

Intergenerational Justice Review



**Issue topic:
Young Carers (II)**

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Family members who take care of their relatives play a vital role in society. Without such people, healthcare systems would collapse. This fact is not widely understood. Among family carers, 'young carers' are faced with specific challenges that can affect their entire lives.

The situation of 'young carers' deserves particular attention now, more than ever. As a result of the societal demographic shift, the consequent alteration of the age structure, as well as the current crises, such as the COVID-19 outbreak, considerable additional burdens are placed on the welfare, health, and care systems. This leads to an increase in the number of family caregivers. In this context, the focus of research, policy, and media attention is almost exclusively on adults, e.g. partners who provide care, forgetting that children and young people often take on a caring role. This leads to a lack of awareness and consequently makes access to support services more difficult. Young carers are confronted with special difficulties and therefore require specific support. In some countries, the term 'young carers' is already known to the public, but there is a lack of social awareness. In other countries, an appropriate term in the relevant language is yet to be developed or widely understood. It is for these reasons that the 2023 double-issue of the IGJR are dedicated to this important topic. While the focus of the previous issue (1/2023) was on the challenges of identifying young carers and the problems they face daily, this issue focuses more specifically on possible solutions and support measure.

The first article by Stephen Joseph, Joe Sempik, Agnes Leu and Saul Becker provides an overview of research on young carers to date and discusses methodological challenges in this context. They argue in favour of a participatory and action-oriented approach to research that can better capture the lived experience of young carers and meet their needs. Research findings indicate that 2–8% of children and young people are carers. This role has an impact on their professional and social opportunities, their health, and their overall well-being. The authors provide an important, but often neglected, international comparison which considers the situation for young carers outside of Europe. They note, for example, that understandings of childhood across the globe differ, and thus the term 'young carer' is subjectively construed. The *de facto* and *de jure* situation for young carers also differs from country to country. In some countries, young carers are offered well-developed services and are recognised in law, while other countries are still severely lacking in awareness of the problem. The article proposes a new agenda for the development of policy, research rigour, and more theoretical sophistication, as well as demonstrating the need for a greater awareness of the importance of interdisciplinary and multi-agency working.

No one should be penalised because of their caring role, either economically or socially. This is the position of the second contribution in this issue, a policy paper published by the European Association 'Eurocarers'. The paper demonstrates why the challenges faced by young carers must be recognised and addressed. It sets out a few key goals, which new measures to support young carers should aim to achieve. Central to this are provisions such as providing young carers with necessary information and advice, off-

setting costs through access to benefits, providing flexible working arrangements, recourse to formal professional care services and carers' leave arrangements, that enable the young people to pursue active social lives and extra-curricular activities. The policy paper highlights two main elements of support that can be provided. Firstly, they argue that to enable young carers to take time out and manage their time better, the provision of appropriate and intensive formal care must be promoted. This must be adequately and consistently supported by legal and policy frameworks at national and regional level. Secondly, they detail the kinds of direct support for young carers which could be provided through training, counselling, psychological, and emotional guidance. This must be preceded by an initial needs assessment by formal services based on a 'whole family approach'. This approach allows the health and social needs of the care recipient, carer, and family to be identified as a whole, which relies on a joint working and commissioning between adult, children, and health services. Such an approach leads to a 'virtuous circle between services', which in turn is important for the mental health of young carers. The policy paper argues in favour of a stronger focus on prevention and early intervention. The authors also argue that we must acknowledge the obstacles to accessing support services on the part of the families concerned. In some cases, a fear that family members could be separated makes young carers hesitant about asking for support or accessing services. Finally, the policy paper provides key messages for various institutions and organisations such as schools, the EU, and support services, with the intention of influencing their policies.

Finally, this issue closes with the book review section, which in this issue is dedicated to intergenerational issues more broadly. Zachariah Tailor reviews Livia Ester Luzzatto's *Intergenerational Challenges and Climate Justice: Setting the Scope of Our Obligations* (2022), which proposes a novel intergenerational theory of justice for dealing with the impacts of climate change on future generations. This monograph considers the circumstances in which responsibility and blame for their actions can be assigned to current people, providing helpful frameworks for national and international policy.

Jörg Tremmel, *Editor*
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Young carers research, practice and policy: an overview and critical perspective on possible future directions*

by Stephen Joseph, Joe Sempik, Agnes Leu and Saul Becker

Abstract: *Many children, adolescents, teenagers, and young adults have caring responsibilities for parents and family members. These young carers and young adult carers are present in every country. Their responsibilities include domestic chores as well as intimate personal care and other forms of helping which are generally seen as the responsibility of adult professionals. First, this article provides an overview and critical perspective on young carers research. Research suggests that 2–8% of children and young people are carers and that the caring role has an impact on their education, health, wellbeing, social opportunities, and employment prospects. Various countries have responded differently with regards to policy: some have well developed services and recognition in law whilst others are only just beginning to recognise the problem. Second, we discuss the issues and challenges for research and propose a new agenda for the development of policy, research rigour, more theoretical sophistication, and a greater awareness of the need for interdisciplinary and multiagency working. Furthermore, we call for participatory and action led research that can provide greater insights into the lived experiences of young people, their needs and how these can be met.*

Keywords: *Young carers; prevalence; research; theory; policy; interdisciplinary*

Introduction

It is over 25 years since Aldridge and Becker (1993) first identified the role that some children, adolescents, and teenagers under 18 years in the United Kingdom (UK) have as caregivers for family members. The term ‘young carers’ is now widely used in scholarly literature and in public policy to describe children and young people who provide regular and substantial care to ill or disabled family members. The term ‘young adult carers’ was later introduced by Becker and Becker (2008) to describe those young adults aged between 18 and 24 years who provide care. The reasons for providing care are complex and often related to the absence of other informally available networks, the lack of suitable formal care arrangements, as well as love and natural family bonds to the person in need. Becker (2007) described the caring continuum as ranging from caring about the person to caring for the person. Caring about reflects the usual activities conducted by most young people, for example, 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; their position on the continuum gradually changes from ‘caring about’ to ‘caring for’. With that comes a heavier burden of commitment and responsibility; their time and attention are taken up with the caring role. Much research has accumulated over 25 years but there remain important gaps. The aim of this article is to highlight those gaps and set the research agenda for the next 25 years. Following an overview of the research and public

policy literature identifying the major challenges and issues facing the field we will discuss the new directions that we think research in this field must now take.

Prevalence and effects of caring

Recognised as an invisible, hidden, and a vulnerable workforce (Stamatopoulos 2015), children and young people with a high level of caring responsibilities have been shown to exist across European countries (e.g. Norway, Sweden, Austria), the United States, Canada, Australia and New Zealand, Sub-Saharan Africa and the Middle East (Leu/Becker 2017a). Whilst there is some variation in estimates of prevalence, figures suggest that between 2 and 8% of all children, young people, and young adults in advanced industrialised capitalist societies are carers, depending on the methodology which is used to identify and count them (Leu/Becker 2019). It is impossible to be more precise than this as the definition of caring, methodology and sampling, are not consistent, and even in the most sophisticated studies truly representative and sufficiently large samples have rarely been obtained. Also, figures are not static but vary over time, by geography of the country, and ethnicity and other demographic factors (Wayman et al. 2016).

Prevalence studies have provided data for developed countries. Until relatively recently data were limited for Africa and Asia; however, a number of researchers have now explored the roles of young carers in these countries and the context in which they enact those caring responsibilities. For example, Robson et al. (2006) showed that, in the midst of the HIV/AIDS epidemic in Lesotho, Tanzania and Zimbabwe, many children and young people had the responsibility of looking after their dying parents in addition to carrying out the domestic chores and work that would normally be conducted by their parents. The prevalence of caring may be higher in African countries than the 8% because of the extent of familial AIDS-illness (Cluver et al. 2012), but as yet sufficiently detailed studies have not been conducted.

In general, however, research shows that young carers and young adult carers in different countries carry out the same range of caring activities (Nagl-Cupal et al. 2015). One useful comparison is between young carers in the UK and those in Tanzania (taken from a study of young carers in these countries who care for parents with HIV and AIDS) (Evans/Becker 2009). All of the children in both countries carried out household chores, and almost half of them (45% in each country) provided some form of personal (intimate) care. The majority of children in both countries (82% and 64% respectively) were also involved in providing healthcare for their parents or families and some also cared for their siblings. While there are similarities, two areas of difference were also observed. Only 9% of young carers in the UK contributed to the household income, however, in Tanzania, almost half of the children were engaged in some form of income generation such as begging or casual work. Many young carers in Tanzania,

therefore, have to provide an income for the household in addition to the caring tasks they have to do. The lack of a state provided welfare system and income protection scheme severely exacerbates the financial difficulties of those families in parts of Africa and other poorer countries – hence, as the parents are unable to earn a wage, they have to rely on their children as providers of income in addition to their roles as carers.

Overall, research shows that the role of young carers is similar regardless of the country or continent but that the detail of that role will be affected by local considerations or circumstances. Having identified that a substantial minority of young people are engaged in caring roles, a major focus of research has been to understand the impact of caring on the young people's, health, wellbeing, education and social and economic life chances.

First, young people who care for individuals may carry out the same tasks as paid and trained health and social care practitioners. But they are unpaid and untrained. They are exposed to numerous risks, and their lack of knowledge about the medical diagnosis and lack of training contribute to those risks (Leu/Becker 2017b). For example, Cluver et al. (2013) showed that children in sub-Saharan Africa who look after parents with AIDS are at greater risk themselves of pulmonary tuberculosis. Second, a wide range of qualitative studies have shown that young carers and young adult carers may experience various economic and social disadvantages and difficulties, including restricted educational opportunities and employment (e.g. Kaiser/Schulze 2015), difficulties in meeting the demands on them in university education (e.g. Kettell 2018), reduced social capital (e.g. Barry 2011), and experience of stigma leading to secrecy and social withdrawal (e.g. Bolas et al. 2007). Metzger-Blau and Schnepf (2008) found that families turn to secrecy as a means to keep the family together as it is felt to be under threat, thus the disadvantages can become compounded. Family relations can also be strained (e.g. Stamatopoulos 2018). Third, there are found to be problems with health and well-being. At school, young carers may experience bullying (e.g. Moore et al. 2009), experience physical injury from lifting (e.g. Fives et al. 2013), experience difficulties in health and well-being (e.g. Hamilton/Adamson 2013), and in some contexts having to go hungry (e.g. Cluver et al. 2012). Fourth, the provision of intimate care transgresses the accepted social norms regarding the relationship between a young person and his or her parent and this may affect their development, social integration, or interaction with their peers. Rose and Cohen (2010) in their meta-synthesis of qualitative research with young people themselves offers a different way of understanding how being a young carer is experienced as an process of identity formation, and that it might therefore be difficult to separate them from this role. Fifth, not all studies show only adverse effects. For example, Svanberg et al. (2010) in their study of children caring for a parent with dementia also emphasised their resilience and that only few showed depressive symptoms. Indeed, much of the above research largely adopts a medicalised approach to understanding the impact of caring as if it were a pathogen that leads to illness, but studies have also shown that caring may be associated with increasing maturity (e.g. Fives et al. 2013), can lead to positive changes (e.g. Joseph et al. 2009a), closer relationships with parents and the feeling of being well prepared for life (e.g. Hunt et al. 2005), and the ability to foster qualities of compassion and empathy (e.g. Stamatopoulos 2018). Finally, young carers may feel invisible and unacknowledged as caregivers (e.g. Bjorgvinsdottir/Halldorsdottir 2013).

Stamatopoulos (2018) in her qualitative focus group study with young carers from both the Greater Toronto area and the Niagara Region of Southern Ontario referred to the “young carer penalty”, to describe how young people who care are disadvantaged, and restricted in their opportunities; those from single-parent and single-child families, and dealing with more stigmatised and debilitating problems had the highest penalty. Other qualitative research has interviewed professionals about their perspective on young carers, emphasising that they are seen as an invisible, hidden, and vulnerable workforce, that is isolated, stigmatised, suffering from restrictions in education, leisure, and employment (Gray et al. 2008). Overall, qualitative research has been very rich in the detail and breadth of the difficulties it has described young people as experiencing. However, it has tended to consist of small scale studies of selected groups of young carers. As such, it is uncertain to what extent findings can be generalised.

When larger scale surveys have been conducted of young carers, a substantial minority are found to have disadvantages and difficulties. In a survey of young adult carers in the UK, for example, Sempik and Becker (2013) found that those still at school were absent for around 5% of their days and reported that caring interfered with approximately a quarter of all of their school days. In other contexts, however, the rate of absenteeism may be much higher. Stamatopoulos (2018) in her study of Canadian young carers found a specific absenteeism rate of 10.8%. In another study, Sempik and Becker (2014a) found that 56% of young adult carers at college or university reported that they were experiencing difficulties with their studies because of their caring and some feared dropping out. In an Australian study, Moore et al. (2006) showed that young carers appreciated school but care responsibility along with a lack of services, family or social issues such as poverty and isolation led to absences and educational failure. Evans and Becker's (2009) study highlighted the anxiety felt by young carers both in Tanzania and the UK. In both countries, the young people feared for the future, for example, they worried about what would happen when the person they were caring for died.

Cree (2003) showed that whilst a sample of 61 young carers from Scotland had many of the worries that are associated with adolescence, such as about their appearance, they also had worries and problems that arose from their caring roles. Almost two thirds reported that they had difficulty sleeping and almost a third reported difficulties in eating. A similar number said that they had self-harmed and had suicidal thoughts. Whilst the survey did not measure specific diagnosable mental health problems, it suggests that those children were in danger of developing such problems in the future, if such problems were not present already. In their survey of young adult carers, Sempik and Becker (2013) reported that 38% of those still at school said they had some form of mental health problem: for those at college or university, the figure was 45% (Sempik/Becker 2014a), whilst for those who had left education and were in work or were unemployed, the figure was 51% (Sempik/Becker 2014b). Lloyd (2013) conducted a survey of 4192 children in Northern Ireland, identifying 12% who said they helped looked after someone in their household. Those children scored lower on measures of health and well-being, reported that they were bullied more frequently and had poorer educational aspirations.

While these studies move beyond the small scale qualitative studies in providing results with larger samples, and thus more useful estimates of the scale of the problems for developing policy, the samples are often selected from carers associations and thus can-

not be said to be truly representative of all young people who care. Studies have reported that recruitment can be difficult, with for example, response rates from schools or health professionals being low (e.g. Thomas et al. 2003).

But even in showing that a substantial percentage of young people report difficulties it is not certain that these can actually be attributed to caring. Illness and injury in the family are often stressful experiences for young people regardless of their caring role (Joseph et al. 2000). Other studies have tested for statistical association between the extent of caring and problems. Such studies are rare and show mixed findings, with some reporting that greater caring activity is associated with psychological problems (i.e. Joseph et al. 2009a; Nagl-Cupal et al. 2014) but not in others (i.e. Kavanaugh 2014; Becker/Sempik 2018; Leu et al. 2019). Correlation does not however imply causality and as yet there are no prospective studies showing a clear relationship between caring and subsequent problems that would lend support to the hypothesis that they are causally related. Kavanaugh et al. (2016) note that there is a need for much larger scale, longitudinal studies.

It seems unlikely, however, that caring has no adverse effect, but as the extent of the problems are unclear and it cannot be assumed that all children and young people who care are actually adversely affected, we have to conclude that there are fundamental gaps in the scientific knowledge yet to be addressed. There is a need for research to untangle how caring is helpful to the development of a young person and in what circumstances it can be detrimental.

Developments in policy

Young carers and young adult carers carry out roles at home that in the general workplace (care homes, hospitals and other similar institutions) would usually be performed by trained and qualified adults (who may also have specific qualifications for those roles). These roles which are usually assumed by adults involve a high level of capability and responsibility and may also involve a high level of specialist skill and knowledge. Additionally, young carers often work long hours in their caring role (often longer than standard employment) and are not paid; and by not being paid they save a substantial amount of money for health and social care services (Leu/Becker 2017b). Due to their relationship with those being cared for, unlike employees, they are not free to leave their work and are tied into their caring role until their circumstances change (which can be much later in their adulthood). Additionally, unlike most paid employment, the hours and times that the young carers are required to work can be unpredictable leading to stress and anxiety. Hence, their ability to develop, and their opportunities for education and employment can be severely curtailed; a point also discussed by Stamatopoulos (2018) who discusses how the older carers in her study were more distressed because their grades and lack of extracurricular activities now directly affected their postsecondary applications. For professionals conducting such work as part of their paid employment they will have received training; be registered with and covered by various professional codes of conduct; able to draw on the support of their agency and organisation in case of difficulties; have colleagues who can offer support; and have insurance to cover any mishaps for which they are deemed as responsible.

In terms of policy, it is reasonable to expect that support for young people in their role should be similarly provided. However, young carers rarely, if ever, receive training for caring roles. This must be addressed. However, even when some form of training is made available, it may not be welcome by a young carer as they may

want to keep their role a secret, feeling it to be an embarrassment, possibly out of fear of shaming their parent, or the consequences of disclosure and the fear of child removal (e.g. Moore/McArthur 2007). Thus, while it might seem self-evident that some form of training and support for young people who have a caring role would often be helpful, and we believe should be available, this is actually a controversial position insofar as it suggests that it is acceptable that young people provide such care in the first place. On the one hand, it is important that young people are active agents of their own lives, but on the other this is not to suggest that the state does not have a responsibility to provide the support needed by families. In making such support available, policy development must consider carefully issues of confidentiality, privacy, and choice.

Better, however, that such support was not needed in the first place. Our position is that the first aim of policy towards this issue should always be to provide support for families such that young people do not have to take on roles that are disruptive to their own development, functioning, and education. However, as the research shows, the issue of young carers and young adult carers is complex, and even if this were fully implemented as a policy some level of caring would continue to exist. Different countries have reacted with different levels of response in terms of recognition in law, policy change, and practical support. Their response has been influenced by a range of different factors.

Becker (2007) first compared the responses of UK, Australia, the US and Sub-Saharan Africa to the issue of young carers in order to develop a country-specific classification. This has been developed further by Leu and Becker (2017a) who propose that country-specific research and the presence of lobbying or championing organisations are important drivers in affecting policy change. Country-specific research is able to show conclusively that young carers do exist in that country and what their needs are, therefore not relying on extrapolation of findings from other countries (Leu et al. 2016a, b). Such local data are important in influencing politicians and policy-makers as the demonstration of such a child welfare issue then requires a response from them. In other words, what might have continued as a hidden 'private' issue has become the focus for public policy and intervention.

Leu and Becker (2017a) have analysed the extent of awareness and policy responses internationally and have proposed a model with seven levels of response. The response levels are based on a number of characteristics which demonstrate the presence or absence of specific legal rights or entitlements for young carers, or other rights that could be utilised on their behalf, for example, as 'children as next of kin' in Sweden (Health Services Act 2010). These characteristics include whether children have rights to receive an assessment of needs as young carers. Such rights do not necessarily need to be legal rights, but if they are not legal rights how strong are they, and are they enforceable? Do the countries have specific welfare or social policies that refer to young carers? Do codes of practice for health and social care professionals specifically refer to young carers as a distinct group, and are they recognised as such by the professions? Is there a level of awareness of the issue of young carers amongst the general population and among health and social care professionals? Are there projects or interventions specifically for young carers? Or specific therapeutic interventions for them? As mentioned above, country-specific local research and an active research presence in the country are also active drivers of policy responses, as is the presence of supporting organisations.

Using these key characteristics, Leu and Becker (2017a: 752) have classified countries according to their level of awareness of the issue of young carers and their policy response. The highest level (Level 1) which they have termed 'Incorporated/sustainable' describes a response where there is "extensive awareness at all levels of government and society of the experiences and needs of young carers; sustained and sustainable policies and interventions aimed at meeting young carers' needs and promoting their health, well-being and development" and "responses and law built on a foundation of reliable research evidence and clear legal rights". They could find no countries that could be placed within that level which is essentially the standard that countries should seek to attain.

The UK (on its own) was classed as 'Level 2' (Advanced) where there was "widespread awareness and recognition of young carers amongst public, policy makers and professionals" and "specific legal rights" among other characteristics. The latter referring to changes in UK law (the Children and Families Act 2014; and the Care Act 2014) which includes specific protection for young carers and support for them. Such changes came about because of research produced in the UK which showed the local situation in detail, and because of the activities of non-governmental organisations and the researchers themselves. They campaigned for policy change and used the published research to raise awareness of the issue among policy-makers. Prior to specific legal protection, the UK had also published in 2008 a National Carers Strategy (since 'refreshed') which set an agenda that by 2018 children would be protected from inappropriate caring; would have the support they need to be able to learn; be able to develop and thrive so as to enjoy a positive childhood; and to achieve against government-set outcome targets.

Australia, Norway and Sweden were classed as 'Level 3' (Intermediate; i.e., "some awareness") and Austria, Germany and New Zealand as 'Level 4' (Preliminary; i.e., "little public or specialist awareness"). Six countries and one region (i.e., the US, The Netherlands, Switzerland, Italy, Ireland, Belgium, and Sub-Saharan Africa) were classified as 'Level 5' (Emerging; i.e., "Growing public or specialist awareness") and four (i.e., France, United Arab Emirates, Finland, and Greece) as 'Level 6' (Awakening; i.e., "Embryonic awareness"). All other countries where there was no evidence of research or policy response were classified as 'Level 7' with "No apparent awareness".

Hence, internationally, there is a wide range of responses to the issue of young carers. The extent of research conducted nationally has an important bearing on the policy response. Generally speaking, countries which have carried out more research were seen as at a higher level in Leu and Becker's framework than others, but their characterisation was not based on the quantity of research but on their estimation of that country's awareness in policy. As a result countries such as Norway and Sweden which have relatively less research activity received a higher classification than some other countries which have greater research activity but still less policy awareness.

Leu and Becker's (2017a) classification system is not fixed but was developed to create awareness and dialogue between social scientists and policy makers internationally, which it has succeeded in doing. New research is emerging all the time; some countries that were lower in the classification are likely to emerge much higher at the next iteration. Although Canada and the United States have been lagging behind in recognising and supporting young carers, research interest in Canada (e.g. Stamatopoulos 2016) and the

United States (e.g. Kavanaugh et al. 2016) is building rapidly, and we might expect to see new developments in policies and community support to follow. It appears, therefore, that policy-makers may benefit from access to local research that shows the status in their own countries, but for those policy makers who already have an awareness of the issues, a lack of research may not impede them in acting to define policy. This may be to take action in response to local and national situations. As much as we, as social scientists, value research data to guide policy and practice we recognise that it is only one road to policy; activism to bring about change is also important in developing policy, and certain types of research may be more attractive to policy-makers than others.

Countries have also responded to the growing international research base on young carers by commissioning their own national research. Switzerland, currently at Level 5, is a case in point (Leu et al. 2016a, b). Researchers in Switzerland have recently completed a number of studies that have estimated the prevalence of young carers and explored awareness of the issues among health and social care professionals (Leu et al. 2019); and in ongoing research they are continuing to explore the experiences of children and young people with caring responsibilities. By conducting national research, the aim is to drive policy changes to improve support for young carers and young adult carers. This is much needed as studies in several countries have shown that the level of practical support received from healthcare and home-help professionals do not meet the needs of young carers and those they care for (Moore/McArthur 2007). In many families in the UK and internationally, the caring roles of children and young people are hidden and remain a 'private' family matter rather than an issue for public policy intervention.

It is clear that we think that increasing awareness is important, but it is not without its problems. The terms 'young carer' and 'young adult carer' are controversial. Parents may feel that they are cast in positions of dependence or inadequacy, and left feeling pathologised and that they are a threat to their children (Newman 2002). There is likely at least some truth to this, but to what extent such an observation generalises to the wider population is uncertain. On the other hand, the benefit of the introduction of these terms and dedicated research interest is that it has led to massive deployment of agencies and services which seems to be valued by young people. Young carers themselves may find solace in the label and value being identified and acknowledged. As such, there are strong arguments for the use of the terms. Similar arguments are often put forward for other labels and diagnoses that people find helpful in understanding themselves and in accessing services, but, as social scientists we need to be much more wary ourselves of the validity of the terms we use. It is one of the dangers of research in this field that it may lead young people to begin to think of themselves differently and potentially negatively. The field has not been without its critics, such as Olsen (2000), who has called for greater sociological understanding of how the term 'young carer' is a social construction that potentially problematises childhood.

As discussed above, research into young carers has developed substantially over the past 25 years, overcoming many of the methodological problems raised at the inception of the field (Olsen 1996). The field has moved from a flimsy evidence base to one that more substantially supports the development of policy; however, much remains to be done to build upon these foundations, and to develop more nuanced understandings of caring and its impacts. Increasingly, it is recognised that the extent and nature

of caring differs geographically across and within countries such that the target population is not a homogenous one, where a 'one size fits all' policy is appropriate (Hill et al. 2009).

Directions for theory, research, practice and policy

In this section, we will consider the challenges and issues and the ways forward for research in six areas: definitional issues that set the agenda, the international focus, research quality, theoretical sophistication, participatory research, and the need for multi-agency and interdisciplinary working and awareness.

Definitional issues that set the agenda for research

One of the problems noted by researchers has been that there is no single definition of a young carer (e.g. Aldridge 2018). Without a universal definition it is difficult to assess prevalence of young carers and young adult carers consistently across studies. As such, estimates of populations of young carers are at variance with each other. Some use census information which is based on reporting by adults in the household. Others use self-identification methods by young people themselves. This is a problem insofar as researchers have seen a need to develop estimates of prevalence that are comparable across countries. Policy makers will be interested in knowing the extent of a problem and this drives researchers to develop such research. The difficulty of developing a clear definition is widely acknowledged by researchers as caring is a highly subjective and variable experience. We suggest, however, that the difficulty in definition is that caring is not one thing, and that once we disentangle it into its components it is possible to develop a clearer and more useful set of definitions. Below, we will provide what we think is a more nuanced conceptualisation.

As already noted, 'young carers' and 'young adult carers' are social constructions, helpful in one way for drawing attention to an issue faced by many children and young people, but unhelpful in other ways if they reify the idea that this really is a single population of young people, all with the same issues, who are all adversely affected by their experiences in the same way. It is understandable that policy-makers want to know what percentage of children and young people are carers but caring is on a continuum and is not a dichotomous experience in which the person is either a carer or not a carer. Also, there are different dimensions to care, for example, the extent of caring (i.e., time spent caring) and the type of care carried out, for example, household tasks or personal care. Striving to produce such an understanding tends to lead to percentages that are either over inclusive of all children who have some caring role or exclusive to those at the more extreme end of caring responsibilities.

We have had personal experience of this in our own recent research in which we conducted a representative survey of 925 young carers in England (Joseph et al. 2019). Our approach to this was in two stages. First, we ascertained the percentage of children who provide some help, no matter how minimal, to someone in their home who was ill or disabled. We found that this was around 20% of all young people; these could, therefore, be classified as young carers in the very broadest sense. Second, using a standardised assessment tool that asks about caring responsibilities – a revised survey version of the Multidimensional Assessment of Caring Activities (MACA-YC18) – we ascertained the amount of caring that the young person did. We found that around 32% of the young carers were carrying out a "at least a high amount of caring" as defined by the assessment tool (7% of the total sample of all the young people), and 9% of young carers were classified as

doing a "very high amount" of caring (3% of all young people). It is this latter smaller group that we would expect are most likely to experience difficulties and be adversely impacted by being carers, but it was the first figure of 20% of all young people that attracted the media attention and that of the various agencies concerned with promoting the welfare of young carers. All of the figures, 20, 7, and 3%, are correct, but it is only through understanding how they each represent different populations that more nuanced policy can be developed.

Becker's (2000) definition that young carers are those that carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adults is often used. This is a broad definition, one which has come under criticism in recent years for a number of reasons; most notably that it excludes the impact of caring (Aldridge 2018). While we agree that bringing the focus on the impact of caring into the definition of what it is to be a young carer adds to the policy relevance, we would argue that this is too exclusive a definition. And, of course, children who provide care can still be categorised as 'young carers' even in situations where there are few negative (or positive) impacts. One definition is too broad whereas the other we would argue is too narrow. But more importantly, it changes the focus of policy interventions to help with the burden of care to reducing the impact of caring on the carer. Policy needs to be able to address all aspects of caring.

As such, we think scientific enquiry should define caring in the broadest sense to be most inclusive in the first instance of all children who take on some caring role, and to understand the gradations of care along the continuum. We propose that caring can be best conceptualised as three concentric circles. The largest is young people who care about, i.e., those who are helping a relative in at least some minimal way with household activities but not to a greater extent than many of their peers who are not carers. The next is young people who care for, i.e., those who have taken on a level of responsibility that involves household activities but also more specialist and medical roles, but not to an extent that it interferes excessively with their social and educational activity. Finally, young people who themselves need care, i.e., those who have taken on caring activities well beyond the level of their peers who are not carers, involving specialised and medical activities, emotional work, and which prevents the young person engaging in the social and educational activities of his or her peers. Each group has its own distinctive needs. Recognising this, policy targets can be more nuanced and responsive to the needs in families. In terms of policy and service goals, the implication would be to focus on prevention, assistance, and mitigation, respectively, as discussed by Purcal et al. (2012) in their analytical framework.

First, disabled and ill family members need to be provided with support such that children and young people are not required to provide care. This must always be recognised as a priority even if meeting such targets in full is unrealistic. Second, even if such support were available, because of family bonds and the wish to help, young people will always continue to provide care and they need support themselves to carry out their caring tasks. Resources need to be provided to young people to help them carry out their caring tasks. Finally, there is a need to be able to identify those children and young people under the most burden who are adversely affected and in urgent need of help not to support their caring activities but to support them and their mental health, education, and other ways in which they are impacted. Most often this will be to help with educational and psychological difficulties,

but in some contexts there may be physical risks. This more nuanced definition goes some way toward avoiding problematising the childhood of all young people who care.

Qualitative research with young carers themselves shows that they themselves feel that the best way that services can support them is to better support their cared for relatives (Moore/McArthur 2007). When asked about their own needs, young carers ask for assistance to participate in community life, to attend school, and to have opportunities to take a break from their caring responsibilities (Moore/McArthur 2007). These are intertwined policy objectives that need to be addressed simultaneously; research designed more explicitly to shape the policy agenda in all three ways rather than being responsive to a more simple notion of caring as a simple dichotomy.

As research moves forward, we must recognise the subtle gradations of caring and that no single definition is adequate. The terms young carer and young adult carer are broad descriptors only, as this is not one single population. We think our concentric circles model is a useful conceptual tool that encompasses different definitions and has clear policy implications.

Developing the international policy focus

Young carers are a global phenomenon and slowly, one by one, countries are beginning to respond to the challenges they face. There is a need to promote research to support and develop locally-based research and international comparisons. However, related to our discussion above, caring is a social construction that is understood in relation only to expectations of what are appropriate duties for a child or young person to take on. It is clear that we are coming from a frame of reference where it is seen as inappropriate for young people to take on unpaid roles of caring that are associated with trained professionals, but these expectations of normality vary from country to country. Thus, a single universal definition that allows meaningful comparisons across cultures is not possible, in the sense that in one culture a young person could be classified as a carer but not in another. Research which attempts such comparisons must be wary of cultural colonisation and exporting the expectations of one culture to another. In this respect, Robson (2004) in writing about the child carers in Zimbabwe states that there needs to be less emphasis on the ideas of childhood as a time of play and innocence and more emphasis on defending their rights to work and be supported in their work.

Young carers do not always self-identify as such, often viewing what they do as part of a normal familial relationship with bonds of reciprocity and love (Smyth et al. 2011); but on the other hand when they do recognise themselves as young carers it can be against a backdrop of expectations about what normal childhood is supposed to be like, thus seeing themselves as somehow deficient (O'Dell et al. 2010). Such a conclusion is borne out by research in a Western context but other research by Skovdal and Andreouli (2011) has shown how in Kenya, there is a different recognition of childhood, in which children are seen as active agents of community life.

Research must approach the topic from within each culture's frame of reference. As such, many factors can affect the policy response including the presence of country-specific research and local championing organisations. However, where resources are scarce, particularly in so-called developing countries, simply showing that young carers are present will not lead to a response – there are insufficient resources to provide support for that specific group. There is need for discussion on what sort of services and

interventions are necessary or appropriate. For example, do we need specific services that are tailor-made for young carers? Or can we use generic services to good effect? And when resources are scarce, how can they best be used to improve the lives of young carers?

One dilemma that arises from the research on young carers is whether children in countries which have no welfare benefits system should be paid for their role as carers so as to obviate their need for finding outside employment? But, if children are paid to continue to act as carers they may become locked in their caring roles and their access to schooling and education will be restricted. This limits their life chances and prevents them from achieving higher goals and better-paid employment. Such young people need appropriate support to break out of the spiral of poverty and caring, and enable them to achieve against the UN Convention on the Rights of the Child and Global Millennium Goals. Most controversially perhaps, it could also be argued that providing support for young carers in any country, rather than providing adequate care for the person they care for, also locks children into an inappropriate caring role and parents into a reliance on their children. Thus, while we think it valuable to use tools and methods that allow for cross-cultural comparisons in research findings, how these findings are interpreted and used by policy makers will not necessarily be the same. Each of our concentric circles has a different policy objective, but which of the circles is given prominence by policy makers and whether the focus is then primarily on prevention, assistance, or mitigation will depend on cultural understandings of childhood, the nature and extent of familial illness, and economic factors.

Ethics of developing the quality of methodology

A broad base of evidence around the nature of caring, its prevalence and potential impacts has been established. As discussed, small scale qualitative research has been carried out with groups of young carers identifying various difficulties. Some survey research has been able to produce figures that give some indication of how widespread problems may be, but on the whole, this work has been with small and selected samples that do not permit generalisation and importantly an understanding that the impacts actually arise as a result of caring. One approach to this latter issue has been to ask adults to retrospectively report on their experiences of caregiving (Lackey/Gates 2001) but while this adds weight to the observation that caring has consequences, it is methodologically limited.

Other statistical correlational research is able to show associations between variables. For example, social skills were found to be positively associated with a higher extent of caring activities (Kallander et al. 2018), but due to the cross-sectional nature of the study it is not clear if children take on caring due to their high social skills or if they develop social skills as a result of caring. Similarly, we know that many young carers experience bullying but what we don't know is whether their victimisation is a result of their caring and whether the extent of their victimisation exceeds that of young people who are not young carers. To find out we need prospective research and research that compares young carers with other young people.

To do this we also need new research that uses established tools that permit comparisons of findings to be made. In the past, much research has tended to use idiosyncratic measurement tools developed for single study use. However, various tools do exist, such as the Young Carers Perceived Stress Scale (Early et al. 2006), and

the Multidimensional Assessment of Caring Activities (MACA-YC18: Joseph et al. 2009b). The latter tool is widely used by carers organisations as it yields scores for a range of caring activities, i.e., domestic activity, household management, emotional care, sibling care, personal care, and financial and practical management. This makes it useful for assessment purposes when used by social workers and health professionals. It has been increasingly used as a survey instrument across different cultures, including the United Kingdom (e.g. Becker/Sempik 2018), Sweden (e.g. Järkestig-Berggren et al. 2018), and Switzerland (e.g. Leu et al. 2019). Increasingly researchers are in need of tools that allow comparisons to be made between young carers and their peers. As such, a revised survey version of the MACA-YC18 (Joseph et al. 2019) was developed to allow it to be used with all young people regardless of their caring role. The revised tool allows comparisons to be made between the everyday helping carried out by young people and those who are in a caring role. It is important to understand that many young people who are not in a caring role help around the home. Researchers need to understand what young carers do against the backdrop of the culturally expected and everyday level of helping by young people.

Tools to assess the effects of caring have also been developed, such as the Positive and Negative Outcomes of Caring (PANOC: Joseph et al. 2009a), which allows respondents to indicate to what extent they feel adversely affected on the one hand, and to have gained benefits, on the other. We think it is important to understand that caring can promote psychological growth for the young person. This is not to imply that we think caring is necessarily a positive event in the person's life, but recognises that in the struggles and challenges faced by the young person, growth can ensue. As such, a focus solely on the destructive aspects of caring is unbalanced and does not provide the scope to understand fully the ways in which policy interventions can be helpful. We think that policy should not be based solely on the idea of mitigation but also on promotion of positive psychological and educational factors. In this way, evaluations should assess not only that problems and difficulties are alleviated but also that positive qualities, such as resilience, strengths, and well-being, are fostered.

We believe greater methodological rigour is needed now to advance the field in the ways described above, but for us this is an ethical issue as well as a methodological one. There is a certain degree of saturation that seems to have been reached in the qualitative literature in describing the range of difficulties and problems encountered by young people who care. As such, we would argue that sufficient work that is essentially descriptive has already been carried out and future work needs to show clearly how it could add a step change to the body of knowledge. Otherwise, we feel research becomes increasingly questionable ethically, particularly in samples that may be upset by the research (Robson 2001), and who give their time without benefit to themselves or their families. The quantitative research is at a more developmental stage, particularly in producing generalisable findings, evidence of causal relationships between variables, and prospective research that can tell us about the impact on future adult life. Larger scale studies with representative samples to determine the extent and nature of the difficulties are needed. Small scale studies with selected groups of young carers simply cannot show conclusively the extent and nature of the problems faced by young carers as one homogeneous group. And as we discussed above in our concentric circle model, young carers are not a homogeneous group. The extent and nature of the problems will likely vary according

to the distinctive needs of each group. As such, while we make the same assumption ourselves that many young carers will likely experience damaged educational prospects, poorer mental health, and restricted life opportunities, and so on, questions about the extent of the difficulties faced by young carers demands larger scale quantitative evidence if they are to be taken more seriously by policy-makers.

More theoretically driven research

Evidence for the adverse effects of caring are limited in the ways described above, and recommendations for policy and practice currently often seem to go beyond the data, making assumptions that young carers will suffer from damaged educational prospects, poorer mental health, and restricted life opportunities. As discussed, there needs to be more rigorous quantitative work that allows for generalisability, understanding of causality, and long term effects; but alongside this there also needs to be greater theoretical sophistication. For example, one of the pressing questions is whether caring has a statistical association with adverse outcomes. As we have seen, research findings on the relationship between the amount of caring activity and measures of well-being and mental health are mixed. However, this is not surprising as we should not expect a straightforward linear relationship between caring and other outcomes. It is known from other areas of similar research such as the stress and coping literature that such a relationship is likely to be moderated and mediated by a number of other factors. To date, research has tended to give too little attention to moderating factors. We must recognise that caring takes place in a sociological context. It is a heavily gendered activity (Aldridge 2018) and influenced by the role of ethnicity, culture, support systems across schools, communities and helping professions (Kavanaugh et al. 2016). How caring activity relates to health and wellbeing is expected to be moderated by such factors, that we might predict strong relationships between caring activity and health and well-being outcomes in some groups but not in others.

As such, we need more theoretically driven approaches. For example, the stress process model used by Kavanaugh (2014) to take into account background factors, the primary stressors of caregiving, but also the secondary stressors such as school performance and parent/child conflict is one example of how research can be developed. Other research by Pakenham and Cox (2015) uses a family ecology framework which takes into account stress-appraisals, coping strategies, and coping resources. Their findings emphasise that higher caregiving responsibilities have direct and indirect adverse effects on youth mental health in the context of parental illness. We might also look to the literature on posttraumatic growth for inspiration on how different personality, social, and coping-related factors are likely to mediate and moderate the relationship between the experience of caring and positive outcomes (e.g. Linley and Joseph 2004).

In particular, we need to understand more about the psychological appraisal factors within the person that mediate their experience of caring. Qualitative research has identified the ways in which young people think about their caring experience, whether they see it as just part of their life, themselves as a caring person, whether they feel they have a choice, and the burden of responsibility they feel (McDonald et al. 2009). It is clear that these very idiosyncratic appraisals of what it means to be a carer, while well documented in the qualitative literature, have failed to translate into the quantitative social survey research as new variables

that can help to explain the complex appraisals that young people make that mediate the relationship between their caring role and other outcomes in their life.

In this way, there is a need to apply more sophisticated theoretical frameworks that can understand that caring and its outcomes are not necessarily as straightforward as has been assumed in some past studies, but rather only understood by a closer examination of moderating and mediating factors.

Young people and those they care for as active researchers

Research with young people most often involves negotiating access through gatekeepers who will often have reasons to refuse access because of fears of a child protection intervention, invasion of privacy, or for other reasons that are deemed to actually be in the best interests of the young person or the family not to take part (Kennan et al. 2012). As such, we believe an important innovation will be for young carers researchers to step back from taking an expert frame of reference. While we think there is a need for greater sophistication in research from the researchers frame of reference, as described above, we also see opportunities for more participatory action research that engages with the young carers themselves and their families, from their frame of reference, and in their perceived best interests. One study that offers a ground breaking example of more participatory research is that by Skovdal et al. (2009) in which young carers in Kenya used photography and drawing to provide accounts of their experiences. Their work helped to shift perspective from young carers as victims to competent social actors, and framed within a social psychology of coping. Other work of this nature has involved world café events led by young carers themselves providing insight into the here and now experiences of a group of young carers (McAndrew et al. 2012).

Participatory research with young people remains relatively rare (Raanaas et al. 2018) but finding ways in which research becomes more participatory, action-focused, and participant-led would seem to be especially responsive to what we have learned so far, in finding ways to engage more ethically with young people who care. However, as we know the time available to young carers to take part in other activities is limited, and as such their ability to participate in research will be constrained. In calling for more participatory research which is additionally demanding, we have an ethical duty to young people to provide sufficient resources so as not to add to their burden. Participatory research can be especially appealing to policy makers, more visible to the public creating awareness, and may also be helpful to the development and experience of the young carers themselves. We would encourage researchers and service providers to think about how a participatory research element can be built into existing and new plans.

Multi-agency and interdisciplinary focus

It has been argued that the concept of a young carer distracts from inadequate state services and legitimises abuse of children, and as such, the focus should be on helping parents fulfil their roles, not in supporting children and young people to be carers (Morris 1997). As discussed above, we agree that it is important that the research into young carers is not misused in this way and that full attention must be given to supporting parents, and other adults with illness or disability, as a first priority of policy. But research into the experiences of young people themselves shows that it is not helpful to see this issue dichotomously and that even if parents are fully supported those identified as young carers would contin-

ue to have their own needs for support (Thomas et al. 2003). Prevention, assistance, and mitigation/promotion require a range of disciplines and professionals to be involved, i.e., educators, healthcare professionals, community workers, and social workers, all of whom bring different skills and expertise (Warren 2007). When not viewed in this dichotomous way, it is clear that the field demands a multi-disciplinary and multi-agency approach.

A study conducted in Germany (Kaiser/Schulze 2014, 2015) showed that professionals working in education, health or social care only regarded support provided by inter-agency cooperation to be effective for children and adolescents who had caring responsibilities and who had problems with school attendance. However, issues of professional confidentiality and the private (and hence invisible) nature of children's caring roles undermined inter-agency working and support. Social workers have a central role as they are the most likely to be working with families of ill and disabled people. Educators and teachers must also be involved as they are in direct daily contact with young people. Within school contexts, ensuring that confidential guidance and counselling is available may be helpful given the often covert nature of caring which may prohibit the use of other services (Banks et al. 2002).

The recognition of the need for a multi-agency approach is mirrored in the need for interdisciplinary research. Each scholarly discipline brings with it its own set of assumptions and positionality. For example, sociologists may conduct research which emphasises the gendered nature of caring and the role of public policy in providing solutions to what are seen as culturally created problems. Psychologists may approach the topic from the perspective of the individual studying, for example, processes of coping and resilience, with suggestions for how clinical or counselling psychologists can be more involved.

But the topic of young caring crosses disciplines of sociology, psychology, as well as education, public policy, social work, law, medical ethics and others, and thus demands greater interdisciplinary working and awareness. For example, interest in resilience and coping may be a helpful line of investigation, but only if it is not at the expense of helping parents fulfil their roles. What we are suggesting is that truly interdisciplinary research is able to offer the bird's eye view on any research and how its significance is positioned within the larger field. Related to this is that the professional groups traditionally involved with young carers tend to adopt an approach grounded in an illness ideology, so policy and practice can become overly driven by a focus on the pathological. While there is a role for this, research also stresses the personal growth, maturity, and identity formation processes pointing to the development of positive psychological and positive educational interventions, which we believe need to become more prominent as we move away in our thinking from an illness ideology that pathologises young people who care. We need to do more than help young people cope, deal with the stress, and so on; we need to help them flourish.

Conclusion

We aimed to provide a critical discussion of the issues and challenges facing young carers researchers in the coming years and to provide directions for how the field now moves forward. First, we proposed a new concentric circles conceptualisation of caring that recognises that the policy targets for all young people will not be the same. A broad definition of caring must inevitably be at the heart of public policy if it is to help address the complex

web of the different needs of families to reduce the burden of care, support young people who care, and address the problems that arise from caring. But a broad definition covers caring in all its forms as if these young people belong to one single population. There are different groups of carers within this wider population. Second, each of the groups represented by our concentric circles will have a different policy objective, but which of the circles is given prominence by policy makers and whether the focus is then primarily on prevention, assistance, or mitigation will depend on cultural understandings of childhood, and social and economic factors in each country. Third, there is already much research of a small scale and descriptive nature that we would now question the ethics of further research which does not offer advances that build on this previous research. There is a need for greater methodological sophistication in research to produce results that are generalisable, able to show the causal relationships of variables, and the longer term prospective impacts. Fourth, more theoretically-driven research is needed. It is clear that not all young people who care have difficulties in health, well-being or education; for some it is likely that the experience of caring is beneficial to them and leads to a maturity and competence in the world that serves them well. To date, the picture painted has been a simplistic one that caring is necessarily harmful. It is not, but it can be, and we now need to understand the mediators and moderators that influence the relationship between caring and these outcomes. Fifth, we see a real problem if there is only research from the researchers' frame of reference and call for participatory and action led research that can provide greater insights into the lived experiences of young people, their needs and how these can be met. Finally, such research must come from all disciplinary corners so that we do not lose sight of the social and cultural process at the expense of psychologising young caring with concepts of coping and resilience, and vice versa, we must not lose sight of the psychological. All disciplines have their approach, and research from any disciplinary corner has inbuilt assumptions for policy and practice, which we now recognise has to be multiagency involving schools, universities, health services, social services and professionals from education, psychology, and social work.

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Eurocarers' Policy Paper on Young Carers*

by Eurocarers – European Association Working for Carers

Abstract: Demographic ageing in Europe is leading to an increasing need for care and a serious challenge for the sustainability of our social and healthcare systems. Informal carers across the EU currently provide over 80 per cent of all care. If not adequately supported, caring can have many difficult consequences for carers. Carers should not be socially and economically penalised as a result of their caregiving activities. Measures designed to support them should therefore aim to recognise them and their vital role in society, provide them with the essential information and counselling they need, give them access to allowances that offset the costs they face and truly values their contribution, develop flexible working arrangements and care leave schemes to allow them to maintain an active life, and improve the provision of equitable and accessible formal care services to ensure carers can rely on professional alternatives to informal care. This policy paper outlines the unique challenges faced by young carers and underscores the significance of addressing them. It briefly discusses different forms of support measures and makes recommendations for better support for Young Carers.

Keywords: young carers; adolescent young carer; policy paper; informal care; family care

Introduction

Europe's demographic ageing gives rise to a growing prevalence of age-related diseases, a growing demand for care, and a serious sustainability challenge for our social and health-care systems. Against this backdrop, community care [1] has become a prominent EU priority in the last few years and the shift towards home-based care is seen as a practical measure to contain the costs of services while also seconding widespread preferences among the elderly for being cared for in their own home.

Informal carers across the EU currently provide over 80% of all care, with women providing approximately two thirds of care, mainly as daughters (in law) and wives/partners. Even in countries with a well-developed supply of formal long-term care, using narrow definitions of informal carers, their number is estimated to be at least twice as big as the formal care workforce. Advances in medicine also mean that carers find themselves having to deliver more and more sophisticated levels of care, with very little training and minimal support. Caring can have – if not adequately supported – many challenging consequences for the (physical and mental) health and well-being of carers, their capacity to balance paid work with care responsibilities, their financial situation, their social integration as well as their access to employment and education.

We strongly believe that people should have the right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring; people needing care should have the right to choose who they wish to be their carers. Carers should not be socially and economically penalised as a result of their caregiving activities. Measures designed to support them should therefore aim to recognise them and their vital role in society; provide them with the essential information and counselling they

need; give them access to allowances that offset the costs they face and truly values their contribution; develop flexible working arrangements and care leave schemes to allow them to maintain an active life; and improve the provision of equitable, accessible and good quality formal care services to ensure carers can rely on professional alternatives to informal care.

Background

Definition of young carers and young adult carers

Young carers are “children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that 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”.

Young adult carers are people aged 18-24 who provide or intend to provide care, assistance, or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child, or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support, or supervision [2].

When young carers are mentioned, young adult carers are generally also meant, unless the context indicates otherwise or the publication is with limited data relating only to young carers.

Young carers and young-adult carers may undertake a wide range of caring responsibilities including practical tasks (such as cooking, housework, and shopping); physical and personal care (such as helping someone out of bed or helping someone dress); emotional support and supervision; managing the family budget and collecting prescriptions; helping to give medicine; or helping someone communicate. Being a young (adult) carer can have a big impact on different aspects that are important to growing up. It can affect a young person's health, social life, and self-confidence – over 45% report that they have experienced a mental health problem. Many struggle to manage their education, working life and caring role, which can cause pressure and stress [3].

Very often families view caring as an extension of family or personal relations rather than as a distinct type of ‘care giving’. Research has shown that in a situation where a young person may be caring for someone who has mental ill-health or who misuses drugs or alcohol, they are less likely to be identified as having caring responsibility within the family. This contributes to the self-awareness issue, meaning that children and young people themselves might not be aware of being carers.

Although there is currently very limited data regarding the number of young (adult) carers across Europe, some national statistics and pilot projects have helped to unveil a substantial – and yet largely unknown – population group. The 2011 Census in the UK, which included an unpaid care question, allowed to collect

statistics about ‘young carers’, i.e. children and young people aged 5 to 17 who provide unpaid care for family members, friends, neighbours or others because of long-term physical or mental ill-health, disability, or problems relating to old age. In 2011, there were 177,918 young unpaid carers in England and Wales. Of these, 54% were girls and 46% were boys.

An increase in the number of unpaid carers aged 5 to 17 was observed in all regions between 2001 and 2011. In England and Wales combined, the number of young unpaid carers increased by almost 19% during this period.

In Ireland, the 2016 Census [4] showed that 3,800 children under 15 years of age engaged in providing care to others, accounting for 1.9% of all carers. Half of these children (1,901) providing unpaid care were aged 10 and under.

According to the 2016 Census in Ireland:

The number of hours care provided per week by children under 15 is 42,227.

The number of hours care provided per year by children under 15 is 2.2 million. [4]

In Italy, young people (15-24 years) with caring responsibilities are thought to number 169,000 (2.8% of same age group) [5] while in the Netherlands nearly one in ten adolescents (13-17 years) live in a household with a chronically sick family member and 65% of them provide help [6]. In Sweden, the only survey study available indicates that 7% of all children aged 15 years carry out ‘substantial amounts’ of caring [7].

Although there are no precise figures about how many young carers there are across Europe today, the above-mentioned data suggests that about 7-8% of children in Europe will have caregiving responsibilities. These are children who are largely invisible to public authorities, social policy and interventions from health and social care services.

The impact of caring

There is no doubt that both young carers and young adult carers are at risk of mental ill-health as a result of their caring situation, and especially among high-intensity young carers [8]. Statistics show that young people with a sick family member tend to have more mental health problems and more adverse outcomes in behavioural, psychosocial, and academic adjustment than their counterparts without a chronically ill family member. Those effects mainly manifest themselves in lower life satisfaction and internalised problem behaviour such as feeling depressed, being withdrawn, and anxiety. They also report a greater need for and use of help and support. The caring tasks often impact on the personal spheres of young people’s lives, such as their education, social participation, and personal development [9]. Furthermore, young adult carers deserve attention, as they are in a delicate transition phase (18-25 years) where they may have to reconcile new life challenges with caring tasks, such as entering the labour market, attending university courses and/or starting their own family [10]. The nature of the care tasks provided also seems to make a difference: adolescents who provide parents with emotional support or personal care reported more mental health problems than those who perform other tasks. Performing domestic tasks is found to be a predictor for overall mental health problems. The intensity of the help given is related to the need for help by the adolescent. It is concluded that growing up with a chronically ill family member and spending a lot of time performing (domestic) tasks are

risk factors for adolescents developing mental health problems and adolescents’ need for help [11].

Being an adolescent young carer is recognised as a risk factor for mental health and well-being, with around 50% experiencing care-related stress and 40% experiencing mental health problems [12].

The most common worries expressed by young carers concern the health of the person being cared for, their own health, who will look after them (if their parent is hospitalised for example), school work, money, bullying, and having no friends. Their most common problems relate to sleeping, suicidal thoughts, self-harm, and eating disorders.

Research has also highlighted a high level of concern regarding young carers and education. The major educational difficulties identified concern punctuality, attendance and problems with homework/coursework. Additional problems cited were difficulties joining in extra-curricular activities, low attainment, anxiety, and fatigue [13].

It is nevertheless important to note that not all young carers will experience all of these difficulties, depending on the availability of support and adaptational strategies; indeed some will have no educational problems at all. Educational disadvantage can be viewed as a continuum ranging from ‘severe’ at one end, through ‘moderate’ and ‘occasional/less severe’, to ‘no obvious impact’ at the other end.

Research has also shown that – provided adequate support is available – the young carer’s personal capacity may be enhanced as a result of caring, so positive aspects may co-exist with the negative effects of caring [14]. For instance, young carers may gain satisfaction from caring [15] and experience a range of enhanced emotional aspects such as self-mastery, self-esteem, maturity, and empathy, together with a greater repertoire of coping strategies [16]. Living with and making allowance for a sick family member on a daily basis can help young people learn to be more understanding and tolerant of (the feelings of) others. Looking at the positive as well as the negative aspects is important for an understanding of what it means for adolescents to have a chronically ill relative at home and to develop interventions to improve the support for them.

Resilience

The ability of the young carer to adapt himself/herself to the challenging situation of caring is defined as resilience and is a crucial factor influencing the coping strategies he/she develops and applies, with subsequent effects on personal well-being. However, it should be remembered that resilience has clear limits and may be not sufficient to guarantee good mental well-being if the situation and risk factors become prolonged in time and intensity [17]. A range of factors have been identified as relevant for promoting resilience across a child’s lifespan [18], and these include, for instance, the presence of strong social support networks, a strong supportive parent (or other relative/significant other), a committed mentor outside the family, a positive school and extra-curricular experiences, mastery and belief in own capacity, self-recognition and re-framing of one’s own situation. The promotion of resilience might pass through different types of interventions [19], focusing on (1) reducing or preventing risks, (2) improving asset resources for adaptive functioning (e.g. access to healthcare, tutoring), (3) enabling adaptational strategies for positive development.

Why the need to address the challenges faced by Young Carers?

Our vision: children have the right to...

Eurocarers strongly believes that everyone – and especially young people – should be protected from any kind of discrimination resulting from their caregiving activities and should benefit from equal opportunities to realise their full potential through social inclusion, education, and employment. In that spirit, the England Care Act 2014 Statutory Guidance defines caregiving activities that are likely to have an impact on the child's health, well-being or education, or which is unsuitable for that particular child as 'inappropriate' or 'excessive'. We therefore call on policy makers to introduce specific positive actions to ensure that young carers and young adult carers' rights to have access to education [20] and employment, to the highest attainable standard of physical and mental health, to (social) participation, to an adequate standard of living and to a family life be respected.

This demand is also in line with the UN Convention on the Rights of the Child. It states, inter alia, that every child has the right to rest and leisure (article 31), education (articles 28 and 29), an adequate standard of living (article 27) and the right to the highest attainable standard of health (article 24). The (daily) challenges and difficulties faced by young carers and young adult carers often stand in the way of exercising their rights. Therefore, they need additional and tailored support measures to ensure that the equality principle is respected [21].

The human rights argument forms the core of our vision. Yet, other forms of argumentation, such as the economic argument, also correctly highlight the need to address the challenges faced by young carers. The economic argument is perhaps overly prevalent in policy debates, but remains very convincing.

Investing in children and young people is a social investment

It is well accepted that prevention is the best medicine. As a consequence of this, we should favour policies that aim to strengthen people's current and future capacities by helping them to 'prepare' for life's risks rather than simply 'repairing' the consequences. Such policies should be seen as social investment. This means taking into account the risks and needs of individuals throughout their entire life, and investing in children and young people, are perhaps some of the best social investments. There is indeed ample evidence that, due to its strong multiplier effect, social investment not only pays off for children individually but also for society as a whole.

It is in that spirit that in 2013 the European Commission adopted the Recommendation 'Investing in Children: Breaking the Cycle of Disadvantage' which was supported unanimously by all European member states. The recommendation states that "breaking the cycle of disadvantage across generations requires an integrated approach focused on children and their families. This means identifying and removing structural barriers and combining prevention and support". The recommendation underlines the need for equal access to inclusive and non-segregated quality education as well as for strong family support. The impact of informal care on young people's life prospects and well-being is a perfect example of the structural barriers mentioned in the recommendation. We can easily make use of this political instrument to advocate for the recognition and support of young carers through a combination of universal and targeted approaches.

Early school leaving is an obstacle to economic growth and employment

Along the same lines, the European Commission has identified early school leaving as an obstacle to economic growth and employment. It hampers productivity and competitiveness, and fuels poverty and social exclusion. Young people who leave education and training early are bound to lack skills and qualifications, and face a higher risk of unemployment, social exclusion, and poverty. This has been recognised in Europe's overarching strategy for smart, sustainable, and inclusive growth – the so-called Europe 2020 strategy, which has set the goal of bringing the share of early leavers from education and training among those aged 18-24 to below 10% [22]. Still, in 2015 there were more than 4 million early school leavers across Europe, only 40% of whom are employed. The 2013 Youth Guarantee Council Recommendation commits EU Member States to ensure that every young person under 25 receives a good quality offer of employment, training, traineeship or apprenticeship within four months of leaving education or becoming unemployed. Now, research has not only highlighted the educational difficulties that many young carers face, we also know that access to employment, training or apprenticeship will only be possible if alternative care options are provided to the caree. So, the fight against early school leaving is also a powerful message to be used for the benefit of young carers.

Poor mental health is a cost for societies

Evidence shows that improved mental well-being during childhood and adolescence has a broad range of impacts across the life course including the prevention of mental disorders. This is important since mental disorders account for one of the largest and fastest growing categories of the burden of disease (OECD 2011), in part because up to 50% mental disorders experienced across a lifetime arise before adulthood [23]. Effective interventions exist to treat mental disorder during childhood and adolescence, prevent it from arising, and also to promote mental health with economic savings even in the short term. However, the majority who would benefit do not receive such interventions which has a broad set of impacts and associated economic costs [24].

It is in that spirit that the Joint Action for Mental Health and Well-being recommends that Member States:

- Promote schools as a setting where the promotion of mental health, prevention of mental and behavioural disorders and early identification of mental disorders can reach all children and young people.
- Strengthen information about the levels of well-being and different mental disorders as well as coverage and outcomes of effective school based public mental health intervention.
- Enhance training for all school staff on mental health and consider schools as part of a wider network with other stakeholders and institutions involved in the mental health of children and adolescents in local communities.

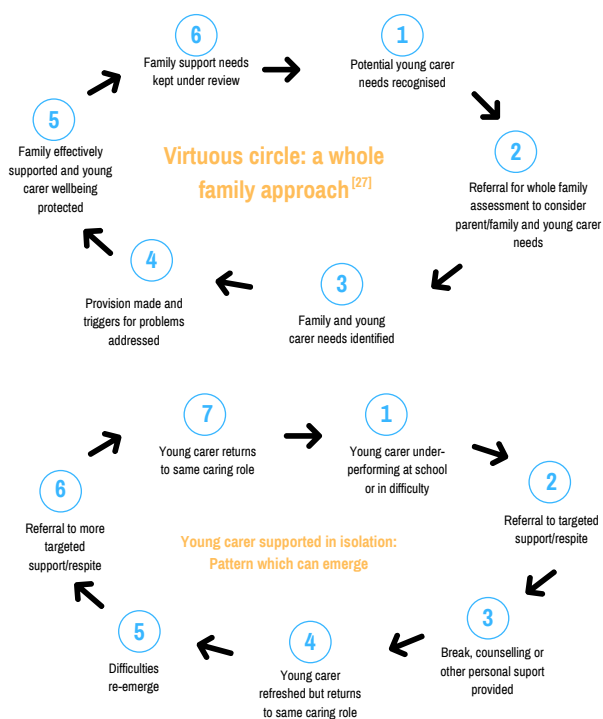
Given the impact that caring responsibilities can have on young carers' mental health and well-being, it is evident that a preventive action aimed to avoid the negative consequences of caring on young people's health is also an effective way to save society the costs of increased health care.

“A Swedish study revealed that the long-term extra-societal costs for children of parents with mental illness and alcohol or drug abuse is 3.5 billion Euros per year” [25].

The measures of support

Overall, there are two main elements with regards to support for young (adult) carers. Firstly, it is crucial to boost the provision of more adequate and intensive formal care services to the cared-for person (enabling respite and better time management of the young carer). We acknowledge that the level of impairment of the cared-for person (usually a parent) and the lack of formal care services received or available are among the main root causes of young people assuming a caring role. However, it is important to note that, despite good faith and will of professionals, some families may resist formal care services for a variety of reasons, including the fear that family members may be separated or that these services may be insufficient to relieve the young carer of his/her caring responsibilities. Furthermore, they might be limited if legal and policy frameworks at country and regional levels do not support these services adequately and/or consistently.

A second option is the provision of direct support to the young carer through training, counselling, psychological and emotional support, following an initial needs assessment by formal services, based on a ‘whole family approach’ [26] which looks at the needs and views of all individuals within the family. The added value of this assessment lies in the possibility to identify health and social needs of care recipients, carers, and the family as a unit. In doing so, this approach contributes to a ‘virtuous circle among services’ which in turn contributes to positive mental health in young carers [27]. The main aim, therefore, is to ensure that services focus greater effort on early intervention and prevention and that they do so by providing properly integrated support around both the person cared for and the family as a whole. However, a limitation is that often young carers lack sufficient information about the services available, and lack awareness of where they can find support outside the family and close networks. Furthermore, they may be too overwhelmed by their caring activities to be able to seek external help or may fear to reveal themselves to ‘not be good enough’ at caring.



Preventative measures are very important to young carers as they can help them to overcome the barriers that are preventing them from accessing positive activities – for example, transport issues or emotional issues related to the anxiety felt by the young carer on leaving the cared for person. Practical (e.g. transport, phones for communication) and emotional support (e.g. building relationships with all family members to ease the anxiety felt by the young carer) can contribute to overcoming these obstacles. Interviews with practitioners and young carer families suggest that engaging young carers in positive activities can effectively address the social isolation they experience. Young carers themselves say that it gives them the opportunity to make new friends and talk to young people in a similar situation to themselves, which in turn helps reduce their levels of stress and anxiety [28].

Recommendations

Ensuring that young carers are identified, their needs are addressed, and the needs of the whole family are assessed requires good joint working between adult and children’s services. Interventions focusing on young carers should follow the following approaches during the various phases of family support or strategic change in the services [29]:

Delivering strategic change

Improving awareness and the identification of young carers

As has been detailed, a lack of identification of young carers means that young people are more likely to take on inappropriate caring roles. Many young carers do not recognise that they are a carer and may not be receiving appropriate support. Furthermore, practitioners across adult and children’s services do not always have a clear understanding and awareness of young carers and how their caring role impacts on their lives, particularly in families where the young carer is caring for a family member with alcohol/substance misuse or mental health issues. Therefore, a key focus of the work undertaken should be to raise awareness of young carers in order to improve identification and ensure that young people and families receive appropriate support. Schools play a vital role in both early identification and in the provision of support for young carers and their families. The desired outcome is that children and young people are able to engage fully with the educational and social opportunities available to them. A key focus should therefore be in developing work with schools. A range of strategies can be used to raise awareness of young carers in schools, identify potential hidden young carers, and provide appropriate support, including:

- Raising the pupils and staff’s awareness of young carers through assemblies, curriculum development, and class based work.
- Providing opportunities and activities where children and young people can identify themselves as young carers.
- Providing training for school staff on addressing and supporting the needs of young carers and their families.

Adult services also have a critical role to play in identifying young carers, particularly given the numbers of children and young people caring for a family member with mental health problems and/or issues of substance misuse. Thus, initiatives should focus on developing links with adult services in order to raise awareness and improve identification. This work should also focus on increasing agencies’ awareness of the support available and the benefits (for adults, children and young people, and services) of taking a family focused approach.

The experiences, needs, and preferences of young carers have been highlighted in various ways by different campaigns in countries such as the United Kingdom [30]. For example, those promoted by Rethink, The Children's Society and Carers Trust [31], as well as the initiatives of the Carers Strategy for Scotland (including individual services and national camps and fests for young carers). Researchers found, by working with young carers [32], that there are some positive examples of good practices which include:

- Young carer groups, young carer forums and young carer days, which help encourage young carers to socialise and help each other, building trusting relationships with peers and staff in a safe environment.
- Awareness campaigns, which often provide information packages, DVDs, websites for raising awareness of young carers, especially in the school context.
- Key workers or outreach workers, who are perceived as befriending and help facilitate skill development for caring tasks.

Individual and group support for young carers can also be based on information and communication technologies (ICTs), like the good practices of the Young Carer App developed by the Carers Federation in the UK [33]. Effectiveness of ICT- and web-based interventions for young carers is still a research issue [34].

Improving integrated working across services, for example adult and children's services, and the health and voluntary sectors

A key component of the whole family approach is to bring together services from different sectors to work more effectively together (for example adult services, children's services, and the health and voluntary sector). This can be implemented through joint planning and commissioning as well as training to improve communication between key partners. Joint planning can make services more flexible and responsive to the needs of all family members, whilst joint commissioning can be cost effective in reducing possible duplication across services.

Joint working requires effective communication and cross-agency support. Staff need to be able to refer young carer families to a range of different services; share information on family need; and review families' progress with the support on a regular basis. Nevertheless, cross-service communication can be hindered by a lack of staff awareness about family issues outside their own service remit and how to address them effectively; and the processes and systems that operate within other services and agencies. This can make staff feel uncomfortable in engaging with and supporting wider family members and may lead to a misinterpretation/misdiagnosis of need. A lack of awareness of the support available from other services means referrals may not always be appropriate and limited awareness of referral mechanisms can make appropriate referrals more difficult. Moreover, the different language and terminology used by different services and agencies can make it difficult for practitioners to accurately communicate and plan effective support for a family.

Delivering family-focused support

Assessment: In order to provide a holistic package of family focused support that meets the needs of all family members, it is important to have an understanding of the needs of the family as a whole. It is therefore important to develop a whole family approach in assessment, enabling both the individuals who need support and those who will support them to identify their own needs and desired outcomes. This is much more likely to result in individual care packages that can be sustained effectively. A

whole family approach will also minimise the risk of young carers feeling forced into undertaking inappropriate caring roles. **Planning and review:** Some existing initiatives (in the UK) are using Team Around the Family (TAF) approaches to bring practitioners who are supporting the family together to provide a coordinated and integrated response to meeting families' needs. This is reflected in the development of integrated care plans and joint delivery across services. The aim is to bring services together and increase joint working and information sharing in order to improve support for families.

Delivery: Key workers can act as case managers and provide (where appropriate) intensive, one-to-one support for the family, providing emotional and practical support, identifying additional support needs and co-ordinating support from other agencies. Practitioners are also encouraged to give young carers a voice by involving them in the overall design of local care provision and in planning individual care packages. Individual communication with young carers and enabling opportunities for young carers to know each other and to meet are also important.

Primary prevention interventions for young carers

From a social work perspective, preventive interventions for young carers can serve to [35]:

- Prevent growing numbers of children who need support as carers.
- Benefit disabled or ill parents and families as a whole.
- Relieve the financial burden on support services presently in place to help children who are already caring.

Findings from interventions targeting social and emotional skills of the young carers pointed out that some types of interventions have positive outcomes on young people's mental health, among others. In this respect, social and emotional skills are defined as a set of interrelated cognitive, affective, and behavioural competencies [36]: self-awareness, self-management, social awareness, relationship skills and responsible decision making. The following available evidence was identified [37]:

- *School programmes:* Their effectiveness relies on the focus on teaching skills, the use of competence enhancement and empowering approaches, the use of interactive teaching methods (including role play, games and group work), well-defined goals and use of a coordinated set of activities to achieve objectives, provision of explicit teacher guidelines through teacher training and programme manuals. These have proven useful to reduce behavioural problems, including aggressive and disruptive behaviours, bullying and victimisation as well as risk-taking behaviour (e.g. alcohol, cigarette and drug use).
- *Out-of-school programmes:* Their effectiveness relies on having specific and well-defined goals, a direct and explicit focus on desired outcomes, provision of structured activities, training of facilitators and use of a structured manual and implementation over a longer period of time. These have proven useful to enhance young carers' skills including self-esteem, confidence, emotional regulation, organisation and leadership, self-worth and relationship with peers and parents.

Key messages [38]

To local, regional, national authorities:

- Identify young carers as early as possible (via improved vigilance and screening tools of professionals).
- Assess young carers' needs and preferences together with the ones of other family members (whole family approach).

- Provide support that is flexible. Indeed, caring can be variable over time. Hence, the system has to be reactive, flexible and proactive. The initiatives carried out by the volunteer sector should be embedded in the system.
- Reduce barriers in accessing support and services and empower young carers to access the system.
- Adopt a lifelong approach, focusing on specific needs at specific times. This approach will ensure that the different needs of young carers and young adult carers are taken into account.
- Improve referrals and collaboration between professionals from different services (youth, education, care, health, family).
- Create a 'market' willing to support young carers.

To the EU

- Support further research on the profile and needs of young (adult) carers.
- Ensure existing good practices are disseminated and made visible across Europe.
- Make use of instruments at hand – i.e. European Semester, European Structural and Investments Funds, European Platform for Investing in Children, Youth Guarantee and Open Method of Coordination – to promote the development of integrated approaches for the identification, support and social integration of young (adult) carers across Europe.

To schools

- Insert the topic of young (adult) carers in the curricula.
- Establish a clear framework of support for young carers, which is embedded into the school's policies and communicated to parents.
- Appoint carer leads to assist young carers so that they can achieve their true potential.
- Put better systems in place to identify young carers and review the impact of caring on their educational performance and attendance, leading to appropriate personalised support.
- Record 'absence due to caring role' as a specific category so that data can be collected and statistics can be analysed.
- Implement a policy and strategy for dealing with bullying of young carers.
- Ensure that young carers receive a regular review of their own needs, by proactively making certain that appropriate action is taken by appropriate services.
- Support young adult carers in the transition to employment.
- Adapt school methodologies so that they can meet young carers' needs.
- Create new opportunities for peer recognition and awareness of young carers among school pupils.
- Make young carers more comfortable at school, satisfied with education, and avoid drop outs.
- Increase the educational and social environment for young carers at school and combat their social exclusion, loneliness, social stigma, unmet educational and support needs (for instance, ensure young carers do not miss out on out of school activities).

To career advice services

- Ensure that advice given adequately addresses and takes account of caring responsibilities.
- Provide clear information about the financial support that exists for young adult carers going to college and university.

- Put in place procedures so that young adult carers know who to tell, how to access services and support and are aware of the nature of the support they can receive.

To general practitioners, health and social care

- Establish systems to identify and regularly assess the health-care and social needs of children and young people in families where family members are experiencing ill health or disability (alongside the needs of their family members).

To young and young adult carer support services

- Help young people access service and information and facilitate contacts with local authorities and service providers.
- Enable young carers to access relevant training to help them in their caring roles.
- Work in co-operation with adult service providers to ensure that disabled or ill parents receive adequate support, thus reducing the need for children and young people to provide care.
- Offer non-formal education, personal development opportunities (to build young carers' confidence) and be a place of welcome where young carers are valued and supported.
- Make young carers aware of what opportunities the young services offer and of practical measures that can support their participation in the youth group (for example, by covering transports costs or facilitating travel arrangements etc.).

To the media

- Raise awareness on young carers and act against the stigma.

To civil society

- Engage media to raise awareness and contrast the stigma.
- Raise awareness in public and in professional workforce.

To young carers

- Be proud of your caring responsibilities, do not be ashamed!
- Don't hesitate to speak up and communicate your needs!
- You are not alone!

* This article was first published 2017 on the website of Eurocarers. <https://eurocarers.org/publications/eurocarers-policy-paper-on-young-carers/>. Individual formal adjustments were adapted to the IGJR specifications and the references were updated and supplemented. The table of contents of the policy paper has been removed. An abstract was added. The original system of endnotes has been retained and supplemented. Eurocarers receives support from the European Union through the European Social Fund + (ESF+) Programme. More information on Eurocarers under: www.eurocarers.org.

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Livia Ester Luzzatto: Intergenerational Challenges and Climate Justice: Setting the Scope of Our Obligations

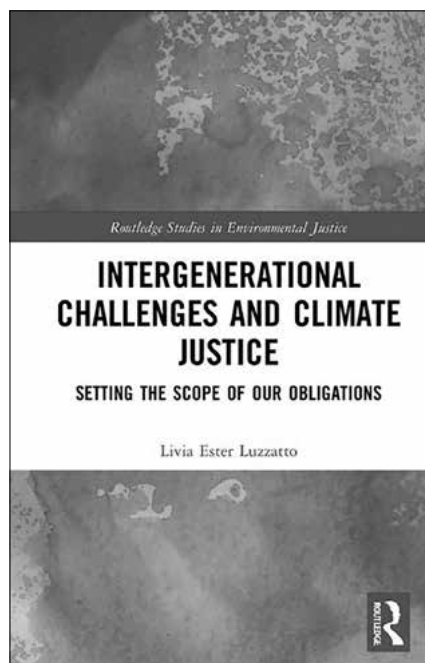
Reviewed by Zachariah Taylor

At a time when the severe impact of human actions on the Earth's climate are unmistakably taking hold, a contribution such as Livia Ester Luzzatto's to the field of intergenerational justice could not be more urgent. Luzzatto's career researching the intersection between climate change, ethics, and business challenges and working as a sustainability consultant has thus far aimed at dealing with this challenge. Entitled *Intergenerational Challenges and Climate Justice*, Luzzatto's monograph endeavours to outline the scope for a theory of climate justice. More specifically, the author considers the extent to which as well as the reason why present generations have distinct obligations to future generations, and in what ways these future oriented commitments could form the basis of an intergenerational theory of climate justice. Luzzatto's account primarily focuses on justice as opposed to beneficence, and she considers collective agents instead of individuals as duty-bearers. In adopting an action-centred methodology, Luzzatto hopes to overcome the typical objections raised against numerous theories of intergenerational justice. The proposed methodology takes into consideration not only intergenerational actions themselves and their potential outcomes, but also the presumptions underlying such actions.

The central contention advanced by Luzzatto consists of three desiderata. An account of the scope of climate justice must be able to i) accommodate uncertainties surrounding future climate change related risks and mitigating activities; ii) be able to respond to climate change as a complex problem of justice; iii) include each future person for their own sake as an end in themselves (16-18). Accordingly, the structure of the monograph follows these three key requirements.

Before getting into the details, it should be noted that the book is positioned within the literature of intergenerational justice and moral theory more broadly. As a deontological account of the scope of climate justice, Luzzatto sets the argument against universal consequentialist accounts of justice; in particular, against classical utilitarianism. This deontological stance circumvents the non-identity objection as well as the non-existence argument.

Dealing with the first desideratum, the uncertainty of climate change after setting the scene, Luzzatto highlights two conditions for an account of scope to be able to deal with uncertainty: i) it must take "each risk-imposition and its justification as the subject of moral evaluation" and (ii) these risks must be understood to give rise to obligations of climate justice if they are both "foreseeable by a reasonable agent at the time of acting, and expose others



to risks to their autonomy-relevant conditions" (25). This argument highlights the difference between our obligations to deal with uncertain risks (about which it is difficult to assign probabilities) and what she describes as 'foreseeable' risks (risks with more easily calculable probabilities). To demonstrate this difference Luzzatto employs two examples, that of an asteroid collision and that of the melting of the West Antarctic ice sheet. While we have reason to believe that an asteroid could collide with Earth and cause a 'doomsday' scenario, Luzzatto writes that it is hard to assign it an exact probability, nor to calculate if our attempts to mitigate such a risk would be effective if it came to pass. In the case of the Antarctic ice sheet on the other hand, while the exact likelihood of it melting entirely remains unclear, it is clear that our actions are increasing the risk of it melting. As we have knowledge of our actions and their consequences in the latter

case, Luzzatto argues that we can assign responsibility and fault to current generations, but not for an eventual asteroid collision where there are more uncertainties.

Luzzatto makes clear and careful justifications of her analytical choices in the book when rejecting consequentialist accounts of climate change for being both over- and under-inclusive. She considers them overinclusive in that they require individuals to consider all of their actions as possibly inducing risk, meaning they cannot adequately distinguish where there is a duty of justice. On the other hand, these accounts (specifically classical utilitarianism in this case) are considered underinclusive for their inability to effectively distinguish between issues of moral relevance to future people. Luzzatto argues that in undertaking actions which contribute to foreseeable risks, the risk-imposing agent presupposes a greater importance of their interests than those of the (future) risk-exposed other. This presupposition is an issue of moral relevance. In addition to being action-centred, then, an account of the scope of an extension of a theory of justice to intergenerational climate change must also be normatively accurate in identifying morally relevant features of our actions.

The second requirement for the scope of an intergenerational theory of climate justice is its ability to acknowledge and adequately account for climate change as a complex problem of justice. In the third chapter, Luzzatto invokes the contrasting views of Dale Jamieson and Stephen Gardiner concerning morality and climate change. On the one hand, Jamieson argues that current moral values and concepts are incapable of dealing with global intergenerational problems such as climate change. Gardiner, on the other

hand, takes a more moderate view than Jamieson, stating that the problem lies not in a lack of terms, but our inability to access the relevant norms of climate ethics. Despite differences in their conclusions, both emphasise the limitations of current moral theories to respond appropriately to climate change.

Luzzatto tends to concur with Gardiner and continues a similar vein of argument. She discusses intergenerational actions (IGAs) as the empirical basis for the proposed account of scope, as well as going on to propose a requirement for coherence and a normative requirement for intergenerational obligations. These requirements both equally involve the application of present values and concepts onto future agents. The coherence requirement stipulates that, because our actions rely upon the assumption that future people are agents, we have an obligation to acknowledge them as such when considering climate justice. Adding to this, the normative requirement states that “insofar as we are committed to basic norms of justice requiring equal respect for agents and their conditions of autonomy, we must extend these entitlements to future agents presupposed by our actions” (68).

The final desideratum Luzzatto establishes for her theory is the inclusion of future people into the scope of an intergenerational climate justice for their own sake, as ends in themselves. In order to argue for this criterion she employs Samuel Scheffler’s view on the value of the concept of a ‘collective afterlife’ for *present* people as a complimentary contrast. For Scheffler, present generations are actually reliant on future generations to provide sustained meaning to their current projects. In other words, the existence of future people, and present people attending to the interests of future people, is conceived as being for the interest and benefit of current people. Whilst Luzzatto does not directly reject Scheffler’s view, the inclusion of future people in the account of scope of this monograph is justified by their entitlement to conditions of autonomy for their own sake. By emphasising “the equal moral value of future people as ends in themselves” (82), Luzzatto differs from Scheffler by being attuned to the foreseeable interests of future generations and taking stock of such interests in intergenerational activities. The overall importance of including future people within the scope of climate justice as ends in themselves cannot be overstated. Potentially unjust future scenarios can be avoided in this sense and any prevailing paternalism incurred by intergenerational concerns can be overcome.

The book concludes with the account of scope laid down according to these desiderata, addressing some counter objections and further considerations.

There are some concerns that arise from the text. Luzzatto somewhat hastily purports the ability of her account to extend both to near and remote future generations without providing much argument in support of this claim. It seems strange, moreover, to leave until the end of the book the question of which generations the account actually focuses on, given that this is a fundamental aspect of scope for any intergenerational theory.

On the issue of reasonable expectations placed upon collective agents to foresee risk, I wonder whether it would be useful to expect more than just the mere minimum from them. The collective agents discussed in Luzzatto’s analysis are typically either authorities on climate change or are in a position of power, such that they have the capacity to influence climate systems much more drastically than other agents. Many such collective agents who fall under the purview of Luzzatto’s analysis include those with vested interests in denying climate change out-right or funding research so as to sow doubt about the threat and prevent actions against

their interests. What is more, those same collective agents with interests in perpetuating actions which damage the climate have historically acted in direct opposition to the expectation of foreseeing, despite the clear threat that their actions imply. I would suggest a stronger commitment to the scope of intergenerational climate justice than simply a minimal grasp of reasonable expectations and duties.

Whilst the manner in which Luzzatto’s account can deal with future uncertainty is commendable, current projections of global heating are already foreboding. With expected warming set to exceed the ‘safe’ 1.5°C threshold, it is evident that serious mitigation strategies are needed immediately. And that foregoes any need for reasonable foresight. This is already a confirmed, manifest fact. Though somewhat uncertainty is inherent in the discussion of the future, as well as the discussion of anticipated future impacts of climate change, some things are certain. Immediate mitigative climate action is absolutely imperative.

Another query arises at the beginning of the third chapter. Perhaps Luzzatto too readily dismisses Dale Jamieson’s strong case for the inadequacy of current values and moral concepts in dealing with climate-related ethical issues. Many of the current moral perspectives on solutions to climate change are imbued with the same logic as the systems that continue to perpetuate and exacerbate the climate crisis. The underlying assumptions of neo-classical economics as well as the dominance of market-oriented and profit-driven economics, for example, only continue to perpetuate moral systems which have few qualms about the detrimental impact of human action on the environment. It seems like a self-defeating strategy to passively accept the very moral concepts and values that contributed to the current dire state of our planet’s climate. Jamieson’s suggestions amount to strong IGAs directed at positively impacting societal norms and attitudes to better deal with climate change. On the other hand, passive or uncritical acceptance of values which reflect the status quo of apathetic climate concern constitute weak IGAs. Despite her general acceptance of current moral frameworks, Luzzatto’s call to redefine moral theories of justice specifically to avoid the worst effects of climate change and attain intergenerational climate justice is praiseworthy.

Finally, it must be noted that a concluding statement in the work, which claims that the “novel methodology allows the account to overcome the intergenerational climate challenge” stands in perplexing contrast to the rest of the book, since Luzzatto at other points regularly stresses her acute awareness of the limitations of the account (126). The action-centred methodology demonstrates promise, but it remains a stretch to claim that it can singlehandedly overcome the intergenerational climate challenge. This concluding statement would make more sense if it continued in the self-aware and mediated tone of the rest of the book and instead described how an action-centred methodology allows this account of scope to begin to develop a theory of justice that could adequately address the intergenerational climate challenge.

Aside from the concerns highlighted above, this book is a thoughtful and timely contribution to the philosophical discipline of intergenerational justice.

Luzzatto’s attempt to answer the pressing question about the scope of our obligations to future generations according to a theory of climate justice is largely successful. The book is concise and accurate, defining a vital but often presumed or neglected aspect of the concerted efforts to take action towards mitigating the threats of global heating and drastic climate change.

I wonder whether the author has ambitions, now that some elements of scope have been skillfully garnered, to work towards further developing a fully-fledged theory of climate justice? The need for such a contribution is certainly pressing.

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