welfare:

Prevention and care for children with a psychiatric / addicted parent (KOPP/KVO)

First Round:

Goals:

"For example, we used to deliver a project when I was working in South London, a programme that's called Kidstime. That's where young carers who are impacted by the mental health condition of a parent the whole family will come to an evening where they will do some group work together to help them to understand about a theme. It could be about medication or it could be about a particular condition. After that introductory bit the two groups separate so you have a parent peer support group, you have a young carers group which is usually more drama or art focused. At the end they come back together and have refreshments and what's really good about that work is that in a two hour session you can have parents and children given the opportunity to talk about things that they probably wouldn't do just at home in front of each other. A young carer will come back from their art group and share something that has a personal important message that the parents didn't have a clue about. It could be about a worry or it could be about something that's more positive about what they really enjoy about their caring role. This is the sort of thing where you can do some great work with young people and send them home and what are the chances that they will talk about that with their family? To be honest, my experience is that either the parents won't ask about it or the child won't share it, but forums where you get positive feedback within generations of families can be really powerful." (E10, R1, UK)

Second Round (Reflection):

Experts were not necessarily critical of the supportive programmes themselves, but rather urged a realistic view of the scope of the programmes. Experts agreed that that excellent programmes tended to be localized. This included programmes such as Kidstime, a NGO for children affected by parental mental illness.

Goals: Be realistic and practical about what formal support is present and its sustainability in a time of post-austerity.

“So we have 1200 school nurses in England for 24,000 schools. Yes, so the maths doesn’t work and similarly Kidstime is a great charity, but the work that they’ve done with schools is fantastic but actually a lot of schools don’t have capacity to do it and the model that they use isn’t necessarily easily replicable. So the capacity and ability to spread what they’re doing isn’t necessarily there. So for me, there’s something about us being really, really practical. We are in ten plus years of austerity, we’ve seen some really great programmes disappearing because there are just not the funds to sustain them, what I feel that we need to do now is take stock of what we know works, what we can sustain, how we sustain it in a practical way and so that we’re not letting down children and young people because that’s just happening right, left and centre and is unforgivable. And then build from there, because hopefully the austerity doesn’t last forever but what we’ve got to do is plan as if it does and I don’t think we’re doing that yet.” (E4, R2, UK)

“the impacts of parental mental health illness on children’s minds must also be centred and addressed. Yes, and I think that’s again going back to some young carers may have experienced trauma and it’s about how do we ensure we’ve got enough funding and support to let them - I guess it’s funding and support so the young person can talk to a counsellor about it when they’re ready. But there’s also the funding and support if that young person’s still caring for someone with drug and alcohol issues or a severe mental health issue. Funding and support to get the house where they’re going back to safe, because they can’t give that mental health support if that young person’s going back to an unsafe house.” (E3, R2, UK)

Relaxing activities / supportive groups

First Round:

Experts involved in young carers projects emphasized the effectiveness of peer support groups for young carers.

Goals: “Befriending”, i.e., young carers befriend each other to offer peer support. The goal would be that once a young carer has befriended another young carer, the young carer would befriend another, and so on. It was also hoped that the young carer would become known in their schools as a source of mentorship and peer support.

“we have got our peer mentoring and befriending project that we run here there are probably 12 in that adolescent group so 15-17 that we have trained to be peer mentors. So they work 1-1 with younger carers to help and support them. Some of those peer mentors will also have been trained as young leaders so they will go along to our group sessions and activities and they will be there for the younger carers. So obviously they are supporting the youngsters but also they are developing their skills so they have got something to put onto their cv and you know, enhance their confidence.” (E9, R1, UK)

Second Round (Reflection):

Digital, online based peer support tends to be most effective with adolescent young carers, however it was acknowledged that the national online support space has been closed because of lack of funding.

Goals: More funding is needed to increase the availability of supportive online spaces.

“we’ve certainly seen with our Young Carer Health Champions that having a Facebook group for them and encouraging that interaction has been really supportive and what you see across all age groups, the thing that tends to be evaluated most highly and most valued by individual carers is that peer support element.” (E4, R2, UK)

“We probably need to do more in terms of promoting that type of thing so that a young adolescent carer would think, “Actually this is automatically the place I’d go to.” So Carers Trust used to have Babble and things like that, that were online forum spaces and they’ve gone because of funding and actually I think they were hugely useful. So having those safe places where people could talk about the things that matter to them, that worried them, that were just appearing in their lives day to day. I think we’ve got to find those appropriate spaces again and build them up and make them recognisable, go to brands in the same way that people know where they want to buy their petrol and their bread or their milk and all those types of things, we’ve got to do the same thing in terms of making places accessible for young people.” (E6, R2, UK)

Individual support

First Round:

Experts pointed to the numerous young carers projects around the UK as the main source of individual support for young carers. Their weaknesses include their remit/commissioning arranging from their respective local authority.

“I think the main forms of support are probably provided by carer services throughout the country. I think over the last ten years, we have seen a rise in specific targeted services for young adult carers, sort of looking back maybe five to ten years ago, there were lots of adult carer services throughout the country, predominately targeted probably carers maybe over the age of 30/35. There were also some services for young carers, children who provide care, but I think due to increasing levels of awareness, we have seen more targeted services for young adult carers, adolescents. Like I said, most of those services are probably provided at a fairly local level, either by local authorities or by voluntary and third sector organisations, who could sometimes be commissioned by local authorities to provide specific support which is very much tailored to the adolescent transition stage.... I think the formal dedicated services provide the very targeted support that young adult carers need. As an adolescent, I think all young people go through some quite specific transitions and face particular challenges in their lives. So, to have services that are really targeted around that and supporting those transitions is really important, so I think the benefits of those sorts of services are that they bring young people of a similar age and with similar experiences together, so they get that mutual peer support from each other. They get support with particular challenges that they might be facing that are different to young carers and to older carers. So, for example, when they are progressing through education and when they need to make choices about the options available to them, so thinking about leaving school, moving onto college, onto

university to getting a job or an apprenticeship, those dedicated services can provide that level of support. I think they are probably the key thing, so support around specific needs and also the peer support from that age group... I think any weaknesses linked to dedicated services for young adult carers are probably often enforced by commissioning arrangements. So, for example, we have a service here in Leicestershire, that provides support up to the age of 18, but they are not able to provide support beyond 18. But at the age of 18 and one day, a young person doesn't stop being the young adult carer. They don't stop having those needs, so it is quite problematic often when they have to turn young people away when they hit a particular age. I think it is where commissioning arrangements put particular age barriers in place that mean a young person can no longer support even though they may need it. I don't think there are any other negative impacts that I am aware of." (E8, R1, UK)

Second Round (Reflection):

The effectiveness of face-to-face informal and formal support with young carers has been well-established. Respite activities with young carers can provide them with avenues of making friends.

Goals:

"a lot of young people say, is that you can't replace the need for face to face time with people. So actually having time to sit in the same room with their peers and laugh and do things that young people do, but also discuss the things that matter to them is really important too. So I think digital is hugely important, but you're never, ever going to replace the need to have that individual contact as well and that we've seen it amazingly through our young carer health champions programme. That the friendships that have built up from that are friendships that are going to last a lifetime. You know, young people who live at opposite ends of the country, have that digital friendship now as well, but it's based on that initial contact where they've come together, done some quite challenging things together, whether it's an outward bound type activity or just an exercise in a classroom, but that face to face contact has given them the foundation for a really long lasting friendship that's providing a lot of support." (E10, R2, UK)

"It's the peer support, it's friendships, it's the friendships. Most of them will build friendships for life out of it, you know, they will often [inaudible] been with this from maybe eight years old, who are now 20, and they've made friends for life, they know they'll talk about just having someone else there that they know is going through the same thing, who is on their level that they can talk to, I think that, I would say that's a big strength of it, and just respite from what's going on at home." (E7, R2, UK)

Courses

First Round: Courses were generally unmentioned by the experts in the UK.

Second Round (Reflection):

Courses were generally unmentioned by the experts in the UK, with the exception of two expert professionals in Northern Ireland. In their local context, their young carers project utilizes courses to help build the skills of young carers.

Goals:

"We also have workshops, that we run in the summer and we have local colleges, so the kids go in and do metal work courses, computer courses, things like that as well, and we try to do cook up programmes throughout the year as well, so just give them basic skills, so that if they do have that role at home they can cook from fresh, then it's healthy and it's cheap and all that thing. " [NI] (E2, R2, UK)

Training for professionals

Second Round (Reflection):

It was overwhelming agreed that professionals in a variety of sectors need to receive more training on how to identify and support young carers. It was thought that certain sectors, e.g., education and health and social care, are ideally placed to build their training on young carers awareness. However, there was one expert view that the role of GPs is not to identify young carers, and rather, that their increased engagement would only lead to the involvement of social services.

Goals: Training should be mandatory for those in health and social care. However, it is important to critically examine the role of GPs and whether how their further involvement could be explored to truly benefit young carers and their families.

"I absolutely agree about the need for more information and training for all professionals, policy makers and teachers. One of the big debates that's going on at the moment is about whether we should be including carers as part of mandatory training, certainly within health and social care. And my gut instinct is obviously yes, because it's what I care about and what I'm interested in." (E4, R2, UK)

"It, kind of, needs to be across the board, you know, workforce development across children and adult social care, mental health, social workers or drug and alcohol social workers, the voluntary community sector, the commissioned services. It

needs to be across the board, because the definition is so broad. I think it's just getting that message across that it's not just GPs and schools. Actually, there's a whole variety of services and professionals that need to be aware." (E5, R2, UK)
"Now I'm not convinced that it's a role for GPs. I don't think GPs in the position, I'm not sure how they could identify young carers and I'm not entirely sure how they would actually interact with other organisations. GPs will identify children who have been victims of abuse and neglect and then pass it on to social services but it otherwise makes you wonder what would the role be of the GP and how they would interact, and I wonder whether the people who suggested that had actually talked to GPs of how the GP role is and it's probably worth looking carefully at how the GP role interacts with social services." (E1, R2, UK)

Informal respite care

First Round:

"I think during the last five years or so, there have been significant pressures upon existing young adult carer services. I am very aware that many services that we're in contact with have been cut back quite substantially. They are not able to offer the level of support that they were previously, so sessions are being cut. There is less staff time available to support young adult carers. They are often having to make decisions around how they focus their resources, so as I mentioned a moment ago really, they might have to potentially offer their support to a narrower group of young people, rather than the full range who could benefit from their services.

So, yes, absolutely, I think austerity has had a big impact upon support. I think also in terms of local authority duties towards young adult carers, I think some of the legislation that was introduced a few years ago potentially offered a really effective system of support and identification but unfortunately without the resourcing at a local level to back it up, many of the intentions of the policy probably haven't played out in practice." (E8, R1, UK)

Second Round (Reflection):

Experts felt that a holistic assessment of young carers and their families must take place, with the goal of reducing or eliminating their caring responsibilities. However, young carers must also feel like they have a continued role in the family, according to their ability and want to provide care.

Goals: Holistic assessment of young carers and their families is needed.

"practical support can also be helpful, but also, if we have a holistic assessment, then actually, we might reduce or eliminate the caring responsibilities in the first place, which could change things for that young carer, and could go both ways as well. If that young carer has been doing that job for a long time, they would need to be supported through that transition of not doing it, which we have seen. Young carers complain about carers coming in, they're not doing it right, and things like that, because they're mini adults, but may not have the skills for diplomacy and respect. They're quite defensive around it. So, they need that time to adapt as well. So, whilst we may say that's a brilliant thing, it is a good thing, but also, those young carers need time to adapt, and actually still feel that they've got a place, and if they want to do that carer role, that they're able to do a proportion that they can cope with, that isn't have an adverse impact." (E3, R2, UK)

"And, I think from a policy point of view, it is maybe more funding and more statutory funding for young carers, to allow them to have activities and also has a knock-on effect with the family, it gives the mum and dad a bit of a break as well and let's them know that the child is having a social life, but more funding, definitely more funding." (E2, R2, UK)

Coping strategies

Second Round (Reflection):

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

"Now, I would stay historically, kind of, late 90s, early 2000s, our young carers project looked very much like, "Are you a young carer? Yes, great. You'll be on the next trip to the cinema," you know, that kind of model of support. Then, from there, we started groups, and then from there, we started working in schools, and it goes on and on, to a point of, actually, these young people are all at different levels. It's great if they can connect with other young carers because that immediately reduces their isolation, but that isn't all a project can do. So, it is about building their resilience. So, we have moved to much more of a resilience based model, where young carers do not stay in the project for the rest of their lives, but they move through levels. So, if they are low level, they are part of the project in the sense that they probably get more of a digital offer, because they have lower level needs. They've got their crisis plan if things change, and they know to contact us if things change, but if they were at a higher level, they would've built resilience. You know, learnt tools, or perhaps we got adult social care in to assess the adult, and have their needs taken care of in a much more productive way, which alleviated some of the care role for the young carer. That kind of stuff." (E9, R2, UK)

"We have run some programmes and activities for young carers through young carers groups and in terms of coping strategies young carers have said that they found the sessions extremely helpful. But again it is that whole thing about continuity of input I think." (E10, R2, UK)

Additional

Second Round (Reflection):

A small number of experts thought that it was important to consider whether young carers automatically need support simply because they are young carers:

"I think identify young carers first and then see if they need support or are you only going to identify children who need support and then classify them as carers and to determine what kind of support they need. I'm not sure if that's useful, it might be worth thinking about because we assume that everybody who is a young carer is automatically in need of support. That's almost a given but it's not necessarily the case." (E3, R2, UK)

Future needs to support the well-being and health situation of (A)YCs

Main findings :

First Round: From summary interview guide:

Within the educational system, mentors and tutors with a good understanding of the life of young carers would be advantageous (P4). Young carers need guidance and information in regards to their own health care needs, and health professionals are ideally placed to provide this (P6). One expert pointed to the need to support entire families, citing high levels of unemployment and inequality facing families in Britain (P3). P5 asserted that professionals are more likely to find young carers in families living in poverty. A "sympathetic" government that is "not consistently hitting the hardest, the poorest, and most vulnerable people" is also needed (P3).

In regards to young carers' own mental health needs, there is a need for the intervention of mental health professionals, especially in light of the dissolution of formal support services because of funding (P7). Young people want a proper understanding of the illness affecting their parent, they want an advocate, and they want to know they are not alone and be with other young people who have similar experiences (P1). P1 points to the model used by the organization Kidstime (a formal support service for COPMI), which uses drama, awareness work in schools, separate parent and child groups, and joint groups on a monthly basis with up to 10 to 20 families. The model espoused by Kidstime helps the parents and children communicate with each other and discover a joint understanding of mental illness which they both accept and understand. P1 emphasizes such dedicated groups are critically important for children with parents affected by mental illness as a "typical" young carers group may not fully address their unique needs and experiences. P1 believes that schools have a tendency to send young carers off to a school counsellor (if there is one) as the first course of action, when in actuality, some children find a discussion of their feelings to be quite distressing as it can make them feel incompetent. P1 prefers an approach that helps a child *think* about their experience, rather than about their feelings. Young carers groups may be beneficial for children affected by parental mental illness, however it can also be stigmatizing if the group only has children with parents with physical disabilities (P1).

In regards to connection of identification and receipt of formal support services, P3 asserts that terminology must refer to adolescent young carers as "children". P2 emphasizes that the growing identification of young carers is helpful, however, without proper services in place, the identification can feel meaningless at best, and harmful at worst. Immediate referral to a young carers service may *not* be what a young carer needs, particularly at the first instance of a parental health diagnosis (P2). Rather, ongoing discussion on a young person's unique needs is recommended (P2). There is also the possibility that receipt of a formal supportive young carers service could enforce dependency on the service, rather than fostering empowerment and self-advocacy (P2).

3.1 Future needs to support well-being / health situation

First Round: From summary interview guide:

More thought must be given to considering *why* children become young carers, as well as whether it is ethical to support a young carer in continuing their caring role (P4). The implementation of Universal Credit means that more work must be done on young carers taking on responsibility for financial and money management within their families, in addition to their other caring responsibilities (P5; P6).

To address the fear of families self-referring themselves to social care services, local charters/covenants providing security to vulnerable families would be helpful (P4). Employers need to be aware of adolescent young carers and have support policies in place to make the workplace environment friendlier for young carers (P7).

Children of parents affected by mental illness should have a lead member of staff trained to work with COPMI and that individual should understand when to contact suspicious and vulnerable families, how to connect the child with their parent, and have a responsibility for engaging other schools in supporting other children with parental mental illness (P1). Ideally, families should be positioned to receive the services of Kidstime if they choose. If children prefer not to use Kidstime, they should have contact with a social worker who was a dedicated 'Children in Need' for parental mental illness professional. The government should acknowledge that COPMI exist and fund social care and health services particularly at the children's level. The government should also integrate Children's Mental Health Services and Adult Mental Health Services (P1). Finally, the impacts of parental mental illness on children's minds must also be centered and addressed.

More research is needed on children caring for parents of substance misuse, and such children must be included into the definitions of young caring (P3).

Experts identified other key stakeholders who are not currently involved in the work to support young carers, such as GPs and primary care services (P3). CAMHS can play a more significant role if they are trained to deliver sessions for children and their families (P1; P4). Additionally, educators within the school system are important stakeholders. Across all sectors, early identification and intervention for all children in need is required (P3).

The period of austerity and the cuts to social care services have meant that young carers support services are intaking young people at severe crisis levels, for example, P2 points to young carers joining the service who are actively suicidal and the Mental Health

Agency reports a several months long waiting list. P9 reports that he has seen an observable uptick in adolescent young carers engaging in self-harming behaviors, particularly female young carers. Furthermore, P2 affirms that the strain on social services in Scotland is so significant that their young carers service is receiving intakes from young people who are not actually young carers; this was also corroborated by P3 in England. For this reason, P2 believes that all young people who have a ill or disabled family member need a professional to assess their needs, even if they may not be providing care for their family members.

Professionals should better inform families of the benefits they are entitled to, and especially, young carers must be made aware of their rights to assessments of their needs (P5).

One expert felt that whilst the recent amendments to legislation giving further rights to young carers has been beneficial, there is also a sentiment that all has been accomplished for young carers and nothing further must be done (P3). This expert alluded to the dissolution of the National Young Carers Coalition and their view that national NGOs such as Carers Trust and the Children's Society do not appear to be leading on work for young carers as strongly as those organizations had in the past (P3).

Finally, whilst it was thought that Brexit will have disastrous effects for families across Britain, it was not thought that young carers will feel the effects as hard as other groups of vulnerable people (P3).

Experts desired to see revisions to the commonly used assessment tools of young caring (e.g., the MACA and PANOC). Overwhelmingly, experts called for further engagement with GPs.

"One thing that I'd be interested in is a real focus on the quality and the quantity of work of statutory young carer's assessments that are being done. My impression is that they're not being done or if they are they're fudged in the sense that they'll say we'll use our child in need assessment to look at what this young person needs, which in my opinion is too generic and doesn't focus in on some of the issues that are exclusive to carers. That being said, I would like to look at some sort of national model of assessment for young carers. I would be very interested in seeing that develop. For example, from personal experience I know that in youth offending there's a tool called The Asset which is like a nationally used assessment tool and it has general welfare question in it, but it also has stuff that's exclusively focused on what's the risk of them committing another offence. It's well evidence-based and established and it can allow people to prescribe interventions to individuals. We don't really have that. We've got some measuring tools. The MACA and PANOC being, perhaps, the most well-known example, but I would like to see a nationally recognised holistic assessment tool that features narrative as well as tick box questions." (E10, R2, UK)

"One of our team in the adult carer service is trying to work towards something called a carer's prescription where it's something that's built into the GP's IT system and they can make a very simple referral. Even that's proving difficult to establish because within such a huge organisation like the NHS even at local level there's so many middle managers to get approval on these little things. It's really tough. This isn't just an issue for GPs. This is an issue for every professional that's working with the adult in the family and that issue is that the child is invisible. The GP might see a patient or it could be a counsellor from a substance misuse service or it could be any number of professionals and they're just seeing a parent. They might see them during office hours when all the children are at school. My personal feeling is that there is often out of sight out of mind. Even if they know that there are children in the home, they won't really go out of their way to explore how they are affected by that adult's condition." (E7, R2, UK)

Second Round (Reflection):

The gap in transitional services remains a problem for (A)YCs; once identified, if there is no available supportive service for them once they hit the legal age of 18, this can cause more stress for (A)YCs. Experts also reported that young carers sought more holistic support, i.e., guidance on career choices, nutrition, and life management skills.

"it's really obvious from what everyone's saying that aside from the basic struggle with identification in the first place, we're then making it so much harder for ourselves by knocking them off another cliff once we've recognised these young people. So we can have young people in huge need, have acknowledged that, have started some great services for them, but all of a sudden, "Well you're 18 so actually sorry, you're off again." And adolescence is hard enough.... "The worst thing you can ever do for a young carer is give them some hope because it always just turns out wrong." And I kind of felt, "Do you know what? That really rings true from what everyone's saying here." That where we're identifying people and giving them a bit of hope, actually we're not then actually giving them the continuity of support and the confidence that actually what we've offered to them is going to continue. And that's reinforced both from an age perspective, from a funding perspective and from an integration of services perspective as well." (E8, R2, UK)

"they're interested in healthy eating, and career advice. They were interested in learning more, going to university and adapt to things like that. Also, life skills, and they wanted to know about more mortgages and tax, because they're taking on some of that responsibility at home, they actually want to get advice on." (E5, R2, UK)

(A)YC needs

First Round:

Experts with roles as young carer project workers expressed that (A)YCs continue to need a supportive adult who listen to them, especially if that adult is a teacher or school administrator. (A)YCs may "additional needs" that require support, i.e., mental health or learning needs.

"certainly the ones in college, there are quite a few of them that do need that extra support. They need to know that there is somebody that will listen and understand what is going on for them and make the allowances that need to be made." (E12, R1, UK)

"having that support in school but also just around their own health because quite a lot of them struggle with their own mental health. Quite a lot of them have their own additional needs.Families that have additional needs quite often

have multiple children with additional needs. So there might be ones that are caring for other siblings but they might have additional needs themselves so again it is having that right support in place for them.” (E11, R1, UK)

“They have various needs. They have issues around social isolation so feeling that they are the odd one out at school. It’s not known that they have challenges at home so feeling isolated is a factor. Sticking with the theme around their relationship with peers there’s issues around bullying sometimes. If they are known to be young carers or that it’s known that they have a parent with disabilities that can be a target for other children to pick on them. That’s the stuff around their peer relationships. The other thing would be that they don’t get the opportunities to access particular interests or passions because they have to go straight home after school or the family’s finances don’t allow them to try out extra-curricular activities. In terms of their emotional support needs there are often worries around the future of the person that they are caring for. What’s the prognosis for a parent or sibling? This is probably less true of the adolescents, but it’s still a factor which is around the whole am I going to catch it thing as well, especially around mental health as well. Because Mum or Dad have this condition, does that mean I’m definitely going to get it, worries around that. Then you’ve got things around practicality so dealing with emergencies.” (E6, R1, UK)

“Educational needs around the fact that home study is difficult, lack of privacy or just no time to do the coursework or homework. Limited ambitions for the future, they self-limit themselves because they don’t think they can leave the cared for person behind or they limit their choices on what course they want to follow or career they want to follow because they think I’ve grown up being a carer so, therefore, I’m going to go into a caring profession and don’t even think about other options.” (E5, R1, UK)

Second Round (Reflection):

There was an agreement amongst the experts that young carers indeed need someone to talk to, whether that be a trusted adult like a young carers project worker or a teacher, or peer support given through a friend.

“One thing I thought was interesting as well was having someone to listen to their story. And I can absolutely see and I think that’s really important. The thing that I know has come through really strongly in terms of carers that we speak to, is absolutely that being heard and understood and having that experience believed. But I think probably even stronger is that being a peer that’s able to do that.” (E1, R2, UK)

Professional and family needs

Second Round (Reflection):

One expert did not feel that the first round interviews sufficiently addressed the ways family life and family practices are involved in supporting young carers. This particular expert thought young carers should be engaged by asking about their family practices.

“there’s something about us also promoting family life and I don’t think we do that really consistently. So there’s a real focus in on what’s wrong and how we address a problem and that’s a very transactional and very medical kind of model if you like, and we tend to get in that, “We’re going to fix this,” type mode. And actually what would be really nice is to think about, “Okay, what’s great for you as a family? And what’s normal for you as a family?” And actually do you want to do things with your family or do you want to do stuff on your own?” And starting to think about that.” (E3, R2, UK)

“I think the biggest thing for me out of the examples was that it needs to be a holistic approach. So, we have a focus on the young carer because that’s our, sort of, reason for being. However, we have a holistic approach to that, in the sense that we realise that, if we put the support in place for the parent or the sibling, or whoever has the cared-for needs, that could reduce or even stop that young person providing care.” (E4, R2, UK)

Working concepts to reach (A)YCs

Second Round (Reflection):

Not mentioned in the first round interviews but expressed in the second round reflections was the work to help young carers self-identify with the label “young carer”. One expert mentioned the new addition of a “tick box” on college admission forms to identify young carers.

“if a young person has been doing it for most of their life yes they wouldn’t recognise that is what they are doing and that is what people call young people that are caring.” (E8, R2, UK)

“we have done again with [specific name of college] College they are having a tick box put onto their admission forms. And again we said no you can’t just say are you a young adult carer? You have got to ask that question ‘do you care for someone at home who might have a long term...?’ So we have phrased it that way because someone probably won’t question or think about that as ‘yes I look after my dad or whatever’. But they are more likely to tick the box than if you say, ‘Are you a young adult carer?’ as if they don’t understand that concept themselves they are less likely to tick that box. So what should they be called? I don’t know.” (E9, R2, UK)

Responsibility

First Round:

It was thought that a variety of sectors should be responsible for the provision of support for young carers, including the educational sector, social care sector, and health care sector. It was expressed that the educational section, i.e., schools and colleges had the most responsibility to support the needs of young carers because of their close proximity to young people. The health care sector (GP, nurses, pharmacies) were emphasized to demand a greater duty to provide support.

“Well I think organisations would obviously be educational establishments, schools, colleges, universities. I would also think like social care teams so where social workers are involved with families where a parent is being cared for and another child is being cared for they would then make referrals into our service. So yes anything around that. And again GPs, hospital environments, mental health services because if you know a parent has got mental health issues or a sibling has got mental health issues that they would get some idea of what the family situation is and look at what extended support is required and refer in to us. And then I suppose other charity support services say if somebody is receiving, if a parent is receiving support for addiction again that organisation is saying, ‘Ok who else is in your family? Who is looking after you? What support could they do with?’” (E2, R1, UK)

“They might be aware you are a carer, what do they do with that information and what do they actually do to help carers? Do carers get priority appointments? Probably not. Yes you know if they are having to constantly get appointments for the person that they care for they quite often don’t bother about themselves. And yes they have got their mental health issues and they have got their physical issues but because they are spending so much time sorting out appointments for their cared for they don’t make appointments for themselves. Or it will be last minute emergency appointments and then they can’t get to see who they need to see. Are there any allowances for that in the GPs surgeries? I don’t think so. They might acknowledge carers but I don’t think probably they are doing enough to actually support carers within the surgery.” (E1, R1, UK)

Second Round (Reflection):

Experts reiterated that the health care sector needed to shoulder a larger burden to support young carers, especially GPs. Those experts directly in the formal support service sector stated that most of their referrals came from schools, rather than from doctors or nurses. It was also thought that the government (national) could do more in terms of concrete policy changes. Generally speaking, formal services across sectors need to be united together, e.g., “joined up”.

“Yes we find that education is one of the major areas. We are quite surprised that actually we don’t get that many through social care. And we do get, again it is fairly low but we do get referrals that come in from you know other sort of support agencies and again GP referrals are quite low as well.” (E7, R2, UK)

“well obviously the government could be doing more. Yes I know they are involved but you kind of think about the issues that those that are having to care full time get what, £60 a week. How are people supposed to live on that? How is that raising their aspirations? So obviously yes the government have got a big part to play” (E11, R2, UK)

“So I think we’ve really missed a gamechanger actually in bringing together systems that ... Our whole government is talking about how we better integrate health and social care and how we make a difference on that basis and yet when it comes to the legislation they’re saying, “Well actually one bit’s responsible and not the other.” So there’s something about us doing that to join things up.” (E4, R2, UK)

“I just picked up there across the board it seems to be noticing that schools can be key to identifying young carers and perhaps then referring them for support or understanding what their needs are, and of course supporting their future aspirations and their kind of career goals and things like that. But actually in the UK, schools and education have reduced ... it’s not as strong responsibility-wise as the local authority and maybe we’re missing a bit of a trick here in terms of, because the local authority has the responsibility to identify and assess the young carers, as opposed to the education system, but it seems to be that schools are the key place for actually identifying young carers and maybe that’s something that we could have a bit of a look at how to strengthen within education, that remit.” (E12, R2, UK)

Funding

First Round:

Overall, funding cuts due to the period of austerity were recognized. It was also acknowledged that young carers projects have been significantly impacted as a result, although the level of impact varies across local authorities. Transportation was mentioned as an issue from service providers, especially recognizing that some young carers may live in rural areas and public transportation is either expensive or unreliable or both.

“we have got a couple of cars but transport is a major issue in some of our young carers, our young adolescents being able to access the service and everything we have got on offer... maybe like more access to grants that they can access that gives them better opportunities. I know a lot of the Carers’ Trust do grant funds but for some of the young ones to be able to learn to drive, but also to be able to have money that they could then go and finance a car and yes they might have the opportunity to maybe work part time. But that is still not going to be enough money but if they could drive and get their cared for around places that would just help them out so much.” (E9, R1, UK)

“It’s an ongoing fight and I suppose the group work stuff ... it is different challenges for different services. The group work can be quite hard to maintain because often it’s reliant on quite small grants but a lot of them. They’re the sort of ones that we are consistently fundraising to deliver on. Understandably, because funds are getting more restricted they have to become more focused. It’s very hard these days to just say we want to deliver ten trips over the summer holidays that are going to be great fun for this group of children that need the support. We have to be a lot more outcome-focused in all of the funding bids. We’ve got a level of stability from local authority funding which mainly helps us to deliver the emotional support and advocacy work, but we are still reliant on some of the hours within the team are currently funded by external funders, which is good. We would like to be less reliant on the local authority in the future with an eye on future budget cuts. It’s hard, there’s always a push pull between what funders want and trying to keep an overall service that is consistent in what we deliver. We don’t want to just change the way we approach stuff because one particular funder happens to want things done in a certain way. I wouldn’t say we’ve had any very recent devastating cuts. It’s probably worth pointing out that before my time in the service it was at least two years since they’d had a

dedicated young adult carer's worker. That's something that we're looking to try and re-establish with future funding bids." (E10, R1, UK)

Second Round (Reflection):

Experts all agreed that funding was a major issues for formal supportive services for young carers. The general consensus was that they were expected to offer more services to meet the demand of incoming young carers referrals but on less resources. Experts also acknowledged that the existing policy in place was difficult to implement without the proper amount of funding.

"certainly funding is an issue because there is that expectation of us being able to do more on less really. And yes it is just not possible. We can't deliver the same level of service on less money. In an ideal situation yes if we had got a lot more staff we could do so much more and that is one of the things that we are talking about is how can we streamline things with the number of staff that we have got but still provide a good service to service users?" (E2, R2, UK)

"But I guess what it doesn't come with, it doesn't come much with financial backing. It has all these things laid out - and again I can speak for Scotland's perspective, that the adult section of the Carers Act comes with a massive boost to infrastructure for adult carers and a financial bolt-on, whereas the Young Carers Act comes with lots of suggestions and enshrines that there should be a service for young carers, but it doesn't bolt on a financial package to that. I mean, the Scottish government are doing that but it's not written down in law that x amount should be provided." (E3, R2, UK)

"it's very much depending on what funding we can get, so if we have specific, if we do photography or do arts and crafts, we have done that in the past, or maybe take them away, a group of young carers away on a residential weekend, we'll do that as well, but it's very much dependent on what money we can get for them..... I think, we had a reduction in our statutory funding, which meant that we were Big Lottery funded for five years, and it was great, because we could get a lot of the young carers off the waiting list and provide a service for five years, it was very consistent. But then that funding, we also had statutory funding as well, which was just, so at the minute it's basically we're running off purely fund-raised money. The statutory funding that is available, is very much social services based, and our service, we wouldn't involve social services." (E7, R2, UK)

Additional

Second Round (Reflection):

Overall, experts shied away from making speculations on how the future needs of young carers will be impacted as a result of Brexit. All experts felt that the effects from Brexit would be negative, but the extent to which young carers would be impacted was generally not addressed. One expert thought that young carers would be more vulnerable than other youths because of the structural inequality already in place.

"I think that they will feel it just as hard, if not harder, and again because I think that poverty - so for example, when the NHS gets cut, that affects me as a young carers' worker because the NHS is providing a service for a cared for person, the young person is relieved because the NHS is there providing the service and the young person gets respite. Once you take that service away, the young person steps up, so it's not like the NHS removes itself or that the CPN - so Community Practitioner Nurses are cut a lot just now. It's not that they just get removed and miraculously the person gets better, they don't. So that care that gets removed has to be replaced and the young person then replaces it - not a young carer, a carer would replace it. So I think if you're looking at Brexit, you're looking at the NHS being cut, you're looking at benefits being affected, you're looking at inflation and what could happen, worst case scenario. As predicted, currently with a no-deal Brexit looking at cuts to the NHS, inflation and the price of food are rising, young carers are affected from all different angles. They're affected by the NHS cuts, they're affected by poverty, they're affected by the impact on our education, they're affected by the removal of school meals - which has happened in England. They are at more risk of being affected than the other. So I think they're at a larger risk of being affected. Yes, so I think Brexit will have a massive impact." (E3, R2, UK)

First round summaries - feedback

Visibility and awareness raising

Second Round (reflection)

One expert reflected on the appearance of young carers as a distinct social group in the other 5 countries, in the same way that young carers have been positioned in the United Kingdom. It was questioned if this view is simply possessed by the European expert professionals, or if this view was also championed by front-line social care professionals working with young carers in their respective countries:

"do they look at young carers as a distinct group or do they look at young carers as part of the population of vulnerable children, or children indeed. It would be interesting to know how they saw them. The impression I get looking through this is that they are a distinct group or people view young carers as a distinct group. Now people in the research view it like that. I wonder how the people who are you know, health professionals in those countries, do they view young carers as something distinct or just part of an overall part of children that requires support?" (E6, R2, UK)

The term "young carers" itself may not be recognizable in all countries, and therefore this mirrors the issues of self-identification of young carers. Experts called for a general language or terminology across Europe:

"the term 'young carers' is not recognisable in all countries, and I agree with that. And I've also heard in some languages the word 'carer' itself doesn't actually translate or exist; my understanding in Italy, but I could be wrong, but I think

when I was there, so just almost a need for a bit of a shared language and understanding internationally and globally about who we are talking about as young carers.” (E8, R2, UK)

Generally, experts were not surprised that there were many commonalities across Europe regarding the issues of awareness for young carers:

I don't think it was surprising that there were commonalities, what was interesting to me when we got into some of the country-specific stuff I think, but I think it kind of reassured my view that there is still a need to be pushing around this awareness and understanding of young carers, perhaps coming to as I said before, shared language and shared agreement almost around, “Okay, are we looking at prevention of young carers and how that can be.” (E5, R2, UK)

“it's almost like carers are hidden in plain sight. So as much as they're right in your face, they just don't see the care. They see the people, they see the story, but the actual underlying care, especially when it comes to youth and that stigma of youth on top of it. I guess I expected that to come out from a unanimous thing from Europe, I imagined, because that's things that would cross borders.” (E11, R2, UK)

One exception:

“The thing that always kind of surprises me is, or the most remarkable thing about this is still the low visibility I think of young carers. Because I think the issue has been raised in a lot of you know, a lot of policy tables and in a lot of the countries and through different sort of ways through youth organisations, through education, through other carers' organisations. And I think I am still surprised that there remains such a low visibility of young carers...I was really quite surprised in places like the Netherlands and in Germany, especially Germany I think. I mean I kind of thought that they would have a very robust sort of social care system in place that would have recognised young carers and carers but I think it tends to be much more focused on dementia and carers of people with dementia. Other than that it just seems to be a family issue rather than seeing it as a sort of separate policy area.” (E7, R2, UK)

Strategies, interventions and programs to support (A)YCs

Second Round (reflection):

As with the other sections, the expert professionals largely agreed with the first round summaries with little comment. One expert professional remarked that it was important to be more specific in seeking specialized support for young carers:

“What do they mean by specialist support. Are they looking at specially trained social workers, are they looking at specially trained - we've got projects you know and support projects for young carers, but what exactly do they need, and I sometimes think, people say these words but I don't think they're clear in their own mind exactly the detail of it. What do you want from that support? Is it a specially trained social worker? Is it the social worker who will bring together people from education and health say, what is that they want and is this going to be like the same for all young carers or is it going to be specifically different for different individuals? So I think we need some kind of clarity there.” (E1, R2, UK)

“there was more in terms of services for young carers than I'd expected on a European scale, so that for me was quite pleasing.” (E3, R2, UK)

Future needs to support well-being / health situation

Second Round (reflection)

Experts agreed that co-production was essential for future work with young carers. They signalled that co-production is a part of some of their current practice, but the goal of centering young carers must be prioritized:

“The importance of that, yes, co-creation is great and I would like to think that in the UK and certainly in Scotland that is our model for looking at developing policy and legislation. And obviously we have young carers now who have had the benefit of support groups. You know they have had the benefit of maybe taking part in events where there are decision makers there and we have a lot of young carers now who are very confident and eloquent when it comes to putting forward their case about being a young carer and the type of support that is needed. But that has taken so much time you know.” (E5, R2, UK)

Country specific results

Visibility and awareness raising

Second Round (reflection)

Overall, experts were not surprised to read that there is low visibility and awareness of young carers in Europe. This follows scholarly research establishing a scale of global young carers awareness. It was also thought that the other countries were at the beginning of their journey to support young carers, following the lead of the United Kingdom. Experts also emphasized that media programmes are only one way to bring awareness to young carers; there are other avenues including national wide dedicated days to recognize young carers.

“I think I was interested to read that there's low visibility of young carers in Europe. I wondered what their methods of knowing young carers were in the first place, because from reading through the whole document, people are at different

levels, stages, or perhaps just coming to the realisation that this is a group of young people that perhaps need some attention. So, I wondered if they had methods of connecting data. For example, in the UK, we use the census.” (E12, R2, UK)

“I think there was a sense, almost, like some countries are on the beginning of their journey, a bit like us, I suppose. Maybe I’m being a bit autobiographical, but I guess when we started back in 99, it was just like, “Wow, I can’t believe these kids are out here.” (E7, R2, UK)

“So, there’s nothing wrong with using the media at all. It really does highlight issues, but it’s not the only thing that happens on a national level. We also have Young Carers Awareness Day in January, and we have Carers Week, and I know lots of organisations and schools and things, take that on board and use that time to make sure there is the assembly that day, or PHS lessons or whatever, whatever. So, it does have a local impact as well, those national days.” (E6, R2, UK)

In response to Sweden’s expert view that children should be free from a caring role, several experts found that to be unrealistic:

“what it is about the Swedish culture, and ‘childhood should be free from having a caring role’. Like, wouldn’t that be great? Yes, it should. I agree, but they don’t. So, I just wondered whether that was an attitude of idealism, and perhaps ignoring the problem. I don’t know. But it felt a bit like the UK, probably 15-20 years ago.” (E3, R2, UK)

In response to Switzerland’s expert statement on migrant young carers, multiple experts were pleased to see that Switzerland highlighted migrant young carers. There was a belief amongst UK experts that the UK needs to do more to address the needs of migrant young carers because of the changing geopolitical landscape:

“I think that something that really has particularly come up in the UK. People are asked to talk about ethnicity they’re not necessarily migrant communities and so on. So looking at different communities, different ethnicities and migrants might be an important aspect of seeing what kind of support is provided. Because it may well be language support.” (E4, R2, UK)

“Does that mean that Swiss children are caring and not getting the support, and migrant children are getting the support, or does it mean that migrant children just take that as a role that they just have to do, so even if they’re not coping with it, for them it feels like it’s a way of life, you know. You don’t reach out for support for it because that’s just what happens. So I guess, yeah, I found that really interesting because I thought for me that brings up lots more questions about, if you compare those two groups of carers, what’s the impact on them? Is one getting impacted worse or more so than the other?” (E1, R2, UK)

One expert questioned whether Italy had health conditions of its population were different in comparison to the other 5 European countries:

“when I read through Italy, so it’s lack of visibility and awareness, a couple of examples of visibility, I wondered what the overall health of the population is in Italy. This may be a completely- and saying this is maybe going to be like a really stigmatised version of Italians, but I’m sure I read an article that said that the health of the elderly in Italy, like the general wellbeing, that elderly people in Italy were much more mobile, much more fit, much more able, much more mentally aware. I think it was in comparison with the UK but it was a European study. I could be wrong but I’m sure it’s because of the high fat and oil and rich diet. So I could be wrong, but I wonder if part of it there is - I’m sure there are adult young carers, but maybe they’ve just not the same health pressures that there are in the UK when it comes to that.” (E11, R2, UK)

Strategies, interventions and programs to support (A)YCs

Second Round (reflection)

It was recognized that the United Kingdom appeared to have more tangible evidence of formal support in comparison to the other 5 European countries, however, it was overwhelmingly expressed that much more work needed to be done within the United Kingdom.

“we’ve done the legislation. That isn’t the hard work. The implementation is the hard work, and I don’t think we’re there yet, and I think we’re at risk of services being cut and this getting missed, and nobody will be there to say, “This isn’t happening,” or not enough people will be there to say, “This isn’t happening.” You know, there’s this really good piece of legislation, but on the practical level, it’s not happening for young carers.” (R6, E2, UK)

It was also recognized that more could be done to unite young carers advocates and programmes across Europe and even the world. It was recognized that that other countries (outside of Europe) also have good practice to emulate.

“there isn’t a central infrastructure service for all young carers groups. There is not. In fact, if it was more of even a global thing, that would be better. For example, Australia, they have a world mental health conference, and Australia are brilliant, and they’re very inclusive. I remember sending a young carers PowerPoint presentation to them, that they were going to include it in the conference, many, many years ago now, but they were really forward-thinking. So, yes, why couldn’t there be something - more connected, joined up, learning from other countries as well. I was chatting with my colleague earlier. There’s brilliant projects across the world. There’s a lot to learn from South Africa, you know, for those clients that are, not just young carers caring for a parent with HIV, but they’ve got it themselves, and how are they managing that as a young adolescent? You know, is safe sex being promoted? Do they know what their options are? That’s something for all of us to learn.” (E7, R2, UK)

The UN Convention on the Rights of the Child was mentioned as a piece of European legislation that could unite supportive interventions for young carers across Europe:

“Obviously, there’ll be different legislation in different countries, and there’ll be different ways that they’ll interpret what support is needed, but I just wondered if there was something that could connect countries together. That might be a place to start.” (E5, R2, UK)

“So the legislation seems to be piecemeal across different countries, so for example you’ve said nothing, not mentioned in the Swedish legislation, and were there others? And also not in Slovenia, which is interesting, Slovenia I find quite interesting because I’ve not heard of any young carers’ work happening there before, so do you know if service is growing out there, how did Slovenia get engaged in the research in the first place, is there some work there?” (E11, R2, UK)

There was an appreciation for the various European nations that recognized the need for whole family approaches in considering the needs of young carers. Historically, the UK has observed the usefulness of whole family approaches:

“What seemed to stand out was that again, the need for whole family support seems to be kind of identified across countries, recognition of the needs of the family as a whole and the needs of the person affected by whatever, ill health or disability is affecting them, so kind of some shared understanding there of the needs of families I think. I was quite pleased to see that really because historically our research and practice and work across the UK has highlighted that as being particularly key so it was quite positive I think to see that there was a bit of a shared understanding internationally.” (E4, R2, UK)

One expert appreciated the approach of the Netherlands by emphasizing a whole family approach. In recent years, the UK has tried to implement a more holistic view of young carers by considering their family:

“I like in the Netherlands, the need to focus on parents of children who are responsible for their care. Yeah, that’s a big one for us because we - I guess again this’ll go back to age, and I think it’s very different when you come to - I think when it’s 15 to 17, a certain amount of working with the child independently is really important because of the dynamic maybe that’s in that parent-child relationship. But I just think it’s a really key point that actually - sometimes I feel like we’d be enhanced if we could draw on a service just to support the parent and not have to rely on NHS or different things, just have a kind of holistic service that’ll provide support for the cared for person. It would be nice. Need for co-creation with young carers I think is brilliant.” (E10, R2, UK)

Future needs to support well-being / health situation

Second Round (reflection)

Experts expressed a positive view of some of the language used by the experts in other countries. For example, one expert particularly liked the use of “fragile” families to describe a young carer’s family in Sweden—the typical terminology in the United Kingdom is “vulnerable families”.

“Fragile families’ that’s quite a new term for me, but I quite like it actually. But I think there’s something about ... I prefer it to the term that we’ve used quite often, which is around vulnerable families, because actually anybody can be vulnerable at any time and fragile actually feels to me, a bit more real and a bit more like an honest description. So if you like, it’s a bit of a, sort of, simplistic reflection on what’s been said there but I think there’s something about us learning from how we talk about families that might be a bit more helpful in terms of getting across the priorities that we see.” (E4, R2, UK)

In response to Switzerland’s expert view that children under 18 should not take on too many responsibilities, the reality of such a view was questioned.

“And interestingly as well, they said, “Children under 18 should not take too many responsibilities.” I’d like to know how they say how much is too much, because I think caring happens without you realising it a lot of the time. So you start maybe by picking up the shopping once a month or maybe cooking an odd meal, helping unload the dishwasher, putting a washing load on and then a few months later you might realise that actually you’ve cooked every meal for the week and you haven’t necessarily realised it. Though I think it’s really hard to say how much is too much and again, this arbitrary age of 18, well how I was at 18 is very different to how I was at 16 and how I was at 20. And I’m not entirely sure, I might have actually been more sensible at 16 than I was at 18. So I think it’s really difficult to pin an age on stuff.” (E7, R2, UK)

In response to the Netherlands’ expert use of “informal carers”, one UK expert preferred “unpaid carers” because the term “informal” could imply a lack of seriousness in the caring role. Whilst no other UK expert explicitly expressed a similar view, this is often expressed in scholarly literature in the UK:

“I’m interested in that they use the words ‘informal carers’, because I prefer unpaid, because I don’t think anything that we do as carers is informal and I think that kind of, undermines stuff but that’s just terminology isn’t it?” (E8, R2, UK)

In response to Slovenia, there was a critical view that their context may problematize families more than the other 5 countries. Furthermore, it was thought that Slovenia may be overstating their formal support for young carers:

“There’s seems to again be very much that idea around integration and how you get people working together. I do kind of worry that that’s potentially more of a problematising perspective there, that perhaps it’s a country that’s not as far on as others....And the fact that they said to build on what they have, but I don’t get a sense of what they do have necessarily. So I think there’s something about us all being really honest, that we’ve probably all got something but we are definitely all a way, way, way off where we need to be in terms of actually identification, giving appropriate support and providing the right opportunities to young people with caring responsibilities.” (E4, R2, UK)

“there’s just a sense that they need to use what they’ve got, and that just needs to be more coordinated. I guess that is what we all want to do really, but they might need some back-up plan to go with that.” (E3, R2, UK)

Generally speaking, there was a view that countries may be overly proud of their work for young carers, whilst minimizing the significant amount of work left to be done in their respective countries:

“I wonder if maybe there was a bit of relief that when someone asks the question, they could think of something, it’s not very much but they could think of something, maybe that was helpful. I also think maybe it’s to do with the understanding of the scope of the issue and the scale of it too. So I guess one of the things that’s really been helpful with the work that Saul Becker has done as well is it’s given us a real red flag in the UK hasn’t it? In terms of being honest about our understanding of the numbers of young people we’re talking about....And maybe they’ve not had that same red flag in other countries, so the fact that there’s some work that’s started, makes people feel, “Actually yeah, we’re on the way and we’re doing it.” Whereas as I was just saying, I can see how we’ve come an awful long way but it is, it’s just kind of like the first little bit of the marathon isn’t it? And if we’re actually going to get things right, we have a huge amount still to do” (E7, R2, UK)

Results - The Netherlands

Visibility and awareness raising

Main findings

First Round:

In the Netherlands, there is an overall consensus among experts that the visibility of and awareness about young carers are still limited. Still, experts stress that this is gradually changing. Young carers are increasingly recognized as a group that needs specific attention, but their lack of visibility remains a major challenge.

...that the visibility and awareness is really insufficient. In schools, with professionals, well, with all kinds of stakeholders in the network (P1, R1, NL)

At the same time there have been tremendous developments in, let's say, the past twenty years, from completely invisible to slowly some awareness about, okay, they are here and they may need some extra support. (P6, R1, NL)

It is mentioned in many policy document, also from municipalities: we need to give more attention to young carers. [...] And then the question pops up: how do we reach them? How do we make them visible? And the moment you ask that question, you realize that you have not been engaged with this topic and never looked for it. And you have never been worried about the visibility of this issue, because if you don't know about its existence, than you're not looking for it. (P3, R1, NL)

Contributing to this limited visibility, the label 'young carer' may not always be recognized by those to whom it is applied, nor by their family members.

...and that the target group, and especially the family around them, the parents in this case, do not feel that it [the term young carer] concerns them. (P10, R1, NL)

Well, often they don't recognize themselves [in the term young carer] and then they find out because you talk or ask questions about it: ah, this is about me? (P2, R1, NL)

Respondents draw attention to the regional differences in such awareness and visibility. As (support for) informal carers has primarily become a municipal responsibility in the Netherlands, experts report considerable differences between municipalities in the extent to which they have attention for young carers within their policies and interventions. At the same time, they stress that the subject has been on the agenda at the national level for quite some time now.

So from the Social Support Act, the tasks that the municipality has for support are decentralized, so they are part of the municipality. And municipalities must also simply shape their informal care policy. And purchasing and arranging a supportive supply of services. In that sense it is really up to municipalities to decide what we do with these young informal caregivers. (P1, R1, NL)

Well I think it differs very much per municipality to what extent this is on the agenda and that is worrying. There are some progressive municipalities that are very active on this, but there are also enough to say: Oh, that is not a problem for us. (P10, R1, NL)

If I then look at a larger scale, more the national part, of how it is brought to the attention ... I know that it is stated in the document that Minister Schippers [Dutch secretary of Health] made at the time, that it is also emphatically stated that young informal carers are a different target group than adult caregivers with other needs and that they need other types of support. (P5, R1, NL)

We have been involved in this subject at the ministry for a long time, also because the House of Representatives asks for it. [...] We have held discussions with municipalities and all kinds of stakeholders. (P1, R1, NL)

Second Round:

Experts generally confirm that visibility and awareness in the Netherlands are increasing, but also stress that much improvement is still required. They mention a lack of recognition and knowledge among professionals working with young carers. The challenge that young carers do not identify themselves as such is also confirmed. At the same time, and without denying the need for increased recognition, some experts draw attention to the risk of overly problematizing the subject, i.e., targeting the group of young carers with interventions while they themselves might not want such attention.

I have the impression that a considerable catch-up has been made about the degree of visibility of young informal carers. Indeed, it remains an issue that they do not recognize themselves as such. (P6, R2, NL)

I have been to a school once and indicated that I wanted to provide information. And then the director stated: there are no young carers at this school. Yes, there are 300 children at school, there are young informal carers but they [professionals] just have no idea what exactly it means. (P7, R2, NL)

That low visibility and the fact that all carers who do not recognize themselves in the term. That is something that comes back everywhere, but as a kind of bottleneck to take further steps, which is quite important. Also the image that prevails about young informal caregivers themselves and the outside world. Yes, that does something, also with prioritization that it can get. (P6, R2, NL)

They do not recognize themselves [as young carers] and they do not want to focus too much attention on themselves. And then we will all pay a lot of attention to that. Something goes wrong there. (P2, R2, NL).

Reflecting on the international results in round one, an expert commented that The Netherlands came off relatively well compared to other countries. Another expert highlighted how the challenge of visibility and identification of young carers seems to be a challenge across the different countries. Especially the limited visibility in Sweden was seen as surprising. Still, an expert stated to be happy to read that, contrary to his expectations, other countries organize a variety of activities for young carers.

these country-specific situation [...] What struck me is that it says 'limited visibility', sometimes something like 'no legislation', that it really depends on the professionals, those who are coincidentally enthusiastic or knowledgeable on the subject... [...] That means we are doing relatively well in the Netherlands. (P10, R2, NL)

...but everywhere the same results come up... everywhere this low visibility comes up. (P2, R2, NL)

Actually, I knew it already, but I was still shocked to see that in all countries the awareness was so low. (P9, R2, NL)

I found it striking that in Sweden, there apparently is a [...] lack of visibility, very low, it says. Well, that is not what I expected in Sweden, because they are also very... well, how do I put it... Child-friendly, and emancipatory to women and children and so on. So it struck me that they apparently not have enough attention for young carers. (R1, R2, NL)

What struck me about Sweden, and I was really surprised because Sweden has an advanced welfare state... That children of parents who passed away [...] are in the picture, but not before that. I didn't expect that. (P3, R2, NL)

I didn't expect that most countries would organize activities for young carers. Good to read that they do have attention for that. (P7, R2, NL)

Local and regional level

First Round:

In the Netherlands, support for informal carers has become part of the Social Support Act ('WMO') which is executed at the municipal level. As mentioned earlier, this has allowed for considerable local variation in the extent to which young carers are indeed addressed as a specific target group. Experts state that only a few municipalities have informal care policies and interventions for young carers, while also pointing out that learning between municipalities is still limited. Some municipalities did organize awareness-raising activities during the 'day of the young carer'.

within the municipal domain there is a lot of reinventing the wheel (...) and that, for example, within smaller municipalities, there is very little knowledge, expertise, time and attention for the target group, so that, yes, the target group is simply not found and supported. So I think we have to go to a situation where there are more overarching programs and that organizations can join." (P5, R1, NL)

Yes, that day for the young carer, which is organized in various places. That generates some more publicity, that's my impression. (P6, R1, NL)

Experts point out that within these municipalities, welfare organizations are generally the actors most involved in raising awareness about the subject of young carers. While young carers seem to be increasingly addressed as a specific target group, some experts also refer to welfare organizations' limitations in terms of resources and ability to reach this particular group, both in terms of resources and appeal.

What I notice is that most local support centers increasingly mention young carers as a specific target group. (P3, R1, NL)

Pretty often you see professionals working there [in welfare organizations] who do a lot with adult carers and then have two or three hours every week to deal with young carers. [...] These are also the professionals that do not really find a connection with youth. And work for an organization that does not appeal to youth. (P5, R1, NL)

An often-mentioned challenge is to not only address the issue of young carers from the domain of social care, but also align with, for example, (preventive youth) healthcare, public health, and education. Experts stress the importance of developing a more integral approach across these domains. They point out how welfare professionals sometimes reach out to and align with other organizations in these different domains, often to make the group of young carers more visible and to raise awareness about their situation and needs. For example, some professionals coordinate with local centers for youth and family care ('CJG') to increasingly identify young carers. Moreover, schools are often targeted by outreach activities. Despite an increasing awareness in schools, however, such outreach activities regularly turn out to be a challenge.

Actually you should look at the domains. That young people not only go to school, but of course come into contact with all kinds of domains in all kinds of ways. And actually we said to each other from the domains Care, Welfare, Education, the municipality, those are all very important domains, where indeed professionals should at least be aware of this target group and integrally develop an approach to that. (P1, R1, NL)

For a while now, I have been working to get the young informal carers in the picture in two municipalities. And my first goal is to make that known to all kinds of organizations and the municipalities themselves. And with the Center for Youth and Family ['CJG' in Dutch] and with partners. And yes, I do that by giving presentations. But I also give guest lessons at schools, for example. (P7, R1, NL)

But what you often see is that collaboration with education is sought. Where welfare organizations give guest lessons in education. [...] And try to get the young informal carers in the picture. [...] But what you often hear is that it is very difficult not only to inform the young informal caregivers themselves, but also to make education more aware of what it means to be a young informal caregiver. (P4, R1, NL)

In education, it is not a term anymore that you never hear, so the past two years there is an increasing amount of attention. [...] I have started a project for studying or young carers and then there was not much you could find about that. No organization, almost no one had or did anything for that. (P2,R1,NL)

Second Round:

In the second round of interviews, experts confirmed the important (potential) role of schools in identifying young carers, as well as the lack of awareness that may keep schools from taking up this role. Furthermore, experts increasingly highlighted the importance of raising more awareness among GPs and other healthcare professionals.

The cure sector in healthcare is not featured now [...] primary care physicians, medical specialists, mental health care. [...] When someone gets diagnosed with breast cancer, then in almost all hospitals and outpatient clinics, they ask: do you have children? [...] But this entirely depends on what disease you suffer from, because with other diseases, [...] the patient's children remain fully invisible. (P6, R2, NL)

Make sure the primary care physicians know what to do with the children. So really primary care, everyone who has to do with that child. (P9, R2, NL)

National level

First Round:

While experts still stress the relatively limited awareness about young carers at a national level, they do identify an increasing amount of attentions on the subject. For example, they refer to a tv-show that was broadcasted on national television and to growing attention for illness and disability on social media.

Of course there was that tv-show 'Tough Ones' ['Bikkels' in Dutch] and yes, that was a really beautiful, honest show. Which may be a stepping stone for parents to have a discussion at home with their children. (P10, R1, NL)

I think they get more attention, so that is positive, if it comes to media. (P9, R1, NL)

There's a lot... also on social media... attention for various diseases, so I believe this generation in general grows up with more visual... well actually that they are more aware that you can talk about these things. I mean, in the past you would never now someone in school and if it wasn't in the news than you thought you would be the only one. (P9, R1, NL)

Experts explicitly mention a number actors that address the subject of young carers on a national level, including the Ministry of Health, Mezzo (an umbrella organization for informal carers' associations), Movisie (a national knowledge institute on the social domain) and the Dutch Youth Institute. One important role of these national actors is to make sure that young carers are on the local agendas of the municipalities who need to arrange support for this group.

In various ways... The minister of course regularly sends letters to the aldermen, for example about informal care, and then in these letters we specifically draw attention to young carers. (P1, R1, NL)

I think that [...] Mezzo, the umbrella organization for informal carers, who acts on behalf of its member organizations [...] to put the theme informal care on the agenda of municipalities... So that is an important partner. (P5, R1, NL)

Moreover, a number of these national actors jointly developed a platform ('JMZ Pro') to create awareness and support and inform professionals who may come across young carers. Furthermore, a series of meetings and a national conference have recently been organized to involve organizations and professionals working in education, youth healthcare, healthcare and social care. The aim of these meetings was to contribute to awareness raising and stimulate a more integral approach across domains to support young carers.

'JMZ PRO', that is an organization that has recently changed shape, but whose goal is to share professionals' knowledge in working with young carers. So they organize network events for professionals to meet up and share their knowledge. (P5, R1, NL)

And we have [...] organized all those events with many, many parties, national umbrella organizations, taking a good look at what is happening within different domains and what could link to supporting young carers. And Movisie [national knowledge institute on the social domain] has developed an advise for that, and there was that meeting last week, and now it is mainly up to local parties to take action together. (P1, R1, NL)

Two week ago we have organized a conference on young carers. Whereby we really focused on the various parties that may have a role in the support structures for these young carers. So education, but also youth healthcare, municipalities, care and welfare of course. And then you see that education is still a bit behind. (P4, R1, NL)

Second Round:

Experts confirmed the increasing national awareness on young carers and even point to a considerable shift compared to the first round of interviews. Multiple experts reported to be invited by media or conferences to speak about the issue. One respondent mentioned how such national attention and increasing public awareness makes it easier to take action at the local level.

Well, what is funny is that precisely this week and last week there was a huge amount of attention for young carers [...] on all levels. [...] Yesterday [the Dutch secretary of health] announced that he will look after the fact that care providers, primary care physicians, who knows who else, have attention for not only the care user itself but also for its network. Especially for the kids that are there [...]. Well, I'm not sure whether you've seen it, but I've had some exposure myself with our own research into young carers in school. [...] It seems that there is momentum, and everybody... many parties suddenly see it. (P3, R2, NL)

Coincidentally I was at a meeting yesterday of the working group on Quality Standards on Overburdened Informal Carers. And the young carer really has a good position there. (P6, R2, NL)

I think that it we have caught up in the extent to which young carers are visible [...] And I think that the fact that the Children's Ombudsman has done research into it and that there is a letter to parliament is reflecting that. Apparently the time is right for thinking about these issues more seriously. And we've moved beyond the phase in which every municipality is muddling through a bit by itself. (P6, R2, NL)

But if the issue is published about, or when more is known about it, then the directors of the university will also see, gosh, that's a big thing [...]. That it gets more national attention [...] then it becomes part of society and of our culture (P2, R2, NL)

Reflecting on the international results of round one, an expert highlighted the importance of the differences between the different national contexts and welfare states.

Huge differences between the countries. Which is not that surprising, but what I look at then... There are of course big differences in the different countries' welfare states. And those different roles of the government in relation to supporting care needs. (P3, R2, NL)

Strategies, interventions and programs to support (A)YC

Laws and regulation

First Round:

Within the Netherlands, there is no law that specifically addresses support for young carers. Despite a growing awareness of this group's existence and needs, experts report that there is currently no clear focus on young carers within national policy making. One expert does refer to the UN Convention on the Rights of the Child as a potential guiding framework, but this convention is not referred to within Dutch policy texts.

There doesn't seem to be much policy attention for young carers on a national level [...] it is increasing, it is taking shape. But you do see that there is no clear focus yet. (P4, R1, NL)

The UN Convention on the Rights of the Child. That says [...] it has the right to information [...]. Just information, and in the other one it says that a child has the right to give an opinion about anything that concerns him or her. (P9, R1, NL)

In the Netherlands, as described earlier, policies and regulation around (support for) informal carers fall under the individual municipalities' jurisdiction, as they execute the Dutch Social Support Act ('Wmo') at the local level. This means that the Dutch national government has an indirect role, i.e., stimulating these municipalities to make sure that support systems for (young) carers are in place. Consequently, there is space for considerable variation in the efforts of different municipalities. On the one hand, experts consider this a challenge but, on the other hand, it is also a deliberate aim to create space for local actors to jointly address the issue.

...the difficult thing is that this is not our (national government) jurisdiction, it's the municipalities'. And that... we have tried to come to agreements and to look how we structurally embed things in policy. But then it is still up to municipalities themselves to develop something. (P1, R1, NL)

On the one hand that's a weakness in the sense that we [the national government] of course can't be directive ourselves, so to speak. But on the other hand, I also notice that when it is not a theme in the national government, that parties do ask for it. Our input is seen as important, or as support to a policy. And well, the question then is whether we leave enough space for the local setting and for local actors to organize it together, while still making sure that it is on the agenda of these local actors. That's how I see our role. (P1, R1, NL)

Second Round:

The second round of interviews revealed a degree of divergence in experts' perspectives on regulation. First of all, several experts were critical of calls for stricter regulation, stressing the importance of focusing on human behavior instead. One expert, reflecting on the international results, also referred to the limited results of legislation that was put in place in the UK.

Yes, you can make regulation for that. But we all now, rules only give some direction [...]. It's the people in society who themselves make this real. [...] And look, in the Netherlands we have plenty of good regulation,. But still, we see that when people interact with one another, that people get hurt or disappointed. [...] Well, regulation is insufficient. A rule is only a kind of guideline and takes the sharp edges of injustices. (P3, R2, NL)

And that is the tension that maybe was not yet featured in this document [results from first round of interviews], but which I heard a lot about. That it is about interaction between, on the one hand, laws and regulation and, on the other hand, what professionals can do and what society is doing itself. So these are no isolated issues, but they interact. (P6, R2, NL)

What I indeed found interesting was that in England they are working on legislation, but that at the same time they say that it does not bring that many results. And it's also mentioned elsewhere, this legislation and structurally embedding it, but actually that may only lead to new questions. (P6, R2, NL)

That said, some experts still advocated for stricter regulation, mentioning the need to force both municipalities, care professionals and schools to take action in involving and supporting young carers.

If they decentralize it to municipalities, than that's okay. But if there are generally speaking no laws or regulations where these municipalities can... 'okay, that's what we need to focus on' [...] than it will become a bit arbitrary... [...] What if on the national level a sort of regulation... that it would be mandatory for every municipality to offer a range of opportunities. (P9, R2, NL)

That's why I am in favor of a care law, so that care professionals know 'oh, there are five or four moments, based on research, where I have to involve young carers, around diagnosis, prognosis, choice of treatment [...] and post-treatment. [...] those are the four clinical moments where young carers need to be involved. Because they always hear things too late. (P9, R2, NL)

The ministry can only stimulate municipalities. But if municipalities say 'sorry, but we don't have time for that now, we don't see it as a problem', then nothing happens. So policies and regulation, and the international convention, that can be highlighted a bit more. That it is not optional, in that sense, but that it is actually mandatory. (P10, R2, NL)

If municipalities say to schools that these awareness-campaigns have to be done by us and that it becomes kind of mandatory for schools to do it, then that would really help. [...] Because now it is all voluntary, for the schools. And if they don't want to join, than they don't join. (P7, R2, NL)

Educational sector

First Round:

Experts discussed a range of interventions and programs that address the subject of young carers in both secondary education (high schools) and tertiary education (vocational as well as academic). While a range of concrete examples are discussed, experts highlight the variability in the extent to which such programs and interventions are actually embedded and implemented within individual schools.

...there are schools actually that always focus on this. That are alert and ask questions about the situation at home. So you can hear that there is a child with illness and care in the family. And there are schools that don't do that at all. (P6, R1, NL)

Experts report a diverse set of aims of these interventions. In part, they focus on young carers themselves by, for example, enabling them to share and learn from their caregiving experiences, by improving their own awareness and recognition of their situation, by providing them with opportunities for leisure and winding down, but also by making sure that existing support structures in schools become more accessible to them.

And then it continues as support, yes, in this case doing activities. Providing some leisure. (P4, R1, NL)

And then also try to help the students in the sense of: how do you translate the things you learn [...] to your future job? [...] So looking at what you already do as an informal carer and looking at your capacities, we try to strengthen the connection between education and what they are doing. (P2, R1, NL)

It helps us to make the care infrastructure in schools more accessible to young carers. (P8, R1, NL)

At the same time, interventions within schools also try raise a broader awareness and stimulate recognition young carers' existence and situation, both among their peers and among school staff. Such initiatives try to make it increasingly normal to discuss the subject of caregiving within schools.

It's meant for all youth, not only young carers. It is how we get people to talk about the subject of young carers. (P6, R1, NL)

Well, what it's about in the end, the main goal, is making it visible. (P2, R1, NL)

They also want to do something with teachers and tutors, as in: how do you deal with it, how will you start a conversation, how do you recognize it [...]? (P2, R1, NL)

One expert also mentioned a more instrumental goal from the school's perspective, i.e., having a financial incentive to lower school drop-out rates.

Yes, preventing school drop-out. That's a really important one, because drop-out means higher costs. And that is legitimate, I think, [...] the university's interest is to prevent school drop-out. (P2, R1, NL)

Below we provide some of the experts' descriptions of concrete examples of interventions within schools. These concern activities in a variety of settings, including a 'share point' for young carers, an 'expertise lab', an elective course for/about young carers, theatre performances, guest lectures, a student symposium and (other) awareness programs.

Share point for young carers (at a university of applied sciences; 'Hogeschool' in Dutch):

That share point [...] is both online and a physical share point and they organize meeting etcetera where students can go to. (P2, R1, NL)

I don't think that 'support center' is the right term, because then young carers are pushed in this corner of: oh, you're sad and your life is so hard. So we called it a 'share point', [...] where they can go for advice or for sharing their story. (P2, R1, NL)

Expertise lab (collaboration by multiple universities):

In Amsterdam, there is, how do you call it, an 'expertise lab', I believe, which is an initiative of [two local universities] and they want to make studying carers more visible and researching interventions. (P2, R1, NL)

Elective course (at a university of applied sciences):

We developed an elective course on studying and caring [for both young carers and other students]. (P2, R1, NL)

Well, the main goal is making it visible, what is informal care, what is a studying carer, what is the importance of having a social network. And it serves a double aim, because many students from care-oriented programs get enrolled. How can you identify carers and how can you provide them with support? (P2, R1, NL)

But also by doing such an elective, students from all different programs come together and so there are both students who provide care and student who don't. Those interactions are already really valuable because sometimes students are surprised... oh, are you an informal... oh. And then it spreads out like a snowball. (P2, R1, NL)

Student symposium (at a university of applied sciences):

And we have done a large symposium for students for a number of years, for 600 students with workshops, by externals but also for three quarters filled in by students themselves who were also informal caregivers. And that was great. They gave workshops, they really stood there rocking. I noticed that they could, they were able to stand above their own story, that had a lot of impact. Other young people suddenly thought: oh wow, I did not know about you, well done. So the image changed, instead of the pathetic youngsters who only had a hard time, they suddenly became a bit of heroes. (P2, R1, NL)

Drama and theatre performance (high schools and vocational schools):

There are a number of plays, theater groups that are involved with this. [...] It's called 'What if' [...] I've seen it and it really grabs you [...] it is not young carers who play it, but they have developed the performance after extensive talks with a large number of young carers (P6, R1, NL)

A youth organization is doing forum theater; that is an awareness-raising intervention that is done in small groups to stimulate the process of recognition. (P8, R1, NL)

Guest lessons (high schools):

We try to do many guest lessons in schools [...] High schools. We do those together with a peer educator [with experience as a young carer]. Who is also a buddy that supports a child or youth who is a young carer. So he knows from experience what it's like. (P5, R1, NL)

But I also do guest lessons in schools [...] I do that together with a drama teacher and we have developed our own program in which we.... An interactive program in which we re-enact real situations of young carers with the students. [...] That way we want to increase the visibility and recognition of young carers. [...] And yes, last year we've visited 20 schools. And we want to do that again this year. (P7, R1, NL)

Awareness programs (high schools):

'Who Cares', a program which they roll out in different schools in the Haaglanden region. [...] That is a program for recognizing and acknowledging young informal caregivers within schools. They have different activities for this. And with that they have a reasonably large reach within education. I think they have reached 50 classes with students last year and they will reach 80 next year. Anyway, that is really about recognizing and acknowledging. (P4, R1, NL)

Within different classes young carers are identified and the underlying goal is that they will also organize activities and invite the young carers that they have identified and provide support. And then it is about support in terms of, well, doing activities, providing some leisure and relaxation. (P4, R1, NL)

With 'Who Cares', what I think is really strong about that, is that it creates a climate in schools that stimulates openness about what is needed to combine school and care. (P8, R1, NL)

In discussing these various examples, experts identified multiple barriers and challenges. These at various levels, i.e., around young carers themselves (i.e., the difficulty to reach them), their family (i.e., the important-but-challenging pursuit to involve parents), and at school level (for whom attention for young carers is only one among many issues to address).

Many great activities are organized and still students stay under the radar [...]. Because we can do whatever we like, but they are also people with really busy schedules. (P2, R1, NL)

What I also see as a pitfall [...] is that the teachers in schools are informed, and the student, also from each other, hear and know about it. But every time we emphasize that we should also involve the parents. [...] Because, well, nice to know all these things as a young carer. But the conversation with the parent about it, you'll have to do that by yourself. [...] So what you would want to see is that... we always offer that we can organize an evening meeting for parents, also about this issue. But that step is often not taken [...] while I do think it is necessary. (P8, R1, NL)

Pitfalls are that... that it is not easy to get access to schools with this subject, because often there are more pressing issues. (P8, R1, NL)

It is good to constantly let it come back in the classes. In practice this can be difficult, though, as schools are overwhelmed with all kinds of themes, like lover boys, etcetera. (P7, R1, NL)

As a positive quality of some initiatives, experts point to their peer-to-peer approach, which helps to ensure that the content and style of programs appeal and are relevant to the target group. Furthermore, one expert stressed the importance of making sure that young carers do not face an additional burden when participating in such programs, highlighting the merits of making these part of the school's curriculum.

So, very much from the narrator's own experience. We also notice that this really appeals to the youngsters themselves, who can find themselves in these stories and can respond from their own situation. So that is an important one. (P5, R1, NL)

So the things we do, we should try to do in, let's say, the curriculum, so that they can get credits for it. (P2, R1, NL)

Second Round:

In the second round of interviews, experts confirmed that even though interesting programs and activities have been developed, these are still not sufficiently used in many schools.

I have the impression, and I am not sure whether it is true, that everything happening around young carers in schools comes from the welfare sector's initiative. And schools cooperate, which is good, but they don't show leadership. (P6, R2, NL)

I also notice it in our school. We have developed great things. And it is being used. But only at a minimal level. (P2, R2, NL)

Moreover, it was confirmed that school programs should take care not to treat young carers as a tragic or pathetic group, but to focus on their strength, resilience and opportunities.

Recently we had a meeting and someone there was really committed to this target group, but was really pushing them in a tragic role. We, the others, felt like, you don't help anyone by doing that. Of course, shit happens, and that is true. And we should not think of this lightly [...]. But don't turn it into one big drama as if someone won't have any chance for happiness for the rest of his life. (P3, R2, NL)

Reflecting on the international findings of the first round, an expert commented to be struck and worried by Slovenia's lack of focus on this issue within the educational sector.

So in Slovenia this is not a theme within education... That makes me think... Ouch, that is... Yes, that worries me. (P1, R2, NL)

Welfare sector

First Round:

Welfare organizations play a variety of roles when it comes to addressing the subject of young carers. As discussed within the previous sections, they play an important role in awareness-raising campaigns and within interventions targeted at schools. In this section, we discuss a variety of other interventions by which welfare organizations work with young carers themselves, with their families and with professionals in various domains. Some of these interventions are developed specifically for young carers, while others have broader objectives but may still be potentially supportive to this group. Below, we discuss the different types of interventions, including their objectives, strengths and limitations.

Individual support for young carers

Welfare organizations can provide individualized support for young carers. This support can either be provided by professionals or by volunteers, in the latter case often by a peer who has also had experience as a young carer.

We still have individual support. This can be done by a professional, a consultant. It is real customization. We consider 'what is needed? Can it be done in a couple of conversations? Or is there a need for more professional or therapeutic support or something like that?' [...] Than we refer them. The individual support also contains the peer buddy project. Every year, fifty young carers are being supported by a peer buddy. For the period of one schoolyear, once a week, they do something entertaining. And also for the part of acknowledgement, a listening ear or relaxation, the pillars I just mentioned. (P5, R1, NL).

One expert particularly discussed a 'peer buddy' program that was organized locally, but was hoped to spread out across the country. While stressing the value of such a program (as it allows long-term support by someone who knows what it is like to be a young carer), this expert also reflects on its limitation (volunteer buddies often move on after a school year; peer volunteers may have their own pitfalls).

The advantage of the peer buddy project is that you can offer long-term support. Imagine a situation in which there is a family member ill for a longer period of time or in which the required care is getting more intensive, that there is someone who comes along every week and is specifically focused on the young carers. The beauty of this is also the expertise, that you know as a young carer that your buddy is in a comparable situation and can talk about that. The disadvantage is actually a bit the same as with the courses. It has an ending. The buddies are often students who go to a next study year or get another internship. Yet they still bonded with the child or youngster. (P5, R1, NL)

What could be another disadvantage, [...] it has been a problem for them too or when they talk about it, they sometimes really argue from the own pitfalls. So you can wonder 'is an expert always the right and proper person to offer support to a child that is in the same situation?' (P5, R1, NL)

That... 'my school coach', that is a [? 0:19:23] trajectory of volunteers. [...] Those informal young carers who are stuck at school, in whichever way, are being supported for some time. [...] And that is with weekly guidance. A guidance plan, setting goals. It is also specifically for young carers. [...] it can be experts but it can also be, well, volunteers with a heart for these youngsters. (P8, R1, NL).

Support groups

In addition to such individualized support, experts also referred to peer support groups in which young carers can meet, exchange experiences, but also relax and take part in leisure activities. One expert mentioned how such support groups may also take up an advocacy role on behalf of young carers. Sometimes these activities are reported to be 'bottom-up' activities, while at other times they are organized and/or facilitated by professional organizations.

I for example also organize activities, really meant as relaxation activities for three different age groups. And you just notice: the youngsters feel the need to get away from their situation for some time. Not having to worry for a while, not having to think about... [...] They are actually always the fifth wheel in the family. Most care always goes to the one who is in need of help. (P7, R1, NL)

Relaxation activities. We organize those twelve times a year with the purpose of stimulating fellow contact and to offer relaxation for the children and youngsters. (P5, R1, NL).

Yes, in for example, I think Nijverdalen, you have a Girls night, in which different girls from the region come together once every two weeks to share experiences. (P4, R1, NL).

Well, we also see that the youngsters themselves, who are involved in informal caring, are clustering. Establishing discussion groups for that. Well, a shining example which I got acquainted with yesterday, is that club in Den Bosch ;Self-evidently? that also created a really cool website. [...] A sort of self-support group-like. That organization tries to gain attention from policy makers, state providers, care providers, as I already mentioned. Like: have us in sight. Also pay attention to what our interests are. (P3, R1, NL).

For example the Fundays, which are offered by many young informal caregiving organizations, are indeed more striving towards providing relaxation, respite. But relaxation in an environment in which children recognize each other. By doing so you resolve some feelings of loneliness, the feeling of being different, of not being familiar with situations in which your friends or classmates are in (P6, R1, NL)

Most experts highlight the value of such peer support groups. One expert did mention the absence of an evidence base as a potential weakness of such activities, but still emphasized their importance. More evidence might help to convince care professionals of the added value of support groups, as professionals may sometimes speak of such groups in a somewhat-belittling way.

The children keep coming back. Yes, it is like, they feel connected with each other (P7, R1, NL)

Well, the fellow contacts, and I do not say that these are not valuable, but they are actually hardly well examined concerning their value, strength and effectivity. Plus, because the methodology is not well researched nor extendedly described, everyone does... well on every place it is being done in a different manner. Because of this I wonder, where lies the strength of that intervention and are we handling it the right way? (P6, R1, NL)

And I know that some aid workers are acting a bit pitying about it and I think, that is not good. But we have nothing to substantiate that it is of added value. (P6, R1, NL)

Courses for young carers

Experts refer to a variety of courses that are offered to young carers. These courses focus on different aspects of (dealing with) caring for a family member, e.g., on setting boundaries and creating space for yourself and your own needs, on growing up within a family where care plays an important role, and on dealing with emotions while caring.

In the courses [...], for a period of mostly six weeks, they once a week work towards some more... well, a sort of autonomy, that their well-being does not depend on the condition of their father, mothers, brother, or sister. That is an important theme. The part of taking space and giving space. (P5, R1, NL)

For example the rock and water training. That is a nice example. [...] It is meant for young children at school in order to indicate their boundaries. [...] So some younger brothers and sisters also benefit from that. (P9, R1, NL)

And the expression of emotions. Because we know that young informal carers easily decipher themselves and because research shows that they often have internalizing behavioral problems, we notice that it is important to teach children and youngsters 'when you are sad, or angry or happy or scared, what do you do?' [...] So that is also part of the courses. Furthermore, it is just really nice they can exchange experiences and advice with other peers that are growing up in a similar environment. (P5, R1, NL)

The small-scale setting of such courses and the opportunity to really focus on a particular subject are mentioned as strong points. Courses are reported to effectively contribute to young carers' ability to deal with their family situation. At the same time, the short time span of a course is mentioned as a risk, as the lessons learned in a course may fade away rather quickly.

The courses... is the advantage that you are really in a smaller group. You see the children more often. It is being done by a professional, so you can really focus on specific situations. And also concretely work on the targets. So that is what I think is very beautiful about the courses. We also measure those beforehand and afterwards. Actually, the feedback we always get from parents is 'the child has become much more relaxed', or 'is less ashamed of the situation at home', or 'dares to invite friends at home now'. So that is very much measurable. (P5, R1, NL).

The disadvantage is that it only lasts six weeks. So you teach the children something. They did get a sense of self-consciousness. They are aware of the fact that they are growing up in a particular home situation, that there is something going on with their father, mother, brother or sister. After that of course, they can still participate in activities or get a buddy, but what we sometimes hear is that it also fades away. (P5, R1, NL)

Training for professionals

One expert particularly discussed the trainings that are offered to various professionals, including social workers, youth workers, family coaches, (child) psychologists, nurses and medical specialists. Another expert also mentioned doing presentations for these professionals, i.e., often those working at Centres for Youth and Family ('CJG' in Dutch). These courses and presentations aim to stimulate professionals' awareness and to equip them with the skills to recognize young carers within their work field, to understand how their care tasks may affect their development, and to know how this group can be addressed (including referrals to third parties). Through these courses and presentations, professionals are stimulated to not only look at those people affected by illness or impairment, but to also focus on the support system around them, including children and youth.

And in the meantime, we also developed a training for professionals. [...] On the one hand to create awareness concerning what is a young informal carer? And when can this cause for development problems in life? [...] And then how do you intervene? About that cycle, from family analysis to acting, about recognition to acting, that is what we equip professionals. [...] Because what we notice is that [...] there is a lot of special attention paid to the one with the disorder, but not to the system around it. (P8, R1, NL).

Yes, well, I for example also give presentations at the Centre for Youth and Family ('CJG' in Dutch). And yes, there they just declare: 'If we only had known this sooner. I know a lot of families with young informal carers, and I refer all of them'. Well, and that shows now. I actually get a lot of referrals from the Centre for Youth and Family from the family coaches where I have held presentations. (P7, R1, NL).

An expert who is involved in such trainings explained about both their strengths and limitations. Participating professionals are reported to be very enthusiastic about the trainings and to recommend them to colleagues. The trainings would really 'open their eyes', helping them to recognize young carers, to reflect on their own (personal and work) experiences as well as emotions on the subject, and to take a more analytical approach to families (instead of only focusing on those people receiving care). Despite professionals' positive response, this expert lamented the limited reach of these courses, portraying their impact as 'a drop in the ocean'.

The success factor is that the scales fall of the eyes of the professionals. That they think, oh, is this a informal young carer? Oh, but then I know a lot of them. Oh... you know? A lot of recognition. [...] Do you want to come to cooperation with the customer, client of young informal carer, than you bring yourself along. [...] So the one says, yes, a lot of sadness come up. And another mentions powerlessness or anger. [...] If you are conscious about that, and learn to act on that ... Only from there on you can meet the other informal carer. [...] The success factor is also that they, again or for the first time, learn to see the family from an analytical perspective. [...] (P8, R1, NL).

And when the training has ended, the participants argue that everyone should follow it. All my colleges should follow this. This is too important. But it is a small group that expands little by little. [...] The trainings are always full though. Only it is just a drop in the ocean. (P8, R1, NL)

Family support

Experts also discussed interventions that are focused on the entire family, not just the young carer. These interventions are not always explicitly labeled as targeting young carers, but they might still provide this group with support and/or relief. One expert, for example, mentions the existence of 'neighborhood support families' to whom a family can be linked for a longer period of time, whereby young carers may be given a time-out on a regular basis.

There are a number of interventions that are interesting, which besides that actually ... that are not being referred to as informal caregiving interventions, but in fact are. And those are the interventions like neighborhood families and support families, where children for a long period of time have a family nearby they can, for example, visit once a week like some sort of time out or recovery time, and where they do entertaining things. There are research programs for these interventions which are quite promising. (P6, R1, NL)

In arguing for a family-based approach, experts also emphasize that young carers should not be addressed as isolated individuals. On the one hand, it was stressed that care professionals should look beyond the person who directly suffers from illness. On the other hand, focusing on young carers also brings in a new risk. Interventions that specifically address young carers may implicitly suggest that these young people are responsible for their own well-being without taking into account parents' responsibilities. Therefore, one expert emphasizes the importance of always involving parents when addressing young carers' wellbeing.

I think that the attention [...] in first instance goes to the parents and to the child with the condition. And that they should be given the notion to also look at the rest of the children, and to, if possible, also record them as extra clients in the caseload to also pay attention to that child. (P8, R1, NL)

If you focus all the interventions you have got on the young informal carers, you give them the impression that they are responsible for the own well-being. [...] You give them the responsibility of bringing themselves in balance. While I think that parents are a crucial factor in this matter. [...] if there is illness in the family, you would wish that the parents are and will remain worthy of nurturing, that they can keep guiding their children in being a child. [...] And the one parent is very good at that, while the other is not. So in the family analysis, the behavior of the parents is very important as is how resilient they are and can remain in guiding their children. (P8, R1, NL).

Second round:

In the second round of interviews, experts re-iterated some of the limitations of interventions used in the welfare sector. These revolve around three issues: (1) interventions not matching the needs of young carers, (2) good interventions that remain underused because people are not familiar with them, and (3) a lack of research to substantiate the effectiveness of interventions in the welfare domain.

Hey a trip to the Efteling [a Dutch amusement park] and you are ... well. So, there has also been thought about supporting the informal young carers, but at the same time you hear that, of course, some do not connect with the needs of the carers themselves. But then what? (P1, R2, NL).

And with welfare work I always find it a challenge, that I think: they are, they do very good things, and they are in the neighborhood. Only the notoriety and the visibility of the offer is very important. I always have the feeling that, also at my regular work, a lot of things are being organized, but that the target groups often do not even know it is there. (P10, R2, NL).

Well, I think that the impact, that there can be done something about that, but welfare work in itself is not very much involved in doing research. [...] welfare work actually does not have that relationship with research institutions. (P6, R2, NL).

Furthermore, while an expert in the first round referred to the temporary nature of interventions like the buddy program as a potential weakness, another expert did not believe that this necessarily was the case.

At the moment a buddy project like that has a specific purpose, which can be reached within a year, that is not a constraint. Children are not always in need of endless professional care. (P6, R2, NL).

Moreover, there was no consensus among experts about the necessity of involving parents when addressing young carers' wellbeing. On the one hand, an expert confirmed the importance of such involvement and mentioned a course on parenting as an intervention that would contribute to the wellbeing of both the parent and the young carer. On the other hand, another expert stressed that in some cases a focus on young carers themselves should be sufficient.

But there is for example also a course [...] meant for patients with serious mental health problems, seriously hospitalized patients, which are being supported in their parenthood. And that turns out not only to be positive for the parenting, but it also turns out to be positive for the recovery of their psychiatric problems. [...] I think that we should head more towards that direction. Towards the direction of how can parents remain good parents despite the fact that they suffer from an illness. And how can they request the help of their children. Causing the family system to be stronger (P6, R2, NL).

An approach by experts in which the whole family is involved. I certainly think that is possible, but not always required. [...] I think that sometimes, sometimes it is enough to solely give support to the young informal carers themselves. That they can pick it up from there. Well and sometimes young carers need a little more support and then it also wakes up the system. I do not think that for every child the whole system should be involved (P7, R2, NL).

Healthcare sector

First Round:

While experts made less reference to initiatives in the healthcare sector than to, for example, the domains of education and welfare, they did stress the importance of healthcare professions paying attention to young carers. They often made this explicit by referring to examples in which this attention was lacking. According to the experts, more attention to young caregivers would contribute to this group's identification and allow for their referral, but it could also support them in a more direct sense, i.e., in dealing with (the care for) the illness of their family member.

The doctor [...] knows there is a father with MS. But does he ever wonder, parents how do you cope with this in relation to your children? How are the children doing? These are the people that make a diagnosis and in addition when care is provided, can signal things. (P8, R1, NL)

Little example. During a buddies meeting, there were four expert buddies that discussed that their father or mother had been at the psychiatric department and that they were treated there for a couple of weeks and that they came home and that a totally different father or mother returned and that all four of them mentioned 'and no one told me what they have done to my mother, what it means to me. Should I be scared for her? What did they do to her at the hospital? She sat there behind locked up. Can someone tell me what is going on?' (P5, R1, NL)

One experts particularly saw an important role for the domain of (preventive) youth healthcare. In some locations, a standard question is asked during regular youth check-ups about possible caregiving to a family member. This, however, is not the standard procedure everywhere.

What I stand for is that in youth healthcare, where in principle children come on a regular basis, [...] the question about young informal carers is actually always being asked. Because if you look closely, a number of problems that can be experienced by children are specifically related to that. (P6, R1, NL)

That is the moment of contact between adolescents... eh... is now part of the youth healthcare. And if it is correct, there is [i.e., caring] also a question being asked. But that is not standard part of it. (P6, R1, NL)

Also beyond the domain of youth healthcare, experts see room for improvement in the recognition and involvement of (potential) young carers. For example, one expert refers to an initiative to rate hospitals in terms of child-friendliness, stimulating hospital staff to improve their communication with this group.

The Foundation Child and Hospital ('Stichting Kind en Ziekenhuis' in Dutch) is working on criteria in hospitals, the children's criteria, which are smileys. You can earn smileys by getting children to talk. How important that is, communication with children. You just have to confront children, if you explain the diagnosis or explain what the treatment contains and more of these things, you can earn smileys for this. As hospital or as department, children's department. And that just works really well. (P9, R1, NL)

Several experts also refer to interventions that are developed within the mental healthcare sector. Within this domain, there seems to be a considerable amount of attention for 'Children of Parents with Psychiatric Problems' ('KOPP' in Dutch). For example, doing a 'children check' is reported to be mandatory for mental healthcare professionals. Programs and interventions developed for this particular group may also be helpful for young carers more broadly.

In psychiatry you have the platforms of the KOPP children, Children of Parents with Psychiatric Problems. The attention for children of parents with an intellectual disability is also increasing. So you see in such a mainstream that more and more attempts are being made to reach and develop those groups to bring them together. (P3, R1)

At this moment, every mental healthcare professional is obligated to do a children check if there is an adult in the... well... in treatment with serious problems, then the question should be asked, do you have children and how are they doing and who is taking care of them now and how is that going? (P6, R1, NL)

That offer [for the KOPP-group] is for all ages from, well, actually from mother-baby intervention in the case of depressive mothers till interventions for youngsters between the age of 18 and 25. So for the whole age range there is a support offer which is well supported and described. A part of that [...] also useful for other problems apart from psychiatry and addiction. (P6, R1, NL)

Of course there have been experiments, also for example with CPPP ('KOPP' in Dutch) children and young informal carers which are combined in a course or training. Actually, at a certain point you should say: yes, all families in which something extra is going on concerning care, whether it concerns a brother, sister or parent, you see a similar dynamic and it is very well possible to give these children the opportunity to share their ideas and experiences (P10, R1, NL)

Second Round:

In the second round of interviews, an expert reflected on the challenge of involving healthcare professionals in efforts to identify and support young carers. While the attention for young carers in healthcare seems to be increasing, a lack of time and money was seen as one of the underlying causes for their still-limited involvement. Moreover, it was mentioned that healthcare professionals may not necessarily see it as their responsibility to focus on young carers.

I still think it is difficult to reach doctors and mental health care. They do not really get involved. Yesterday, I happened to be at a meeting of [...] the workgroup 'Quality Standard Overworked Informal Carers' [...] There the same issue was mentioned and they also discussed what the reason for that could be. And how it works precisely. And then the discussion results in time and money. Healthcare has no interest in acknowledging informal young carers. But I would almost argue that it might have changed a little since the letter of minister Hugo de Jonge, in which he stated that it most certainly concerns health care. (P6, R2, NL)

Future needs to support the well-being and health situation of (A)YCs

(A)YC Needs

Specifying the needs of young (i.o. older) carers

First Round:

Experts stress the importance of differentiating the specific needs of young carers compared to what they often refer to as 'normal' or adult carers. It is increasingly recognized that young carers' needs are different from those of adult carers, but experts state that there is still a lack of insight among professionals and policy makers about what these differences entail.

In the document that minister Schippers [of Health] at the time drew, that emphatically stated that young informal carers are certainly a different group than adult informal carers and are in need of different support. (P5, R1, NL)

To start, I would like to argue that you should regard young informal carers as a different group within, let's say, the national policy concerning informal care in the Netherlands. That would be nice. So I think that it is important because both young informal carers and young-adult informal carers have, I think, different supportive needs than other informal carers. (P4, R1, NL)

This also shows that we do not have a clear perspective on, well, who exactly are these young informal carers, right? What is the size of this group? What support do they need? (P4, R1, NL)

This shows that the focus really lies on the traditional informal carer. Where you actually see that these are often people of middle-age who take care of, for example, elderly. (P4, R1, NL)

You do not want people to fall between two stools. It is a group of people which is generally overlooked, or, as I mentioned before, is not being supported the proper way. Respite care is something which is an important topic among adult informal carers. I think that among young carers it is much more about seeking relaxation and meeting peers than, well, respite care. (P1, R1, NL)

Second Round:

No specific remarks were made on the (importance of the) difference between young and adult carers within the second round of interviews.

Need to be informed and involved in professional care for family member

First Round:

Multiple experts highlight the need to improve the provision of information to young carers in relation to their parent's or sibling's condition. Too often, children and youth are left with unanswered questions and worries that result from a lack of information. Such information can be disease-specific, but also concern issues of care planning and dealing with the family situation. When making decisions that affect young carers, experts highlight the need to involve these young carers in such decision-making processes. There may be a tension between 'not wanting to burden them' and 'involving them, because it affects them'. Still, one expert highlights that leaving someone in the dark can also be experienced as a burden.

You know, It would be so nice to not only have leaflets and other kind of information concerning common illnesses for grownups, but also for children. 'What is the thing my brother or sister has?' Or 'my father or mother was diagnosed, or has an illness, what does that mean?' Only that small piece of information provision, it could mean a lot. Because children can be very worried or are able to take certain things completely out of the context, which may cause a lot of stress. Something which is quite easy to take away. (P5, R1, NL)

I think, briefly said, we are obligated to them to no longer have a generation which grows up searching for information (P9, R1, NL)

And we also noticed in the siblings research, that there was some more, yet some older siblings, but they said: yes, you know, I just like to be involved from time to time in the conversations concerning future plans. [...] Because soon I will be my parents legal representative and then, I would prefer knowing how things should be understood than not knowing a thing. (P10, R1, NL)

And in the end it is about navigating between saying, on the one hand, [...] we want to get them out of that situation and get the burden off them. But on the other hand, you can also think, [...] this is also the situation as it is. That 'burden' also means not worrying anymore about the things that you do not know about. (P10, R1, NL)

Second Round:

Experts confirm that there is room for improvement when it comes to providing information to young carers. They highlight the differences that exist between the information that is available for this group in relation to different diseases or conditions. One expert points to the Dutch mental healthcare sector, but also to Sweden and Norway, as good examples where information provision to children/youth is a standard procedure, or even mandatory. Another expert argues that it should become mandatory that young carers get involved by healthcare professionals in the Netherlands too, while also mentioning the merits of having a specific care professional trained to explain diagnoses to children.

There are enormous chances. The care for breast cancer shows that there are opportunities. But it is completely dependent on the kind of disease you carry, because with other diseases, patients and children of patients seem totally invisible. (p6, R2, NL).

Providing information to young carers about handicap and disease, well, at the CPPP KVO that is always there. Learning about the diagnosis, and then I think, where are the health care services? In fact, we should have the same obligation as Sweden and Norway, the obligation to provide information about the disease to the children (P6, R2, NL).

That is why I am pro healthcare law, so that the caregivers know 'oh'... there a five, four moments, stated in research, where the young carers should be involved. And those are the diagnosis, the prognosis, what treatment will be done and what will happen after the treatment. (P9, R2, NL)

Than a professional would... than you would have to agree on whether it is okay to explain the treatment in children's jargon...?' That is why, if someone is trained to converse with children, as a parent it is less shocking. And then you notice it has such positive feedback. (P9, R2, NL)

Listening to and recognizing (A)YC's story and situation

First Round:

Experts emphasize that young carers and their experiences should be recognized, meaning that they should get enough space to really talk about their situations and needs. Such space and recognition may be important in a professional context, for example within their school, but even more so within their personal environment. Also, peer support can play an important role here.

What I hear from students is the need of acknowledging the existence of the situation. In other words, discussing the situation. [...] I find myself doing it sometimes, damn it, they have not done their work properly, such lazy people. While of course there can be good reason for them not to make the test or not to prepare the exam. So that acknowledgement and being able to talk about it, well, that is an evident need from the students themselves. (P3, R1, NL).

So, if they only ask, 'it is quite a lot right, all the things that are happening. How are you doing now?' 'What would you like or do you have any questions?' Let them know they are being seen and heard. And not as a checklist passing by, like, 'do you have any questions? No? Okay'. But seriously providing them notice. (P5, R1, NL)

That is what young carers also report in research 'I like the fact that there is someone, a professional or mentor, that listens to me, but I like it even better when people in my own environment help me out'. (P5, R1, NL)

And meeting peers, I think that that is the key. If you look closely, you will see there is a need for acknowledgement, a listening ear, relaxation and if you bring them together with other children, who also have a mother with a depression or a sibling with autism, that means a lot. (P5, R1, NL)

Experts explain why it is so important that young carers are granted space for sharing their emotions and frustrations, also when they do not necessarily seek practical support to 'fix' their situation. They point to the risk that young carers keep such feelings for themselves, with mental health issues as a possible result.

Most problems with children and in puberty and maturity arise when there is no space to express frustrations and emotions. As long as you can express these, you can come a real end. And depression or eating disorders are at the end all extreme manifestations of not being able to express your emotions. (P10, R1, NL)

That they are able to say, even though the situation cannot be changed, that they can get very angry or sad. [...] Given children the space to express themselves, and not confusing that with having to fix the situation. Because some things cannot be fixed, but that does not mean they cannot be there. (P10, R1, NL)

So that he is not only the young hero, but also the child that needs support, that needs help dealing with his sadness and emotions, with his coping and at the same time feels a strong need to hide that for the outside world because he does not want to cause more burden on the family. (P6, R1, NL)

But I notice that professionals think, when youngsters say: I do not need help, professionals think, okay, they might need help, and then they offer them help. But that is not what the youngster needs. He just wants to have a conversation. (P9, R1, NL)

Second Round:

In the second round, one expert mentioned how professionals sometimes do not sufficiently recognize the challenges of a young carer's situation, even if the latter explicitly identifies him- or herself as one. Another experts mentions the importance of tools that can help professionals in their conversations with young carers, helping them to get a good insight in the latter's wellbeing.

They probably do not have a clear image of what it means to be a young informal carer. And yes, if a child suggests he is one, it should be taken seriously. [...] If someone does not understand, let's say, what the burden of being a young carer entails, then that persons will not give a referral. They might think that it is normal. If that is your attitude, than of course you will not refer. (p7, R1, NL)

From the hospital, a child tool has been developed, [...] If you only ask the child 'how are you and your brother', they fall silent. But if you ask 'how do you feel, at school or at sports or when you are with your friends?', it will gain a more overall perspective (P9, R1, NL)

Be careful not to problematize

First Round:

Experts often point to the risk of overly problematizing the group of young carers. They do not want to be portrayed as people you should feel sorry for. When professionals problematize young carers too much, there is a risk of not reaching this group at all. Instead, experts draw attention to the positive qualities of young carers, to the resilience that they often have developed, and stress the importance of recognizing these positive aspects. While experts point to potential problems that young carers may face in their development and acknowledge that these should not be denied, most still argue for a more positive frame when portraying and addressing this group.

They do not want to be pitied or do not want to be portrayed. (P6, R1, NL)

Of course you should not pretend like being a young informal carer is very festive, but when I for example mention: 'wow, that is very good of you', they often look at me quite surprised and say: 'oh, most of the time I am being told 'wow, you must have a really hard time'. And that is the difference. (P2, R1, NL)

Concerning us, reaching out to young informal carers depends on the people that offer support and the way in which the theme is presented. It should be anything but problematizing. (P5, R1, NL)

Also look at the other side. Look at what it can bring to someone's personality and development. Emotionally, they can be really strong people, the ones who are in these situations. Good thing they have enough resilience to make the best out of it. And it's okay to acknowledge that, as in, great how you managed to grow into this balanced person, despite these setbacks. (P3, R1, NL)

While I do agree that you shouldn't problematize it, we shouldn't ignore that there can also be negative effects. And we should really try to prevent those. (P6, R1, NL)

Second Round:

In the second round, experts confirmed that painting a predominantly negative picture of young carers is undesirable. Focusing on young carers' positive qualities instead may sometimes be a challenge for professionals.

Nothing's so frustrating as a response like: oh, how sad for you. That's not what they are waiting for. (P3, R2, NL)

Recognizing the resilience that those people have, and appeal to that. That's something professionals don't like at all, because it means that they're less important than they thought they were. (P3, R2, NL)

Create relief and space for young carer to be him-/herself

First Round:

Despite experts emphasizing the strength and resilience of young carers, they also stress the importance of setting boundaries and creating space for them to get some relief, be themselves, and pursue their own paths. Professionals can stimulate such boundary-setting, as one personal example of an expert indicates. Moreover, while it may be a painful realization that their children are burdened, parents also have an important role in making sure that children can have a 'normal' development that goes beyond his or her identity of a carer.

I think we should be clear on the boundaries of children's responsibilities, things that are not good for children. [...] that we support children and let them develop a different identity than that of a carer. (P6, R1, NL)

...that it can be painful for families to realize what it really means for young carers. It is painful because parents do not want their children to be burdened or sad. [...] but only by recognizing it, you can start looking for what helps, so that parents can move on and look for the support that suits their children. (P6, R1, NL)

My hope is that it also results in lasting opportunities for young carers' development [...] that these young people can pursue their own paths. Despite disease or impairment in the family [...] that they can develop as a child. (P8, R1, NL)

...that attendant said: your brother is safe here, you don't have to worry, we will manage it and he will be okay here, he likes it here. Go lead your own life. [...] so I didn't have to relief the family anymore [...] choosing for yourself can be really hard. (P9, R1, NL)

Second Round:

Reflecting on this subject, one expert pointed to the importance of finding a balance between taking the burden off young carers, while also recognizing their own desire to care for their family member.

...you try to take the burden of children and youth as much as possible [...] while at the same time [...] for the kids it can be important to be able to do something. And then I think: it is also important to respect that. (P10, R2, NL)

Needs at professional level

Recognizing (A)YCs

First Round:

According to the experts, it is important that care professionals increasingly recognize young carers during their work. They should identify them and, if relevant, know to whom they can be referred for additional support. This is mentioned for (health)care and welfare professionals, but also for school teachers. When professionals encounter a care situation in a family, they should always check and ask: are their children involved?

That there are [...] care professionals that keep an eye out for young carers. (P5, R1, NL)

Issue number one: see me. You know, just: see me. Just say hi, when you enter a room. So visibility, that is the biggest step. (P9, R1, NL)

Make sure that we are in the picture with other professionals, like neighborhood teams or organizations where treatment and identification takes place. So that is about awareness raising with professionals who see more children [than we do]. (P5, R1, NL)

A home care professional or community nurse of course sees a lot. When a young carer is in the picture in a family... what you would like is that all those professionals are aware of the role of young carers and feel free to ask about it and make referrals to support. (P1, R1, NL)

That they ask adult carers questions like 'do you have kids?' in a first check or questionnaire. (P5, R1, NL)

Experts mention that having more attention to young carers does not require complex changes or interventions. Professionals should mainly become more aware of the issue. At the same time, an expert mentions that because there are already so many things a professional needs to take into account, it is understandable that young carers may turn out not to be a priority in practice.

This is no rocket science. It's just... it's about awareness raising of professionals and being aware of the needs... and then you can already get a long way. (P10, R1, NL)

Actually it's really simple. Ask an informal carer what he wants, which solution he sees. And often he knows. But we hesitate to ask them because we already have a solution. (P2, R1, NL)

Professionals of course already have a lot to take into account. It's also about domestic violence, poverty, debt relief, addiction. And then young carers end up somewhere a bit low on that list of priorities. (P5, R1, NL)

Second Round:

In the second round of interviews, experts confirmed the need for raising professionals' awareness about young carers, as they are, reportedly, often still unaware of their existence. The importance of care professionals and school teachers' ability to identify young

carers is confirmed. Experts stress that it is not just about identification. Professionals should also become more aware of how they can deal with this group and how they can better involve them in a family member's care trajectory.

Many organizations just don't know that this group even exists or that there is support for them in the first place. And that needs attention. (P7, R1, NL)

That it's not only going through the parents about the children, but that you also try to see whether the children can join the table, to a certain extent, in a conversation. So involve them in a more direct way. And ask them about their experiences and what they need. (P10, R2, NL)

That you also have attention for the children that live at home and take care of their parents. And how you can identify them in an early stage. (P1, R2, NL)

Aligning to individual (A)YCs' needs

First Round:

Experts emphasize that deciding whether and how support to young carers' can be offered should always happen in a conversation with young carers themselves. Failing to do so often means that activities are offered that later turn out to be irrelevant. Sometimes, during such conversation a professional may also find out that he or she cannot provide the support that is required. Either way, tailoring support to an individual young carer's needs requires professionals to be flexible and have sufficient room to maneuver.

The most important thing is that you find out what the target group wants. Because if you start coming up with these things by yourself, than it does not work, which I've also noticed with my programs. (P7, R1, NL)

As a professional you get there with a mind full of knowledge of what is possible. But you let that all go, until you hear, wait, is this what you're looking for? Well, then I'll go and look... Yes, you know, it's like you have a library and say, okay, I can recommend this. What do you think about this? No? Okay, then we'll look a bit further. (P9, R1, NL)

So then have you actually asked what they want? And did you develop your services based on that, or did you just come up with things [...] and think: wait, nobody is actually coming. (P10, R1, NL)

Don't be convinced that you can help them, because every Jack has his Jill. So there is no one size fits all, you know. (P9, R1, NL)

So it's a call for flexibility within an organization, give us the space to actually respond to specific needs, specific situations. (P3, R1, NL)

Second Round:

In the second round, experts confirmed that an individual young carer's specific needs should guide professional support efforts. One expert connected this to this current research, stressing that it should not be the international experts who come up with new solutions. Furthermore, it was mentioned that when young carers themselves do not see something as a problem, we also should not do this. Moreover, an expert argued that a diverse range of support activities should be offered in any local setting to be able to match individual young carers' diverse needs.

Also with these other countries.. We're all jumping on top of it and we're coming up with all kinds of things. And they think all these things are need, and research... and somehow that group itself is staying under the surface. [...] Actually, the research should lie much more with them. As in: what do you want? Because we can come up with things, but these may not be the right things. (P2, R2, NL)

In our work we're inclined to think in terms of signaling and identifying. But then you're automatically thinking in terms of problems. While it's the question whether you're actually making a connection with the target group, in this case young carers, because they may not see it as a problem. (P10, R2, NL)

That every municipality is obligated to provide various possibilities. Because not every kid is the same. (P9, R2, NL)

Taking a systemic (family) perspective

First Round:

As mentioned earlier, engaging with young carers requires a shift in perspective: from focusing on the person that is suffering from illness or impairment to focusing on the broader (family) system that they are part of. Experts highlight the importance of increasingly paying attention to the (emotional) dynamics within a family. They stress the merits of staying in touch with several family members when delivering care. One expert also argues that dealing with family members should get more attention within professional training programs.

I believe time is a first requirement, to have more time to have attention for the family. And for the children. (P5, R1, NL)

Okay, in short, communities need to be built instead of care provision. You know, you shouldn't always focus on the triangle [...] client, professional, family member. But you should put the family central in care. Where is that brother or sister coming from? [...] Having email addresses of the family members. (P9, R1, NL)

That's what my brother's attendant said. He said: 'but we were never trained for this. And... even 70% of my work is about being in touch with the family.' [...] So, I think that changes are needed within these training programs. (P9, R1, NL)

As part of a systemic perspective to young carer support, parents and broader support structures should also be involved. This should support young carers to find opportunities for relief every once in a while and prevent them from getting overburdened.

I actually feel that a lot of support to young carers should also include parenting support, to help parent see that their children can get stuck because of the responsibilities that they're getting, or that they're taking. And that parents have a role there, in that they create more options for their children. (P6, R1, NL)

And that can also be: I'm looking for someone closeby with whom she can go on an outing or just chat with. [...] So that the family as a whole is supported in properly dealing with it. (P6, R1, NL)

Second Round:

Experts confirmed the importance of taking a family-oriented perspective, while also stressing the importance of looking beyond the family and also including the broader social network. However, one expert also sees barriers to the actual engagement of this broader network, as people may be hesitant to ask for support, but also to offer support.

That the starting point is really the needs of young carers and the direct environment. That's mentioned somewhere: 'include the family as a whole when providing support'. I think that that works well, indeed, because in the end it is about the dynamics between family members. (P10, R2, NL)

I think that there's a role for those places where kids already go to. So that's education, but it can also be a sports club [...] the neighborhood, the informal network... Because I think that they can also have a really important role in the eventual support to the family. And in providing young carers with some relief. But I think that you have to deal with a lot of hesitation among people before they take the step to provide support. And there's a huge hesitation in asking for help on the side of the family. (P10, R2, NL)

Needs at organizational level

Collaborate for an integrated approach

First Round:

Much of what has been said so far, either directly or indirectly, touches upon the issue of collaboration across multiple domains. Experts stress the importance of developing integral approaches that move across education, welfare and (youth) healthcare. On the one hand, such collaboration can especially be developed at the local level, with municipalities in a coordinating role. On the other hand, experts point to the importance of not reinventing the wheel in every location, but to learn from one another at a regional or even national level. Still they also mention that regional collaboration may be challenging because funding is often arranged locally.

...then we said to each other that the domains of Care, Welfare, Education, the municipality... those are important domains, where professionals should at least be aware of this group and should develop an integral approach. (P1, R1, NL)

That you have to collaborate more between different organizations [...] to provide that support for young carers in an integral way. (P4, R1, NL)

And build on existing structures, right? Because I think that between the municipality and education there already is this [...] working group. And youth healthcare, there you can involve the Center for Youth and Family or the Municipal Public Health Service [GGD] [...] or primary care [...]. I think if you use existing structures, and existing institutions, that you can already come a long way. (P4, R1, NL)

If you would do it together and develop something where all these organizations can work with, then it would be much more efficient. Only then that's not possible, because the budget belongs to one municipality, and before you've managed to bring that together.... (P5, R1, NL)

Second Round:

Experts confirmed the importance of developing an integral approach across multiple domains and of exchanging lessons learned within and between different regions. 'JMZ Pro', a platform for professionals working with young carers, was mentioned as a good way to facilitate such learning, while the municipality was also mentioned as an important actor to make this learning possible. Moreover, an expert mentioned that before we can start thinking about collaboration, individual actors should take their responsibility in recognizing the issues of young carers in the first place.

With 'JMZ PRO' [...], it's all about teaching one another about good practices and that not everyone reinvents the wheel. So that you help each other to improve your support. (P7, R2, NL)

We can point out, well, how things go here and that it goes well. But a municipality has to come along there, because if they don't, then it's tough luck for that support point. (P7, R2, NL)

An integral approach [...] Then I think: great, but before that, they first have to become aware of the reasons why they [young carer] ask for attention in the first place, and about seeing their own role and responsibilities. And also taking these [...] I think that now this is often not the case. And then you can... It's a precondition before even talking about collaboration. (P10, R2, NL)

Reflecting on the international results from round one, an expert commented on how Slovenia seemed to be the only other country besides the Netherlands where the ambition of creating an integrated approach was mentioned so explicitly.

Slovenia mentions that indeed. Develop that integral approach, coordinated by different ministries. Well, okay, ambitious. Great. (P1, R2, NL)

Involved stakeholders

Responsible actors

First Round:

Experts stress that different actors play an important role—or have the potential to do so—on different aspects in the approach to young carers (e.g., (youth) healthcare and schools on identification and referral, municipalities on coordination, etc.). In particular, education and healthcare are highlighted as domains where actors should increasingly take responsibility when it comes to young carers (which will be elaborated in more detail in the next sections). For now, it is important to say that it is seen as a major challenge that most actors do not see young carers as their primary responsibility.

Nobody feels explicitly and directly responsible when it comes to these youth. (P8, R1, NL)

That is [...] a really tough one, as it all concerns different parties and different funding sources, etcetera. Who feels overall responsible for when we're talking about this particular group? (P10, R1, NL)

Second Round:

One expert gave an example confirming that different parties will remain responsible for different aspects around the support to young carers, as these different actors have different fields of expertise.

And that is something for social work, you can teach these kids how to deal with stress. The general issues around growing up with disease and care within a family. That's what you can do as social work, but it's not up to social work to explain about cancer. (P6, R1, NL)

3.4.2 Healthcare

First Round:

Experts argue for a more pronounced role for healthcare organizations and professionals—in hospitals, general practice as well as home care—in activities to support young carers. Reflecting on their current role, experts see considerable room for improvement. The fact that healthcare professionals are directly involved with the family members suffering from illness or impairment puts them in an ideal position to ask, or otherwise identify, whether any children or youth are affected or burdened with providing care.

I still have to come across positive stories about a primary care physician asking [whether there are children involved]. And that also has to do with privacy, and with those mere ten minutes that they have. And I'm not pointing fingers to say 'they're not doing it right', but I do feel that there is only limited knowledge there (P9, R1, NL)

Look, for home care staff, they're in touch with the ill person, they're in touch with the ill person's partner. They see children walking around, but don't always think: let's ask how that child's doing. (P8, R1, NL)

I think that at the location where care takes place, which is in hospitals, in treatment centers, let's say all the places where people get diagnosed, in those location there should be a lot more attention for young carers. Because before they [young carers] have reached a welfare organization that offers something, a lot of time has passed and the problems have gotten worse. (P5, R1, NL)

Second Round:

Experts confirm both the importance healthcare professionals' potential role in identifying young carers as well as the improvements that are still required to fulfill this potential. Some experts indicate that improvements are indeed being made. The current minister of Health in the Netherlands is drawing attention to young carers. Furthermore, a new nursing quality standard for overburdened informal carers is developed in which there is specific attention for young carers.

Primary care physicians, when it concerns this target group [...] I think they have an important role in identifying young carers. (P1, R2, NL)

Yesterday [the secretary of Health] announced that he will keep an eye on care organizations, family doctors, and who knows what else, to not only have attention for the person needing care, but for his network too. Especially when there are children involved. (P3, R2, NL)

The working group Care Quality Standard for Overburdened Informal Carers. And there... the young carers really got a nice spot there. [...] That quality standard is mainly aimed at nurses and aides and they of course see a lot around the patient, they can, well, get a better view of the family system. (P6, R2, NL)

Reflecting on the international results from round one, an expert comments that, as in Sweden and Norway, information sharing with children should be mandatory.

In fact what you would need to do, like in Sweden and Norway, is to make it mandatory that there is information about a disease that can be shared with children. (P6, R2, NL)

3.4.3 Welfare

First Round:

While relying on other actors for identifying young carers and getting them referred, experts see a key role for the welfare domain in providing support to young carers. Experts also stress welfare organizations' important and ongoing role in raising awareness and stimulating recognition of young carers within schools.

Actually in most cases young carer support should be done by the welfare organizations, like I said. But it would be really great if there's also a place within care organizations or hospitals where that is possible. (P5, R1, NL)

A support point for informal care that is also doing guest lessons, or another informal care organization that approaches schools to seek that collaboration. (P4, R1, NL)

That you have to collaborate more between different organizations [...] to be able to integrally provide that support for young carers. So collaborate between, for example, education and municipality and between education and welfare organizations. (P4, R1, NL)

Second Round:

A number of experts confirm the key role of welfare organizations and professionals in developing expertise about young carers among professionals in other domains and catalyzing the development of activities for this group.

I'm under the impression, but I don't know whether it's true, that everything that happens around young carers in education is initiated and catalyzed by the welfare sector. (P6, R2, NL)

We [welfare professionals] are of course the ones within the municipality who know most about this group. So we are also the ones who can best convey that to professionals and teachers. (P7, R2, NL)

3.4.4 Schools

First Round:

Education is mentioned as a key domain for reaching young carers. Still, experts highlight the challenges in this area—in terms of access, awareness and expertise within schools. They point to considerable room for improvement, e.g., through awareness-raising and training of school staff. Moreover, experts suggest two concrete innovations that could support the position of young carers in schools and beyond. First, one expert questions why schools have special arrangements for top athletes, but not for students who need extra time or space because of caregiving. Developing such an arrangement for the latter group may be supportive. Second, another experts argues for making the subject of young carers a mandatory part of any care-oriented training program.

Yes, the place to reach them is in education. So that, that would be a logical partner to engage. And that often turns out to be challenging. (P4, R1, NL)

Still there are many teachers who don't see that there are also informal carers in their school. Not because they have bad intention or because of stupidity, but if you've never had to deal with it, then you won't see it. (P2, R1, NL)

That also depends on the specific teacher, but generally speaking it's often like: I don't know what to do about it. [...] and they want to be supported in that. (P2, R1, NL)

There's an arrangement for top athletes at university who get... yes, they get extra days leave, [...] I would also like to see that arrangement for young carers, but that's not happening yet. (P2, R1, NL)

In an ideal future every care training program has at least someone who teaches and really knows something about, well, 25 years of research into the impact [of a family member's disease] on brothers or sisters. (P9, R1, NL)

Second Round:

In the second round of interviews, experts confirm the important (potential) role for schools. They see it as an important responsibility for schools to refer young carers to other organizations that can provide additional support. Lastly, an expert pointed to the importance of schools being flexible when a student-carer may not be able to do its school work because of their situation at home.

Of course schools are the ones who see these kids the most. So they often know most about them. And they're the ones who are there first when help is needed, who can start that. (P7, R2, NL)

Professionals, schools, that that responsibility also lies with them. And they need to be trained for that [...] and they should be able to make referrals. (P7, R2, NL)

...a school should be able to be flexible, [...]when a child misses its mother for three weeks and therefor can't do its homework or take exams. (P9, R2, NL)

Reflecting on the international results from the first round, one expert pointed to the international differences in school infrastructures, which may affect which tasks a school can or cannot take upon itself.

So I know that they have a whole range of care tasks there [Sweden] that are part of the schools. Nurses, social work. That's really institutionalized in that setting. Also because children spend an important part of the day in school or in

after-school day care. So there is an infrastructure for that. But in other countries, I don't expect that infrastructure in schools. (P3, R2, NL)

Public authorities

First Round:

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

I think municipalities have a coordinating role there [i.e., concerning an integral approach]. (P4, R1, NL)

We [the Ministry of Health] actually try to, well, [...] have the conversation of 'well, if you're developing an informal care policy, than try to include an integral approach to young carers'. And don't forget that group. (P1, R1, NL)

The Dutch national government should make sure that, how do you say this.... That there is a national way. At least some kind of collaboration, or some uniformity that you know which steps to take. (P9, R1, NL)

I wish that the government would earmark funds for [...] supporting young carers [...] so that it can't be spent on a new shopping mall, so to speak. So that municipalities will really take that responsibility, that they, well... that they can't get away from it. (P9, R1, NL)

Second Round:

In the second round, experts highlight the differences between municipalities in terms of developed policies and interventions to support young carers. Moreover, experts point to the important role that municipalities can play in stimulating the exchange of lessons learned and in creating a framework that stimulates local actors to pay more attention to young carers (e.g., to make sure that schools organize awareness-raising activities) and ensuring an integral and coordinated approach.

Well, I notice that very many municipalities are just getting started, while others are already much further along. (P7, R1, NL)

If municipalities will tell the schools that these awareness-campaigns that we do must be done, that it becomes mandatory for the schools to do them, then that would really help. (P7, R2, NL)

Yes, I think that the local government should provide some guidelines. And that this target group [...] is recognized and that policy is made, but also resources are made available. Because that is of course often not yet the case. And that they're willing to work together with one another and share knowledge, because otherwise they will remain [...] separate activities that run parallel from each other. And that's a waste of money. (P10, R2, NL)

Overall needs at societal level

Awareness, acceptance and reduction of stigma

First Round:

Experts highlight the importance of breaking the silence around the subject of young carers. It should be normal to talk about it and young carers should be able to speak freely about their situation. In the end, young carers should not always be seen as a 'target group', but as normal participants in society. It seems that things are currently changing in that direction, but experts also indicate that there is still much improvement to be made.

Actually this should become part of the culture [...] That it's normal, that it's a part of life and of society. But we're not there yet. (P2, R1, NL)

Breaking the silence... The silence around these situation, that's an important factor. [...] We're not familiar enough with the phenomenon to talk about it with each other. [...] And I also see, well, it's becoming more of an item, in the public debate, the political debate, it gets attention. So the attention is growing. (P3, R1, NL)

My prediction? Well, let's call it my hope [...] That we, as a society, will become much more aware of the impact of disease in a family. [...] And that it's normal to have attention for that. [...] there's so much special and specific attention for it, because it is a target group... But [I hope] that it becomes more normal to talk about it with one another. (P8, R1, NL)

Second Round:

One expert reports to be a bit puzzled by the emphasis on stigma in the international findings of round one, not understanding why caregiving would be stigmatized. Several experts report that, in the Netherlands, it is becoming increasingly normal to talk about the issues surrounding young carers, which they see as a positive development.

Stigmatizing... [...] Yes... That puzzles me... Because what's stigmatizing about... is that related to the particular disease of the parent or family member? [...] chronic conditions like MS and ALS or rheumatoid arthritis or brain injuries... are those stigmatized? (P3, R2, NL)

...the issue gets more known. I'm really happy that it's getting clearer that people who provide informal care are not pathetic. (P3, R2, NL)

I'm convinced that slowly but steadily people are taking more interest. That is has become more legitimate to ask attention for it. Because earlier you would get responses like: it's not that bad, is it? (P6, R2, NL)

(Civil) society

First Round:

Several experts mention the importance of looking beyond formal and professional support to young carers. 'Society', which may entail civil society organizations but also people's informal social networks, has an important role to play in supporting young carers. People's social networks can also play a role in referring young carers to professional support. One experts also connects this importance of informal support to policy developments in the direction of government downsizing and citizen participation.

It's also about the football club, the sports clubs where the youth are part of. It's about looking after one another, and having the conversation. Knowing what is going on with others, and the moment you notice that someone is in a rough spot or is almost collapsing, then you help to refer this person to a solution. (P1, R1, NL)

For example, it was almost Christmas, and they said: what are you doing for Christmas? Who can you go to? [...] Actually, and maybe that is the last step as a care professional, you are leaving at some point. You have to realize that. You have to make sure you are not needed anymore. (P9, R1, NL)

We, as a society, are choosing for a smaller role for the government. So then I think, well, if society says it's no public responsibility, than society will have to show responsibilities. (P3, R1, NL)

Second Round:

In the second round, experts confirm the importance of looking beyond formal legislation and professional support services and draw attention to the role of informal support and social interactions.

And with laws [...] you don't do anything about how people behave themselves decently. And that is, I believe, one of the most important issues. How do we, as a society, deal with recognizing and acknowledging it? (P3, R2, NL)

And how important is it that we... [...] as an environment, as a family, stand around these children, and then you can get things moving, instead of it being only professional support. (P6, R2, NL)

One expert refers to first-round findings from Switzerland, pointing to the idea that 'the entire society is responsible' as an interesting observation.

Switzerland, they wrote that the entire society is response and needs cultural change. I thought that was a really interesting remark, because you can indeed wonder about raising awareness in society: what young informal care is, what are their support needs, what are its risks. (P6, R2, NL)

Working concepts

Involvement of (A)YCs in developing interventions

First Round:

There seems to be a broad consensus among experts that involving young carers in the development of interventions and policies is a key ingredient for success. Failing to do so means that activities turn out demand driven and potentially irrelevant.

And you always have to do it through co-creation. You always have to... almost develop it together with these young people. (P9, R1, NL)

...discuss it with students themselves, what exactly do they need? And what do you want? And what can we offer in response? So that we're not making it up on their behalf. (P3, R1, NL)

when you're developing policies around young carers, or support, then I think it's really important to involve young carers themselves. (P4, R1, NL)

Yes, we just really ask those children what they want [...] we can make it up ourselves, but if we start doing things they don't like, then there is no point. (P7, R1, NL)

Second Round:

In the second round, experts confirm the importance of involving young carers themselves, while also stating that this is currently not done sufficiently.

We also have to... more than we do now... also simply look at good approaches together with those directly involved, look at what they really need (P3, R2, NL)

Development of technology or apps supporting (A)YCs

First Round:

When developing technological solutions to support young carers, experts stress at least two different aspects that are important to take into account. First, when developing a European app, an expert highlights the importance of making sure that such an app is well-embedded and supported at various levels and organizations, i.e., at a national political level, but also within municipalities and in organizations working with young carers. Second, an expert warns that using technology does not automatically mean that an intervention actually appeals to young people.

...that European app, make sure that it is well-embedded [...] Yes, I'm really hoping for that European app [...] if you present it [...] to the Parliament, but also make sure that it's supported by VNG [the umbrella organization for Dutch municipalities] and by the youth organizations... That it's supported broadly. (P9, R1, NL)

What I often see with a website and who knows what else, that I think, well.... It makes me wonder, it starts with: what are the things you identify with as a child, as young person, as a parent, do you speak the same language? [...] And then I think there is a mismatch every once in a while. (P10, R1, NL)

Second Round:

In the second round, experts reflect on some of the merits of using digital technologies in order to reach and appeal to young carers.

Digital support programs have been developed [...] in which children and youth get help through some kind of chatroom or... Well, I work with Instagram and WhatsApp and that way I keep in touch with young carers. (P7, R2, NL)

Make sure that [...] the hospital has an online tool with which young carers can chat with someone. (P9, R2, NL)

Expectations

Growing awareness and support as well as demand and burden

First Round:

On the one hand, experts are positive about the growing attention for young carers and their support needs. It is stressed that this growing attention is a requirement, as it will have a preventive effect both on people's wellbeing and on public spending. On the other hand, experts are afraid that changes in the Dutch welfare state (making sure people are able to live at home for longer, while trying to contain costs) will result in a greater burden for young carers. The risk is that 'cutting costs' in the welfare state will eventually result in rising costs when (young) carers get overburdened. As such, experts again stress the importance of focusing on and answering to young carers' support needs.

...the fact the a strange term like 'informal care' became something meaningful for many people, that says something about how we are seeing and acknowledging that social capital that we have as a society. And that will also be the case for those people that will face this at a young age. (P3, R1, NL)

And then we say: we'll make sure that the people that need care will continue to live at home as long as possible. Those are great ambitions, but it has consequences. That means that the people it concerns, in this case the family and the children and youth, that they.... There should be attention for that: what do you need for that? (P10, R1, NL)

And then you're cutting costs, but of course that is not really true. Because the costs will always come. If people get overburdened, there will be costs. If people can't go to work because they are caring all the time, those are also costs. (P10, R1, NL)

Second Round:

In connection to this issue, one expert critically responds to the Swedish findings in round one. It was mentioned in these results that they tried to work towards a 'youth free from a caring role', which this expert portrayed as 'a utopia'.

And then Sweden. Really interesting. 'Youth free from a caring role'. That is an interesting utopia. [...] it would be great, but.... Other countries formulate it a bit better.... [...] Yes, it was Italy. They said 'we should teach them how to deal with it so that the care role is not forced upon them' (P9, R2, NL)

Results - International/European level

Visibility and awareness raising

Main findings:

First Round:

Although awareness and visibility on young carers is increasing in countries in Europe, for example through (more) research, conferences or awareness raising events, there is consensus among the experts that there still is a lack of (structural or long-term) visibility and awareness raising on the topic of young carers. Moreover, some experts point to differences between, but also within, countries in Europe concerning visibility and awareness raising. In specific, differences in visibility and awareness of young carers in schools and health care were reported.

"I went to young carers conference in Sweden last year [...], [were data was presented on] [...] ranking of countries where UK was at the top and then progressively, sort of say Germany and Sweden also at the next level down in terms of recognition. But there was some other countries where rates were so much lower. I think partly it's because of financial reasons but also maybe cultural reasons." (P2, R1, UK)

"So, I would say that in Germany, there is not much visibility on young carers and young adult carers but the awareness is growing." (P5, R1, Germany)

"First, they did the study [on young carers in 2014] and then there was also an awareness raising campaign [by the ministry] and also the carers' organisation took this topic on board." (P1, R1, Austria)

"It's [family caregiving] already a marginal topic and then this will be something within this area where really a very small group of people is really aware of this." (P1, R1, Austria)

"[Some schools] may not have that interest in thinking about what support... you know, the fact that their young people may be carers. Whereas larger schools where you have a much wider population of students may have more prevalence of that situation of young people in the school. So somewhere the schools don't want to accommodate their needs as carers. And others that can identify the carers within the school but then over time, the school sort of loses interest in maintaining that support for example [...] in terms of getting assignments and exams and so on but over time they become much more resistant to allow students to have extra time per se." (P2, R1, UK)

"From my experience, I've been doing this job, [...] for the European Commission for [...] years now, they are not visible.....it was quite interesting because the percentages were quite different. Like 4 percent in one country and 10 or 11. So, you'd have to know what exactly they are measuring and how given the lack of visibility and the lack of awareness that there even are young carers. And there is also lack of data." (P4, R1, Ireland)

"Some of the variation [...] are projected in local area in relation to working with key stakeholders in schools for example and GPs. That largely dictates what is the visibility of [...] of young carers within local areas. Because some local areas are much better than others in terms of first identifying the adolescent young carers particularly I think in schools and colleges where they may not themselves identify as carers [...]." (P2, R1, UK)

Second Round (Reflection):

In general, experts agree with the summary of results of round 1 of the Delphi study. For example, it is stressed that awareness is increasing, but long-term awareness is not necessarily guaranteed in most countries, even in countries scoring relatively high on awareness of young carers, such as the UK. In addition, one expert reported that the term is not known in all countries, which is crucial in identifying them.

'The question here is how this can become part of the mainstream discourse about carers in general because that's a really long time we have already long-term care in the older people and some marginal issues and then carers as more marginal and then you have caring children. And then sometimes then it might pop up because of a study or because of an article or one journalist taking it up or even some policy makers, but the question is how sustainable this is and how much it can be mainstreamed in discourses about children, youth, on the one hand, and on the other hand, on carers in general.' (P1, R2, Austria)

"Well, I totally agree with the visibility and awareness raising with all the points mentioned...one of the hardest points is to identify young carers which says the term young carers is not recognisable in all countries and so I think this is crucial to identify young carers." (P5, R2, Germany)

'I would expect that the UK is further along in terms of visibility and awareness but it's still nowhere as perfect and so it's maybe just further along on that scale in terms of the types of things that are being identified [in other countries]' (P2, R2, UK)

[...] 'I think it's just quite striking the visibility of the problem in every country for example be it the levels of it vary massively as well' (P3, R2, UK)

'I think there is an awful lot of similarity actually. Obviously, some countries have a more legal framework and some don't but in terms of their approaches, I think that they are quite similar.' (P3, R2, UK)

One expert disagreed - was amazed - by the acceptance of some experts that children perform a role as carer and the need for gatekeeping and screening to prevent children from having to fulfil these roles.

"...the acceptance of children performing these roles and tasks. And I really, really think there needs to be more around that. It's set and complete and it shouldn't be. There's need to question the fact that children are required to fulfil these roles, especially the heavier ones. It's not okay, it's not in line with their rights so instead of the solution seems to be asked very heavily on supporting them, but actually, there needs to be some gatekeeping to prevent this." (P4, R2, Ireland)

Local level and regional level (results of local level in combination with regional level, because it is sometimes difficult to separate local from regional level in the different countries)

First Round:

Diverse types of organizations are mentioned by experts as responsible for identifying young carers. Some organizations specifically address the needs of young caregivers, such as carers' organisations. In addition, organizations not specifically focussing on young carers, but with services targeted at the care recipient, such as health care organisations, or services for young people in general, such as schools, leisure clubs, social service organizations, voluntary organisations or children's helplines, are mentioned. In the UK, local authorities are - by law- responsible to identify carers using 'carers assessments'. In practice, local authorities can subcontract organisations to perform the assessments, such as a young carers centre.

The main organisations I think in the UK are Carers Trust and the Children Societies. But they will work with schools and GPs sort of network with other groups where young people are in contact more generally with the teachers or with local authorities to help identify young carers. (P2, R1, UK)

Sometimes the NHS workers are involved, and particularly mental health services, occupational therapists, [...] sometimes are involved in supporting the person with care needs. But sometimes it's about schools, further education, colleges and charities, voluntary sectors, young carers groups. And sometimes quite often, for example like I said about refugee groups, it might not be a young carers' group specifically to, it might not be a voluntary sector organisation specifically for carers, it just might be one of the young people's many needs so it might be a slightly different organisation that picks it up. (P3, R1, UK)

"I would imagine, that in where children are, which is primarily schools, but it can be doctor [services], they can also be in regular leisure activities that these adults are sensitized to raising awareness of where they think that a child might be experiencing a particular stress in the home which one of those stresses could be caring responsibilities for sick or disabled relatives." (P6, R1, Belgium).

"The responsibility for identifying young carers would be local authorities, social services departments. [...] Schools are increasingly identifying young carers as well, but the main responsibility in law is the local authority." (P3, R1, UK)

Experts mention that there are differences in the level of awareness on the topic of young carers in organizations such as schools, welfare organizations and social services. Moreover, concerning the role of schools, it is questioned by some experts what the extent of the responsibility of school concerning problems of (A)YCs is.

"Within the provider organisations, there are also awareness raising campaigns." (P1, R1, Austria)

Then there is the question with the school and how far can teachers become aware of this and get into the situation? Do they see this as their task? Because they might not see themselves as social workers. (P1, R1, Austria).

Second Round (Reflection):

In addition to round 1, it is addressed that although the role of the health care system is mentioned, this could be done more elaborately, specifically mental health care services are mentioned. In specific for Austria, the expert points to the role of social workers and the fact that they are not involved in long-term care and hence possibly not recognizing (A)YCs.

'There is a lot said about schools and there is some here about GPs but many people that are cared for by young carers are for example in different health settings and not so much GPs but mental health works or whatever or they are in hospitals or in different other health settings.' (P1, R2, Austria).

'It's also concerning the professions, social workers and similar professions, that might not always be aware of this but for example in Austria, social workers are not involved in long-term care whatsoever or almost not. And so I think that they are also lacking then any awareness of young people as carers.' (P1, R2, Austria)

National level

First Round:

Numbers on (A)YCs are available in some countries, such as the UK and Austria. These estimates of prevalence figures of (A)YCs within countries may differ depending on the specific definition of (A)YCs used. Some also address that the number of (A)YCs is probably higher than one would expect.

“So, I think depending on what ages you are looking at and also I think how you define... or how those estimates are derived, it’s dependent on different numbers of young adult carers there are in the UK.” (P2, R1, UK)

“[...] Different people use different things so quite often in practice, different local authorities may use a slightly different definition. Sometimes the definition doesn’t specifically mention and allow for drug or alcohol which as we know lots of young people are caring for people with some of those issues. So, I think that makes a difference to the level of identification.” (P3, R1, UK).

“What was [...] noteworthy in that meeting [in the European Parliament a few months back] was the numbers of people in the room who themselves had had experience of being fulltime carers for relatives as children even if their current job as adults are not specifically involved in activities promoting or raising awareness about the issue. So, I think it’s more prevalent than you’d normally come across in society, is what I’m saying.” (P6, R1, Belgium)

“It was a study where they did a survey in around 100 schools and 500 classes and they got more than 7,000 questionnaires. And from these, so this was a representative sample, and from this, they identified what I said before, 43,000 young people. [...] It was many more than originally estimated, the number [of young carers aged 5 to 18 years]. [...] It was surprising and especially in Austria it became kind of a key area for the ministry.” (P1, R1, Austria).

Young carers can be identified ‘directly’ by asking young people themselves or ‘indirectly’ by approaching their family. Moreover, professionals working with young people -in general- could identify (A)YCs when they meet young people experiencing problems in diverse areas of life, not necessarily directly related to caregiving.

“In the [government] census, they ask [question on caregiving to] the so-called head of the household. So, they may not be asking the younger people directly. In local authorities, I think there is a number of ways. It might be through the person with care needs or the person they’re supporting. This is the idea of a whole family assessment and so when they assess those with care needs, they are also supposed to also look at who might be caring for them, which might be a child but it might be another adult in the households. And then there’s routes where they will identify them directly. So, this is supposed to be happening in [carers’ assessments].” (P3, R1, UK)

“I guess there would be tonnes of ways of identifying. [...] How about those children who have depression. [...] I would imagine that there are a number of children who are seeking support because they have adult responsibilities of caring for others. [...] So, there is all kinds of signs that if the child is not coming forward because of being ashamed or fearful or whatever, that there are hopefully adults in professional capacities who can identify where a child is needing support.” (P6, R1, Belgium).

“[...] If they have any psychological support providing or welfare and pastoral care for children in the school environment, that would be a logical for the school for children to share what’s going on at home. And in some countries, there are additional social [services] that may be attached to schools where they can identify where the families that are experiencing this particular stress or strain which is impacting on the capacity of child to go to school regularly or to learn effectively.”(P6, R1, Belgium).

Second Round (Reflection):

The definition of (A)YCs is also reflected on, also addressing the use of different definitions by young carers themselves.

‘[...] The young carers that I’ve spoken to don’t seem to have a consistent view on what that terminology should be, so I don’t know that there will ever be a terminology that meets the needs of everyone and everyone is satisfied with.’ (P2, R2, UK)

Furthermore, three experts reflected on the finding on migrant children in Switzerland.

“I think that didn’t get raised for the UK but I think it happens, from my experience, happens in the UK as well, that refugee children are a group that also contains quite a lot of young carers. I think that’s interesting that it’s come up in Switzerland and none of the other countries because quite a lot of them also have quite a lot of migrant families. So it’s interesting that it only came up there.” (P3, R2, UK)

“I like that somebody made a reference to migrant children. I think that’s useful because in deed, there are many instances of parent where children end up taking over the parenting roles because the parent is so traumatized, so that’s useful. I wonder about needing a law. It seems to be adding more fragmentation to already fragmented systems. Because they shouldn’t be there in the first place.” (P4, R2, Ireland)

“I think it’s interesting the coping being different between migrant children and Swiss children. I suppose that speaks to sort of cultural understanding and cultural comfort levels around perception of what children should do and how we communicate. Again, I think maybe the situation for migrants is more difficult and therefore perhaps migrant children who are carers are able to derive some utility from their caring role and that helps them in terms of the general situations. And also the fact that I don’t feel it’s necessarily healthy for children to hide the fact that they are carers or they are having problems so that’s probably not an ideal situation if that’s how Swiss children are discriminated. [...] It could be the case [in the UK] but I’m not aware of it. I don’t think I have met or worked with any migrant children who are carers.” (P2, R2, UK)

In addition, one expert suggested to gather more insight in the data and actual numbers across the countries.

“What would be beneficial, of course...is being able to better identify the scales and knowing ... because in order to ensure the national authorities put the correct focus on this, it’s good to have some numbers or be able to say what’s up.” (P4, R2, Ireland)

Additional

First Round:

In the interviews, a barrier mentioned to identifying (A)YCs is that adolescents may not - or do not want to - identify themselves as caregivers. In addition, one expert specifically reported that (A)YCs should not be carers and there seems to be acceptance that they provide care. In specific, refugees were mentioned as a group with a relatively high percentage of young carers, who often were identified in education in the UK. Furthermore, experts report that professionals working with children may not always recognize young carers and/or relate the problems of adolescents to caregiving.

"[...] a lot of young people would rather view themselves as being supporting within their households by taking on responsibilities [...], that may provide them a certain degree of utility in terms of feeling better about themselves and feeling great about their contribution. But not wanting to necessarily define that as something that is related to being a carer as such. But just about someone who watches over their household." (P2, R1, UK)

"I had the impression sometime that there was far too much acceptance of the fact that children should be providing all that care and then looking at how to make it easier for them or better. But we really need to question why... question and not tolerate and not accept that they have to do this." (P4, R1, NL)

"I have worked quite a lot with young refugees and often they are doing quite a lot of caring and they don't kind of necessarily recognize it. [...] Schools, and in fact colleges, further education, a lot of young people, particularly young refugees, actually asylum seekers go there at 16 and it's often picked up there. So, they've got multiple needs and that is just one of them." (P3, R1, UK)

"The problem is how to identify them at school for example. If teachers see problems or get aware of this, this could be one way to identify them, it's the main area." (P1, R1, Austria).

"So sometimes you have a negative impact on the health of the young carer, for example, which might be also something where perhaps GPs are not always aware of this but this might be one reason for specific health problems of young people." (P1, R1, Austria).

Another topic that was mentioned by some experts was the rights of the child. Central was the relation between rights of the child and the activity of caregiving by people under 18 years old. In particular the rights of the child 'to have their voices heard and to respect the individual journey of the child' (P6) were emphasized in the context of caregiving in young people. In addition, one of the experts reported on rights of the child and screening for adverse childhood experiences.

"[...] Recognizing that children and young people have rights. They have rights to have leisure time, they have rights to play, they have rights to education, they have rights to respond to the care giving. And how children can ensure that they can access those rights, recognizing that some children also get a certain amount of recognition or award from their caring responsibility [...]. Some families need to make sure that they have other forms of care so the children can be released from that care if it's unreasonable and inappropriate for the children to be taking those levels of care, in other cases, it might just be giving that emotional support to children who are in caring responsibilities and making sure they are coping and they can manage all of the other things that they want and should be doing in their lives around school and having fun and relationships and all that." (P6, R1, Belgium).

"Obviously, when it comes to registration in terms of the rights of the child and so on in terms of what can be affected and what responsibilities one will expected to take on, I think on a regulatory perspective, I think there's work needs extreme regard that in that area." (P2, R1, UK).

"But maybe another area that definitely is linked to what you are doing is adverse childhood experiences (ACE). And I don't know, I suppose depending on how you define young carers or maybe you use, I suppose there are different degrees because depending on the time or the trauma involved in young care, it should be picked up when looking at adverse childhood experiences." (P4, R1, Ireland).

Second Round (Reflection):

Reflecting on the discussion of the rights of the child in Round 1, it was specifically stressed that children's rights in general implies that children do not have to take up the caring responsibility (in Round 2).

"There should be a right not to care for their parents, at least until 18. But this is not a special legislation, that should be in the rights of children and youth." (P1, R2, Austria).

"Because then we are just promoting, to some extent, child labour which is not legal. Although you can't even call it child labour because they are not paid, are they?" (P4, R2, Ireland)

"[...] It raises issues around how we recognise children who are under 18, who might otherwise be recognised as having agency for their own decisions, are nonetheless taking on adult responsibilities. [On an] European level, [there needs] to be increasing awareness and recognition of children's rights". (P6, R2, Belgium).

Strategies, interventions and programs to support (A)YC

Main findings:

First Round:

Different types of support interventions in different sectors are mentioned or a lack of, including (i) laws and regulation including the carers' assessment in the UK, (ii) support (or a lack) from school counsellors and teachers, (iii) provision of information, (iv) peer group/network activities for (A)YCs, (v) mentoring/individual support, (vi) fun activities, (vii) carer's card, (viii) mental health services for young people, and (ix) professional care for the care recipient. Strengths of (some) of these support interventions are increasing awareness on the topic of young caregiving, relieving the care tasks of young carers, high value attached to support interventions by young carers, and positive effect on mental health of young carers. Weaknesses mentioned are a lack of financial resources for (long-term) commitment, unfamiliarity on the topic of young caregiving among professionals working with young people or the care recipient, regional differences in level of support, and lack of a whole family approach.

"My main knowledge is around some of the things that were set out in terms of the national strategy in the Children and Family and Care Acts. That's is there is a sort of support for aspects of young people's lives and includes providing services for the person they care for as a means of supporting the carer. So, that is a national strategy that, I guess, in terms of their health and wellbeing, the idea behind that is that caring for less or doing less inappropriate levels of care through that assistance of personal care." (P3, R1, UK)

"There are brochures that are distributed at schools and I think also doctors, [...] by the carers' organisation and also by provider organisations. [...] There were some ads on the street and things like that" (P1, R1, Austria)

"...a lot of teachers wouldn't recognize young carers because they have never heard of them. There are support strategies: you can contact the youth welfare office, I think that's the English translation. But it doesn't have a good reputation in Germany and a lot of teachers, in my opinion, what I heard, a lot of teachers are hesitant to contact the youth welfare..." (P5, R1, Germany)

"[There are] organised events where young people can gather to share experiences with other young carers. So, it may be that some are done like every other week, for example, biweekly or some that may be more done sort of electronically [...]. (P2, R1, UK).

"Some children need to be... or families need to make sure that they have other forms of care so the children can be released from that care if it's unreasonable and inappropriate for the children to be taking those levels of care, in other cases, it might just be giving that emotional support to children who are in caring responsibilities and making sure they are coping and they can manage all of the other things that they want and should be doing in their lives around school and having fun and relationships and all that." (P6, R1, Belgium)

"I think one of the main issues too is simply in terms within country inequality in terms of what's available and how services are distributed." (P2, R1, UK)

Second Round (Reflection):

In general, most experts agreed with the information of round 1. In the information below, some specific comments mentioned in round 2 on (i) laws and regulations, and (ii) strategies, interventions and programs in educational sector, welfare sector and health care sector and best practices are presented.

"One of the few real outstanding instruments, but it is not about young carers but about carers in general, is this assessment of family carers in the UK. But I don't know how seriously this is done and how it's really implemented. Also with the caps that are ongoing. [...]. (P1, R2, Austria).

"What I found really striking, in the UK, the legislation does talk about the rights of the person with care needs and the young carer. And since it's sort of in that caring relationship, it's striking how that's missing in the strategies and interventions kind of part of the relationship. [...]. I think that was quite remarkable, really." (P3, R2, UK)

"I absolutely agree that there is at the moment, because of the lack of intervention and some services and support, probably children are taking on a burden that is beyond what they should be doing. But then the intervention is not to say you shouldn't be caring at all, the intervention is to say what do you need in order to support you in the best possible way." (P6, R2, Belgium)

Strategies, interventions and programs

Laws and regulation:

First Round:

Description of law and regulation

The UK has specific legislation for carers; The Children and Family Act 2014 and The Care Act 2014.

Goals of law and regulation

The Children and Family Act 2014 and The Care Act 2014 include rights of young carers in the UK. Central is the carers assessment to assess the needs of carers, including adolescents, by local authorities. Needs of carers could for example be respite care to relieve the care responsibility of young carers. The Care Act also specifically focuses on the transition to adulthood of young carers.

"The Children and Families Act that which was 2014 but probably implemented in 2015, has the requirement on local authorities to identify young carers. [...] They have a responsibility to identify young carers, so that would be up to the age of 18 under that law. (P3, R1, UK)

"And then also the Care Act which was also [from] 2014 where it's supposed to do transition assessment of the young persons coming up to the 18, so as they are 17 [...] as they start becoming an adult under the law, to see what their needs will be going forward." (P3, R1, UK)

Strengths and weaknesses of law and regulation

Strengths of the acts in the UK and the carers assessment mentioned are that carers assessment can be performed by local authorities, but they can also contract other organisations to perform this, such as charities, to perform the assessment. Moreover, one expert points to the relative unique position of the UK with the assessments for carers.

"[The carers assessment] could be done by local authority in a lot of cases but they can also subcontract that out. So, in some cases, it might be voluntary sector doing assessments that the local authority is funding them to do." (P3, R1, UK)

"As far as I know, this is really relatively unique in the UK that you have this carers' assessment." (P1, R1, Austria).

A critical reflection concerning laws and regulation in the UK are that the level of financial resources available to first identify - and second to support - (A)YCs. Furthermore, not all young carers take the carers' assessment. An UK expert also stated that even if (A)YCs take the carers assessment, it is difficult to receive actual help. There is a role for schools and GPs to encourage (A)YCs to take the assessment and to help them access services.

"[...] In England [...] there's been lots of cuts for funding local authorities, massive, I mean millions. So, I think they are struggling to in practice implement a lot of things that are established by law. There is a carer's assessment which every carer is entitled to if they meet the criteria, and that does include children and young people and it's an assessment of their needs. [...] In practice, this is happening to very few people. (P3, R1, UK)

"There is now a requirement that doctors do assessments of the needs of the carer individually from the care recipient. So, a lot of young people you find are not aware of that but the charities will take on that role in terms of encouraging young people to have the assessments. And so, in terms of the assessment, I think one of the issues there is that, [...] there is a lot of cuts and so on and so that makes it very difficult." (P2, R1, UK)

Second Round (Reflection):

The unique feature, but also its critical elements, of carers assessment in the UK are underlined in the second round of the Delphi interviews. In addition, carers assessment is specifically mentioned as interesting interventions for other countries than the UK.

"There are very few services available out there so the carers' assessment may not be able to provide what the young person needs. So it's probably good to have an assessment but if you are encouraging them to take it, then you probably need to manage expectations that they may not be financially eligible, but they might just not be available for them." (P3, R2, UK)

This [carers assessment] is something we recommend in general for carers. So it's nothing really specific for children as carers but this needs to be a programme in general for carers and whether by this it will be possible to identify more or to better identify children as carers, I'm not even sure, but at least it could be. I think it's the only instrument that might bring us a bit further. And this is also an area for further research [...] of such programmes." (P1, R2, Austria).

While reflecting the results on law and regulations of the first round of the Delphi interviews, one expert discussed the level of visibility of organisations working on rights of young carers on an European level.

"I know there are organisations in place that like to do [...] look at legislative frameworks for young carers across Europe and internationally in fact. [...] I don't know whether they are [visible enough at this moment]. I don't know how you improve that visibility. (P2, R2, UK)

Educational sector

First Round:

Description of intervention in education

Support from school counsellors and teachers were mentioned by the experts. Furthermore, it was noted that organizations supporting young carers distribute information on the topic of caregiving, for example brochures, on schools. These organisations also provide support with managing care and school.

"There are brochures that are distributed at schools and I think also doctors, by the way, by the carers' organisation and also by provider organisations [...]. And they are also helping them with school. If they have difficulties at school, they are giving support with school." (P1, R1, Austria)

Goals of intervention in education

Support by school counsellors and more awareness among teachers may improve the mental health of young carers by reducing stress due to combining care with school. Another aim of interventions in education is to identify young carers.

"When it does happen, it [Support from school counsellors] is very helpful because although they [young carers] might not see the school counsellor, it might just be that their teachers are more aware of it and that just takes some sort of stress

off them which is going to help their mental wellbeing. So, I think that's a good thing about them. But school can be very stressful for lots of young people and if they've got all this other stuff going on in their life." (P3, R1, UK)

"If you are not picked up by social services or you don't go to a young carer's group, then maybe [contact with schools] is another way you can be picked up." (P3, R1, UK)

Strengths and weaknesses of intervention in education

More attention is being given to young carers and their challenges in schools according to some of the experts. A good student-teacher relation was reported as an important support strategy. Although schools are becoming more aware of the challenges young caregivers may face, an expert from the UK points to the differences in the level of awareness of caregivers between schools. High work loads of teachers and a shortage of school counsellors are mentioned as possible explanations.

"In terms of their mental health, I think they [schools] are trying to pick up and support young people in schools a lot more, in the state schools a lot more." (P3, R1, UK)

"...the student-teacher relationship is an important support strategy because if students feel recognized, feel able to talk openly in school or to share information with the teachers...if that doesn't work, the students find excuses for coming late, for having headaches and all these possible issues but if you can talk openly to your teachers, the students have like a pillar, a person to talk to..... the recognition and feeling you can talk or you can trust the school or the teachers is one of the most important factors" (P5, R1, Germany)

"I think it [support programs for young people in schools] is very patchy. So, in the area where I live in, it's actually quite good but I don't think that's the case everywhere. [...] Although I think people are becoming more aware about it, I think it's quite hit-or-miss. So, I guess a negative thing would be that it's quite difficult to access and it just might happen on having a sympathetic teacher who realizes what's going on. [...]. There are not many school counsellors, teachers are very stressed so I think, like I said, it's really a hit-or-miss." (P3, R1, UK)

Welfare sector:

First Round:

The experts reported on a number of interventions of in welfare which are presented below.

- Provision of information
 - Information flyers, brochures, website
 - Childrens' helplines
 - National information campaign

"There is a website [www.superhands.at] [...] where you can also find information on different diseases or what you might need to know in order to care. [...] What the disease is or what people might need to know or what children might need to know when they are young carers." (P1, R1, Austria)

"There are, of course, general hotlines for young people where they might turn to. [...] Where they can turn to but this is then general support [...]. Following the awareness campaign by the ministry, also these hotlines then try to get a bit more aware of this and to also address this group." (P1, R1, Austria)

"This campaign [awareness campaign by the government] is mainly information and brochures and something on the website. This was all starting from one study that investigated this topic. [...] It's mainly for young carers in this case." (P1, R1, Austria)

"They [Carers Trust and the Children Societies] provide information on their website for example group supports and contacts." (P2, R1, UK)

"There is also Carers UK [...], their business is looking at maybe all carers from all regions. So they will have interest to [ensure that] some information [is] available to them [carers] through their service, through their website or through their system for the young people." (P2, R1, UK)

- Group support for young caregivers
 - Peer groups
 - Organised network events (both offline and online)

"At times they [Carers Trust and Childrens Society] provide information on their website for example group supports and contacts. They also arrange networking facilities for young people's participation." (P2, R1, UK).

"There are peer groups where they invite young carers so that they can get to know each other and exchange experiences." (P1, R1, Austria).

"They [Carers Trust and the Children Societies] also arrange networking facilities for young people's participation." (P2, R1, UK)

- Mentoring/individual support

- Mentoring sessions with staff from welfare organisations
- One-to-one support

"[Carers Trust and the Children Societies] also offers mentoring as well in terms of support when the young people may have particular needs with regards to their caring roles." (P2, R1, UK)

"The Children's Society and Young Carers Association do the mentoring services which I think primarily are about access to services as well as active services, and [...] one-to-one support." (P2, R1, UK)

- Fun activities
 - Holiday activities

"They [Superhands] provide also services for example like respite care or holidays for children who are caring for their parents." (P1, R1, Austria)

"The Children's Society also runs [...] a three-day event for young carers every summer in the UK. [...] Young carers who come to the facility where they camp, where they stay at residencies and then they have activities over the weekend, a lot of which is outdoor activities". (P2, R1, UK)

- Carers' card

"We had an example in one of our meetings where there was a carers' card I think, I'm not sure if it was specific to young carers. But this card sort of identified someone as being a carer and therefore meant they didn't have to explain their situation in those settings, particularly in relation to benefits and for more so carers' support." (P2, R1, UK)

Goals of intervention in welfare sector

Goals of peer support/national network meetings mentioned are (i) providing relaxation and fun, (ii) sharing experiences/interact with other young caregivers in similar situations, (iii) providing information on care and support, (iv) enhancing coping strategies/empowerment of young carers, (v) (temporarily) relieve the care responsibility/offering respite, (vi) recognition for the care provision, and (vii) informing children on their rights.

"Using those peer groups as a kind of support networks to help children understand that they are not alone in the kind of responsibilities that they have and being able to do more work with children in terms of raising their awareness of what skills or qualities the kind of work that they are doing is bringing out in them, but also [...] recognizing that children and young people have rights. They have rights to have leisure time, they have rights to play, they have rights to education, they have rights to respond to the care giving, and how children can ensure that they can access those rights," (P6, R1, Belgium)

"Offering these kinds of peer supports and respite care and enabling children to talk to others who've been in similar roles is really, really empowering. And they are able then to move on in their lives and also use the experiences that they have had as a strength in their lives. whatever negative experiences children experience but it's about supporting those children to move on but also to build on their experience as building their own resilience to have good coping strategies. [...] Sometimes they are better equipped to deal with issues in adulthood because of the different challenges and traumas that they have experienced. If it is correctly handled and if they get the necessary support to work it through and talk about it and understand what's good, what's bad, why they can be angry, why they don't need to feel guilty and all those kinds of emotional work that needs to go on with kids to help them understand their experience." (P6, R1, Belgium)

"So it's [three-day event by Children's Society] a very fun thing. They also get mentored. Obviously, they are talking and sharing experiences with other young people. [...] I think it is positive that is related in terms of young people interacting and gaining support. I think that is assisting them get away from some of their responsibilities for a short period of time and I think that is very helpful." (P2, R1, UK)

"I think that's why the difference that they [Carers Trust network groups] do to society, that's a lot of work in mentorship and in terms of making sure that the young people have a say." (P2, R1, UK)

"I know some of our member [organisations] are doing which is more around bringing young cares together and offering them opportunities both to find respite, so taking time, weekends, away and not having those kinds of responsibilities but having fun." (P6, R1, Belgium)

"There is a website where you can find all this and where you can also find information on different diseases or what you might need to know in order to care." (P1, R1, Austria)

Strengths and weaknesses of intervention in welfare sector

Peer groups and networking events are valued highly by young carers. Experts mention the positive effects on mental health of young carers. Some experts also report the positive effects of (temporary) relieve of care responsibility. Moreover, it is discussed that peer groups might enable the application for other types of support such as welfare benefits or school programs.

"The carers I have been in contact with, young carers, have all spoken very highly of the networking event [three-day event by Children's Society]." (P2, R1, UK)

"Young carers groups, people find it very useful in terms of their mental health and wellbeing to talk to other people that are similar situation. [...] They get a break, they get to talk to people who kind of understand their situation. And another really good thing about it is they are often helped with many other things in their lives. So, they might help with

problems at school or they might help with financial problems, they might help them apply for welfare benefits. So, I think those are all really positive things, people find it very positive. [...]" (P3, R1, UK)

"I think that [three-day event by Children's Society] is assisting them get away from some of their responsibilities for a short period of time and I think that is very helpful." (P2, R1, UK)

"I think the thing that works really well are the network groups which are supported very well by Carers Trust. So, I think that's why the difference that they do to society, that's a lot of work in mentorship and in terms of making sure that the young people have a say." (P2, R1, UK)

Despite that peer groups are valued highly both by young carers and experts, one expert states that peer groups only are not enough for effective support for young carers. Another expert points to the weakness of support interventions typically only reaching the young carer and not his family. Related to this is that there are differences in the extent to which respite care can be arranged for the person cared for that enables young carers to actually participate in support activities, such as a weekend away. Moreover, regional differences in the availability of support services were mentioned. Furthermore, one expert pointed out that it is important to identify on where the child is to provide support and create awareness. Difficulties with the transfer to adulthood and continuation of support services are also a weakness of interventions in the welfare sector according to one expert.

"It's fantastic that they [young carers groups] are supporting the young carer but sometimes, more services are needed for the person they are caring for as well and I don't know if there would be a way of kind of mingling that up. I think a lot of young carers groups are quite good, [but] I don't think it's the whole picture [...] I know young carers groups are good at helping people access services but it probably needs to be just young carers group plus something else." (P3, R1, UK)

"And what you can do only is often just support the children in this situation at school. Because, with informal care services, you might not even reach the family or you might not be able to enter the household, these difficulties." (P1, R1, Austria)

"I think in terms of actually getting results and implementation, you need to focus on where the child is, so local, regional, national. Of course, on a broader regional, European, global level, it's good to have more general awareness, but actually you need us close to the child. So, the community, community services, the school, the school would be aware, maybe supporting children who are helping or who have difficult home environments because of care issues." (P4, R1, Ireland)

"I think that would be directed by the level of support [for the person they care for] that's available for them to take part in these activities, for example the weekend away. [...] So that's also something that I think is different depending on where you live and what resources are available." (P2, R1, UK)

"The degree to which young carers can maintain support and can be supported as it were in terms of maintaining support and transitioning when they are no longer perceived as being a young person. So when they reach age 21 or 25 or whatever it is, that programs are in place specifically targeting young people maybe having arrangements for those carers to transition into adult services." (P2, R2, UK)

Experts report increased financial possibilities to start peer groups for adolescents, but also point to the difficulties for the welfare sector to arrange support due to the way these organisations are financed and recent budget cuts.

'The carers' organisations, of course, are small and voluntary, they are working with volunteers and so they have, of course, not enough resources but they are active in this field also and are aware of it too.' (P1, R1, Austria)

"Lots of funding before went to the under 16-year-olds but this was changed. I think over the last few years is that they extended to like young adults. Regionally, the area I'm in, they've got good young adult carers groups situated within the local authority." (P3, R1, UK)

"So there is a lot of cuts and so on and so that makes it very difficult. And then in terms of what services are necessarily available, they are all necessarily." (P2, R1, UK)

Weaknesses of information campaigns mentioned are that it may increase awareness on the topic, but many organisations are not yet in contact with young carers. Furthermore, it was stated that awareness was probably only created for a short period of time.

"The problem [with awareness campaigns] is that they [organisations] might not yet be in contact with young carers because they might not be aware that there are services and they might not take them up, so this is a bit the problem." (P1, R1, Austria)

"Because it's such a small group, it's very difficult to really get an understanding for that because of course, if people then see it, I think they are for some moment touched but I think that the main thing here is going into prevention and identifying these types of situations". (P1, R1, Austria)

Two experts discussed the lack of evidence-based for support of young carers.

"There is also not so much evidence. There is a question also what is evident here is the evidence that the young carer survives or that young carers finish school." (P1, R1, Austria)

"I think that [whether programs have actual benefit] probably seems to be the case anecdotally but we don't actually know for sure. I think there has been very little research on this.. I mean, certainly talking to young carers and practitioners seems to be the case but we don't know systematically if it is". (P3, R2, UK)

Health care sector:

First Round:

Description of interventions in health care sector

One expert mentioned mental health services for young people funded by national health services in the UK.

"You [have] the CAMHS, Children and Adolescent Mental Health Services, so that's within the NHS." (P3, R1, UK)

"I guess, just going back to the national, there is things around young people's mental health, there has been adult strategies document for young people's mental health but they will specifically mention young carers as a vulnerable group. So, likely, any mental strategy for young people will certainly include young carers, possibly as a specific group." (P3, R1, UK)

Experts also discussed the care services for the care recipient as a means of support for young carers.

"I think there are care services [for the care recipient] available, there are day cares available, there is home help available [...]." (P1, R1, Austria)

"My main knowledge is around some of the things that were set out in terms of the national strategy in the Children and Family and Care Acts. That's is there is a sort of support for aspects of young people's lives and includes providing services for the person they care for as a means of supporting the carer." (P3, R1, UK)

Goals of interventions in health care sector

Experts state that a goal of providing care services for the care recipient will relieve the burden of caregiving of young caregivers by reducing care tasks by handing over to professional care.

"[...] We are in a situation where services are being cut back so, the extent to which if there are services available for the person being cared for, that can well mean that the young carer is spending less time providing care. So, I think that the extent to which generally services to be expended it would have a positive impact on all carers, particularly on the young carers giving." (P2, R1, UK)

"That is a national strategy [in the Children and Family and Care Acts] that, I guess, in terms of their health and wellbeing, the idea behind that is that caring for less or doing less inappropriate levels of care then through that assistance of personal cares." (P3, R1, UK)

Strengths and weaknesses of interventions in health care sector

A positive aspect of having (professional) care for the person the young carer is providing care for is that young carers are relieved from the care tasks which may positively affect their mental health. Furthermore, a strength of (general) mental health services for young people is that the support is valued by young carers that used these services. The expert adds that an advantage of mental health services is that they typically are designed specifically for young people.

"I think that to the extent to which generally services [for person being cared for] to be expanded it would have a positive impact on all carers, particularly on the young carers giving. (P2, R1, UK)

"They [young carers] actually do find that [CAMHS, Children and Adolescent Mental Health Services] very, very helpful to support their mental health. So that's the pro of that type. I don't think... in my opinion, it doesn't necessarily have to be support specifically for young carers, it's just being able to access it as young people. So, the pro is that it's very geared up for their age group." (P3, R1, UK)

Weaknesses of health care discussed were the unfamiliarity of care organisations with young people assisting their parents or brothers or sisters in the household. Also, one expert mentioned that young carers feel that they do not - or are not able to- fully take part in the communication and decision-making between the care recipient and the health care professionals. Furthermore, professionals sometimes assume that young carers will take up care tasks, without discussing the option of formal care services with the care recipient and young carers.

"I think there are care services [for the care recipient] available, there are day cares available, there is home help available [...], but of course they are not sufficiently prepared to face these situations and so perhaps something like a case management around the young carers, this might [help]." (P1, R1 Austria)

"And one of the things that we hear quite often is that young people, in relation to the person that they care for, may be excluded from any discussions around that person's needs, despite the fact that they are the one that are a large part responsible for looking after that person. So, they feel excluded from any discussions about the needs of the person that they care for. They also say that GPs may not... even in situations where they are included, may not speak to them directly and so they may... again, these people talk to the cared for person without regard for the role and responsibility that the young person has, so they find that very difficult. They find that their GP quite often may in some respect may

then do the opposite when they then rather than insisting on the person needing services, they may then see the young carer as a willing provider of the services and therefore may assume that the cared for person needs services from the young person who's there. So they feel slightly exploited in that sense.” (P2, R1, UK)

Best practices

Experts shared information on best practices of support for young carers.

“The Children’s Society runs [...] a three-day event for young carers every summer in the UK. I think it’s the largest one in the UK but I think there are others. [...] Young carers who come to the facility where they camp, [...] have activities over the weekend, a lot of which is outdoor activities [...]. So it’s a very fun thing. They also get mentored. Obviously, they are talking and sharing experiences with other young people. So that’s also very well received by young people. I think that’s positive in terms of young people interacting and gaining support. I think that’s assisting them get away from some of their responsibilities for a short period of time and I think that’s very helpful.” (P2, R1, UK)

“I hear most about concerning the charity Carers Trust that organised events where young people can gather to share experiences with other young carers. [...] I think in some respect, Carers Trust and Children’s Society are taking a lead. So I think organisations like Carers UK will often direct towards carers in the society. And Carers Trust itself will direct towards Children’s Society.” (P2, R1, UK)

“There are some specific organisations that are really focusing on them. One is for example [...] is a service by a service provider where they address especially young carers. One is called Superhands (www.superhands.at). They provide also services for example like respite care or holidays for children who are caring for their parents, usually, and gives tips on where to turn to for help and what other possibilities there are and for example also in [the process of] grieving.” (P1, R1, Austria).

Second Round (Reflection) on strategies, interventions and programs in educational sector, welfare sector and health care sector and best practices:

In general, experts agreed with the information presented in the section on interventions of the first round of the Delphi study. Experts emphasized the value of peer support and the need for flexibility in the school and long-term commitment of schools to the topic of caregiving.

“I think the only thing I would, like we spoke about last time is the extent to which the young carers are able to interact with other young people, I think that seems to help in terms of coping strategies.” (P3, R2, UK)

“[...] I am always surprised that schools are not flexible with young carers. So on the one hand you could say that a good school programme would allow flexibility in terms of missed classes and opportunities to write exams at different times and so on. But I think perhaps maybe in order to address some of the longer term needs and sort of to maintain awareness and to maintain support, it would be helpful for the schools to engage with the young carers on a regular basis in order to have a better handle on how they are managing their situation. (P2, R2, UK)

One expert stated that problems with financing welfare services for young carers have increased. Moreover, another expert mentioned the risk of children taking on a (too) large responsibility due to a lack of support services.

“I think in some respect, it’s gotten worse more recently as a result of cuts to local authorities in terms of the budgets. Some areas may have had support groups for young carers in the past but have now discontinued funding for those.” (P2, R2, UK)

“I absolutely agree that there is at the moment, because of the lack of intervention and some services and support, probably children are taking on a burden that is beyond what they should be doing. But then the intervention is not to say you shouldn’t be caring at all, the intervention is to say what do you need in order to support you in the best possible way.” (P6, R2, Belgium)

One expert responded to a finding of round 1 of the Delphi study (including all country results) that not all support programs are specifically designed for young carers, which could be a good thing as these programs may be sensitive to problems with other aspects of young carers’ lives than caring alone, but may also not be sensitive enough to the specific needs of young caregivers.

“There is a point on the strategies where it says that sometimes programs don’t always aim for young carers in particular. I think that’s quite an important point because there are specific needs but also most young carers don’t just have one need. And so programs that are not specifically for young carers may have the advantage of picking up multiple needs and they may avoid some of the social visibility and self-identification problems. On the other hand, they may not be specific enough. So, I think that’s not necessarily a disadvantage that it doesn’t aim for young carers in particular. But you’d have to be quite careful about such to try meet both the specific needs and the more general needs.” (P3, R2, UK)

A critical remark was also given on the type of available support in the light of the legislative framework in the UK with its emphasis on both the young carer and the care recipient, while this care relationship is typically not specifically addressed in interventions for young carers.

“What I found really striking, in the UK, the legislation does talk about the rights of the person with care needs and the young carer. And since it’s sort of in that caring relationship, it’s striking how that’s missing in the strategies and interventions kind of part of the relationship. [...]. I think that was quite remarkable, really.” (P3, R2, UK)

Future needs to support the well-being and health situation of (A)YCs

Main findings

First Round

In Europe (including the UK), support programs need to be sensitive to the individual situation of carers and aim to (i) raise awareness and early identify young carers, (ii) improve skills and provide emotional support to move on and strengthen resilience-also early on in the care process (prevention and gatekeeping), (iii) provide support for the person that is being cared for, (iv) ensure that children are aware of and can access their rights, and (v), reduce stigma about mental illnesses and increasing the reputation of care (in Germany). In many countries, including the UK, there should be less inequality within countries in the level and distribution of support for (A)YCs. Involvement of different stakeholders, including young people, but also schools and the neighbourhood, is addressed. More funding is needed to better support (A)YCs and it is important to broaden the scope in respect to age, raise awareness, gather more data and improve systems.

"It will be necessary to help [...] the family, you have to help the person in need of care, you might also have to help the carer, especially to help the carer to help himself or herself, and probably even surroundings, there might also be the wider family. So, it's a bit complex and even in an ideal world, difficult to imagine perfect help because it needs to be adapted to the individual situation."(P1, R1, Austria)

"Education is a big issue for them [young carers]. So I think the education support on one-to-one basis would be very good. I think recognition from the school in terms of flexibility, in terms of the time." (P2, R1, UK)

"So, if you can focus on the gatekeeping that should be in place to a child having these unreasonable and unacceptable demands being put on them, that would be fantastic. And then you know in many countries, there are networks of civil society organizations working on rights of the child. I am not sure all of them currently include the focus on young carers, but they should do as well." (P4, R1, Ireland)

"One thing is of course for example discharge management in hospitals, this should be one bullet point or one something to tick where the discharge manager has a look at the family situation, might be one. Then also to get in contact with the local care professionals. And then, pharmacies have also strategies for dementia friendly neighbourhoods or cities or now even countries. That you train hairdressers and people at the supermarket to be aware of this. But here, dementia is one thing young carers, I think it's more difficult."(P1, R1, Austria)

"I would consider it really important that even if you said in your proposals you are focusing on 15 to 17, you just focus on children, meaning any human being below the age of 18, make it more rights-based. I'll send you an article also on child rights-based research, of which we don't have very much. So, first of all, that would be very important. One, to raise awareness on the scale and extent of the issue. And then... so, more data will help. Secondly, as we already discussed, beware of only looking at the resilience of the child. I think 80 percent of the effort needs to be on improving systems. If we talk about a child rights-based approach, the definition is looking to realize all the rights of the child by increasing the capacity of the duty bearers with respect to those rights and increasing the capacity of children to claim their rights." (P4, R1, Ireland)

"coming to a point to where mental illness is not a stigma anymore or is nothing special anymore people need to be ashamed of. Because for the young carers, of course, there are a lot of young carers who are carrying a burden which lead to problems in development and especially education... raising the reputation of care would lead to support everyone who cares. And then young carers or young adult carers would be a group within the caring family." (P5, R1, Germany)

Second Round (Reflection):

In round 2, we also discussed the ideal situation for young carers. Most of this discussion had a large overlap with the findings of round 1. In round 2, experts also addressed new topics such as the need to focus on transfer to adulthood, the risk of a lack of parenting due to the illness of a parent, and the question whether specific legislation for young carers is needed and the importance of respecting the autonomy of children. One new intervention was mentioned; an mobile app for carers. Some experts underlined the importance of some findings, such as the whole family approach and the need for flexibility in offering support to different types of young carers. Furthermore, experts reflected on the importance of some unique interventions, such as the assessment of carers.

"I think an ideal situation would be one where they have access to information and support, be it in terms of financial support or be it in terms of advice or information or services for the person they care for. And that support perhaps allows them to have more input into how to improve the situation but then also then also looks at the holistic wellbeing and allows them to progress in the ways that they would like to progress in their lives, individual lives. And one in which people have an opportunity to express to their peers and to other young people and to wider society about the roles that they have and what's involved in them for them as young carers. And certainly, one situation in which young carers feel supported particularly in education over the long term. But I think all of that is good but does probably require more funding and the resources remain unavailable either within an existing system but perhaps money to support young carers. And maybe the way to do that is to look at longer term outcomes and sort of make that argument from a sort of cost-effectiveness perspective."(P2, R2, UK)

“For me that is all about the professional aspect of the professionals engaged in supporting those interventions. The skills of professionals to be caring about children, listening to what children need and having access to the support. The practical financial, emotional, whatever is needed to intervene in the most appropriate way on the basis of what the young person and his or her family require. It’s about investing in good quality professionals who are empowered to listen to children and adapt their intervention according to what children and families articulate as their most pressing need.” (P6, R2, Belgium)

“I think someone I recall speaking to mentioned an ICT app in terms of a way of sharing information about health and social services and other programmes. I think those are positive ideas.” (P2, R2, UK)

“One of the few real outstanding instruments, but it is not about young carers but about carers in general, is this assessment of family carers in the UK.” (P1, R2, Austria)

“Any strategy shouldn’t necessarily focus on only the young people providing a high number of hours but should also consider the impacts on children who may be less visible because they are not providing a high number of hours or less visible because they are of a younger age.” (P2, R2, UK)

“I think the whole family approach is a good idea. I think then you get more a sense of what level of responsibility the child may have in terms provision of care.” (P2, R2, UK)

“I find whole-family approach very important and again to get stakeholders involved and again, I guess professional expertise to know the possible stakeholders to be involved on a round table for example...” (P5, R2, Germany)

“I would perhaps not have said there was a need for legislations specific for the group of young carers, I don’t know [...] whether there is a need for specific legislation. That surprises me somewhat [...]. I don’t think it’s appropriate to be developing legislation according to every particular group of children in vulnerable situations. Awareness raising and professional training, more of joined-up thinking in professionals, absolutely.” (P6, R2, Belgium)

Future needs to support well-being / health situation

First Round:

More awareness on the topic of young caregiving is needed to improve the support of young carers. Furthermore, the importance of early identification of young carers is addressed. The crucial role of professionals in health care and the (social) network of families in identifying young carers is stated. In addition, the expert from Germany stress to reduce stigma on mental illnesses, provide practical and emotional support in school and after school to university to reduce the care burden.

“Supporting these [young carers] children and of course of at most importance, the question is how you can find different ways to relieve them from this situation. I think a good thing is that there is growing awareness. I think that we still don’t have any solutions for this.” (P1, R1, Austria)

“The main thing here is going into prevention and identifying these types of situations from the [start]. Probably it starts from the health system where people might still have contact to the formal care system in health care. But then the question is whether doctors, nurses or other hospital staff are aware of the family situation, take this into consideration. There is also social work in hospitals that might be one way to get in contact because I think it’s very important to have, as soon as possible, some link to the formal care system. Because the English, if you have a carers’ assessment, this family or these persons are only in contact with the formal care system and as long as they are not there, it’s difficult. So you need to find preventative measures at all levels on how to identify this group.” (P1, R1, Austria)

“Also including pharmacies where if you develop some awareness, if there is a child that is for the nth time buying diapers or other things, care-related things, the question is, as a pharmacist, will you be able to get into contact with this person and so on. So, it’s easy but I think it might be necessary in the neighbourhood and with the relevant professions to build up kind of a network.”(P1, R1, Austria)

“...the first is to reduce stigma about illness and disability. I think it’s always coming back to this point because I think it’s the most important point. But being practical in school, it has to be of course in the curricular of schools, talking about illness and disability and caring. But then it will only be like a short part within their education. So, I think raising awareness could be a possibility. But being realistic, this could be of course difficult because there are a lot of issues in school and if you want in every school awareness days about issues” (P5, R1, Germany)

Furthermore, the importance of prevention is stated, also underlying the possible risks and associated costs for society at large of not identifying and offering effective support to young carers.

“I think part of it is raising awareness of the importance. I also think some of these kinds of interventions are not the most expensive, so that needs more raising awareness of what the costs are when you don’t offer these types of support early when children having this experience. [...] Because once you are dealing with the consequences of the mental health breakdowns, what I have heard from the burden that some of these children are carrying from quite a young age, unless they get that support, it will manifest itself in all kinds of mental, physical, psychological issues and most likely could be very costly to deal with in the public health system and criminal justice system and all kinds of areas where the cost is much greater. [...] I think there is, in some countries, much greater awareness of mental health, and the cost of poor mental health. So, I think framing the kinds of interventions as means of preventing poor mental health later down the line, there could be more political guidance. (P6, R1, Belgium)

“There is a role in terms of what we do in terms of resources that recognises the large impact young people [...] for health and situational outcomes and that they may have on the society as a whole in the future. So that they may think about the financial constant so that they may make a great argument [...] earlier to alleviate some of the longer-term costs that may be associated with as a result of being a young carer.” (P2, R1, UK)

Experts state the importance of offering support services after young carers are identified.

“To make them [young carers] understand [...] that there is help but then there should also be help of course because this is also frustrating if you identify young carers and then you cannot really support them. [...] once you have identified young carers, there should be action plans.” (P1, R1, Austria)

An expert also specifically addressed to look at similar cases of young adults with for example parents in prison and learn from these cases.

“I was thinking maybe to look at similar issues that weren’t much discussed. And I’ll give you an example of children of parents in prison who experience lots of difficulties, they may also be stigmatized. Where they wouldn’t have had a lot of visibility, a of support, maybe no support, no understanding from the justice system either.” (P4, R1, Ireland)

It is discussed that (A)YCs have different needs (not all children or care situations are alike), implying that the support needed will depend on the individual circumstances. Co-design of support interventions is stressed by one expert.

“I think involvement of young carers in terms of making sure that it’s designed in a way that they see as being helpful. I think they are actually flexible so I think a lot of young carers have different needs depending on their own situation and the situation of the person that they care for.” (P2, R1, UK)

“The level of need varies also in young carers [...]. So, there are those who life is really put on hold while they are caring which, obviously, is unacceptable for the child and needs to get intervention from services that are able to enable that child to continue with their own life, with their own studies, with their own relationships, with their own interests. There are others where it might be a few hours per week and it’s manageable and that’s all.” (P6, R1, Belgium)

“It’s also about enabling that child to feel good about what they are doing, how they manage that, maybe the frustration, the anger when they are not able to do the things that other kids are doing during that time. And providing kind of peer group support to also help children and young people understand that they are positives, there are also many, many, many negatives but if it’s something that the child and the family need and get value from, then it’s not always appropriate to say that the child shouldn’t be having any caring responsibilities. Sometimes the child is able to gain self esteem and gain some value from that work. But it really depends on the individual circumstances.” (P6, R1, Belgium)

Experts mention that a mentoring/individual approach focusing on challenges in the care situations, but also other challenges in life, would be beneficial to young carers.

“I think the mentoring approach is very good [...]. It is a model where they can help different young carers access different type of services, [...] they could be education, they could be care related, they can be social care related and some of them can help guide them in terms of what they may need and where they may find it in the community. I think that would be very good. And I think doing that in a one-to-one basis is very good [...].” (P2, R1, UK)

“I think a lot of young carers have multiple kinds of things going on so it’s not just counselling they need. Maybe they need help getting welfare benefits or other sorts of support.” (P3, R1, UK)

Experts address that it is important to aim for a whole family approach, where not only the needs of young carers are assessed, but also from their family.

“[It is important] that there is professional support to the family [...]. The question is how far you can convince the whole family to participate in such programs [...]. This is a general challenge of social work in general, how to deal with families in difficult situations and the care thing might often be only one, I mentioned. So there is the young carer, there might be one or two parents, there might be brothers and sisters, I don’t know, it might be a very complex situations where professional support in terms of social work is provided.” (P1, R1, Austria)

Expert advice to involve stakeholders, such as health care professionals, social work, schools, in developing and offering support services. In specific, a case manager is suggested for complex care situations. Within the specific context of schools, it is proposed by experts to have one person that is specialized in challenges of caregiving working in the school.

“I would like to see some sort of dedicated, more – it used to be the case – but sort of more dedicated personal support staff.” (P3, R1, UK)

“So in the beginning [after identification of young carers] you might in any case expand care, professional community care services that are also working in an outreach.” (P1, R1, Austria)

“At least in sufficiently complex situation, a case management approach would be needed. [...] That there is one case manager or contact person for example for the young carer and the user and the client and that then a care package is organised around this situation. [...] This is already taking place in care for older people in general with older carers, with younger carers, the case manager would of course then add perhaps also other services like support at school or a social worker or whatever is needed. But it might be important to have one trustworthy person or one person that has a trustworthy relationship with the young carer and the person in need of care to develop services.” (P1, R1, Austria)

"I think the difficulties they [young carers] have in school, I think of how engaged in school matters as well in terms of identification and maybe one-to-one support or somehow involving the network of stakeholders in terms of education to be on board and to have someone to act as an advocate within the school for young carers as well." (P2, R1, UK)

"More school counsellors or [...] a general support worker [...]. And, you know, just somebody that's kind of got maybe less or no teaching responsibility whose role is these sorts of things [supporting young people]." (P3, R1, UK)

"The Children's Society and Young Carers Association do [...] the mentoring services which I think primarily are about access to services as well as active services. But I think potentially there [...] is a role where they could like to have some educational support. I think that would be, from my experience with young carers, they would welcome that change to have, whether they are struggle or not with school, in terms of the time. Towards support in that area it could be very beneficial to them. I'm not 100 percent sure whether that is included in the emergency services that are provided by the charity but they do have one-to-one support. So ideally, that would include some aspects of support as well." (P2, R1, UK)

Second Round (Reflection):

Experts questioned the need for specific legislation, which was mentioned as one of the results in round 1.

"I would also say it's the more general support for carers would be in the first place and all the other things should be into it because most countries signed the Children's Rights Charter and things like that, so this up to really youth policy in general. So I would not see a reason for a specific legislation for young carers". (P1, R2, Austria)

"I guess legislation could mean they address the inequalities within countries but I suppose it's difficult, I think, to legislate behaviour as it were." (P2, R2, UK)

"There is a need for legislations specifically for young carers'. I think this is quite a problematic, [...] they also have multiple needs and I think if you start compartmentalizing like specifically for young carers, you might miss other needs. But even more to the point, I think as young carers change age groups, as carers change age groups, very specific legislation, they often kind of get the support they need but then get to the next age group and go through the whole process again." (P3, R2, UK)

New interventions were addressed by a couple of experts: a mobile app for carers.

"I think they [ICT app] are still in development at the moment, at least one that I'm aware of in the UK that's targeted at carers more generally. And that obviously will have benefits to the young carers as well. So I think that's an effective and perhaps innovative way of trying to get information to people and particularly young people." (P2, R2, UK)

One expert stressed the importance of the need to focus on the transfer to adulthood and the possibility to use support services among young carers.

"I suppose what we haven't really spoken about is also the degree to which young carers can maintain support and can be supported as it were in terms of maintaining support and transitioning when they are no longer perceived as being a young person. So when they reach age 21 or 25 or whatever it is, that programs are in place specifically targeting young people maybe having arrangements for those carers to transition into adult services." (P2, R2, UK)

One expert commented on the finding of round 1 'to care about children not for children', and emphasizing the importance of children's autonomy, and awareness that caring has positive effects, and finding the balance between positive and negative effects from caregiving.

"[...] We need to care more about children and ensure that children have access to the support and the understanding of their situation. But it's not that you are taking over the child's autonomy to make decisions themselves about the extent to which they feel capable or not of contributing to the care of somebody who is in their family who they love and they care for. And that I think is the way that we need to support and train professionals is being able to intervene, being able to offer support but not to take away the energy of the child to decide for themselves the extent to which they feel capable or not of offering care. And I absolutely agree that there is at the moment, because of the lack of intervention and some services and support, probably children are taking on a burden that is beyond what they should be doing. But then the intervention is not to say you shouldn't be caring at all, the intervention is to say what do you need in order to support you in the best possible way." (P6, R2, Belgium)

"I think the idea that children should be free from having a caring role but I think while I can see the thinking behind that, I think maybe it's a lofty goal which may be unrealistic. I think it's inevitable that children in families where an adult has a disability or maybe a sibling has a disability are likely to have some caring role. And a point, what we hear from young carers sometimes they actually derive some utility from that involvement. I think maybe having a goal of them being completely free of caring may not be realistic and not necessarily in their best interest. [...] I think feeling like they have more responsibilities than their peers and therefore that gives them more resilience and a greater sense of accomplishment in terms of managing the day to day and the responsibilities makes them maybe feel more adult in terms of the things that they have to do relative to their peers." (P2, R2, UK)

Experts agreed with the advice to focus on the whole family. Furthermore, one expert added to the discussion on the family-focused approach that it is important to address that there may be a lack of parenting due to illness of parents. Furthermore, the value of professional care for care recipients offering young carers some respite was underlined.

“The very important point on future needs is this thing which I think comes up quite a lot about the need to have a kind of whole system, whole family approach because there is more than one person involved in the caring relationship.” (P3, R2, UK)

“A whole family approach is [...] a very good approach. And this is a tricky one but obviously we know that the earlier you kind of get support, then the better. I think later on there is some things about how you might pick up these families quite early. And I think that’s really, really important. You can’t really optimize that if it comes in too late.” (P3, R2, UK)

“I think the need to focus on the parents because I suppose we talk a lot about the support that children are given to family member with a disability, particularly parents, and what that means in terms of what the child is giving up in terms of time and the added responsibility. But then we are also maybe less focused on the lack of parenting that they may then also receive because of a parent who is either reliant on the child or has other concerns is not sort of present in the way that most parents are.” (P2, R2, UK)

“I would want to add to think more broadly about care for the person they care for to sort of take care for the care task. Not just something short term because that’s probably better nursing, certainly. And quite useful, there probably needs to be a bit more than that. [...] Young carers often do want more services for the person they care for and they want something regular so a paid carer or someone similar to come in so that while they are at school, they don’t have to worry or they don’t have to miss school for sorts of things. And more mental health support for their parents.” (P3, R2, UK)

Experts reflected on the potential value, and need for research on its value, of the carers’ assessment and preventative screening in other countries. Experts also stressed the importance of learning from other sectors or countries.

“This [assessment of family carers] is something we recommend in general for carers. So it’s nothing really specific for children as carers but this needs to be a programme in general for carers and whether by this it will be possible to identify more or to better identify children as carers, I’m not even sure, but at least it could be. I think it’s the only instrument that might bring us a bit further. And this is also an area for further research [...] of such programmes.” (P1, R2, Austria)

“One thing is this learning from other situations. I don’t know anything about this parent in prison, whether there are programmes and what they are looking like. But of course, it might also be an interesting thing.” (P1, R2, Austria)

“I think there is some learning that could happen in similar situations but also learning that can happen across the countries, that would be good. [...]. I suppose in practical terms it’s learning at a professional level. So, I think what we do is very good, I think, engaging with people who have information in different countries. When I say academics, I think we do study things across countries and are aware of what’s going on in other countries. But I suppose I’m less aware of that being available to people on the ground as we are providing services so it’s about what mechanisms are in place to do that.” (P2, R2, UK)

“I like the suggestion about learning from sort of similar support systems, the children, the one they’ve mentioned is parents in prison. And there’s likely to be others like children of parents with mental ill health and things like that. I think it’s actually a very good idea that could work in a lot of countries [...] to look where there are other systems in place where there might be similarities.” (P3, R2, UK)

“It talks about the adverse childhood experiences screening. That sounds like one possible top tool. And also because it picks many different experiences, so it would pick up ...a tool like that seems like it could be a good strategy because it picks up not just early but also multiple needs.” (P3, R2, UK)

“I think there was an interesting point on the first point under Sweden which is identify fragile families at an early stage and provide support and that’s a really, really good point” (P3, R2, UK)

Experts missed information on the efforts being made for ‘long-term’ awareness on the topic of young caregiving.

“The sustainability issue is not really mentioned but of course, if you have an area or an issue where you are still in the original awareness raising phase, you might not always think about their sustainability, but perhaps you should also think of that right from the beginning [...], for example by including this in curricular and structure it or standardize it in counselling centres or this type of support facilities”. (P1, R2, Austria)

“What I have heard when I have had meetings with young carers is that they sometimes recognised and so there is an awareness there but then over time the school or the particular teachers then become less supportive. And so I suppose to the extent to which there is an ongoing discussion about how the child is managing the situation, so on the one hand you could say that a good programme, a good school programme would allow flexibility in terms of missed classes and opportunities to write exams at different times and so on. But I think perhaps maybe in order to address some of the longer term needs and sort of to maintain awareness and to maintain support, it would be helpful for the schools to engage with the young carers on a regular basis in order to have a better handle on how they are managing their situation.” (P2, R2, UK)

“I think it would be, first of all, about care in general to get this on the agenda and it should not be then a topic for one press conference about young carers but something that should be built in the long-term care system to avoid that children and youth have to care for their parents or even grandparents and if so, then they should be treated as carers with specific rights.” (P6, R2, Belgium)

"I think, from a legislative and funding standpoint, I think maybe there could be more analysis of the long-term effects on young carers, so maybe looking at the impacts for them and the impact for the wider society of them maybe of having ailments or being less productive in the labour market and so forth. Perhaps that would raise awareness and more so increase momentum as it were in terms of various support." (P2, R2, UK)

One expert reflected on the importance of recognizing that the heterogeneity among young carers, including young carers in designing interventions, and the need for flexibility in offering support. Others stressed the importance of not only focusing on needs of young carers due to caring, but also recognize the diversity in their needs.

"Young carers cover a number of different situations [...]. There may be high numbers but a number of them may not be particularly providing a large number of hours. So I think flexibility in terms of [...] how best to support different people depending on their particular needs I think is perhaps important." (P2, R2, UK)

"I think cocreation with young carers is important. My experience is that they have a good sense of how things can improve for them. [...] I think it's difficult because different individuals have different needs and therefore cocreation can result in a wide variety of ideas. But at the same time, that flexibility is needed." (P2, R2, UK)

"I think we have to be really careful not to kind of compartmentalize these young people either by age or by need. [...] The idea about screening on the adverse childhood experiences to include multiple needs, that seems like a really useful strategy. I don't necessarily disagree [with having just the young carers as a specific group], but I think that's not their only need [...]." (P3, R2, UK)

"I agree very much with the idea that support is needed, more support is needed but interventions should be developed in cocreation with the young people. Recognizing that this noticing children and listening to their needs is not necessarily everything what they say, it's also about listening more broadly to their situation and emotional needs." (P6, R2, Belgium)

One expert repeatedly reported on the media echo of a TV programme on carers in general and study on young carers and stressed the indirect importance of the programme and the study on the current discourse on caring and young carers.

"...in Germany there is a high media echo to TV programmes and I think I need to specify because there was a high media echo on carers in general and the media echo on young carers got higher due to one study" (P5, R2, Germany)

(A)YC needs

First Round:

Needs of (A)YCs formulated by experts were ability to access support services for young carers themselves, including respite care, more information on what services for young carers are available, and strategies to improve coping.

"I think getting children away for example at least for holidays or something from this situation might also be an important step." (P1, R1, Austria)

"I'd also like to flag child helplines. [...] Child Helpline International which are based in Amsterdam. There's something to be said for bringing them into the picture so they can better support children who might call the helpline in young caring situation." (P4, R2, Ireland)

"Definitely I would agree that you need support for the young carers themselves, what people think to find help for the sort of direct mental health support and support and understanding and education and then work." (P3, R1, UK)

"Young carers associations where you are offering these kinds of peer supports and respite care and enabling children to talk to others who've been in similar roles is really, really empowering. And they are able then to move on in their lives and also use the experiences that they have had as a strength in their lives. [...] Whatever negative experiences children experience but it's about supporting those children to move on but also to build on their experience as building their own resilience to have good coping strategies." (P6, R1, Belgium)

Noted by experts is the need for more recognition for the role of young carers, including awareness among peers, but also by schools.

"I think also one interesting thing I saw in terms of awareness is that I think the young carers also giving awareness amongst their peers who might not be carers. The carers may have an understanding of what they are experiencing. And they can also benefit which I feel is a really good... to the recognition of their responsibility and the recognition of their contribution. [...] I think that's something that is positive for them. So I think the recognition by their peers and by the service providers, probably in schools as well, I think that would be helpful for young people, young carers." (P2, R1, UK)

One expert also states that it is important to increase awareness among young carers of their rights as a child.

"Making children aware of their general rights is of course an important step. And also to make them understand that they are carers and that this does not mean that they have to give up themselves completely but that there is help [...]." (P1, R1, Austria)

Experts mention that more professional services for the care recipients are needed, with emphasis on the quality of care and more information on the availability of these services.

"I think we need better services for the person they care for. Would be top of my list. I think it's very, very varied so, it depends what their care need is. Obviously if it's like kind of a more physical disability, it's going to be around personal assistance and paid carers. [...] So, it could vary from things like paid carers or better mental health services, or help with addiction [...], not necessarily better but maybe more of and provided more promptly probably. I think that's probably very good it's just I'm not sure there's enough of that." (P3, R1, UK)

"Because their parents often have mental health problems and people don't take up or don't want to take up services that might be there and then young carers get into this situation. And so therefore I think it's very important to inform them about this availability. But even then, it might be difficult for them, how to convince your parent to take up services. I think this is a main dilemma in this situation." (P1, R1, Austria)

"[...] They [young carers] feel excluded from any discussions about the needs of the person that they care for. They also say that GPs may not... even in situations where they are included, may not speak to them directly [...]. But I think the main thing is about communication. So they enjoy that communication and the way that they are communicated to." (P2, R1, UK)

"Sometimes, more services are needed for the person they are caring for as well." (P3, R1, UK)

One expert specifically mentions the importance of access to financial support for young carers, being financial compensation for young carers, the care recipient or schools.

"I think a lot of young people that help their families don't have much money so there's issues around carers' allowance and there's hardly any adult welfare benefits like Universal Credit and disability allowance, disability benefits. [...] I think some of the rules around this are a bit complicated. So, some of those are household benefits, some would be directly for the young carer. So, I think the rules around it are a bit complicated so sometimes the eligibility criteria make it quite difficult to access." (P3, R1, UK)

"Back to schools. There's various groups of children for whom school will get the pupil premium which is a little bit of extra money and that means they are more able to find support. So it might be looked up to children, for example, fall under that category. I don't know if young carers do but it would mean a bit of extra money for the school if they identify young carers and therefore they can support them." (P3, R1, UK)

Second Round (Reflection):

One expert reflected on the need for information on the illness of a care recipient and the potential drawbacks of informing young carers.

"Children have the right to receive information about their parents' illness'. Obviously, I think it's important and I think it's something that young carers that I have spoken to in this country talk about, and particularly in terms of the lack of respect with regards to their role and therefore feeling like they don't shouldn't be involved. And we can understand why that would be the case in terms of not wanting to burden a young person with that type of responsibility but I suppose it's a catch point too because given their role and the responsibilities that they do have, I think it's just a question of verification and feeling like the judgments that are made around this are being done carefully." (P2, R2, UK)

One expert stated the risk of potential negative effects on the care recipients when young carers are not accurately supported.

"[...] Thinking about better outcome for the person that they care for as well. I suppose most young carers that I spoke to would also say that the person that they care for is disadvantaged as a result of the young person not feeling like they are being supported." (P2, R2, UK)

An expert stressed the difficulty of separating needs related to caregiving and other types of needs of young people.

"It is sometimes difficult to separate [...] the caring needs of adolescent or young carers and their other needs". (P3, R2, UK)

One expert pointed to the access of young carers to financial services and its potential conflict with other financial support a family receives.

"We need to kind of think about the eligibility rules for sure are quite complicated and conflict with other benefits and also the amount." (P3, R2, UK)

Professional and family needs

First Round:

Issues addressed are that schools need more funding and staff (especially student counsellors). Furthermore, professionals should have less individual care load, more guidance on how to deal with young carers, and more funding.

"Generally, there needs to be more funding for a lot of these things [support for young carers] because I think there are some good ideas and a lot of goodwill but it's difficult when you are very stretched with responsibilities and stuff and the kind of support you can actually provide." (P3, R1, UK)

"I guess that there's a lot of work that needs to happen in both helping adults in professional capacities who are in contact with children to be able to be aware of what to detect and there is also probably more investment that's needed

in different kinds of professions that can enable these children to get access to the necessary support that they need.” (P6, R1, Belgium)

Second Round (Reflection):

Discussed in Round 2 was also the importance of coordination in the support of young carers.

“I would say that coordination is also something that I find to be very important. Again, it’s dependent on the resources obviously but I think any time you have people in place, you can provide support but not necessarily have a specific task but have awareness of a number of different areas in which support may be required and have the contacts able to make those things easier to access. And then also the outlet for the people to express their frustrations and make sure that the people are supported. I think there is a role for some form care coordination. That’s also very flexible in terms of the needs of the people involved.” (P2, R2, UK)

Responsibility

First Round:

Experts mention different organizations responsible for identifying and support young carers, including schools, family, social work, health care, social network of families.

“I think this shared responsibility calls the whole range of professions. Ultimately, ideally, we want families and parents to be able to be advocates for their own children. But if that’s not possible and the parents have abdicated their responsibility for making sure their child has a proper childhood, then, yes, it’s most direct contact and there is also the need for the political level investment in community care services, in prioritizing these kinds of outreach supports for children and families that can work with children and families over time to identify jointly the solutions they are going to find to get children’s lives back on track.” (P6, R1, Belgium)

“In an ideal world, of course you would have neighbourhood integrated care teams or social workers that could address such situations. I think this needs to be tackled mainly on a local level because you need to know, what are the resources available around this situation and then in their respective setting.” (P1, R1, Austria)

“If possible and if on a local level where people know each other, which is always less the case, this might, of course, also neighbours or friends of course, but this is not always available and that’s not always appropriate, as I said. In that case you need professional guidance and support.” (P1, R1, Austria)

Second Round (Reflection):

In round 2, experts agree with the findings of round 1 that supporting young carers is a shared responsibility.

“[...] The need for collaboration between various stakeholders. So, the ones mentioned here are education, welfare, healthcare and local authorities. I think those two were really, really important points.” (P3, R1, UK)

“About responsibility, there needs to be a shared responsibility of family and parents as advocates for their child, which you put the word ideally which I think is the best word you can put in because this would be ideal but it seems difficult if on one hand parents do not recognise help or their child needs help, or on the other hand if they don’t want to get help.” (P5, R2, Germany)

“It’s all those involved, from local authorities to ministry and to the professional groups and in the end, also the neighbourhoods. So, depending on what but if we say at the moment the priority might be awareness raising and identification, then it’s quite a lot of stakeholders. I don’t know whether there could be one in the lead national level or at the different levels. There should be, of course, one. But it cannot be put on carers’ groups alone, so it should be taken up by the authorities at the different levels.” (P1, R2, Austria)

“...for example Switzerland, the whole society is responsible and there is a need for a cultural change, I think this is very important. Which is, again, like the cultural change, I would describe as reducing stigma, making illness and disability more visible and more normal within the culture. More flexibility is needed in school, yes. But then again, we come to the point talking about achievement” (P5, R2, Germany)

In Round 2, one expert adds that it may be difficult to create more awareness in the current system and that a new way of organizing support for young carers may be needed.

“If you build on existing infrastructure, you still need that awareness. [...] New organisational structures that specifically are aware of the issues and can respond to them specifically. And I think that perhaps would be helpful. I think an attempt to create opportunities and change things within the existing systems is difficult unless you have people who are really in touch with and are aware of the particular issues that relate to young carers.” (P2, R1, UK)

One expert adds a critical reflection on the role of the health care sector in supporting young carers.

“I think the healthcare is a bit underrepresented for the moment [to support wellbeing of young carers]”. (P1, R2, Austria)

The integral approach is also underlined in Round 2.

“I think the integral approach is a very helpful approach. I think it’s a very helpful way and I think maybe one of the ways in which young carers could get more support is by having ... I think we had an example in one of our meetings where

there was a carers' card I think, I'm not sure if it was specific to young carers. But this card sort of identified someone as being a carer and therefore meant they didn't have to explain their situation in those settings, particularly in relation to benefits and for more so carers' support. So I think that's very helpful, an integrated approach maybe allows that to happen." (P3, R2, UK)

Funding

First Round:

More funding is needed to support young carers, also in light of recent cut-back in the UK.

"But ultimately, I think a lot of it comes down to money and finances. So, I think one of the things that we see a lot is that [...] for any system to work, [...] that more funding is necessary. And that includes more funding for doctors because I think that will alleviate some of the burden on young carers." (P2, R1, UK)

"Generally, there's got to be more funding for a lot of these things because I think there's some good ideas and a lot of goodwill but it's difficult when you are very stretched with responsibilities and stuff and the kind of support you can actually provide." (P3, R1, UK)

"What young carers say is that when they do see a care professional, [...] they are certainly very willing and very engaged so I'm not sure it's individual care professionals, I think it's at a higher level because I think there is a lot of willingness among teachers, among care professionals, among carer posts, I don't think it's individual but I think it's commissioners or policy makers is possibly there. [...] I think there's questions to be asked about where that funding comes from and it's an ongoing discussion in this country how it's fund but that it's underfunded, that seems to be without doubt." (P3, R1, UK)

"It has to be public money and most likely it's public money from local authorities and regional authorities through social healthcare... we would be advocating for more investments in community-based child and family services, so kind of outreach centres with professionally trained psychologists, social workers, family support workers, community organisers who that level for outreach particularly in vulnerable communities. And ideally, these are through local authority funding. Now, I know that that's a big challenge because local authority money is usually coming from national governments and there's a lot of restrictions on funding." (P6, R1, Belgium)

More visibility of (A)YCs in society, for example by carers week, may also lead to more public funding.

"I think awareness of the society as a whole is important and maybe then, that may result to a deal of sympathy and that may then lead to more funding and in terms of studies, more money on providing services." (P2, R1, UK)

Second Round (Reflection):

In the second round the need for finances and the risk of not being able to offer services after identification of young carers are underlined.

"There is not enough funding for social care services and there is not enough funding for young carers' groups, there is not enough funding for the things that young carers would find useful so it's sort of we are having an assessment of needs that you need to have. If you identify a need, you need to be able to support it." (P3, R2, UK)

"I think all of that [support] is good but does probably require more funding and the resources remain unavailable either within an existing system but perhaps money to support young carers." (P2, R2, UK)

"[...] School and college does seem to be very important for young people, young carers. And to support that, then schools do need multiple counsellors or more funding, more dedicated staff." (P3, R2, UK)

Additional

First Round:

Mentioned by an expert is that it is also important to increase recognition of children's rights on a EU-level is needed and sharing information on what works with other EU countries.

"There can be awareness raising at the European level. And I think that we have [...] a role in bringing a greater replication of the Rights of the Child into EU policymaking. [...] There is, obviously, from our perspective or scope, an importance of bringing all of these issues to European level in terms of raising awareness and raising the bar in terms of expectations from the member states and the provisions and then looking at where it's already working well or better and then those places and see how that experience can be brought into other countries. [...] Europe's future depends on children growing up happy, healthy, confident, educated. That doesn't mean that all children never experience trauma, they do, but they need the support to integrate their life experiences and then build that into being more resilient or becoming more successful adults. And if they haven't had the necessary support, whatever those traumas and whatever that disadvantage they experienced in childhood, will undoubtedly have implications for mental health and autonomy capacity and everything else in adulthood. And supporting young carers is one part of that." (P6, R1, Belgium)

Experts note the difficulty of separating needs of (A)YCs from needs of children in general. It is questioned whether you need specific interventions for (A)YCs, because caring can be seen as one of many challenges in life.

"I don't think it makes sense to, I don't know, to install a service for young carers only. It can be of course you have a citation or website or projects for young carers but one service that only focuses on young carers would probably not be sufficient, it will always be necessary to combine different parts of services according to the situation." (P1, R1, Austria)

"We do need to have young carers associations because they always help the peer groups to connect to one another and have similar experiences. [...] For us it would be difficult to say if it is a specific issue of raising awareness to young carers or is it a specific awareness in that we are raising the need to give children and young people the support to cope with all the varied experiences and traumas that children will have, whether it be children who are in the child protection system or at risk of going into the child protection system, whether it be young carers, all the different circumstances." (P6, R1, Belgium)

Second Round (Reflection):

Two experts stated that it is a good thing not to problematize young caregivers, as mentioned by experts in the Netherlands.

'I like the Dutch comment, [...] not to problematize the group.' (P6, R2, Belgium)

"I was also thinking about the point for the Netherlands that young carers focus on their own strength and do not problematize the group and I thought yes, I totally agree with it." (P5, R2, Germany)

In addition, one expert stressed again in the second round that we need to focus on identifying system gaps and focus on prevention and another reported on the need of more visibility.

"...let children be children. In these strategies and interventions, there is too much focus on young carers instead of focusing on the system gaps for the lack personal assistance, say for people with disabilities or support for chronic illness or what about when you have a parent who has mental health issues...The best way to support them would be to limit what they have to do." (P4, R2, Ireland)

"Making young carers visible is one point which could be done in the whole Europe. I think this is the most important point which relates to all other points like support." (P5, R2, Germany)

Appendix 2: Search Terms for the Academic Literature Review Study

PubMed		
Search	Query	Items found
#69	(#59 OR #61)	576
#67	(#66 NOT #60)	734
#66	(#64 AND #65)	778
#65	"Young Adult"[Majr] OR "Child"[Majr:NoExp] OR "Adolescent"[Majr] OR puberty[majr] OR Schoolchild*[ti] OR school child*[ti] OR schoolage*[ti] OR school age*[ti] OR elementary school*[ti] OR primary school*[ti] OR grade school*[ti] OR kid[ti] OR kids[ti] OR boy*[ti] OR girl*[ti] OR prepube*[ti] OR pre-pube*[ti] OR preadolescen*[ti] OR pre-adolescen*[ti] OR junior school*[ti] OR junior high*[ti] OR middle school*[ti] OR tween*[ti] OR adolescen*[ti] OR teenage*[ti] OR teen[ti] OR teens[ti] OR youth[ti] OR youths[ti] OR underage*[ti] OR junior school*[ti] OR junior high*[ti] OR middle school*[ti] OR high school*[ti] OR highschool*[ti] OR senior high[ti] OR boy*[ti] OR girl*[ti] OR pube*[tw] OR young people*[ti] OR minors[ti] OR young adult*[ti] OR Schoolchild*[ot] OR school child*[ot] OR schoolage*[ot] OR school age*[ot] OR elementary school*[ot] OR primary school*[ot] OR grade school*[ot] OR kid[ot] OR kids[ot] OR boy*[ot] OR girl*[ot] OR prepube*[ot] OR pre-pube*[ot] OR preadolescen*[ot] OR pre-adolescen*[ot] OR junior school*[ot] OR junior high*[ot] OR middle school*[ot] OR tween*[ot] OR adolescen*[ot] OR teenage*[ot] OR teen[ot] OR teens[ot] OR youth[ot] OR youths[ot] OR underage*[ot] OR junior school*[ot] OR junior high*[ot] OR middle school*[ot] OR high school*[ot] OR highschool*[ot] OR senior high[ot] OR boy*[ot] OR girl*[ot] OR pube*[tw] OR young people*[ot] OR minors[ot] OR young adult*[ot]	342293
#64	"Caregivers"[Majr] OR Caregiver*[ti] OR Carers[ti] OR Carer[ti] OR Care Giver*[ti] OR Caregiver*[ot] OR Carers[ot] OR Carer[ot] OR Care Giver*[ot]	27496
#63	("Young Adult"[Mesh] OR "Child"[Mesh:NoExp] OR "Adolescent"[Mesh]) AND "Caregivers"[Mesh]	7625
#62	(#61 NOT #60)	7
#61	("Young Adult"[Majr] OR "Child"[Majr:NoExp] OR "Adolescent"[Majr]) AND "Caregivers"[Majr]	9
#60	young caregiver*[tiab] OR young carer*[tiab] OR young adult caregiver*[tiab] OR child caregiver*[tiab] OR child carer*[tiab] OR child care giver*[tiab] OR children caregiver*[tiab] OR school age caregiver*[tiab] OR sibling caregiver*[tiab] OR adolescent caregiver*[tiab] OR teen caregiver*[tiab] OR youth caregiver*[tiab] OR son caregiver*[tiab] OR daughter caregiver*[tiab] OR young informal carer*[tiab] OR parentif*[tiab]	569
#59	young caregiver*[tiab] OR young carer*[tiab] OR young adult caregiver*[tiab] OR child caregiver*[tiab] OR child carer*[tiab] OR child care giver*[tiab] OR children caregiver*[tiab] OR schoolage caregiver*[tiab] OR school age caregiver*[tiab] OR sibling caregiver*[tiab] OR adolescent caregiver*[tiab] OR teen caregiver*[tiab] OR youth caregiver*[tiab] OR son caregiver*[tiab] OR daughter caregiver*[tiab] OR young informal carer*[tiab] OR parentif*[tiab]	569

Embase

No.	Query	Results
#3	#1 OR #2	1877
#2	('young adult'/exp/mj OR 'child'/mj OR 'infant'/mj OR 'preschool child'/exp/mj OR 'school child'/exp/mj OR 'adolescent'/mj OR 'sibling'/exp/mj OR 'only child'/exp/mj) AND 'caregiver'/exp/mj	371

#1	((((infan* OR young* OR child* OR 'school age*' OR sibling* OR adolescen* OR teen OR teens OR youth OR son OR sons OR daughter* OR 'emerging adult*')) NEXT/3 (caregiv* OR carer* OR 'care giv*' OR 'caring role*' OR 'caring task*')):ti,kw) OR parentif*:ti,ab,kw OR 'early caregiv*':ti,ab,kw OR 'young caregiver*':ab OR 'young carer*':ab OR 'young adult caregiver*':ab OR 'child caregiver*':ab OR 'child carer*':ab OR 'child care giver*':ab OR 'children caregiver*':ab OR 'school age caregiver*':ab OR 'school aged caregiver*':ab OR 'sibling caregiver*':ab OR 'siblings caregiver*':ab OR 'adolescent caregiver*':ab OR 'teen caregiver*':ab OR 'teens caregiver*':ab OR 'youth caregiver*':ab OR 'son caregiver*':ab OR 'daughter caregiver*':ab OR 'young informal carer*':ab OR 'children as care*':ab OR 'child as care*':ab OR 'emerging adult care*':ab OR (((infan* OR young* OR child* OR 'school age*' OR sibling* OR adolescen* OR teen OR teens OR youth OR son OR sons OR daughter* OR 'emerging adult*')) NEXT/3 ('caring role*' OR 'caring task*')):ti,ab,kw)	1578
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Psychinfo

#	Query	Results
S3	S1 OR S2	2,174
S2	TI (parentif* OR "early caregiv*" OR "young caregiver*" OR "young carer*" OR "young adult caregiver*" OR "child caregiver*" OR "child carer*" OR "child care giver*" OR "children caregiver*" OR "school age caregiver*" OR "school aged caregiver*" OR "sibling caregiver*" OR "siblings caregiver*" OR "adolescent caregiver*" OR "teen caregiver*" OR "teens caregiver*" OR "youth caregiver*" OR "son caregiver*" OR "daughter caregiver*" OR "young informal carer*" OR "children as care*" OR "child as care*" OR "emerging adult care*" OR ((infan* OR young* OR child* OR "school age*" OR sibling* OR adolescen* OR teen OR teens OR youth OR son OR sons OR daughter* OR "emerging adult*")) N3 ("caring role*" OR "caring task*"))	776
S1	TI (((infan* OR young* OR child* OR "school age*" OR sibling* OR adolescen* OR teen OR teens OR youth OR son OR sons OR daughter* OR "emerging adult*")) N2 (caregiv* OR carer* OR "care giv*" OR "caring role*" OR "caring task*"))	1,714

Appendix 3: Exclusion criteria for the Academic literature review study

Table Exclusion criteria

Exclusion code	Explanation
First round ti/ab screening - include studies about young carers	
NRC	About the development and psychology of the child in general, with no ill family members.
NRIC	About the illness or a problem/deficiency of children themselves, how children or their parents cope with that.
NRMED	About developing treatments for the ill child in the field of medicine OR about dental health care.
NR>24	About older informal caregivers caring for their parents (E.g. studies discussing the topic of adult children, caring for their parents with dementia)
NRPP	About how (how healthy parents and caregivers parent their children, including situations of divorced parents)
NRSR	About healthy sibling relations.
NRINMO	Influence of YC tasks on motivation for profession
NRIMP	Too implicit about YC
SP	This is a study protocol, no outcome yet
NRTA	About the effects of technological assistance from healthcare for parents in remote areas
NRLE	About the longterm effects of role-reversal / parentification (E.g. studies discussing childhood adversities and risks for alcohol misuse)
NRYCG	About youth caregivers (parents and other caregivers)
NRRM	About research methodology not specifically in the field of young carers
NRGS	About grief studies (E.g. coping mechanisms for children who grief)
Second round ti/ab screening - include studies about interventions	
1. Descriptive	When the study only described situations of young carers (e.g. the influence of the caring situation on their mental health and well-being)
2. Comparative	When the study makes a comparison between children with and without an ill family member
3. Prevalence	When the study states numbers of prevalence of young carers
4. Questionnaires	When the study is about validating questionnaires
5. Non-Western	When the study is conducted in a non-western country (e.g. the impact of HIV/AIDS in Kenya)
Full text screening	
I. Descriptive	When the study only described situations of young carers (e.g. the influence of the caring situation on their mental health and well-being and the need for support) No intervention evaluated.
II. No full text	Abstract was submitted and published for a conference or other presentation



More information: www.me-we.eu
#youngcarers



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