

Journal of Youth Studies 20(6), 750-762, ©2017 Verlag Taylor & Francis

Diese Artikelfassung entspricht nicht vollständig dem in der Zeitschrift veröffentlichten Artikel. Dies ist nicht die Originalversion des Artikels und kann daher nicht zur Zitierung herangezogen werden.

Careum unterstützt Open Access und stellt diesen Artikel als Post-Print (letzte Manuskript-Fassung nach dem Peer Review-Verfahren) online zur Verfügung. Die Verlagsfassung darf aus urheberrechtlichen Gründen nicht online zugänglich gemacht werden. Sie ist unter der doi: 10.1080/13676261.2016.1260698 abrufbar.

A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'

Agnes Leu & Saul Becker

Abstract

The reality for many families where there is chronic illness, mental health problems, disability, alcohol or substance misuse, is that children under the age of 18 are involved in caring. Many of these children – known as 'young carers' – will be providing regular and significant care, either episodically or over many years, often 'hidden' to health, social care and other welfare professionals and services. These children have most often been invisible in social policy and professional practice. What are the reasons why some countries recognize young carers as a priority for social policy while others (most) do not? What are the key factors that influence a country's awareness and responses to these children? This article provides an original classification and analysis of country-level responses to young carers, drawing on published research, grey literature, policy documents and the authors' extensive engagement in policy and practice networks for young carers and their families in a wide range of countries. The analysis identifies two of the key factors that influence the extent and nature of these policy responses, focusing on the importance of a reliable in-country research base and the contribution of influential national NGOs and their networks.

Keywords: classification, cross-national comparison, young carers, in-country awareness, policy responses

Introduction

While there is general awareness that many adults around the world provide unpaid care to elderly, chronically sick or disabled family members, far less is known about the contributions that *children* under the age of 18 make to family care. These children, 'young carers' as they are referred to in some coun-

tries, can be defined as young people under the age of 18 who 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 any other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision (Becker 2000, 378).

Research shows that young carers provide many forms of care, including personal and intimate care, emotional support and supervision, household management and domestic duties, child care, health and medical care, and self-care (Carers Australia 2001, 9; Gays 2000; National Alliance for Care giving 2005, 2; Morrow 2005, 58; Moore 2005, 5; Warren 2007). Estimates vary as to the number of children in caring roles in different countries but figures suggest that between 2-8% of all children in advanced industrialized capitalist societies will be carers, depending on which methodology is used to identify and to count them (Becker and Becker 2008; Cass et al. 2011; Hill et al. 2009; Howard 2010; Hunt, Levine, and Naiditch 2005; Warren 2007; Wayman, Raws, and Leadbitter 2016).

Research from a number of countries also suggests that young carers are often drawn into caring roles because there is no alternative (Becker, Aldridge, and Dearden 1998, 21-26). Most families in which children provide care have low income, are often reliant on state benefits, and cannot afford alternative forms of care. Nor do these families have private health or care insurance. There is a social justice, health inequalities and child health and well-being case to be made here. These children constitute a 'hidden army' of carers in all countries, largely irrespective of the nature of their welfare regime or the nature of their 'mixed economy of care' (Hill et al. 2009; Evans and Becker 2009). Consequently, young carers need to be recognized, identified and supported as a distinct group of children with specific needs.

What have some countries done, and why have most nations done nothing at all? The authors have reviewed the published literature and research from all countries that have produced articles, reports etc., by searching databases and bibliographies in published research, including the Oxford Bibliography of Young Carers (Becker and Leu 2014, 1). Additionally, the authors have collected and collated grey literature, policy documents and information from their contacts and networks in countries where young carers' services have emerged or developed; and they have drawn on their site visits and knowledge of country-level responses gained from over twenty years of engagements with policy makers, governments and service providers internationally. The classification of the countries was developed based on the following five questions: 1. Does country X. recognise or do anything *specifically* about YCs? 2. Does country X. *define* them as YCs (or anything else i.e., 'children as next of kin')? 3. What does country X. *do* in terms of policy and services? 4. Does country X. have any *legislation* that is *specific* for YCs or could be used to support YCs? 5. What factors have been particularly influential in moving policy and practice forward for YCs in country X.?

Cross-national Comparisons and Classification

Figure 1 identifies the few countries that have so far developed any discernible level of awareness and policy response to young carers and where there is some published or grey literature. Some, such as the UK and Australia, have policies and systematic responses for the identification and assessment of young

carers, while a few more are now 'catching up' and developing their awareness and thinking about how they should proceed (including, for example, Sweden, Norway, Canada, New Zealand, Switzerland, Austria, Germany, France, although to varying degrees). The available (and sometimes limited) research from these countries has provided a relatively uniform picture of the characteristics, experiences and needs of young carers, showing that these children have far more in common, irrespective of where they live, than that which divides them by geography (Evans and Becker 2009). In other words, a young carer in the UK looks similar to a young carer in Australia, Sweden, Norway and the USA – despite each country's welfare system being different. There will of course be country-specific nuances, variations and differences, but the needs of children who are carers appear to be relatively uniform in advanced capitalist societies.

In 2007, Becker provided the first preliminary review of awareness and responses to young carers across a number of countries, showing that only a handful had developed any research evidence base and specific policies (Becker 2007). Almost a decade later, the authors develop, extend and update this analysis and ask 'how we can understand and categorize the different and emerging types and levels of policy response to young carers across (more) countries?' Figure 1 provides a new classification.

[Figure 1 here]

Research Evidence, NGOs and Policy Transfer

Whilst some countries have identified and have responded purposefully to the needs of their young carers, a few others have been very slow to respond, and most countries in the world appear to have done little if nothing at all (Levels 6 and 7, Figure 1; Becker and Leu 2014, 1). What is clear, however, is that those countries with the largest and most robust and reliable research evidence base are the more 'advanced' in terms of their awareness and policy responses to young carers. In other words, they are the countries that would be classified as at Level 1, Level 2 and Level 3 in Figure 1. Moreover, countries with strong and influential NGOs also appear to be more 'advanced', as our analysis shows. In some countries, these two factors are linked – NGOs have been instrumental in commissioning, funding or publishing research and in utilising the findings and evidence to influence policy, law and practice.

L2 Advanced: The UK

In the UK, it was the work of a University research group, the Young Carers Research Group, in particular Becker, Aldridge and Dearden, which initially focused on young carers and developed a body of research evidence for more than a decade, a «fundamental cornerstone of literature on the subject» (Oreb 2001, 10). Aldridge and Becker's earliest research (1993) on a dozen young carers in Nottingham is generally acknowledged as being the «firing gun» for the emerging interest in young carers by academics, researchers and policymakers in the UK, and for raising initial awareness amongst the public (Becker and Leu 2014). The UK can be characterized as *advanced* in terms of awareness of young carers, research, law, social policy, government guidance and service delivery. Young carers in the UK have specific legal rights (as carers and as children) as well as access to a national network of dedicated services. They are referred to in the policy and guidance documents of government, social care, health and education agencies. England, for example, introduced legislation for young carers as early as 1995 (Becker 2011), with

various other pieces of relevant legislation since then, with the most recent being the 2014 Children and Families Act and the Care Act. The 2014 legislation committed English local authorities to ensuring that carers are identified, offered an assessment and, where appropriate, to ensure that the necessary support structures are in place to protect and promote their mental health and well-being. English councils are now required by law to identify and assess young carers under 18. Beside legal rights to an assessment of their own needs and of their ability to provide and continue to provide care, as well as rights to services, many young carers in England could be considered as «children in need» and they and their families therefore have a right to specific support and interventions (Becker 2007, 36). In Scotland, the government plays an important role by working with key organisations especially the Scottish Young Carers Services Alliance (SYCSA). These organisations run an annual festival where direct exchange between young carers and government officials takes place. In Ireland, young carers are recognised by the state in The National Youth Strategy 2015-2020 as a cohort of marginalised and disadvantaged young people within the Irish population. Although there is an absence of legislation, there are policies and services that are delivered to young carers by statutory and non-statutory organisations. In order to lobby, raise awareness, research, develop policy, and establish support for young carers, Family Carers Ireland (formerly The Carers Association) have an established Young Carer Programme and employ a full-time Young Carer Development Manager who is funded by the Irish Government. However, it is clear that this level of resource is not adequate to provide a comprehensive service or support.

The reality is that although governments across the UK have responsibilities, and even with a well-developed legal structure and welfare system, young carers still fall through the gaps in policy and legal safety nets, and through adult and children's services. In practice there is some distance between the legal foundation and the actual implementation of the law. First, the UK legal framework is complex and varies from one country to another (as we have shown above), with an abundance of regulations and guidance for each country (England, Scotland, Wales and Northern Ireland). Many professionals are not aware of the specific legal requirements and responsibilities placed upon them to identify and support young carers (and their families in some cases). Second, there is a gap between the ambition and purpose of the law - to identify, recognize, assess and support young carers - and actual implementation on the ground by those professional groups (including social workers, health and medical professionals, teachers, and so on) who have responsibilities in this area. Third, the resources available to professionals to implement the law are often insufficient to do the job properly, especially in an economic climate of 'austerity'. Despite good legal intentions, most young carers in the UK have not had their legal right to an assessment met (Dearden and Becker 2004) and most young carers receive no dedicated support at all.

Despite this 'service gap', there is nonetheless a relatively advanced legal and policy framework to identify and support young carers and their families. Non-governmental Organisations (NGOs) have played a key role in the UK in moving the policy and practice agendas forward and in determining the nature and level of awareness and response to young carers locally and nationally (Becker 2007, 41). In the UK, the Children's Society and Carers Trust, two national NGOs with local branches and services, have been especially important in campaigning for young carers, raising awareness and developing services for them over a period of almost twenty years. The Children's Society has published studies, guidelines and models of best practice (Frank 1995; Frank, Tatum, and Tucker 1999) as have other NGOs including

Barnardos, Carers UK and others. More recently, the National Young Carers Coalition (NYCC), a partnership of around a dozen NGOs, charities and organizations, originally led by Carers Trust and now by the Children's Society, secured a legal victory for young carers and their families in 2014, helping to deliver new legal rights to assessments and support that are referred to above.

Level 3 Intermediate: Australia, Norway and Sweden

Australia inhabits an *intermediate* position and it is closest to the UK in terms of awareness and policy responses. There is a growing Australian-specific research evidence base, partial rights in some regions and a growing distribution of young carers projects and initiatives. The earliest studies of young carers in Australia can be traced back to the early 1990s. It was the NGO, the Alzheimer's Association of South Australia, which for the first time highlighted the situation of children in families with dementia (Alzheimer's Association 1995, 7). This study was first and foremost one of children *affected* by a parent's illness. The following two Australian studies, from the nationwide NGO, Carers Association of Australia Inc (1996, 1997), focused specifically on young carers and provided the first substantive attempts to research Australia's younger carers. The Australian and the UK research on young carers identified similar policy issues and showed the importance of supporting the young people and their families through a 'whole-family approach' (Banks et al. 2001; Cass et al. 2011; HM Government 2008, 2010; Kroehn and Wheldrake 2006; Moore and McArthur 2007). Thanks to successful funding as well as undertaking national research on young carers (Oreb 2001, 11), Australia has increased its efforts and success with regard to the recognition and identification of young carers. The country implemented the Carer Recognition Act in 2010 and since then, young carers are explicitly noted in the statement of core principles: *Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential* (Australian Government 2010, 9)

There is a growing awareness and identification of young carers, and specific attention (and rights) under the 'children as next of kin' legislation and initiatives in Norway and Sweden. Norway has a long tradition of focusing on children's behaviour and how parents function as a parent. Within the government's «children as next of kin-commitment» (2007-2010), the country has mainly focused on giving information to the child who is 'next of kin' to a parent with some health condition; helping these parents to look after their own children; giving the child a place to share/talk about what is on their mind; helping children and parents talk together; giving the child, parents or family the opportunity to meet others in the same situation; and giving the child or the family a break (activities, vacations) etc. The focus on children as 'next of kin' started with children of mentally ill and drug addicted parents under the age of 18. In 2009 the government decided to include children of somatically (physical) ill or injured parents. This commitment was prioritized because research revealed that interventions with children as next of kin was far from consistent across Norway. While children as next of kin could get significant help in one region, a patient elsewhere would not even be asked if she or he had children. In 2010 there was a change in health legislation to strengthen the rights of children as next of kin. The Norwegian Health Personnel Act (2010) placed a duty on health personnel to protect minor children as next of kin. The focus here is on providing the appropriate support that young children of parents with mental illnesses, drug addiction or severe physical illness or injury may need due to their parent's condition. Furthermore, health institutions covered

by the Act must now have child support personnel with a responsibility for promoting and coordinating the support to be given by health personnel to these children. However, under the Norwegian Health Personnel Act, children who are siblings of a sick child and children who have lost a parent are excluded.

In Sweden, similar developments have taken place. The National Board on Health and Welfare has a government assignment to improve the support for children as next of kin. Similar to Norway, the Swedish legislation does not use the term 'young carer'. Since 2010, health personnel have an obligation to respond to children's needs for information, advice and support when parents or other adults in their household suffer from substance misuse, psychiatric or severe illness, or die unexpectedly. This has not yet been fully delivered. The implementation is an important part of the government's commitment to improve the support for these children.

Level 4 Preliminary: Austria, Germany and New Zealand

In Austria there is little awareness and recognition of young carers, a small research base and very few dedicated services at local levels. The first and only young carers research study was carried out by the Department of Nursing Science, University of Vienna on behalf of the Austrian Federal Ministry of Labour, Social Affairs and Consumerism in 2012 (Nagl-Cupal et al. 2012). There is growing public awareness of young carers through media attention, and since 2009 young carers can – based on the Austrian Federal Care Allowance Legislation (§ 21a) – receive government grants for compensation benefits. This provision (§ 21a) initially addressed only adult carers but the Federal Ministry of Labour, Social Affairs and Consumer Protection recently extended its remit to include young carers (BMAASK, n.d.).

In contrast to a growing body of research on the situation of adult family caregivers, in Germany little is known about the specific situations and needs of young carers. They are not recognized as such, neither in the health or social sector, nor in education. Positive tendencies indicate some growing interdisciplinary research collaborations of educational scientists, doctors, psychologists, child and adolescent psychotherapists, public health professionals – with a focus on the areas of absenteeism, drop-out and resilience (Kaiser and Schulze 2015). New Zealand is similar to Austria and Germany, with only very limited research and service provision at a local level (Carers New Zealand, n.d.).

Level 5 Emerging: including Italy, Netherlands, Switzerland and the United States

In spite of Italy being one of the European countries with a high proportion of informal carers (Riedel and Kraus 2011) there is still little awareness and attention from policy makers and practitioners to the needs of young carers. There is no distinction between younger and older carers and hence a lack of attention to the specific group and needs of Italian young carers. Some organizations as well as research projects address specific subgroups of young carers (e.g. Boccaletti 2014; Farinella 2015). Nevertheless the current research base is underdeveloped. Prevalence data on a national level, as well as any in-depth investigation of the experiences, needs and outcomes of caring on children, are missing.

The Netherlands, where young carers are called 'jonge mantelzorgers', has mainly focused on the children of parents with mental problems of addiction (these children are called 'KOPP/KVO' – Kinderen van Ouders met Psychisch Problemen/Kinderen van Verslaafde Ouders). Care professionals describe young informal carers as a group who warrant extra attention (De Klerk et al. 2014). In 2016, a Dutch agenda on

future informal care and support was established, including some statements with regard to young carers. There are some organizations offering special courses and support for young carers; schools, however, appear to pay virtually no attention to this group (De Klerk et al. 2014, 5). Under the Law on Domestic Violence and Child Abuse the use of the 'Kindcheck' (childcheck) is obligatory for professionals in healthcare in contact with adults with serious mental or addiction problems to assess the safety of children involved, and this should of course extend to young carers in these situations.

In Switzerland, it is the Young Carers Research Group led by first author, which initially focused on young carers and is developing a body of research evidence. Since December 2014, young carers have found national attention in Swiss media and politics. The Swiss Federal Council (2014a) described in its Action Plan different fields of action, which are intended to improve the situation for all carers. As part of implementing the Action Plan special attention is to be paid to the specific needs of young carers (Swiss Federal Council 2014b). NGOs such as Pro Infirmis and Cancer Care are sensitive to the issue, raising awareness and investing in programs and information concerning young carers.

Researchers and policy makers in the US have been very slow in engaging with the research and policy agendas for young caregivers despite some early studies and an estimate of the numbers nationally. Gates and Lackey in the US (1998) examined the impact of care giving on young people looking after adults with cancer and chronic physical illness (Lackey and Gates 2001), while Beach (1994, 1997) focused on the impact of family care giving on children where a parent has Alzheimer's Type Dementia. Other small-scale studies (Bauman and Draimin 2003; Shiffren and Kachorek 2003; Winton 2003; Siskowski 2004; Shifren 2009) add to the US research base on children's care giving experiences and outcomes. NGOs such as the National MS Society and Cancer Care invested in programs and information concerning young carers. In 2003, the United Hospital Fund (based in New York) brought together these and other researchers, policy makers, former child caregivers and interested parties, including researchers and policy makers from the UK, for the first US seminar specifically on young caregivers. The discussion included preliminary plans for the research on the extent of young caregiving in the US, which was published in 2005 at a second seminar in Washington DC, again attended by policy makers and researchers from across the US, UK and Australia. The research, published by the nationwide NGO, National Alliance for Care giving (2005) provides the first estimate of the prevalence of young caregivers in the US (1.3 - 1.4 million children). Those attending the 2005 conference hoped that this study would provide the 'tipping point' from which services would be developed. It did not. To date, there has been little attention paid to the particular needs of young carers in policy or service responses. Like adult caregivers, young caregivers in the US have no specific legal rights. Today there is still only one dedicated initiative that we are aware of in the US, the American Association of Care giving Youth's (AACY) program, the Care giving Youth Project (CYP), which works in partnership with the School District of Palm Beach (Barber and Siskowski 2008). In 2014, the Caregiving Youth Institute (CYI) was established by AACY, and since 2015 the Caregiving Youth Research Collaborative (CYRC) is a platform used by researchers and professionals with the objective of developing projects as well as bringing together research and practice for youth caregivers and their families. The mentioned report and organizations use the term 'Youth Caregiver', to focus mainly on those carers under the age of 18. However, in the US in general the term 'Young Caregiver' is used to cover caregivers aged 18-40 years old. In the US, NGOs have played some

role in funding research and in increasing general awareness of young caregivers, but they have not had a national policy breakthrough and their impact is limited, unlike NGOs in the UK and Australia. This lack of 'power' to influence, shape and deliver legal rights and service developments for young carers in the US, combined with a small research base, leads to our categorization of the US as 'emerging', despite a larger research base than in some other countries which have 'overtaken' the US in terms of policy and practice.

So why is the most advanced capitalist society in the world at L5 in our classification? There are a number of possible reasons. One explanation could be related to the nature of the US 'welfare system'. This offers some of the benefits of systems in other developed countries, such as health insurance, pension, housing allowance and childcare. The difference to many other countries (with welfare *states*, such as the UK) is that this protection remains partial and individualised, and the distribution of 'welfare' (a term with negative associations in the US) and support can create significant inequalities and stigma. In essence, the US welfare system, unlike that in the UK, relies very heavily on private insurance-based benefits and services, secured through personal or employer contributions, and often provided by 'for profit' companies rather than by government as a Collective Good. Government provided welfare especially can often be stigmatising and lower quality. Thus, young carers in the US have few options to seek or receive good quality public services and support. Additionally, the nation's poverty rate rose past 15% (46 million) in 2010 (U.S. Census Bureau), which is the highest level since 1993. Research evidence suggests that there is a relationship between financial resources, *and/or* the absence of adequate professional support services, *and* children's greater participation in care giving (Becker 2007; Becker, Aldridge, and Dearden 1998; Dearden and Becker 2000; Laird 2005; Price 2006; Robson et al. 2006). A further reason for the slow progress in recognising young carers as a distinct social group in the US is the country's (negative) attitude to children's rights and participation. The US is one of the very few countries in the world that does not endorse the UN Convention on the Rights of the Child.

Level 6 Awakening: including Greece, Finland, the United Arab Emirates and France

In Greece there is a general lack of specific policies that support family carers. The organisations and the programmes which support carers are limited and they usually focus on the carers of elderly people. Research about caring children and adolescents in Greece is almost non-existent. Given austerity and the imposed financial settlement on Greece regarding loans and debts, it is perhaps not surprising that the interventions of the State in some key social policy areas are practically absent. In the current economic climate the few existing NGO activities are not adequate to cover the needs of young (and adult) carers.

France, the United Arab Emirates and Finland are also only now just 'awakening' in terms of awareness of young carers. There are still no specific policies for young carers in these countries. In Finland the starting point for research seems to be 2016, with funding for the Central Association of Carers (2016-2018) with the aim of mapping out the situation of young carers (Eurocarers, n.d.).

Conclusions

We have shown that there is a range of different responses to the issue of young carers across different countries. This varies from support for the young people in policy and legislation through to a total lack of recognition and no support. The question is, therefore, what drives policy and legal change? What are the causative factors? In the UK and Australia, where support for young carers is the most developed, non-governmental organizations (NGOs) have played a key role in raising awareness and campaigning for change. They have also played a strategic role in steering and shaping public discourse and policy developments through engaging with policy makers and politicians. In order for them to be able to carry out this role, they have drawn upon research findings that are specific to their countries.

We suggest that the presence of a champion organisation or individuals which can draw upon a reliable and country-specific evidence base are the drivers of policy and legal change. It is worth noting that the academics who have produced the research findings have also championed the cause of young carers. They have not simply published their work and relied on others to interpret and make use of them.

The existence of a robust country-specific research evidence base provides an important foundation for policy developments and service responses. Policy makers may prefer to have a home-grown research evidence base to inform their local and national decisions rather than drawing or relying on research from other countries, even when research findings are or are likely to be similar. The more developed and country-specific the research is, the more advanced the policy and legal frameworks appear to be. Having the research evidence is not sufficient by itself to bring about change, as the case of the United States clearly shows.

Whilst country-specific research is important, the exchange of ideas and experiences between countries enables such research to be conducted. Academics and key individuals from the NGOs have created an 'international community of research and practice'. They have met at conferences and events, and through these and other networks have shared ideas and research, facilitating policy development and practice transfer. Knowledge and ideas generated in one country, and models of best practice, have been transferred across some geographical boundaries and welfare systems. For example, a 'whole family approach' (Frank and Slatcher 2009) is becoming the dominant paradigm in some of the countries now developing specific services for young carers and their families - the model originating in the UK. The Australian approach to including young carers up to the age of 24 in their definition and service delivery has informed the development in the UK of new research, policy and services for young adult carers aged 18-24 (Becker and Becker 2008). Additionally, validated psychometric instruments developed in the UK (Joseph et al. 2009; Joseph, Becker, and Becker 2012) to measure and assess the nature and extent of caring amongst children, and the impacts, are now being used in a dozen countries, including Norway, Sweden, Switzerland, USA and Australia. These tools enable policy makers and practitioners working with young carers to identify and assess young carers and, over time, will enable cross-national research and comparisons. As the transfer of knowledge and policy increases between countries and over time, so the classification presented here, will also need updating, as will the analysis of the factors that have influenced these developments.

Authors Confirmation

The authors confirm that the text is original and has not been published or submitted elsewhere.

Acknowledgment

Many thanks to the Centre of Advanced Studies (CAS) at Nottingham University (UK) for the financial support within the Highfield Fellowship as well as all our colleagues working with YC around the world for their appreciated feedback.

Reference List

- Aldridge, J., and S. Becker. 1993. *Children Who Care: Inside the World of Young Carers*. Loughborough, UK: Loughborough University, Young Carers Research Group.
- Alzheimer's Association. 1995. *My Parent has Dementia: A Child and Adolescent Perspective*. Glenside, South Australia: Alzheimer's Association.
- Australian Government. 2010. *Carer Recognition Act 2010*. No. 123. Australia: Australian Government, Social Services.
- Banks, P., N. Cogan, S. Deeley, M. Hill, S. Riddell, and K. Tisdall. 2001. "Seeing the Invisible Children and Young People Affected by Disability." *Disability and Society* 16 (6): 797-814.
- Barber, M., and C. Siskowski. 2008. "Youth Caregivers: Unrecognized Providers of Care." *Pediatrics* 121 (4): 873-874.
- Bauman, L., and B. Draimin. 2003. *Children as Caregivers to their Ill Parents with AIDS. Final Report*. New York: Ittleson Foundation.
- Beach, D. 1994. "Family Care of Alzheimer Victims: An Analysis of the Adolescent Experience." *American Journal of Alzheimer's Care and Related Disorders & Research* 9: 12-19.
- Beach, D. 1997. "Family Care Giving: The Positive Impact on Adolescent Relationships." *The Gerontologist* 37 (2): 233-238.
- Becker, S. 2000. "Young Carers." In *The Blackwell Encyclopaedia of Social Work*, edited by M. Davies, p. 378. Oxford: Blackwells.
- Becker, S. 2007. "Global Perspectives on Children's Unpaid Care Giving in the Family." *Global Social Policy* 7 (1): 23-50.
- Becker, S. 2011. "Informal Family Carers." In *Social Work: An Introduction to Contemporary Practice*, edited by K. Wilson, G. Ruch, M. Lymbery, and A. Cooper. 2nd edition, 426-255. London: Pearson Longman.
- Becker S, J. Aldridge, and C. Dearden. 1998. *Young Carers and Their Families*. Oxford: Blackwell Science Ltd.

- Becker, S., and F. Becker. 2008. *Service Needs and Delivery following the Onset of Caring amongst Children and Young Adults: Evidence Based Review*. Cheltenham, UK: Commission for Rural Communities.
- Becker, S., and A. Leu. 2014. "Young Carers." In *Oxford Bibliographies in Childhood Studies*, edited by H. Montgomery. New York: Oxford University Press.
- Boccaletti, L. 2014. *Sostenere i Giovani con Responsabilità di Cura*. Welfare Oggi.
- BMASK. n.d. "Pflege und Betreuung." Austria: Bundesministerium für Arbeit, Soziales und Konsumentenschutz. Accessed March 15 2016.
<http://www.pflegedaheim.at/cms/pflege/dokument.html?channel=CH2791&document=CMS1363690612967>
- Carers Association of Australia Inc. 1996. *Forfeiting their Futures to Care: A Report on Younger Carers' Contributions and Needs*. Canberra: Commonwealth of Australia.
- Carers Association of Australia Inc. 1997. *Questions of Responsibility: Children and Caring in Australia*. Canberra: Commonwealth of Australia.
- Carers Australia. 2001. *Young Carers Research Project: Background Papers*. Canberra: Commonwealth Department of Family and Community Services.
- Carers New Zealand. n.d. *Are you a Young Carer?* Young Carers New Zealand. Accessed May 20 2016.
<http://www.carers.net.nz/information/are-you-young-carer>
- Cass, B., D. Brennan, C. Thomson, T. Hill, M. Hamilton, and E. Adamson. 2011. *Young Carers: Social Policy Impacts of the Caring Responsibilities of Children and Young Adults*. Sydney: Social Policy Research Centre.
- Dearden, C., and S. Becker. 2000. *Growing up Caring: Vulnerability and Transition to Adulthood; Young Carers' Experiences*. Leicester, UK: Youth Work Press for the Joseph Rowntree Foundation.
- Dearden, C., and S. Becker. 2004. *Young Carers in the UK: The 2004 Report*. London: Carers National Association.
- De Klerk, M., A. de Boer, S. Kooiker, I. Plaisier, and P. Schyns. 2014. *Hulp geboden. Een verkenning van de mogelijkheden en grenzen van (meer) informele hulp* [A Helping Hand. An Exploration of the Opportunities and Limitations for (more) Informal Help]. Den Haag: SCP. Accessed March 9 2016.
http://www.scp.nl/english/Publications/Summaries_by_year/Summaries_2014/A_helping_hand
- Eurocarers. n.d. "[Looking for Young Carers in Finland](http://eurocarers.org/Looking-for-young-carers-in-Finland)." Accessed May 20 2016.
<http://eurocarers.org/Looking-for-young-carers-in-Finland>
- Evans, R., and S. Becker. 2009. *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*. Bristol: Policy Press.
- Farinella, A. 2015. *Siblings: Essere Fratelli di Ragazzi con Disabilità*. Trento: Edizioni Centro Studi Erickson.

- Frank, J. 1995. *Couldn't Care more. A Study of Young Carers and their Needs*. London: The Children's Society.
- Frank, J., and C. Slatcher. 2009. "Supporting Young Carers and their Families Using a Whole Family Approach." *Journal of Family Health Care* 19 (3): 86-89.
- Frank, J., C. Tatum, and C. Tucker. 1999. *On Small Shoulders. Learning from the Experiences of Former Young Carers*. London: The Childrens Society.
- Gates, M. F., and N. R. Lackey. 1998. "Youngsters Caring for Adults with Cancer." *Image: The Journal of Nursing Scholarship* 30 (1): 11-15.
- Gays, M. 2000. "Getting it Right for Young Carers in the ACT'." In *7th Australian Institute of Family Studies Conference: Family futures: issues in research and policy*, Sydney, 23-26 July 2000.
- Hill, T., C. Smyth, C. Thomson, and B. Cass. 2009. *Young Carers: Their Characteristics and Geographical Distribution*. Canberra, Australia: Social Policy Research Centre.
- HM Government. 2008. *Carers at the Heart of 21st-Century Families and Communities*. London: Department of Health.
- HM Government. 2010. *Recognised, Valued and Supported: Next Steps for the Carers Strategy*. London: Department of Health.
- Howard, D. 2010. "Cameron Warns on Child Carer Cuts." *BBC News*, 16 November.
- Hunt, G., C. Levine, and L. Naiditch. 2005. *Young Caregivers in the US: Findings from a National Survey*. Bethesda, MD: National Alliance for Care giving and the United Hospital Fund.
- Joseph, S., S. Becker, F. Becker, and S. Regel. 2009. "Assessment of Caring and its Effects in Young People: Development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for Young Carers." *Child: Care, Health and Development* 35 (4): 510-520.
- Joseph, S., F. Becker, and S. Becker. 2012. *Manual for Measures of Caring Activities and Outcomes for Children and Young People* (2nd edition). London: Carers Trust. Accessed January 19 2016.
<http://professionals.carers.org/young-carers/assessments,3063,PP.html>
- Kaiser, S., and G. C. Schulze. 2015. "Between Inclusion and Participation: Young Carers who Are Absent from School." *Journal of Cognitive Education and Psychology* 14 (3): 314-328.
- Kroehn, A., and K. Wheldrake. 2006. *A Current Perspective: What Services and Young People Say about Best Practice and Gaps for Young Carers in Australia*. Canberra, Australia: National Youth Roundtable, Department of Families, Community Services and Indigenous Affairs.
- Lackey, N. R., and M. F. Gates. 2001. "Adults' Recollections of their Experiences as Young Caregivers of Family Members with Chronic Physical Illnesses." *Journal of Advanced Nursing* 34 (3): 320-328.
- Laird, S. E. 2005. "International Child Welfare: Deconstructing UNICEF's Country Programmes." *Social Policy and Society* 4 (4): 457-466.

- Moore, T. 2005. *Stop to Listen: Findings from the ACT Young Carers Research Project*. Lyneham: Youth Coalition of the ACT.
- Moore, T., and M. McArthur. 2007. "We're All in it together: Supporting Young Carers and their Families in Australia." *Health and Social Care in the Community* 15 (6): 561-568.
- Morrow, R. 2005. *A Profile of Known Young Carers and Identification and Snapshot of the Ones Who Are Hidden*. Perth: Curtin University of Technology.
- Nagl-Cupal, M., M. Daniel, M. Kainbacher, M. Koller, H. Mayer. 2012. *Kinder und Jugendliche als pflegende Angehörige; Einsicht in die Situation gegenwärtiger und ehemaliger pflegender Kinder in Österreich*. Vienna: Universität Wien.
- National Alliance for Care giving in collaboration with the United Hospital Fund. 2005. *Young Caregivers in the U.S.: Report of Findings September 2005*. Bethesda: NAC.
- Oreb, M. 2001. *Children as Carers Report: An Overview of Literature and Projects on Children as Carers*. Adelaide: Carers Association of SA Inc.
- Price, K. 1996. *How Do I Get them to Come? Interim Report*. New South Wales: Interchange Respite Care (NSW) Incorporated.
- Riedel, M., and M. Kraus. 2011. *Informal Care Provision in Europe: Regulation and Profile of Providers. Research Report 96*. European network of Economic Policy Research Institutes (ENEPRI).
- Robson, E., N. Ansell, U. S. Huber, W. T. S. Gould, and L. van Blerk. 2006. "Young Caregivers in the Context of the HIV/AIDS Pandemic in Sub-Saharan Africa." *Population, Space and Place* 12 (2): 93–111.
- Shifren, K. 2009. *How Caregiving Affects Development: Psychological Implications for Child, Adolescent and Adult Caregivers*. Washington, DC: American Psychological Association.
- Shifren, K., and L. V. Kachorek. 2003. "Does Early Care Giving Matter? The Effects on Young Caregivers' Adult Mental Health." *International Journal of Behavioral Development* 27 (4): 338–346.
- Siskowski, C. T. 2004. "Middle School Responses to Family Health Questions: The Effects of Family Care giving on the Education of Middle School Students with Family Health Issues." Unpublished PhD Thesis, Boca Ratan, FL, Lynn University. Accessed January 21 2016. www.boca-respite.org/children.doc
- Swiss Federal Council. 2014a. *Support for Relatives Providing Care and Nursing. Report on the National Action Plan*. Accessed February 8 2016. <http://www.bag.admin.ch/themen/gesundheitspolitik/14437/index.html?lang=en>
- Swiss Federal Council. 2014b. *Unterstützung für betreuende und pflegende Angehörige Situationsanalyse und Handlungsbedarf für die Schweiz*. Bern: Swiss Federal Council.
- Warren, J. 2007. "Young Carers: Conventional or Exaggerated Levels of Domestic and Caring Tasks." *Children and Society* 21 (2): 136-146.

Wayman, S., P. Raws, and H. Leadbitter. 2016. *There's Nobody Is there –No one who Can actually Help? The Challenges of Estimating the Number of Young Carers and Knowing how to Meet their Needs.* London: Children's Society.

Winton, C. A. 2003. *Children as Caregivers: Parental and Parentified Children.* Boston: Pearson Education.

Figures

Levels 1-7	Characteristics	Country Example
<p>1</p> <p>Incorporated/ Sustainable</p>	<ul style="list-style-type: none"> ▪ 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 ▪ Responses and law built on a foundation of reliable research evidence and clear legal rights 	<p>None</p>
<p>2</p> <p>Advanced</p>	<ul style="list-style-type: none"> ▪ Widespread awareness and recognition of young carers amongst public, policy makers and professionals ▪ Extensive and reliable research base, and growing ▪ Specific legal rights (national) ▪ Extensive codes and guidance for welfare professionals and national and local strategies ▪ Multiple dedicated services and interventions nationwide 	<p>United Kingdom</p>
<p>3</p> <p>Intermediate</p>	<ul style="list-style-type: none"> ▪ Some awareness and recognition of young carers among public, policy makers and professionals ▪ Medium-sized research base, and growing ▪ Partial rights in some regions ▪ Small but developing body of professional guidance ▪ Some dedicated services and interventions, mostly local but a few nationwide 	<p>Australia Norway Sweden</p>

<p>4</p> <p>Preliminary</p>	<ul style="list-style-type: none"> ▪ Little public or specialist awareness and recognition of young carers ▪ Limited research base, but growing ▪ No specific legal rights but other laws may be applicable or relevant ▪ Few, if any, dedicated services or interventions at national or local levels 	<p>Austria</p> <p>Germany</p> <p>New Zealand</p>
<p>5</p> <p>Emerging</p>	<ul style="list-style-type: none"> ▪ Growing public or specialist awareness and recognition of young carers ▪ Small but growing research base ▪ No specific legal rights but other laws may be applicable or relevant ▪ No specific services or interventions for young carers, but other services might be applicable 	<p>Belgium</p> <p>Ireland</p> <p>Italy</p> <p>Sub-Saharan Africa</p> <p>Switzerland</p> <p>The Netherlands</p> <p>United States</p>
<p>6</p> <p>Awakening</p>	<ul style="list-style-type: none"> ▪ Embryonic awareness of young carers as a distinct social group within the «vulnerable children» population 	<p>Greece</p> <p>Finland</p> <p>United Arab Emirates</p> <p>France</p>
<p>7</p> <p>No response</p>	<ul style="list-style-type: none"> ▪ No apparent awareness or policy response to young carers as a distinct social group 	<p>All other countries</p>

Figure 1 Classification of in-country awareness and policy responses to 'young carers'