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To cite this article: Agnes Leu, Elena Guggiari, Daniel Phelps, Lennart Magnusson, Henk Herman Nap, Renske Hoefman, Feylyn Lewis, Sara Santini, Marco Socci, Licia Boccaletti, Valentina Hlebec, Tatjana Rakar, Tjaša Hudobivnik & Elizabeth Hanson (2021): Cross-national Analysis of Legislation, Policy and Service Frameworks for Adolescent Young Carers in Europe, Journal of Youth Studies, DOI: [10.1080/13676261.2021.1948514](https://doi.org/10.1080/13676261.2021.1948514)

To link to this article: <https://doi.org/10.1080/13676261.2021.1948514>



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Published online: 14 Jul 2021.



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Cross-national Analysis of Legislation, Policy and Service Frameworks for Adolescent Young Carers in Europe

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ABSTRACT

Despite some national examinations of policy responses for young carers (YCs), this study provides a first comprehensive cross-national comparison of the different legislation, policy and service frameworks that exist to protect and support adolescent young carers (AYCs) in six European countries (Italy, Netherlands, Slovenia, Sweden, Switzerland and United Kingdom) and how these are enacted. Until now, research has focused on estimating numbers of AYCs and the impact of caring tasks. A preliminary examination of policy responses to YCs was followed by expert interviews. Case study analysis of 25 interviews and a cross-national synthesis were undertaken before incorporating feedback from former YCs. Different responses to YCs were found, ranging from protection and support in policy and legislation and a definition for YCs, to a total lack of recognition and support. Findings highlight the potential to extend existing legislation, policy and service frameworks to include AYCs, and the importance of recognising and raising awareness of YCs. Awareness should be raised at all levels of society for example with professionals in health, social and education sectors and the general public. A definition for YCs is needed, so AYCs can self-identify and AYCs should be recognised as an important target group for policy makers.

ARTICLE HISTORY

Received 24 September 2020
Accepted 22 2. Appendix added as supplemental material in CATS. Please add supplemental link on the first page June 2021

KEYWORDS

Young (adolescent) carers; transnational analysis; legislation; policy; expert interviews

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 Supplemental data for this article can be accessed at <https://doi.org/10.1080/13676261.2021.1948514>

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Introduction

Many young people across the world carry out a significant role in caring for an ill and/or disabled family member or significant other. 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 which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.' (Becker 2000, p. 378).

The caring tasks performed by YCs can include a variety of activities (e.g. Dearden and Becker 2004; Warren 2007), such as domestic tasks, household management, personal care, emotional care, sibling care, financial (Joseph et al. 2009; Leu et al. 2019; Stamatopoulos 2018). Becker, Aldridge, and Dearden (1998) proposed that children's caring roles can be classified as domestic, nursing, intimate and personal care, emotional care, household management, and child care. Becker (2007) suggested that caring tasks can be viewed in terms of a continuum ranging from caring *about* the person to caring *for* the person. *Caring about* includes activities that are conducted by most young people, such as helping with cleaning and tidying and carrying out basic domestic chores. In cases where there are difficulties, disability or illness within the family, the young person may increase their level of care by spending more time carrying out domestic chores and taking on intimate, specialised and medical care (Joseph et al. 2020). Research shows that the role of YCs is similar regardless of the country or continent (Nagl-Cupal et al. 2014) but that the detail of that role will be affected by local considerations or circumstances (Joseph et al. 2020).

Despite the lack of specific figures, this phenomenon of YCs and their caring roles have raised attention in many countries. Leu and Becker (2017) classified the awareness and responses to YCs in different countries, such as the United Kingdom (UK) (classified as being at an advanced level, with systematic policies and responses) as well as in Sweden, the Netherlands and Switzerland (at different degrees of development level) and Italy and Slovenia (at an initial stage of awareness). Being a young carer is a risk factor for impaired mental health, well-being and social exclusion (Aldridge and Becker 1999; Aldridge and Becker 2003; Ali, Krevers, and Skärsäter 2015). Research has highlighted that being a YC exacerbates health inequalities during the life-course (Becker and Becker 2008; Sempik and Becker 2014a; NHS England and Ipsos MORI 2017). YCs often experience the consequences of social exclusion, with higher absenteeism and drop-out rates than peers from education and low employability (Dearden and Becker 2004; Hounsell 2013; Kaiser and Schulze 2015; Moore, McArthur, and Morrow 2009; Audit Commission 2010; Sempik and Becker 2013; Sempik and Becker 2014b; Stamatopoulos 2018). YCs may also experience stigma, which in turn leads to secrecy and social withdrawal (Bolas et al. 2007) and they might struggle with bullying at school (Moore, McArthur, and Morrow 2009; Lloyd 2013). Further, failing to adequately support YCs has long-term negative consequences for society as a whole (Becker and Becker 2008).

Although many studies have focused on the negative impact of the caring role, positive effects on YCs have also been reported. Svanberg, Stott, and Spector (2010) emphasised

the increased resilience of young people caring for someone with dementia, and that only a few showed depressive symptoms. Cassidy, Giles, and McLaughlin (2014) also reported increased resilience in YCs where role demand is not overly excessive and is socially recognised. Joseph et al. (2020) highlighted results of studies affirming that caring may be associated with an increasing maturity (e.g. Fives et al. 2013). Furthermore, caring can lead to positive changes (e.g. Joseph, Becker, and Becker 2012), closer relationships with parents, feeling well prepared for life (e.g. Hunt, Levine, and Naiditch 2005), and the ability to foster qualities of compassion and empathy (e.g. Stamatopoulos 2018).

At least one study has explored how policies ‘formalise’ the role and status of informal carers in a subset of European countries, but this is in relation to adult carers (e.g. Zigante 2018). Research in relation to YCs has primarily focused on estimating the prevalence of YCs and exploring and documenting the outcomes and consequences of caring (e.g. Hunt, Levine, and Naiditch 2005; Leu et al. 2019; Leu and Becker 2019; Lloyd 2013; Lux, Eggert, and Suhlmann 2016; Nagl-Cupal et al. 2014; Stamatopoulos 2015a). However, there are still important research gaps, for example, it is not yet fully understood how caring is helpful to the development of a young person and in what circumstances it can be detrimental (Joseph et al. 2020). Although there has been some examination of policy in individual countries (e.g. Banks et al. 2002; Becker 2007; Cass et al. 2011; Kavanaugh et al. 2016; Stamatopoulos 2015b), there is a lack of studies that provide a *comprehensive transnational comparison of the different legal and policy frameworks* that apply to YCs and how they work in practice. As suggested by Joseph et al. (2020), the issue is quite controversial because, although some form of training and support for YCs can be helpful and should be available, providing support can suggest that it is acceptable for young people to provide such care in the first place. The authors therefore believe that, in making support available, policy development must carefully consider issues of confidentiality, privacy, choice and what are appropriate levels of caring.

The present study addresses this gap in research with respect to YCs and forms part of the overall project ‘Psychosocial support for promoting mental health and well-being among adolescent young carers (AYCs) in Europe’ (ME-WE), funded by the European Union (Horizon 2020) (Hanson et al. 2018). The project aimed to exploit the complementary expertise and longstanding experience of a Eurocarers consortium – a non-profit organisation that advocates for the rights of carers, including YCs and AYCs, across Europe. These research and carers organisations (Eurocarers members) were either active or particularly interested in the field of YCs/AYCs, had existing synergies and the strong networks of Eurocarers and the consortium partners would enable strong connections with – and broad impact on – a variety of stakeholders, as well as support the participation of AYC’s. The study offers, for the first time, a transnational analysis of legislation, policy and service frameworks for younger carers and examines the ‘gap’ between legal provision and its actual implementation. The study is intended to support the development of evidence-based policy and practice responses to the needs of YCs and their families in Europe and beyond.

Methods

The main goal of the study was to analyse the development and implementation of policies, legislation and service frameworks addressing AYCs, i.e. YCs aged between 15 and 17, in six

countries: Italy (IT), Netherlands (NL), Slovenia (SI), Sweden (SE), Switzerland (CH) and the United Kingdom (UK). As well as the practical and strategic benefits of the collaboration as discussed, countries were selected as they complemented each other in terms of geographical coverage of Europe and represented diverse stages of development of awareness on AYC's, focus on research, service models and policy responses for young people and AYC's (Becker 2007; Leu and Becker 2017). Furthermore, the ME-WE project would benefit from working on clusters of these countries defined by their stages of development of awareness of AYC's to maximise the potential mutual learning and exchange within the consortium. The research aimed to explore how policies/legislation/service frameworks are enacted in the 'real' world, their strengths and limitations and what has driven their development. Although the goal of the overall ME-WE project was focused on AYC's, it was necessary to understand the broader picture and therefore explore legislation and policy frameworks relevant to YCs of all ages. Coordinated by the Swiss research team in collaboration with their five country partners, a case study approach was adopted. The main activities consisted of a preliminary examination of the different countries' policy responses to the issue of YCs, together with expert interviews, a country case study analysis and cross-national synthesis. Former YCs were involved in the process by providing feedback on some parts of the country case studies pertaining to their own country.

Preliminary examination

A preliminary examination of the different policy responses to the issue of YCs within the six countries was conducted using a systematic Google search and search terms and examining the websites and publications of universities, government and non-governmental organisations (NGOs). Inclusion criteria included: (1) legal provisions on a national, regional and local level and policy and service frameworks that provide protection and support for YC and their families; and (2) specific and non-specific legal provisions and policy frameworks that benefit YCs of all ages. Exclusion criteria were: (1) practice guidelines; (2) advice and resources for supporting YCs; and (3) other literature focusing on topics such as impact of caring on health, well-being and education. A secondary aim of the preliminary examination was to identify academics and professionals working in the field of YCs or related fields, who could participate in the expert interviews.

Expert interviews

The aims of the expert interviews were to explore what legal provisions and other policy frameworks exist in the six European countries that provide support and protection for YCs and how they are enacted in the real world. Interviews also aimed to explore how legislation defines and constructs YCs, the strengths and limitations of legislation and policy frameworks, how changes in legislation and policy were achieved, the attitudes of experts towards existing legislation and policy frameworks and their hopes and goals for the future. Based on the results of the preliminary examination (background information about individuals) along with knowledge of country partners, a priority list of policy and legal experts was developed. 25 expert interviews were conducted (four in each country, five in the UK – see Appendix A). In two cases the interviews were conducted with two interviewees simultaneously. Questions for the interview guidelines were

initially based on the classification of in-country awareness and policy responses to YCs (Leu and Becker 2017), and then adjusted to the specific aims of the study (see Appendix B). Interviews were carried out between May and September 2018 by researchers from the respective partner countries, either by telephone, video-conferencing or in person. Interviews were conducted either in English or in the country partners' native language, lasted an average of one hour and with participants' permission were recorded, transcribed and pseudonymised (then translated into English if necessary for analysis).

Case study analysis

Twenty categories (e.g. 'specific legislation', 'non-specific legislation', 'future goals and hopes') were developed primarily from the interview guidelines, with some being developed inductively from the interview data (see Appendix C). A thematic analysis was undertaken by coding interview segments according to these categories and storing them in a Microsoft Access database at the first author's university. Each text segment was also coded in relation to the level it related to (national, regional or local level) and its origin (country and interviewee number, or preliminary research). The countries within the UK (i.e. England, Wales, Scotland and Northern Ireland) were studied separately due to their different legislation, policy and service frameworks specifically addressing AYC's and the different enactment of legislation and policies. Case studies were then developed for each country by analysing and summarising the text segments for each category. Where necessary, information was cross-checked with the original data from the preliminary examination or with an internet search. First drafts of the country-specific case studies were sent to the expert interviewees and country partners for validation of specific details and general feedback before final versions were developed.

Cross-national synthesis

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

YCs' participation in the research process

About 9 young adult carers and former YCs (aged between 18 and 25) in the six countries under analysis were recruited through country stakeholders and through the Eurocarers Young Carers Working Group. They were presented with selected sections from the draft case studies and responding to focussed questions on a structured written template, they shared their opinions on the future goals and hopes of experts with regards to the situation of YCs and on the enactment of legislation, policy and service frameworks within their own countries.

Ethical approval and consent to participate

A jurisdictional enquiry was submitted to the Cantonal Ethics Committee in Zurich and clarification was received stating that the research project did not fall within the scope

of the Human Research Act and as such, authorisation was not required (BASEC Request-No. Req-2018-00270). The study was conducted in compliance with the established ethical guidelines of the Declaration of Helsinki (World Medical Association 2013). Informed consent was received from all participants who were informed of their right to withdraw at any time without any repercussions. Principles of confidentiality were upheld.

Results

Experts discussed legislation that was both specific to YCs and non-specific, yet could impact YCs. Legislation that was classified as 'specific' included explicit recognition of and/or a definition of young people with caring responsibilities. 'Non-specific' legislation related to legislation that lacks any specific recognition or definition of YCs but nevertheless has the potential to protect and support children with caring responsibilities.

Specific legislation

Only the four countries in the *United Kingdom* (England, Wales, Scotland and Northern Ireland) make specific reference to or specifically recognise children's caring roles within their legislations. Both England and Scotland define YCs whereas in Wales, children with caring responsibilities are included within the general definition for a carer. Within The Children (Northern Ireland) Order 1995¹, there is a duty to carry out an assessment where 'a child ('the carer') provides or intends to provide a substantial amount of care on a regular basis for a person aged 18 years or over'. Despite the explicit recognition of and/or definition of children who have caring responsibilities, the provisions in legislation related to YCs in England, Wales and Northern Ireland are themselves contained within broader legislation for children and families. Only in Scotland does legislation for YCs sit within legislation that is specific to carers (Carers (Scotland) Act 2016).² Here, there is a duty to prepare a 'young carer statement' for YCs which sets out their identified personal outcomes, any needs they may have and the support for them (if any) to be provided by the local authority. In England, provisions for YCs fall within the Care Act 2014³ and the Children Act 1989⁴ (amended by the Children and Families Act 2014⁵) which work together in order to bring about a preventative and 'whole family approach' to identification, assessment and support. Similarly in Wales, the Social Services and Well-being (Wales) Act 2014⁶ provides the legal framework for improving the well-being of people who need care and support.

The legislation in *Sweden* could be viewed as falling somewhere between the specific and non-specific divide. There is no specific reference or provision for children with caring responsibilities within the Healthcare Act (2017)⁷ or the Patient Safety Act (2010).⁸ However, children with parents who have a mental disorder or disability, a serious physical illness or injury, or are addicted to alcohol or other addictive agents, or unexpectedly die, so called 'children as next of kin', are explicitly recognised within the Healthcare Act (2017) as being a group of children who should be particularly taken into account. Further, it is recognised that some within this group of children are likely to have caring responsibilities.

In the other countries (Switzerland, Italy, the Netherlands and Slovenia), recognition of the needs of children with caring responsibilities, and support for them and their families,

is reliant upon 'non-specific legislation' related to education; health and social care; children, youth and families; carers in general; child safeguarding and protection (see Appendix D).

Non-specific legislation with the potential to support AYC's

The analysis of 'non-specific' legislation considers whether countries have legislation in place that, despite not being specific to YCs, could nevertheless be used to support or protect this group. Non-specific legislation that either already supports children with caring responsibilities or has the potential to do so is found within all six countries. However, the support and protection established stems from diverse legislative frameworks that act in different ways, including: (1) supporting and protecting children or adults with care and support needs (Health and social care legislation); (2) protecting children and young people generally and their development (Children and youth legislation and safeguarding and child protection legislation); (3) supporting families and parental responsibilities (Family legislation); (4) through children's rights to education, or mandatory schooling (Education legislation).

- (1) Firstly, support and protection to AYC's can be provided indirectly by providing support to children and adults in need of assistance through health and social care. This can prevent or reduce the necessity for children to take up caring roles in the first place by ensuring that the needs of those with care needs themselves are met. This kind of legislation is present in all the study countries. In Italy, the National Attendance Allowance (Law n. 18/1980)⁹ guarantees a monetary transfer of approximately 500€/month targeting people with disabilities (upon disability recognition by entitled public bodies): the amount can be spent discretionary by the beneficiaries e.g. for purchasing support services, such as private homecare services. In Sweden, the Healthcare Act¹⁰ for example sets out that the purpose of healthcare is 'good health and equal treatment for the entire population'. It states that those with the greatest need for healthcare should be prioritised for care and that healthcare services shall work to prevent ill-health. In Switzerland, the Social Security Law¹¹ provides financial funding for families (care credits) and in the Netherlands, the Social Support Act¹² makes provision for the support of people who have difficulty participating in society or who cannot care for themselves. Where parents, siblings or families receive support, this ought to lessen any need for a child to take on a caring role.
- (2) Support and protection can also be established through Children and Youth Legislation. The role of child protection measures was a common feature of the interviews. Experts in all six countries discussed child protection legislation within their own country (such as the Swedish Social Services Act¹³, the Civil Codes in the Netherlands¹⁴ and in Switzerland¹⁵) as well as how YCs at risk should be protected and supported by these laws, for example by ensuring caring roles are considered when assessing family situations.
- (3) Family legislation can also be seen as support for YCs. Each country has in place general legislation to protect all children and families. This general legislation has the potential to safeguard children from being impacted negatively by caring responsibilities at various levels, such as (a) by recognising these children as a specific group

- with needs, (b) by supporting their identification and (c) through child protection measures, as previously mentioned. The Children and Young People Act (Scotland)¹⁶ for example, ensures a single planning framework (Child's Plan) will be available for children who require extra support, whilst the Family Code¹⁷, that came into force in Slovenia in 2019, makes provision to assess and protect children. In the Netherlands, the Child and Youth Act¹⁸ aims to protect and support children through early identification and intervention and by promoting parenting skills.
- (4) Finally, support and protection can be established through education legislation that protects a child's right to education and which therefore should ensure that YCs maintain their attendance at school. It also relates to schools identifying and supporting AYC's – through the education legislation¹⁹ in Slovenia for example, which regulates how schools should communicate with social care, if they notice a child with special needs or in case of domestic violence.

Enactment of legislation

How legislation translates into practice is dependent upon several factors: the existence of implementation guidelines, the particular characteristics of local authorities and on the type of support underpinned by legislation. In some countries, experts reported a lack of guidelines in place to support legislation. For instance, in Italy, in order to use the resources of the Fund for non self-sufficiency (art. 254 of the Law 27 December 2017, n. 205)²⁰ to support carers (as defined from art. 255 of the same Law) specific regulations are required which are currently unavailable. Regional variations were also found. In the Italian region Emilia-Romagna, the implementation methods of the Regional Law 28 March 2014, n. 2²¹ are defined, while in Abruzzo and Campania no implementation guidelines have been issued. In Scotland, an implementation steering group is in place and the government has an implementation plan for the Carers (Scotland) Act.²² In many countries, regional and local authorities are responsible for the enactment of legislation. In Switzerland, the cantons receive recommendations from the Federation about how to translate legislation into practice; however, implementation varies from canton to canton. In the UK, local authorities have a duty to identify and assess YCs, but they have different approaches to enacting this legislation. In some local areas, for example, local working groups have been established to implement their duties through a multi-agency approach, while in others, there is a lack of understanding of their responsibilities and a lack of connectivity between children's and adult services.

Changes in legislation

YCs were first specifically included and defined in legislation in the UK, in the Care Act 2014²³ and the amendments made to the Children Act (1989)²⁴ by the Children and Families Act (2014).²⁵ YCs and their families should now be identified and assessed and are entitled to receive a consideration of support under law. In Scotland, YCs were previously not mentioned in legislation since it was assumed that they were covered by the provisions within the Children and Young People's Act (Scotland).²⁶ However, following consultation, the Carers Act²⁷ now explicitly includes YCs. Although Italy does not have a definition for 'young carers' in legislation, family carers have for the first time

been defined in legal terms by the Emilia-Romagna Regional Law (2014).²⁸ At national level, draft laws for legislation to recognise carers have been submitted since 2017 and discussed at the Senate Labour Commission.

Different key stakeholders were involved in the development of specific and non-specific legislation in the six European countries. These stakeholders were for example different ministries (IT, NL, SI), NGOs including family associations (IT), or private and state organisations (SE). Young people and carers were also involved in the process, in the UK for example. Experts reported several key drivers that had helped bring about changes in legislation. Slovenian experts cited workforce pressures for example as one driver, specifically the high workload of social workers (for the Family Code²⁹) and of the police (for the Domestic Violence Protection Law³⁰), as well as analysis of other European legislation which led to changes in child protection measures. UK experts highlighted the role played by research and the partnerships formed between academics and the voluntary sector, which raised awareness of YCs and their needs.

Experts from several countries mentioned the importance of the ratification of the United Nations Convention on the Rights of the Child (UNCRC) by their national legislation (e. g. CH, NL, SE). Legislative changes were also commonly associated with changes in paradigms. In the Netherlands, the introduction of the Child and Youth Act (Jeugdwet)³¹ brought about significant decentralisation and a transformation of approach which focused on the role of the family and social networks in the care process, on prevention, and better coordination and integration of services. In Switzerland, there is a paradigm shift from the welfare approach to the right based approach, which has led to children being better informed about their rights. In the UK, an individual approach to supporting YCs was supplanted by a 'whole family approach'.

Specific policy and service frameworks

Policy and service frameworks specifically targeting YCs were reported in Switzerland, England, Scotland and Northern Ireland. In Switzerland, the Action Plan for support and respite of relatives providing care³², and the Federal research programme³³, target all carers, including minors. Policy and service frameworks in England, Scotland and Northern Ireland address the identification of YCs, their needs for support (especially in education), and improving their outcomes. The policy paper 'Carers Action Plan 2018–2020'³⁴ in England also addresses the issue of transition for young adult carers. Experts from the remaining countries (NL, SI, SE, Wales) did not report any specific policy and service frameworks. In Italy, flexibility with school attendance plans and attainment for YCs was however reported to have been improved by accessing the special educational needs route. This happens only in the regions where awareness campaigns and specific studies and programs for YCs have been previously carried out (e.g. in Emilia-Romagna).

Non-specific policy and service frameworks

Non-specific policy and service frameworks that can indirectly support YCs and their families were not mentioned by experts in Sweden, whereas many were reported in other countries. For example, the Dutch Ministry of Health, Welfare and Sports launched three programs aimed at enabling the participation of all disabled people and their

relatives.³⁵ Slovenia supports young people with the 'National Programme for Youth'³⁶, with the goal of empowering young people – especially those with special needs. Moreover, youth centres in Slovenia provide a range of support for young people in need. A similar approach was found in Switzerland. Here, the Federal Social Insurance Office developed a child and youth policy and the organisation 'Health Promotion Switzerland'³⁷ supports cantonal action programmes which focus, among other areas, on supporting children and young people's mental health. Non-specific policy and service frameworks differ among the UK countries. For instance, in England, the Pupil Premium³⁸, consists of additional funding for publicly funded schools to provide additional support for disadvantaged pupils. In Scotland, the national approach 'Getting It Right for Every Child (GIRFEC)³⁹ aims to improve outcomes for all children. Experts in Northern Ireland mentioned several non-specific policy and service frameworks, for example, strategies for children and their families (namely the 'Children and Young People Strategy 2017–2027'⁴⁰ the 'Strategy for Supporting Families 2015–2020'⁴¹) as well as the guidance 'Understanding the Needs of Children in Northern Ireland (UNOCINI⁴²)', aimed at practitioners who provide services to children, young people and families.

Enactment of policy and service frameworks

The enactment of policy and service frameworks was found to be facilitated where cooperation and collaboration between healthcare institutions and social services were taking place, where guidelines and indicators had been developed and where there was sufficient funding in place. One example of key guidelines in England and Wales is the template 'No wrong doors: working together to support young carers and their families' (ADCS, ADASS, The Children's Society, and Carers Trust 2015).⁴³ This promotes cooperation between adult's and children's social services and partnerships with health and third sector partners. 'The Care Act and Whole-Family Approaches' (Department of Health, 2015)⁴⁴ also in England and Wales provides guidance for practitioners working in adult social care about considering the needs of the whole family. In the Netherlands, there is a national website for supporting children of parents with psychological or addiction problems.⁴⁵ This is targeted at professionals, children, parents and municipalities and provides information on interventions and guidance for cooperation between organisations. In Slovenia, 'youths with fewer opportunities' are prioritised according to different measures, within formal to non-formal education and youth programmes.⁴⁶ Whilst having sufficient funding supports the enactment of legislation, in Italy, where local areas are highly financially autonomous, it was found that the quality of social services varied even between neighbouring areas.

Changes in policy and service frameworks

Generally there has been an increased focus on children's issues and changes have come about in many different ways and facilitated by many different stakeholders. Sweden for example now considers the impact on children within all policies. In Slovenia, the EU Youth Strategy 2010–2018⁴⁷ was a catalyst for the development of the youth policy framework, as was the youth wings acquiring their own Secretary which provided the political weight for the introduction of the National Programme for Youth.⁴⁸ Different

ministries and the youth sector were involved in the development of the Youth Policy Framework. In Switzerland, YCs had not always been included in policy and service frameworks and children were not originally included in the Action Plan (2014)⁴⁹, however, a petition from the Parliament addressed their exclusion and YCs are now explicitly mentioned in policy. Some opposition to change has occurred, however, for example in Northern Ireland where it was felt the Children and Young People's Strategy 2017–2027⁵⁰ might have created unnecessary bureaucracy.

Moving forward: what needs to happen?

Experts proposed a range of goals and suggested a variety of ways forward. There was consensus by experts of the importance of recognition and awareness by professionals of children with caring responsibilities, of their caring roles and the negative impacts. This was viewed as a necessary precursor to establishing their commitment. They proposed improving recognition and awareness of YCs (the difficulties they experience and the impacts – positive and negative – on their own and their families' lives) at all levels of society. This includes raising awareness and recognition with professionals in health, social and education sectors, the general public and with policy makers. Suggestions to achieve this were through NGOs, by training professionals (CH, UK) and through information campaigns and the media (SE).

Secondly, some experts proposed that a definition for YCs is needed to facilitate self-identification and that YCs should also be recognised as an important target group by policy makers. Whilst acknowledging that the best interests of a child can be different for every child (CH), the application of the UN Convention on the Rights of the Child should recognise YCs and their needs. Thirdly, experts highlighted that more knowledge and data was required and a more evidence-based approach was needed to highlight the issue. Other key areas of development that were proposed included the development of a more whole family and preventative approach through legislation, the adoption of a life-course approach and early intervention and support for AYC's as they transition to adulthood. Lastly, experts asserted that YCs should be protected from inappropriate caring (NL, SE) and attention should also be given to what their rights should be (NL, SE, UK), although it was highlighted that it was not defined when caring roles were 'over the limit' and what caring is acceptable for YCs to undertake (SE).

YCs' views

AYC's, young adult carers and former YCs (collectively described here as YCs) in the six countries were asked their opinions on the enactment of legislation, policy and service frameworks within their own countries, as well as about the future goals and hopes expressed by experts. Difficulties in commenting on the enactment of legal provisions and policy frameworks due to a lack of experience and knowledge were reported by YCs and our data does not allow us to compare their views across countries. However, generally, the YCs thought some existing laws were not working well in practice. They did report however that there is no awareness of the topic and that YCs receive limited information about their rights, about support opportunities or about a parent's illness. YCs also reported that schools were key and should be more understanding and

supportive towards YCs. They highlighted the lack of support offered to them and that their caring roles are not considered by health professionals.

YCs generally affirmed the future goals/hopes of experts, including the need for national legislation or strategy for YCs, or the adaption of existing legislation and defining YCs in order to improve their identification. They felt that recognition and awareness of YCs should be increased across the health and education systems, and with the general public. They confirmed there was a particular need for improved support and awareness in schools and at the school/work transition period and underlined the importance of early intervention and prevention, the 'whole family approach' and providing support for parents to reduce the burden on YCs. YCs agreed with the experts that the participation of YCs (although difficult) and families were needed to improve understanding of support needs. Some YCs also reported their own hopes for the future, including forums for mutual support and more emotional and psychological support for AYC's as well as families. They also highlighted the importance of reducing stigma associated with vulnerable groups, including different groups of YCs.

Discussion

In this study, a range of different policy and legislative responses to AYC's across the six countries were found. This varies from protection and support for YCs in policy and legislation and a definition for YCs, through to a total lack of recognition and support. In all countries, non-specific legislation and policy exist that holds the potential to protect and support this group. However, irrespective of current measures in place, in practice YCs are often not recognised and are falling through gaps in policy and legal safety nets, and between adult and children's services. Crucially, the study sparked several foundational and ideological dilemmas or questions that individual countries must address before any steps are taken towards the development of legislation and policy in regards to YCs.

One key question raised is whether it is acceptable for any country to have children in a caring role in the first place, and if so, to what degree? Moreover, without an accurate understanding of the reality of the situation for children with caring responsibilities, reliance on existing social welfare systems is perhaps disingenuous. As stated by Nordenfors and Melander:

'A strong welfare state (from which the children's and the youths' parents and their next of kin should get support, care and assistance) together with ideas about children not having to perform care and take responsibility at too high a level, have contributed to the notion that children do not need to become carers in this country (Sweden). This means paradoxically that individual children are left alone without support, sometimes with a very high level of care as a result.' (Nordenfors and Melander 2017)

This view that posits that YCs should not exist and that if appropriate services are delivered to the person needing care, children could get on with the ordinary business of growing up (e.g. Olsen and Parker 1997) contrasts with an approach (such as that underpinned by legislation in the UK) that recognises, defines and supports YCs. Adopting this opposing approach fundamentally means accepting that children do assume caregiving roles. Such acceptance opens the door to criticism that such a system may in effect be

entrapping children and young people into roles which they should be free from, and in so doing, violating their rights.

According to the aforementioned contrasting approach, YCs do exist and therefore they need to be identified, protected and supported. Aldridge and Becker (1996) recognise that 'in an ideal world where the voluntary and statutory support services are willing and able to provide extensive or unlimited support, the role of YCs would be greatly reduced.' (71). However, it is also recognised that where health and welfare systems are pressurised, carers will be expected to undergird these systems by providing support for the cared-for person. In any case, many will choose to take on caring roles. Indeed, in the last few decades, social and demographic forces and forecasts internationally have led to an increase in informal care, as well as the development of policy and legislation that recognises the rights of those who provide this informal care and 'to some extent 'formalises' the role of informal carers' (Zigante 2018). As Aldridge and Becker (1996) stated 'in such a context, it is important that the role of (adult and) YCs is fully appreciated and valued.' (71). Moreover, experts argued that concrete recognition and protective measures for YCs is a central consideration.

A second question that was raised is whether or not specific legislation and policy are necessary to protect and support AYC's, or whether a better direction would be through existing non-specific legislation/policy. It is true, as other findings from the ME-WE project show, that whilst the level and type of support available for YCs differ (with most countries mainly offering support on a local level), within the UK, which does have specific legislation and policy, there are hundreds of interventions to support YCs (Nap et al. 2020). However, arriving at a definitive answer to this is complex and many things need to be considered that are specific to individual countries, such as the effectiveness of current non-specific legislation/policy at recognising, identifying, protecting and supporting AYC's and how specific legislation/policy would fit with what already exists. Moreover, by introducing specific legislation/policy for YCs, how does this fit with the narrative that children should not be taking on caring responsibilities in the first place? Does this inevitably necessitate defining what is an acceptable/inacceptable level of caring, and assessing levels of caring as has been attempted in UK legislation (Children and families act (96: young carers), 2014; Care and support statutory guidance 2014). If conversely, YCs are to be supported through existing non-specific policy and legislation that does not recognise YCs as a distinct group, then it must be critically examined how effectively these measures are working for children and young people with caring responsibilities. For example, how effectively do safeguarding and child protection measures protect and support these children in practice? Where they are effective, they will likely act in a preventative capacity.

Protection and support for adults providing informal care has focussed on supporting them in their role as carers, through policies and legislation that provide recognition of their carer status, financial allowances, employment and training rights, as well as support for their health and well-being (e.g. van Groenou, Marjolein, and Boer 2016; Zhang and Bennett 2019; Zigante 2018). Furthermore, the reconciliation of unpaid care and employment is growing on the policy agenda (European Commission 2018). However, AYC's are legally children and as Aldridge 2018 reminds us 'the under 18' marker is both important and necessary because it recognises the status of the 'child' in a legal context' (157). Consequently, protection and support for YCs should be

fundamentally different from that for adult carers. The provisions in England, although recognising and defining YCs, do however view YCs as children first and are underpinned by a preventative principle (e.g. [ADCS](#), [ADASS](#), [The Children's Society](#), and [Carers Trust 2015](#)).

Indeed, taking a preventative approach was generally advocated by experts and was in place in several countries. Its intention being 'to take a holistic view of the person's needs and to identify how the adult's needs for care and support impact on family members or others in their support network' ([The Care Act 2014, 2014](#)). However, there are other types of support that YCs report to be helpful, such as web-support, counselling and group counselling (Ali et al. [2013](#)), psychoeducation, confidential and anonymous support, information from healthcare professionals, and support online (Grové, Reupert, and Maybery [2016](#)). These targeted forms of support for children with caring responsibilities can complement a whole family approach and provide supplementary provision where support for families is in place, yet children continue to have needs for support (Otto et al. [2019](#)). The (former) YCs who participated in this study also wished for different types of support (e.g. in school, information for professionals, emotional support), although they highlighted the importance of considering each situation individually.

The fact that experts (and YCs) felt recognition and awareness of YCs should be increased across different sectors, showed that awareness among professionals is often lacking (Leu et al. [2020](#)). Among others, the reasons include a patient-focused approach within healthcare and a lack of clarity about the distribution of responsibilities and competences. As a consequence, no one felt in charge of initiating supporting measures (Leu, Frech, and Jung [2018](#)). To secure the commitment from professionals, they not only need heightened understanding of the issues, as was put forward by experts, but for it to be effective, professionals need to know how to effectively support AYCs. Moreover, professionals require adequate capacity and the necessary resources. Ensuring these are available is perhaps one role that specific legislation and policy could play.

The marked difference between the response of the UK, with its specific legislation, and that of other countries, is unsurprising considering its early research on the topic (multiple publications from the 1990s, both qualitative and quantitative); its level of awareness of children with caring responsibilities (a quarter of a century of published and highly visible/ impactful research, multiple TV documentaries and news items, and greater public recognition of the role of informal (family) carers of all ages); and its longstanding targeted support for YCs by dedicated services (hundreds of specialist projects provided by multiple NGOs in touch with tens of thousands of YCs at any one time). Moreover, the UK has a long tradition of awareness and promotion of both children's rights, and carers rights (as enshrined in legislation). However, not all countries have this cultural and historical context.

History, culture, public awareness, politics – all matter when it comes to awareness of and recognition for YCs. So too does the nature of the welfare systems (or welfare states) in different countries (an aspect of history and culture). Space prevents a more detailed discussion here of history and culture, but these factors are important in understanding individual countries' responses to YCs and their families.

The challenge facing countries is that before legislation or service frameworks can be introduced, a clear policy direction must be forged. And in order for policy to be developed for this group, a sufficient level of awareness and recognition must be achieved. Paradoxically, however, without mechanisms in play that identify YCs and assess their

needs and the needs of their families, then recognition and awareness are muted and the issues remain veiled. Breaking this inertia is dependent therefore on responding to the research that highlights the issues and prevalence of children with caring responsibilities – which is reflected by Leu and Becker (2017) who report that awareness and policy responses are more advanced in countries with a large and robust and reliable research base. Traction could also be gained from learning from the UK, who lead the march on the classification of in-country awareness and policy responses to YCs (Leu and Becker 2017) where research developed early, and where a clear policy path has been forged and crowned with legislation.

Study limitations and strengths

Limitations of this study need to be taken into account. Firstly, the experts' own familiarity with legislation and policy would have guided the direction and content of the interview leading sometimes to interviews focusing on particular legislation and policies, whilst potentially omitting others. Secondly, not all the experts who were initially prioritised were interviewed. This was due to experts declining to take part in the interviews or being uncontactable. Thirdly, there might have been differences between the definition of YCs in legislation and policy documents and definitions used by the experts themselves. It is also worth noting that due to the inevitable delay between data collection and reporting, changes in legislation and policy may have taken place. For example, in the Netherlands in 2019, a national child minister with a focus on YCs was appointed by the national ministry of health. This study has also several strengths. Firstly, in order to ensure the interview guidelines were appropriate for each individual country context they were developed collaboratively with a former YC and country study partners. Second, the identification and interviewing of experts provided direct access to their country specific knowledge about legislation and policy frameworks. Third, providing experts, country partners and YCs opportunity to feedback on the initial case study drafts, validate specific points, and to answer remaining questions, provided triangulation to help ensure greater validity of the findings (Noble and Smith 2015).

Conclusions and implications for policy and practice

Although experts' views differed as to the need for specific legislation and policy, study findings highlight the potential to extend existing legislation, policy and service frameworks to include YCs. Until such legislation and policy are actualised specifically for these children, they will likely continue to fall through the gaps. Awareness should be raised at all levels of society, for example with professionals in the health, social and education sectors and with the general public. A definition for YCs is needed within national legislation, using as a basis the Becker definition with potential revisions including extending it to non-familial caring roles and removing the criteria of significant or substantial caring (as in UK definition) so that YCs can identify themselves. YCs need to be recognised as an important target group for policy makers. Therefore a multi-faceted approach involving different stakeholders is needed, e.g. different ministries, the education sector and NGOs. Ways to ensure the participation of YCs in research, policy and practice initiatives should be taken on board, in order to improve understanding of their situation and to gain their ideas for improving support within each country (Phelps 2017).

The importance of cross-national studies cannot be overstated. The study findings fill an important international research gap. For the first time there is a transnational analysis of legal structures, policies and service frameworks for YCs that enables us to identify benchmarks and the strengths and limitations of different systems. This will be particularly helpful for those countries where the legal structures, policy and service frameworks are only just emerging or are non-existent. This enables us to develop evidence-based policy and practice responses to the needs of YCs and their families, aimed specifically at promoting the development, education, health, well-being, future employability and life chances of AYC's in all European countries and worldwide. How the responses that have emerged in this study can be implemented in the different countries needs further research.

Notes

1. <http://www.legislation.gov.uk/nisi/1995/755/contents>
2. <http://www.legislation.gov.uk/asp/2016/9/contents/enacted>
3. <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>
4. <https://www.legislation.gov.uk/ukpga/1989/41/contents>
5. <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>
6. <https://www.legislation.gov.uk/anaw/2014/4/contents>
7. https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag_sfs-2017-30
8. https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientsakerhetslag-2010659_sfs-2010-659
9. <https://www.gazzettaufficiale.it/eli/id/1980/02/14/080U0018/sg>
10. See fn. 7
11. <https://www.admin.ch/opc/de/classified-compilation/19460217/index.html>
12. <https://wetten.overheid.nl/BWBR0035362/2018-08-01>
13. https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453
14. <http://www.dutchcivillaw.com/civilcodebook01.htm>
15. <https://www.admin.ch/opc/en/classified-compilation/19070042/201801010000/210.pdf>
16. <https://www.legislation.gov.uk/asp/2014/8/contents>
17. <http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO7556>
18. <https://zoek.officielebekendmakingen.nl/stb-2014-105.html>
19. <http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO5896> and <http://www.pisrs.si/Pis.web/pregledPredpisa?id=PRAV9598>
20. <https://www.gazzettaufficiale.it/eli/gu/2017/12/29/302/so/62/sg/pdf>
21. <http://demetra.regione.emilia-romagna.it/al/articolo?urn=er:assemblealegislativa:legge:2014;2>
22. See fn. 2
23. See fn. 3
24. See fn. 4
25. See fn. 5
26. See fn. 16
27. See fn. 2
28. See fn. 21
29. See fn. 17
30. <http://www.pisrs.si/Pis.web/npbDocPdf?idPredpisa=ZAKO7373&idPredpisaChng=ZAKO5084&type=doc&lang=EN>
31. See fn. 18
32. <https://www.bag.admin.ch/bag/de/home/strategie-und-politik/politische-auftraege-und-aktionsplaene/aktionsplan-pflegende-angehoerige.html>

33. <https://www.bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitspolitik/foerderprogramme-der-fachkraefteinitiative-plus.html>
34. <https://www.gov.uk/government/publications/carers-action-plan-2018-to-2020>
35. <https://www.rijksoverheid.nl/documenten/rapporten/2018/09/30/programma-volwaardig-leven>
36. <http://www.pisrs.si/Pis.web/pregledPredpisa?id=RESO93>
37. <https://gesundheitsfoerderung.ch/kantonale-aktionsprogramme/basisinformationen/dachkonzept.html>
38. <https://www.gov.uk/guidance/pupil-premium-effective-use-and-accountability>
39. <https://www.gov.scot/policies/girfec/>
40. <https://www.education-ni.gov.uk/consultations/children-and-young-peoples-strategy-2017-2027>
41. <https://www.northerntrust.hscni.net/2015/01/06/northern-trust-launch-supporting-families-strategy/>
42. <https://www.health-ni.gov.uk/publications/understanding-needs-children-northern-ireland-unocini-guidance>
43. <https://www.local.gov.uk/sites/default/files/documents/no-wrong-doors-working-to-27d.pdf>
44. <https://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf>
45. <https://www.trimbos.nl/kennis/kopp-kvo>
46. i.e. <https://www.gov.si/podrocja/izobrazevanje-znanost-in-sport/izobrazevanje-otrok-s-posebnimi-potrebami/>; <http://www.pisrs.si/Pis.web/pregledPredpisa?id=PRAV9598>
47. <https://eacea.ec.europa.eu/national-policies/en/content/youthwiki/13-national-youth-strategy-slovenia>
48. See fn. 36
49. See fn. 32
50. See fn. 40

Acknowledgements

First of all, we would like to thank the European Commission for its financial support of the project. This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 754702. We would like to thank our country project partners and their teams for providing their comments and suggestions throughout the course of the project, as well as for their support with the interviews with experts in their own countries. We would also like to thank the experts in all the six European countries involved in the study, who provided their knowledge and expertise. We would also like to show our gratitude to all the young adult carers and former YCs who supported us in this project by sharing their personal experiences regarding the enactment of legislation, policy and service frameworks, as well as their goals and hopes for the future. Their opinions are extremely valued and vital for this project.

Funding

This study forms part of a major pan-European young carers project that received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement n° 754702. The authors thank also Linnaeus University for covering the open access fees.

Authors' contributions

AL, DP, EG contributed to the study design, conducted the CH data collection and analysis and the cross-national data analysis and synthesis work. SS, MS, LB conducted the IT data collection; HNH, RH conducted the NL data collection; LM, EH conducted the SE data collection; VH, TR, TH conducted the SI data collection; FL conducted the UK data collection;

EG, DP, AL were responsible for writing the first and all consecutive drafts and the submitted paper. EH contributed to the overall study design and acquired the funding and led the ME-WE project consortium. All authors provided critical commentary in the draft revisions. Further, they all approved the submitted version of the manuscript and agreed to be personally accountable for the accuracy or integrity of any part of the work.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This study forms part of a major pan-European young carers project that received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement n° 754702. The authors thank also Linnaeus University for covering the open access fees.

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