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Young Carers

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Introduction

Until the 1990s, the roles that children and young people undertake in providing informal family care received virtually no academic or policy recognition. If awareness of these children did exist, they were generally referred to as "young carers," although different countries have different phrases (for example, "young caregivers" in the United States or "children who are next of kin" in Norway). Despite a number of definitions in use, most have the following in common: young carers are young people under eighteen years old who provide care, assistance, or support to another family member, often on a regular basis. They take on significant or substantial caring tasks and levels 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 another relative with a disability who has some chronic illness, mental health problem, or condition requiring care, support, or supervision. Many definitions emphasize the negative outcomes that caring has on children (for example, restricted social and educational opportunities). The United Kingdom has the most extensive body of research and publications on young carers and is the most advanced in terms of policy responses and legal provision, with a track record of twenty years of research, fifteen years of specific government legislation, and a national network of hundreds of services. Apart from a few other countries (including Australia, Canada, New Zealand, Norway, Sweden, Switzerland, Germany, Austria, and France), most nations and governments have not engaged in identifying and supporting young carers, even though it is likely that 2 to 4 percent of all children take on caring roles within their families. An older group of carers, aged eighteen to twenty-four, are now being referred to as "young adult carers." This article discusses both groups. A distinction is made here between carers who are under the age of eighteen ("young carers") and those who are between the ages of eighteen and twenty-four ("young adult carers") because both groups are at a different developmental stage in their lives and "career" as carers. One group consists of those legally considered "children"; the other, those legally considered "adults." Although both groups have experiences and needs that are similar, they have important differences that require separate identification and discussion. Moreover, in terms of governmental policy and services, young carers are generally the responsibility of children's services, whereas young adult carers are the responsibility of adult services (in the United Kingdom, they are the responsibility of adult health and social care services). This distinction has major implications for the delivery of services and interventions for young carers, young adult carers, and their families.

General Overview

A growing body of publications is available on young carers and young adult carers, mostly from the United Kingdom, but an increasing numbers of refereed journal articles from Australia, Europe, and a few other countries, including the African continent, are now discussing the issue of young carers. Becker 2007 provides the only article, as of the early 21st century, that looks at young carers in cross-national perspective and reviews the level of awareness in different countries, suggesting reasons why there is considerable variation but also some overlap in country responses. As of the early 21st century, only a couple of textbooks are available on young carers because the field is relatively new and very few academics are heavily engaged in researching in this area. Nonetheless, the earliest textbook by Becker, et al. 1998 deserves to be examined as many of the themes within it have been replicated over the last fifteen years by other researchers and practitioners. Most publications in this field are refereed journal articles, but a significant number of shorter items have been published in practitioner journals. Such practitioner articles are not cited here because they are often anecdotal in nature and, in most cases, have not been subjected to rigorous peer review.

Becker, S. "Global Perspectives on Children's Unpaid Caregiving in the Family: Research and Policy on 'Young Carers' in the UK, Australia, the USA, and Sub-Saharan Africa." *Global Social Policy* 7.1 (2007): 23–50.

Provides the first and, as of the early 21st century, only review of awareness and responses to young carers across a number of countries. A useful introduction to the general field of young carers because it not only explains how the issue first came to the attention of researchers and governments but also gives a broad overview. Offers a model to explain the differences between young carers and other children and suggests the prevalence of young carers based on research from a few countries.

Becker, S., J. Aldridge, and C. Dearden. *Young Carers and Their Families*. Oxford: Blackwell Science, 1998.

The first "textbook" on young carers providing a short but wide-ranging review of the issues as conceptualized fifteen years ago. Many of the themes and issues presented here are replicated in newer studies, including the authors' classification of caring roles by children which has been used by many since then.

Early Representations

The rate of publications on young carers became more active in the first half of the 1990s, when a few UK researchers were able to secure funds to conduct small qualitative studies focusing on the experiences and needs of child carers. Aldridge and Becker 1993, the authors' earliest research on a dozen young carers in Nottingham (UK), is considered to be the "firing gun" for the growing interest in young carers by academics, researchers, and policymakers. Their follow-up study a year later is still one of the very few that focuses specifically on the parents' perspective of receiving care from a child. Frank 1995 also published a small-scale study at this time—the first of many published over the next twenty years by the Children's Society. The Children's Society went on to champion young carers and to pioneer services for them and their families and has published guidelines and models of best practice. Frank, et al. 1999, the second study from the Children's Society, was the first to research adults who had been carers in their own childhood, in order to get a retrospective account of their experiences. This approach has been used by various researchers since then, including Lackey and Gates 2001, but the information obtained is subject to limitations imposed by adult memories, recollections, and reworkings of past experiences. Bibby and Becker 2000 provides an anthology of young carers' own writings and poems, providing a clear sense of the experiences and needs of young carers in their own words and written during the time that they were carers. Thomas, et al. 2003 focuses on the invisibility of young carers and their unmet needs.

Aldridge, J., and S. Becker. *Children Who Care: Inside the World of Young Carers*. Loughborough, UK: Loughborough University, Young Carers Research Group, 1993.

An early and highly influential qualitative study generally acknowledged as being the tipping point for raising awareness of young carers in the United Kingdom and leading to the engagement of government and policymakers. Draws heavily on verbatim accounts and is the first to present a young carers' "rights" perspective.

Aldridge, J., and S. Becker. *My Child, My Carer: The Parents' Perspective*. Loughborough, UK: Loughborough University, Young Carers Research Group, 1994.

The follow-up to Aldridge and Becker 1993, this study is one of the very few as of the early 21st century that specifically asks ill and disabled parents about their experiences of receiving care from their children.

Bibby, A., and S. Becker, eds. *Young Carers in Their Own Words*. London: Calouste Gulbenkian Foundation, 2000.

An anthology of short items, poems, and interview transcripts giving a space for young carers to talk about their experiences, needs, and wants in their own words. Very powerful.

Frank, J. *Couldn't Care More: A Study of Young Carers and Their Needs*. London: Children's Society, 1995.

The first publication on young carers by Frank and the Children's Society on young carers. Over the years Frank and the Children's Society have been responsible for many of the publications about models of best practice.

Frank, J., C. Tatum, and S. Tucker. *On Small Shoulders: Learning from the Experiences of Former Carers*. London: Children's Society, 1999.

The first publication seeking retrospective accounts of caring experiences during childhood from adults reviewing their past.

Lackey, N. R., and M. F. Gates. "Adults Recollections of Their Experiences as Young Caregivers of Family Members with Chronic Physical Illness." *Journal of Advanced Nursing* 34 (2001): 320–328.

The results from this descriptive, retrospective study accentuated how important it is for young carers to be informed about the illness and caring tasks and to have adequate support systems, as well as to have some time to "still be a child."

Tatum, C., and S. Tucker. "The Concealed Consequences of Caring: An Examination of the Experiences of Young Carers in the Community." *Youth and Policy* 61 (1998): 12–27.

This article offers an overview of the experiences and characteristics of young carers with reference to the findings of a small-scale qualitative study.

Thomas, N., T. Stainton, S. Jackson, W. Y. Cheung, S. Doubtfire, and A. Webb. "'Your Friends Don't Understand': Invisibility and Unmet Need in the Lives of 'Young Carers.'" *Child and Family Social Work* 8.1 (2003): 35–46.

The research developed an alternative definition of a young carer which is, from the authors' view, intended to be a more inclusive definition. Such an adoption has a number of implications, not least of which is widening the scope of service provisions.

CONTROVERSY AND DEBATE

The early publications and representations of young carers and their families did not go unchallenged. Indeed, the research by Aldridge and Becker 1993, Aldridge and Becker 1994, and Frank 1995 (all cited under Early Representations) provoked furor among some academics, campaigners, and advocates who approached this issue from a disability rights perspective. Keith and Morris 1995, the first article specifically challenging the earliest publications on young carers, attacked what the authors saw as inappropriate representations of families with disabilities, disabled parents, and their children. A response in the same journal, *Critical Social Policy*, by Aldridge and Becker 1996 provoked a series of counter-responses in the same journal and elsewhere. Olsen 1996, Morris 1997, and Olsen and Parker 1997 all argued forcefully against a "young carers paradigm," suggesting that the focus on young carers took attention and resources away from the needs and rights of disabled parents and, at worse, labeled disabled parents as "bad parents." The debate was highly influential, setting the foundation for what would later become a "whole family approach" to meeting the needs of young carers and their families—the dominant and official means of working in this field in the United Kingdom as of the early 21st century. Newman 2002 and Wates 2002 both emphasized the importance of a greater focus on the needs of disabled parents.

Aldridge, J., and S. Becker. "Disability Rights and the Denial of Young Carers: The Dangers of Zero-Sum Arguments." *Critical Social Policy* 16.48 (1996): 55–76.

The authors agree with the disability rights perspective that policies and service provision must be investigated in order to determine the extent of recognition and responsiveness to the needs of both young carers and family members requiring care.

Keith, L., and J. Morris. "Easy Targets: A Disability Rights Perspective on the 'Children as Carers' Debate." *Critical Social Policy* 15.44–45 (1995): 36–57.

From the authors' perspective, defining the children of disabled parents as "young carers" serves to undermine both the rights of disabled people and the rights of children.

Morris, J. "A Response to Aldridge and Becker—"Disability Rights and the Denial of Young Carers: The Dangers of Zero-Sum Arguments." *Critical Social Policy* 17.51 (1997): 133–135.

Morris argues that community care policies and the notion of "care" construct people with disabilities as "dependent people" and undermines their rights to choice and control in their life due to inadequate support. Focusing on the needs of carers draws attention away from the needs and resources required to support people with disabilities adequately.

Newman, T. "'Young Carers' and Disabled Parents: Time for a Change of Direction?" *Disability and Society* 17.6 (2002): 613–625.

The article emphasizes the importance of a radical review of the dedicated services to young carers, particularly their place in the overall structure of support services for families affected by illness or disability.

Olsen, R. "Young Carers: Challenging the Facts and Politics of Research into Children and Caring." *Disability and Society* 11.1 (1996): 41–45.

This paper reviews existing research on young carers focusing on the relationship between disability and parenting in order to point out how parental disability affects the domestic and caring tasks of children.

Olsen, R., and G. Parker. "A Response to Aldridge and Becker—"Disability Rights and the Denial of Young Carers: The Dangers of Zero-Sum Arguments." *Critical Social Policy* 17.50 (1997): 125–133.

Olsen and Parker question the use of a children's rights approach to the issue of "young caring" when, for instance, children's rights to continue to "care" conflict with parents' rights to have their parenting support needs met. In their view, there exists a very real danger that providing services which support the child in the role of a carer will obstruct the development of services aimed at overcoming parental dependence.

Wates, M. *Supporting Disabled Adults in their Parenting Role*. York, UK: York Publishing Services, 2002.

The author outlines measures that would aid local authorities in developing and implementing supportive, joint strategies to help disabled adults in their parenting role and, in this way, safeguard the welfare of children.

Counting Carers

The methodology used to “count” young carers in any country will, of course, determine the numbers identified and the potential for governments and others to respond. Crudely put, large numbers of young carers would suggest that the issue is one for social policy rather than a private family trouble. Very few countries have any, or certainly much, reliable data on the number of young carers, and even that data can be disputed because of the methodologies used. In the United Kingdom, both the 2001 and the 2011 censuses included a question about whether people looked after or gave any help or support to family members, friends, neighbors or others because of long-term physical or mental ill-health or disability or problems related to old age. The analysis of UK census data by Becker and Becker 2008 shows that around 2 to 3 percent of all children and about 5 percent of all young adults aged eighteen to twenty-four have a caring role. However, the census requires parents to disclose formally the caring role of their children; therefore, this is likely to underestimate seriously the extent of caring among young people. Consequently, the British Broadcasting Corporation (BBC), adopting a different methodology, conducted a survey in the United Kingdom asking secondary school pupils to self-disclose their own caring roles (Howard 2010). Eight percent of all pupils revealed that they performed intimate and personal caring roles within their families. Other statistical methodologies have been used by Hunt, et al. 2005 in the United States and Cass, et al. 2011 in Australia. Hill, et al. 2009 provided evidence of the geographical distribution as well as the characteristics of young carers in Australia based on an analysis of national data sets undertaken for the National Youth Affairs Research Scheme (NYARS). Estimating accurately the “true” extent of caring among children is problematic. However, the numbers are important because they have resource implications in terms of government responses and service development. Warren 2007, in a small-scale survey, suggests that up to 10 percent of children in the United Kingdom are young carers—hidden from public view and not receiving any recognition or support.

Becker, S., and F. Becker. *Service Needs and Delivery following the Onset of Caring amongst Children and Young Adults: Evidence Based Review*. Cheltenham, UK: Commission for Rural Communities, 2008.

Provides secondary analysis of census data to reveal the “official” extent of caring among children and young adults. Also reviews the available literature at that time and is a useful overview of the literature and evidence on young carers and young adult carers.

Cass, B., D. Brennan, C. Thomson, T. Hill, C. Purcal, M. Hamilton, et al. *Young Carers: Social Policy Impacts of the Caring Responsibilities of Children and Young Adults*. Sydney, Australia: Social Policy Research Centre, 2011.

The findings of this policy-focused quantitative and qualitative study provide innovative contributions to theories of care provided by young people; evidence about the diverse socioeconomic and demographic characteristics of young carers and care recipients; the impacts of caring on their education, employment, social participation, and health; and the development of supportive policies and services.

Hill, T., C. Smyth, C. Thomson, and B. Cass. *Young Carers: Their Characteristics and Geographical Distribution*. Canberra, Australia: Social Policy Research Centre, 2009.

The report presents recommendations for ways to identify young carers, especially hidden young carers, for the purpose of designing and providing age-relevant services and supports in regions where they are most required.

Howard, Dave. “Cameron Warns on Child Carer Cuts.” *BBC News*, 16 November 2010.

Adopting an alternative methodology to the government census, the BBC surveyed over four thousand secondary school pupils directly about their caring roles and found that eight percent of pupils were performing intimate and personal care and that even more will be providing other forms of caregiving within their families. These figures are now widely accepted as a more accurate number than that generated by the government census.

Dearden, C., and S. Becker. *Young Carers: The Facts*. Sutton, UK: Reed Business, 1995.

The first of three national surveys of the characteristics of young carers in the United Kingdom, based on data for over six hundred young carers.

Dearden, C., and S. Becker. *Young Carers in the United Kingdom: A Profile*. London: Carers National Association, 1998.

The second national survey, with data on 2,303 young carers in contact with dedicated services. The finding that many young carers had educational difficulties helped to engage education ministers and teachers for the first time in issues around the educational attainment of young carers.

Dearden, C., and S. Becker. *Young Carers in the UK: The 2004 Report*. London: Carers UK, 2004.

The third national survey of young carers in the United Kingdom and the largest as of the early 21st century with data on the characteristics of 6,178 young carers. One in five young carers provide intimate and personal care; 82 percent are providing emotional care and supervision.

Gays, M. "Getting It Right for Young Carers in the ACT." Paper delivered at the 7th Australian Institute of Family Studies Conference, "Family Futures: Issues in Research and Policy," Sydney, 23–26 July 2000.

This paper has begun the exploration of young people's caring role in Australia. Because caring has been shown to affect a young person's health, education, and social development, provision of support through services and legislation is long overdue.

Moore, T. *Stop to Listen: Findings from the ACT Young Carers Research Project*. Lyneham, UK: Youth Coalition of the ACT, 2005.

The findings pointed out the life experiences and specific needs and goals of young carers in an attempt to identify more responsive and accessible service delivery.

Morrow, R. *A Profile of Known Young Carers and an Identification and Snapshot of the Ones Who Are Hidden*. Perth, Australia: Curtin University of Technology and Carers WA, 2005.

Part of this research project was to profile known young carers. Because there is significantly less research in Australia, the research was conducted in the United Kingdom and includes findings related to caring as well as policy change and government lobbying.

Smyth, C., M. Blaxland, and B. Cass. "'So That's How I Found Out I Was a Young Carer and That I Actually Had Been a Carer Most of My Life': Identifying and Supporting Hidden Young Carers." *Journal of Youth Studies* 14.2 (2011): 145–160.

Often young carers do not identify themselves as carers because intrafamilial bonds of love and reciprocity do not encourage them to view the relationship as anything other than a "normal" familial relationship. This paper draws on qualitative research with young carers and service providers to explore the issue of self-identification among young carers.

Hunt, G., C. Levine, and L. Naiditch. *Young Caregivers in the US: Findings from a National Survey*. Bethesda, MD: National Alliance for Caregiving and the United Hospital Fund, 2005.

This survey provides the first national data about children who are carers in the United States. As a broad national survey, this report provides an outline about the number of carers among children nationwide, recognizes the role of children in giving care, and how the caregiving role impacts the life of a child.

Warren, J. "Young Carers: Conventional or Exaggerated Levels of Domestic and Caring Tasks." *Children and Society* 21.2 (2007): 136–146.

This study presents new evidence of what children and young people generally do to assist in the home (for ill or disabled as well as nondisabled or well family members) and examines how the lives of young carers differ from children and young people who are not carers.

Caring Roles

Many research studies classify the caring roles of children using a typology first suggested by Becker, et al. 1998 (cited under General Overview). Drawing on their own qualitative studies and the first national survey of young carers in contact with dedicated support services conducted by Dearden and Becker 1995, Becker, et al. 1998 suggest that children's caring roles can be classified as domestic, nursing, intimate and personal care, emotional care, household management, and child care. This classification has been replicated and confirmed by many studies across the world since then. Two further national surveys of young carers in the United Kingdom conducted by Dearden and Becker 1998 and Dearden and Becker 2004 provide additional statistical profiles of the caring roles and outcomes of young carers in the United Kingdom. These three surveys are the only large-scale surveys of their kind in the United Kingdom. The average age of young carers supported by projects in 1995, 1998, and 2004 remains the same, at just twelve years old. Over half of the young carers are from single-parent families, and most are caring for ill or disabled mothers. In the 2003 survey, 56 percent were girls, and 44 percent were boys; 16 percent were from minority ethnic communities (virtually no change since 1997). A growing body of research publications from a few other developed countries confirms this profile of the caring tasks and responsibilities of children. In Australia, Morrow 2005 suggests that one way of differentiating what young carers do from other children is to examine household tasks as "Instrumental Activities of Daily Living" (such as taking out the rubbish or cleaning) and "Activities of Daily Living" (such as moving relatives around the house, dressing, toileting, showering and bathing, and getting them in and out of bed). Morrow argues that "non-carers will not bath, shower and toilet a sibling or parent" (Morrow 2005, p. 58). Other research evidence from Carers Australia 2002 shows that young carers spend most of their time either providing care or thinking about the person with care needs unlike peers who are not carers. Gays 2000 suggests that Australian young carers take on caring tasks and levels of responsibility not found among other (noncaring) children and that young carers report more injuries, start housework at a younger age, perform a wider range of jobs around the house, and do these tasks more often and on a regular basis. Moore 2005 found that the roles of Australian young carers are more intense than their non-caring peers and are most often provided without supervision or support.

Becker, S., J. Aldridge, and C. Dearden. *Young Carers and Their Families*. Oxford: Blackwell Science, 1998.

The first textbook on young carers which sets out the key issues and provides various frameworks for understanding the caring roles and contributions made by children.

Carers Australia. *Young Carers Research Project: Final Report*. Canberra, Australia: Commonwealth Department of Family and Community Services, 2002.

This report provides the number, characteristics, and needs of young carers in Australia in relation to facilitating their social and economic participation in the community.

Why Children Care

Publications have provided a range of explanations for why children are drawn into caring roles. Aldridge and Becker 1993 introduced the concept of “election” whereby some children are elected and socialized into a caring role by other family members, a theme continued in the work of Robson and Ansell 2000 in an African context. Others, such as Becker, et al. 1998 (cited under General Overview), refer to the onset of illness or disability as the “trigger” to the need for caregiving. Expectations based on religion and culture can also be very powerful, drawing some children and young adults into unpaid caring roles as shown by Shah and Hatton 1999 and Jones, et al. 2002. Expectations based on age are also important. Becker and Becker 2008 have shown that, as young carers get older, families have growing expectations and place demands on them to provide more care. Other studies make explicit reference to the fact that low income (and in Africa, chronic poverty) distinguishes most of the families in which children are known to be caregivers. A common theme in many of the publications is that poverty restricts severely the opportunities of families and carers to purchase alternative forms of care and support, which consequently forces households to rely on children for care and supervision. Looking at the family constellation, Nagl-Cupal, et al. 2012 found that the number of adults in a household does not show a statistically significant influence on the emergence of children’s care. Children with only one parent in the household in Austria, in contrast to other countries (United Kingdom, Australia), are no more frequently in a caring role than are children with several adults in the household.

Aldridge, J., and S. Becker. *Children Who Care: Inside the World of Young Carers*. Loughborough, UK: Loughborough University, Young Carers Research Group, 1993.

The first study to present a young carers “rights” perspective. This work introduced the concept of “election” whereby some children are elected and socialized into a caring role by other family members.

Becker, F., and S. Becker. *Young Adult Carers in the UK*. London: Princess Royal Trust for Carers, 2008.

The report provides new insights into the diverse experiences and needs of young adult carers and points out that one of the factors drawing children and young adults into caring roles is that children are most often co-resident or live near to the person(s) that they support.

Jones, A., D. Jeyasingham, and S. Rajasooriya. *Invisible Families: The Strengths and Needs of Black Families in Which Young People Have Caring Responsibilities*. York, UK: Joseph Rowntree Foundation, 2002.

The report is the result of a pioneering collaborative study that fully engaged young black people in the research process. The findings highlight significant gaps in service provision—namely, the inappropriate nature of many services currently available to black young people and their families—and makes recommendations to improve services.

Nagl-Cupal, M., M. Daniel, M. Kainbacher, M. Koller, and H. Mayer. *Kinder und Jugendliche als pflegende Angehörige; Einsicht in die Situation gegenwärtiger und ehemaliger pflegender Kinder in Österreich*. Vienna: Universität Wien, 2012.

In contrast to other studies in the United Kingdom and Australia, this work found that the number of adults in a household does not show a statistically significant influence on the emergence of children’s care. Children with only one parent in the household are no more frequently in a caring role than are children with several adults in the household.

Robson, E., and N. Ansell. “Young Carers in Southern Africa.” In *Children’s Geographies: Playing, Living, Learning*. Edited by S. L. Holloway and G. Valentine, 174–193. London: Routledge, 2000.

The study has documented the material, familial, and geographical contexts of orphans' livelihoods and how the work performed by these children constitutes an unacknowledged dimension of the social reproduction of many rural and urban families.

Shah, R., and C. Hatton. *Caring Alone: Young Carers in South Asian Communities*. Ilford, UK: Barnardo's, 1999.

The finding arousing most interest was that South Asian young people received no support with their caring from extended family members. Isolation and cultural stereotyping by professionals was also identified.

Impacts of Caring

A significant body of research evidence shows that many young carers experience one or more negative outcomes. Aldridge and Becker 1999, Aldridge and Becker 2003 (cited under Impact on Physical and Mental Health), and Thastum, et al. 2008 focus on young carers' restricted opportunities for social networking and for developing peer friendships, as well as their limited opportunities for taking part in leisure and other activities. Becker and Becker 2008 refers to poverty, social exclusion, and the difficulties that young carers face in their transitions to adulthood and adult services. Educational problems (poor attendance or punctuality, underachievement, and bullying, discussed in the section on Impact on Education) are also identified in much of the research as negative outcomes for some young carers. Aldridge and Becker 2003 (cited under Impact on Physical and Mental Health) and Evans and Becker 2009 refer to a sense of "stigma by association" (particularly if parents have mental health problems, misuse alcohol or drugs, or have HIV/AIDS). Dearden and Becker 2000 and Becker and Becker 2008 identify the lack of understanding from peers about young carers' lives and circumstances, the keeping of "silence" and secrets, and the significant difficulties in making a successful transition from childhood to adulthood. Becker and Becker 2008, on transitions, shows that the impacts of caring on children can affect not only their childhood but also their adulthood. In one of the earliest studies on young carers' transitions, Dearden and Becker 2000 shows that the difficulties of "leaving home" can delay young carers' own independence and exacerbate educational and employment choices and opportunities. A larger study by Becker and Becker 2008, drawing on interviews, surveys, and secondary analysis, is the first mixed-methods investigation to show the difficulties that young adult carers aged eighteen to twenty-four face in the United Kingdom and the policy and service responses. Their qualitative data provide new insights into the diverse experiences and needs of what is another "hidden" and neglected group of carers.

Aldridge, J., and S. Becker. "Children as Carers: The Impact of Parental Illness and Disability on Children's Caring Roles." *Journal of Family Therapy* 21.3 (1999): 303–320.

Reviews the evidence on the wide-ranging impacts of caring on children.

Becker, F., and S. Becker. *Young Adult Carers in the UK*. London: Princess Royal Trust for Carers, 2008.

This research monograph is the first to focus on carers aged eighteen to twenty-four and is credited with bringing this hidden group to the attention of government, policymakers, service providers, and practitioners. It shows the impacts of caring on carers aged eighteen to twenty-four and argues for a greater awareness of the specific needs of young adult carers and more coordination between children's and adult services.

Dearden, C., and S. Becker. *Growing Up Caring: Vulnerability and Transition to Adulthood; Young Carers' Experiences*. Leicester, UK: Youth Work Press for the Joseph Rowntree Foundation, 2000.

One of the earliest studies to look at the impact that caring has on the transition of young carers to adulthood.

Evans, R., and S. Becker. *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*. Bristol, UK: Policy Press, 2009.

This book shows the range of impacts on children in Africa and the United Kingdom who are carers for family members who have HIV and AIDS. Despite economic and social structures being very different, the caring roles and impacts are not dissimilar.

Thastum, M., M. B. Johansen, L. Gubba, L. B. Olesen, and G. Romer. "Coping, Social Relations and Communication: A Qualitative Exploratory Study of Children of Parents with Cancer." *Clinical Child Psychology and Psychiatry* 13.1 (2008): 123–138.

The findings of this qualitative study identified five coping strategies used by the younger generation to cope with the parent's illness: helping others, parentification, distraction, keeping it in the head, and wishful thinking. The "healthiest" adaptation was related to factors within the family system, which has implications for the provision of help.

IMPACT ON PHYSICAL AND MENTAL HEALTH

Two of the few books on young carers—Aldridge and Becker 2003 and Evans and Becker 2009—show how caring roles can vary depending on the specific condition/illness of the person needing care. Parents with mental health problems, for example, will often need more emotional support than intimate and personal care. Parents with HIV and AIDS need more intimate care but require much emotional support as well. The impact of these caring roles and responsibilities on children's own physical and mental health are also discussed in these texts. Additionally, McAndrew, et al. 2012 discusses health problems and impaired mental health and emotional difficulties among young carers. Pakenham 2012 identifies some of the positive outcomes and adjustments of caring for someone with a mental health problem. Reupert, et al. 2012 identifies some of the interventions that can help young carers adjust better to their parents' mental illness.

Aldridge, J., and S. Becker. *Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals*. Bristol, UK: Policy Press, 2003.

Focusing on children in families in which a parent has a mental illness, this book shows the impacts that caring in these situations can have on children, including their own mental health.

Evans, R., and S. Becker. *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*. Bristol, UK: Policy Press, 2009.

By examining caring relationships within families affected by HIV and AIDS, the outcomes of caregiving, children's and families' resilience, and the factors influencing whether children become involved in care work, this book makes an important contribution to the growing research evidence on young carers and the impacts of HIV and AIDS on families globally.

McAndrew, S., T. Warne, D. Fallon, and P. Moran. "Young, Gifted and Caring: A Project Narrative of Young Carers, Their Mental Health, and Getting Them Involved in Education, Research and Practice." *International Journal of Mental Health Nursing* 21 (2012): 12–19.

This paper emphasizes that young carers need rapid access to services—that is, access to what they need, when they need it. There is still a hole in the net—namely, a lack of appropriate support for young carers.

Pakenham, K. I. "Caregiving Tasks in Caring for an Adult with Mental Illness and Associations with Adjustment Outcomes." *International Journal of Behavioral Medicine* 19 (2012): 186–196.

The first longitudinal study examining the positive adjustment outcomes in mental health carers.

Reupert, A., R. Cuff, L. Drost, K. Foster, K. van Doesum, and F. van Santvoort. "Intervention Programs for Children Whose Parents Have a Mental Illness: A Review." *MJA Open* 1, suppl. 1 (2012): 18–22.

The review identified the range of interventions that clinicians might employ when working with children whose parents have a mental illness. The conclusion of the study was that providing psychosocial education about mental illness to children is the core component.

IMPACT ON EDUCATION

Academics and policymakers have a growing interest in the impact of caring on children's education and educational outcomes. However, the findings concerning the impact on young carers' performance in education and their attendance at school are mixed. Banks, et al. 2001 and Eley 2003 found that young carers report no adverse effect on their schoolwork. However, many, if not most, other studies report that young carers do have difficulties in finding the time or the energy to do homework and many report negative educational experiences and outcomes for young carers. Aldridge and Becker 1993; Dearden and Becker 2004; Frank 1995; Frank, et al. 1999; and Noble-Carr 2002 all describe school problems caused by nursing and other caring roles, such as poor concentration due to lack of sleep and the resulting poor grades, deficiencies in reading and writing, as well as unauthorized absences. Studies concerning long-term consequences for young carers and young adult carers as former caregivers for family members found that school impairment led to an inequality in educational opportunity for many of them later in life. On the other hand, Frank, et al. 1999 found that previous caring roles have led to some young carers to seek employment in social and caring professions, which—in their own opinion—was due to the skills acquired through their caring roles. The literature identifies young primary carers in particular as being at risk of leaving school early. Moore's studies (Moore 2005 and Moore, et al. 2009) found that young carers were often discriminated against within the educational system because of lack of awareness by teachers and other students of what caring entails, stigma surrounding disability, and inflexible teaching practices.

Aldridge, J., and S. Becker. *Children Who Care: Inside the World of Young Carers*. Loughborough, UK: Loughborough University, Young Carers Research Group, 1993.

This early and highly influential qualitative study is the first to present a young carers "rights" perspective. It discovered through in-depth examination of the young carers case histories the reality of the effects of caring. These effects are nowhere more evident than in education where young carers continue to be neglected, sometimes even punished, for something that is beyond their control.

Banks, P., N. Cogan, S. Deeley, M. Hill, S. Riddell, and K. Tisdall. "Seeing the Invisible Children and Young People Affected by Disability." *Disability and Society* 16.6 (2001): 797–814.

This paper reports on two studies examining the nature of the role performed by young carers and its impact on their lives and found, in contrast to other authors, that young carers report no adverse affect on their schoolwork.

Dearden, C., and S. Becker. *Young Carers in the UK: The 2004 Report*. London: Carers UK, 2004.

The report of the third national survey found that the overall incidence of missed school and educational difficulties has been reduced. Despite an improvement in the general picture since 1997, many young carers continue to experience educational difficulties, and too few of them have had a formal assessment of their needs.

Eley, S. "Diversity among Carers." In *Reconceptualising Work with "Carers": New Directions for Policy and Practice*. Edited by K. Stalker, 56–71. London: Jessica Kingsley, 2003.

Although young carers' schoolwork did not appear to suffer unduly from carrying out caring duties, the young people stated that balancing school attendance, homework, and caring obligations could be tiring and that schools could do more to support young carers.

Frank, J. *Couldn't Care More: A Study of Young Carers and Their Needs*. London: Children's Society, 1995.

This report examines the needs of young carers and considers the impact that this responsibility has on their social, personal, emotional, and educational development.

Frank, J., C. Tatum, and C. Tucker. *On Small Shoulders: Learning from the Experiences of Former Carers*. London: Children's Society, 1999.

This study with adults who had been young carers found that over 70 percent felt that their education had been significantly affected by their caring responsibilities. It shows as well that young carers are likely to experience significant difficulties in making a successful transition from childhood to adulthood.

Moore, T. "Young Carers and Education: Identifying the Barriers to Satisfactory Education for Young Carers." *Youth Studies Australia* 24.4 (2005): 50–55.

The report states that young carers' access to education is limited by systemic, cultural, and practical barriers, which, in the most part, exist as a result of the decisions of policymakers and the wider community. As a result, only 4 percent of young primary carers aged fifteen to twenty-five years are still in school (compared to 23 percent for the general population in this age group).

Moore, T., M. McArthur, and R. Morrow. "Attendance, Achievement and Participation: Young Carers' Experiences of School in Australia." *Australian Journal of Education* 53.1 (2009): 5–18.

This qualitative research project found that significant caring responsibilities, a lack of appropriate and responsive support services to meet family needs, and a lack of awareness and understanding within the education system significantly reduced young carers' capacity to engage fully with their learning.

Noble-Carr, D. *Young Carers Research Project: Background Papers, A Carers Australia Project*. Canberra, Australia: Department of Family and Community Services, 2002.

Based on the study results, young carers are more likely than their age peers to have low participation rates in education, training, and consequently in employment. Many frequently missed school, had less time to complete homework, felt worried and distracted when they were at school, and experienced limited connectedness with the school community.

POSITIVE OUTCOMES AND RESILIENCE

Much of the earlier research on young carers in the United Kingdom, Australia, and other countries where there is interest in this field reported a range of negative outcomes of caring on children. More recently, since around 2000, a number of studies have identified a range of positive outcomes of caring on children, sometimes identified alongside the negative ones. Dearden and Becker 2000 found that caring developed children's knowledge, understanding, sense of responsibility, maturity, and a range of life, social, and care-related skills. Caring also helped to bring many children closer to their parents in terms of a loving, caring, relationship. Aldridge and Becker 2003 showed that caring can allay some of

the children's fears, concerns, and anxieties that they have about their parent's condition because it gives children some control and direct involvement in the provision and management of care. Aldridge and Becker suggest that in some instances caring can actually help to enhance parent-child relationships and can make children feel included, when outside the domain of the family, they are often ignored or even excluded (not consulted, not recognized) by health, social care, and other professionals. Becker and Becker 2008 shows how important the caring relationship is to young adult carers and how they structure their lives, relationships, choices, education, training, and work around caring responsibilities and how this can help to develop their knowledge, maturity, and transferable skills. Some, like Newman 2002 and Evans and Becker 2009, have suggested that focusing on family or children's resilience may offer some explanation for this. A "resilience" perspective helps to explain individual differences in accessing and using support, and in coping with stress and adversity. The concept of resilience emphasizes people's strengths in coping with adversity and their agency in engaging with protective factors that may help to reduce their vulnerability. For many young carers, their exposure to the stress of the caring role, family illness/disability, or substance misuse, coupled with other risk factors, can compromise their ability to remain resilient. As Dolan 2012 and Evans and Becker 2009 show, social support and positive parental roles are critical to developing children's positive adjustments and resilience. For those working with young carers, it is important that building resilience becomes part and parcel of their work. Scottish Young Carers Services Alliance and Carers Trust 2012, while looking for ideas and resources they could use to promote positive mental health and well-being, developed a toolkit which aims to provide activities using the notion of building the resilience of young carers. Factors long associated with mental health and well-being—such as achieving goals, having positive relationships, doing well in school, and feeling hopeful—seem to promote resiliency and so may lead to positive mental health. Skovdal, et al. 2009 shows how young carers' expression of their own agency can also develop their expertise and resilience. Svanberg, et al. 2010 identifies various coping strategies for young carers.

Aldridge, J., and S. Becker. *Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals*. Bristol, UK: Policy Press, 2003.

Along with many negative outcomes, the authors find that some children report positive benefits to them of caring for their parent(s) with mental health problems.

Becker, F., and S. Becker. *Young Adult Carers in the UK*. London: Princess Royal Trust for Carers, 2008.

This research monograph shows the positives as well as the negatives of caring among young adult carers. Many respondents talked about the bond between them and their parents and how difficult it would be to leave them to go to higher education or to move away.

Dearden, C., and S. Becker. *Growing Up Caring: Vulnerability and Transition to Adulthood; Young Carers' Experiences*. Leicester, UK: Youth Work Press for the Joseph Rowntree Foundation, 2000.

Although this study finds many negative outcomes, it also identifies some positives. However, despite the positive outcomes for some children in their sample, the authors also observed that all the children experienced some negative consequences as well, which were often severe.

Dolan, P. "Travelling Through Social Support and Youth Civic Action on a Journey Towards Resilience." In *The Social Ecology of Resilience: A Handbook of Theory and Practice*. Edited by M. Ungar, 357–366. New York: Springer, 2012.

The connection between resilience and social support and how each is affected by individual, family, and wider ecological factors that can be addressed at the level of social policy was explored. It discusses the question, how can resilience be built at multiple levels through youth civic action?

Evans, R., and S. Becker. *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*. Bristol, UK: Policy Press, 2009.

This book discusses in some detail the concept of resilience and how it can be applied to young carers. Protective factors may be associated with personal attributes, family characteristics, or aspects of the wider community; however, they are likely to be context specific and may vary cross-culturally.

Newman, T. "Young Carers and Disabled Parents: Time for a Change of Direction?" *Disability and Society* 17.6 (2002): 613–625.

One of the first articles to introduce the concept of resilience into the debate about young carers.

Scottish Young Carers Services Alliance and Carers Trust. *Young Carer's Mental Health Toolkit*. London: Princess Royal Trust for Carers, 2012.

The toolkit provides activities that use the notion of building resiliency for young carers.

Skovdal, M., V. O. Ogotu, C. Aoro, and C. Campbell. "Young Carers as Social Actors: Coping Strategies of Children Caring for Ailing or Ageing Guardians in Western Kenya." *Social Science & Medicine* 69 (2009): 587–595.

To counterbalance the representation of young carers as victims of damaging circumstances that compromise their psychosocial well-being and to develop a critical thread that views children as social actors, this study explores how young carers cope with challenging circumstances, often with skill and ingenuity.

Svanberg, E., J. Stott, and A. Spector. "'Just Helping': Children Living with a Parent with Young Onset Dementia." *Aging & Mental Health* 14 (2010): 740–751.

The study explores whether children of younger people with dementia can be compared to other young carers; how the impact of their caring affects their mood, burden, and resilience; and what could promote how they cope.

ADJUSTMENT, COPING MODELS, AND MEASURES

Although physical illness among adults is prevalent, few studies exist that examine the relationship between parental illness and child functioning. Armistead, et al. 1995 examined the relationship between parental illness and child functioning and delineated variables that have been identified as qualifiers of this relationship. The authors outlined dimensions of physical illness that may be important in the relationship and discussed possible mechanisms for the association between physical illness and child functioning. Ireland and Pakenham 2010 identifies key indicators of poorer adjustment among young carers. Even though parental illness may have adverse impacts on youth and family functioning, research in this area has suffered from the absence of a guiding comprehensive framework. Pedersen and Revenson 2005 used a Family Ecology Framework for understanding adolescents' reactions to parental illness which they present to evaluate existing research that examines the direct effects of parental illness on family functioning and youth well-being. Pakenham and Cox 2012 tested a conceptual model of the effects of parental illness on youth and family functioning derived from the Family Ecology Framework. Pakenham, et al. 2007 identifies social support as a strong indicator for positive adaptation. One obstacle to clarifying the impact of competing demands on the development of young carers was an absence of a psychometrically sound scale to assess the specific problems faced by these children. Early, et al. 2006 developed a measure of the demands of the caregiving role, focusing specifically on young carers and taking into account the social and educational context within which they perform the role. Cassidy and Giles 2013 uses the Young Carers Perceived Stress Scale to identify positive adaptation. Joseph, et al. 2009 developed two psychometric instruments: one to measure the extent of caring on children (MACA-YC18) and a second to measure the positive and negative outcomes of caring on children (PANOC-YC20). Both these scales are now used in a dozen countries.

Armistead, L., K. Klein, and R. Forehand. "Parental Physical Illness and Child Functioning." *Clinical Psychology Review* 15 (1995): 409–522.

This study highlights the variables that have been identified as qualifiers of the relationship between parental illness and child functioning. It outlines dimensions of physical illness that may be important in the relationship and discusses possible mechanisms for the association between physical illness and child functioning.

Cassidy, T., and M. Giles. "Further Exploration of the Young Carers Perceived Stress Scale: Identifying a Benefit-Finding Dimension." *British Journal of Health Psychology* 18 (2013): 642–655.

This study explores the Young Carers Perceived Stress Scale.

Early, L., D. Cushway, and T. Cassidy. "Perceived Stress in Young Carers: Development of a Measure." *Journal of Child and Family Studies* 15 (2006): 165–176.

The authors identified with the Young Carers Perceived Stress Scale posit a positive dimension of caring which appears to have potential in terms of measuring benefit-finding in this group.

Ireland, M. J., and K. I. Pakenham. 2010. "Youth Adjustment to Parental Illness or Disability: The Role of Illness Characteristics, Caregiving, and Attachment." *Psychology, Health & Medicine* 15 (2010): 632–645.

The study results reveal a set of predictors of poorer youth adjustment, such as dealing with a gradual illness/disability onset, being a male, feeling isolated, having lower perceived maturing, and having less choice in caregiving. Findings highlight young caregiving as an important target for service and policy planning.

Joseph, S., S. Becker, and F. Becker. *Manual for Measures of Caring Activities and Outcomes for Children and Young People*. London: Princess Royal Trust for Carers, 2009.

A manual for practitioners that provides two instruments for identifying, assessing, and measuring caring roles and outcomes for young carers. The tools enable practitioners and researchers to "score" roles and outcomes and evaluate whether there is change over time. The BBC used the MACA tool to identify hidden young carers in schools (Howard 2010, cited under Counting Carers).

Joseph, S., S. Becker, F. Becker, and S. Regel. "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 (2009): 510–520.

A technical paper that provides the details of how two psychometric instruments were developed to measure the extent of caring among young carers and the positive and negative outcomes. Also provides the tools.

Pakenham, K. I., J. Chiu, S. Bursnall, and T. Cannon. "Relations between Social Support, Appraisal and Coping and Both Positive and Negative Outcomes in Young Carers." *Journal of Health Psychology* 12 (2007): 89–102.

Examining a stress/coping model of adjustment in early caregiving, the regression analyses show social support as the strongest predictor of adjustment, whereas coping and choice in caregiving emerged as weaker predictors, and stress appraisal was found to be unrelated to adjustment.

Pakenham, K. I., and S. Cox. "Test of a Model on the Effects of Parental Illness on Youth and Family Functioning." *Health Psychology* 31 (2012): 580–590.

Testing a conceptual model of the effects of parental illness on youth and family functioning, the study shows that parental depression directly affects family functioning, which in turn mediates the effects onto youth adjustment.

Pedersen, S., and T. A. Revenson. "Parental Illness, Family Functioning, and Adolescent Well-Being: A Family Ecology Framework to Guide Research." *Journal of Family Psychology* 19 (2005): 404–419.

This study presented and used the first conceptual family ecology model for understanding adolescents' reactions to parental illness, which the authors believe is essential for developing effective interventions for families experiencing parental illness.

Cross-National Perspectives

As Becker 2007 shows, most countries in the world have not engaged with the issue of young carers. Few have a reliable research base or have developed policy responses. Despite an early publication by Becker 1995 suggesting that young carers are a hidden group in Europe, it took over a decade longer for a few researchers and academics in other European countries to conduct research in their countries. For example, Schnepf and Metzger 2005 published an insight into the familial and personal situation of children and adolescents as carers in Germany, in particular, the extent of caring activities that they provide. Schlarmann, et al. 2008; Schlarmann, et al. 2011a; and Schlarmann, et al. 2011b published the evaluation of the first project for young carers in Germany. O'Connell, et al. 2008 looks at the experiences of young carers in (Southern) Ireland. Nagl-Cupal, et al. 2012 was the first published study in Austria that provided a deeper insight into the situation of young carers by evaluating the current situation of children who care and the situation of former young carers and young adult carers. What is very surprising is the dearth of publications from Europe—and, for that matter, from other parts of the world—about young carers. This reflects a lack of awareness about children who care and the contributions that they make to informal family care, as well as a lack of engagement by academics and by policymakers. However, since 2011, indications are that more European countries, particularly Norway and Sweden, are recognizing the importance of conducting research on young carers and examining the policy and practice implications, although the publications arising from this work have not yet materialized.

Becker, S., ed. *Young Carers in Europe: An Exploratory Cross-National Study in Britain, France, Sweden and Germany*. Loughborough, UK: Loughborough University, Young Carers Research Group, 1995.

The first publication to examine the issue of young carers in a number of European countries, reviewing the legal and policy framework in countries and linking this to qualitative evidence on what young carers do.

Becker, S. "Global Perspectives on Children's Unpaid Caregiving in the Family: Research and Policy on 'Young Carers' in the UK, Australia, the USA, and Sub-Saharan Africa." *Global Social Policy* 7.1 (2007): 23–50.

Provides the first and, as of the early 21st century, only review of awareness and responses to young carers across a number of countries, showing that only a few countries have developed research and policy.

Metzger, S. *Kinder und Jugendliche als pflegende Angehörige: Erleben und Gestalten familialer Pflege*. Bern, Switzerland: Verlag Hans Huber, 2007.

Metzing has named as the first central phenomenon “keep the family together.” The severity of the disease but also the “number of shoulders” are the crucial points. The smaller the family, the more likely it is that children or grandchildren may also be included in the care.

Nagl-Cupal, M., M. Daniel, M. Kainbacher, M. Koller, and H. Mayer. *Kinder und Jugendliche als pflegende Angehörige; Einsicht in die Situation gegenwärtiger und ehemaliger pflegender Kinder in Österreich*. Vienna: Universität Wien, 2012.

The first publication to examine the issue of young carers in Austria.

O’Connell, C., J. Finnerty, and O. Egan. *Hidden Voices: An Exploratory Study of Young Carers in Cork*. Research Working Paper 08/07. Dublin, Ireland: Combat Poverty Agency, 2008.

The first study in Ireland exploring the impacts of caregiving on young carers and their attitudes and feelings in relation to their caring responsibilities. The findings pointed out that a greater level of awareness of the existence and of the needs of young carers on the part of social professionals is essential for helping with early identification and in devising appropriate responses.

Schlarmann, J. G., S. Metzing-Blau, and W. Schnepf. “The Use of Health-Related Quality of Life (HRQOL) in Children and Adolescents as an Outcome Criterion to Evaluate Family Oriented Support for Young Carers in Germany: An Integrative Review of the Literature.” *BMC Public Health* 8 (2008): 414.

The integrative literature review shows that the KIDSCREEN questionnaires seem adequate to evaluate the intervention because their items cover young carers’ needs and problems most accurately.

Schlarmann, J. G., S. Metzing-Blau, and W. Schnepf. “Implementing and Evaluating the First German Young-Carers Project: Intentions, Pitfalls and the Need for Piloting Complex Interventions.” *Open Nursing Journal* 5 (2011a): 38–44.

This paper provides an insight into the social reality of young carers and on the difficulties of doing research with this particular group in Germany.

Schlarmann, J. G., S. Metzing-Blau, S. Schoppmann, and W. Schnepf. “Germany’s First Young Carers Project’s Impact on the Children: Relieving the Entire Family; A Qualitative Evaluation.” *Open Nursing Journal* 5 (2011b): 86–94.

The first German study to evaluate the intervention’s impact on the children and focus on the effectiveness of a young carers group. The study findings describe the participants’ experiences with SupaKids, the first young carers project in Germany.

Schnepf, W., and S. Metzing. “Kinder und Jugendliche als pflegende Angehörige: Eine Untersuchung zu Bedeutung und Konstruktion familialer Pflege, welche von Kindern und Jugendlichen erbracht wird.” *Pflege & Gesellschaft* 10.1 (2005): 61–62.

The first publication in Germany that gives an insight into the familial and personal situation of children and adolescents as carers—namely, the extent of caring activities they provide.

YOUNG CARERS IN AFRICA

Since around 2000, a growing number of publications have examined children's caring roles in sub-Saharan Africa. To some extent these publications have become a sub-library in the overall literature on young carers, with a small group of academics being the primary authors in this field. The work of Evans 2005, Evans and Becker 2009, and Evans 2010 is important because Ruth Evans has conducted a number of studies in Tanzania and elsewhere focusing on the roles of children within African families, especially in the context of the HIV and AIDS pandemic. Evans and Becker 2009 is the first and only book to date on young carers in Africa and draws on qualitative data to provide suggestions for policy and practice. The works by Robson and Ansell 2000 and Robson, et al. 2006, also key authors in this field, contribute greatly to our understanding of the roles and responsibilities of children who care in Southern Africa and the reasons that children are forced into caring roles. Skovdal, et al. 2009 examines young carers in Kenya from a social psychological perspective.

Becker, S. "Global Perspectives on Children's Unpaid Caregiving in the Family: Research and Policy on 'Young Carers' in the UK, Australia, the USA, and Sub-Saharan Africa." *Global Social Policy* 7.1 (2007): 23–50.

This article shows how and why different countries have responded differently to the issue of young carers. The classification of country-specific responses enables all countries to be identified and compared.

Evans, R. "Social Networks, Migration and Care in Tanzania: Caregivers' and Children's Resilience to Coping with HIV/AIDS." *Children and Poverty* 11.2 (2005): 111–129.

This paper illustrates the impacts of the HIV/AIDS epidemic on children and families in northern Tanzania and shows the coping strategies, such as migrating to urban areas as a survival strategy, that young carers adopt at the household level.

Evans, R. "Children's Caring Roles and Responsibilities within the Family in Africa." *Geography Compass* 4.10 (2010): 1477–1496.

This article conceptualizes the socio-spatial and embodied dimensions of everyday caring roles, activities, and outcomes of children and young people in Africa on a range of spatial scales and provides an overview of the available research, linking with the literature on young carers in the Northern Hemisphere and geographies of children and youth.

Evans, R., and S. Becker. *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*. Bristol, UK: Policy Press, 2009.

This book is an important landmark in childhood studies and shows the range of impacts on child carers in Africa and the United Kingdom whose family members have HIV and AIDS. Despite economic and social structures being very different, the caring roles and impacts are not dissimilar.

Robson, E., and N. Ansell. "Young Carers in Southern Africa." In *Children's Geographies: Playing, Living, Learning*. Edited by S. L. Holloway and G. Valentine, 150–166. London: Routledge, 2000.

The study has documented the material, familial, and geographical contexts of orphans' livelihoods and how the work that these children perform constitutes an unacknowledged dimension of the social reproduction of many rural and urban families.

Robson, E., N. Ansell, U. S. Huber, W. T. S. Gould, and L. van Blerk. "Young Caregivers in the Context of the HIV/AIDS Pandemic in Sub-Saharan Africa." *Population, Space and Place* 12 (2006): 93–111.

Against a background of rising adult mortality and morbidity in the context of the HIV/AIDS pandemic in sub-Saharan Africa, this paper provides both quantitative and qualitative evidence for the existence of a largely neglected group of young people with increased responsibility for caregiving.

Skovdal, M., V. O. Ogotu, C. Aoro, and C. Campbell. "Young Carers as Social Actors: Coping Strategies of Children Caring for Ailing or Ageing Guardians in Western Kenya." *Social Science and Medicine* 69 (2009): 587–595.

This paper shows a further understanding of caregiving children in Africa by looking at how local constructions of childhood can facilitate their agency and resilience, paying particular attention to the role of identity and recognition.

Policy

The UK government (HM Government 2008 and HM Government 2010) has set out its intentions and priorities for young carers in various national carers strategies: "Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve..." (HM Government 2008, p. 123). This approach, to protect children from inappropriate caring, is the official approach adopted in the United Kingdom and requires a "whole family approach" to working with young carers and their families (see the section on Practice). Banks, et al. 2002 argues that young carers need good information and guidance, but their invisibility makes this problematic. The policy issues identified in the Australian literature on young carers are broadly similar to the ones in the United Kingdom. The importance of supporting young carers and their families through a whole-family approach and the most appropriate and effective ways in which this might be done are issues that receive attention. Supporting young carers will contribute to the well-being of the care recipient and the whole family, and conversely, supporting the person requiring care will benefit the young carer. The issues for social policy in Australia are outlined by Cass, et al. 2011, whereas Kroehn and Wheldrake 2006 and Moore and McArthur 2007 offer views of the best practice in Australia.

Banks, P., N. Cogan, S. Riddell, S. Deeley, M. Hill, and K. Tisdall. "Does the Covert Nature of Caring Prohibit the Development of Effective Services for Young Carers?" *British Journal of Guidance and Counselling* 30.3 (2002): 229–246.

This paper shows the need for clear guidance and information for young people whose schooling has been affected because they are providing care for an ill or disabled relative.

Cass, B., D. Brennan, C. Thomson, T. Hill, C. Purcal, M. Hamilton, et al. *Young Carers: Social Policy Impacts of the Caring Responsibilities of Children and Young Adults*. Sydney, Australia: Social Policy Research Centre, 2011.

The first national carers strategy for Australia, introduced in 2011. Young carers are explicitly noted in the 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.

HM Government. *Carers at the Heart of 21st-Century Families and Communities*. London: Department of Health, 2008.

The second national carers strategy for the United Kingdom builds on the first of a decade earlier. Chapter 6 (pp. 121–140) focuses on young carers.

HM Government. *Recognised, Valued and Supported: Next Steps for the Carers Strategy*. London: Department of Health, 2010.

This is a "refresh" of the 2008 national carers strategy by the new UK coalition government. It tweaks some priorities but essentially confirms the decision by the coalition to support young carers by protecting them from inappropriate caring roles.

Kroehn, A., and K. Wheldrake. *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, 2006.

Evidence from Australian studies about income support and payments for young carers found that they perceived applying for and receiving financial assistance to be complex processes. Providing appropriate forms of income support for young people undertaking care, particularly those in low-income family circumstances, needs further research and policy deliberation.

Moore, T., and M. McArthur. "We're All in It Together: Supporting Young Carers and Their Families in Australia." *Health and Social Care in the Community* 15.6 (2007): 561–568.

Of considerable significance is the finding that young carers in the study felt the best way that services could support them was to provide better support for their cared-for relatives. Although some young carers did access formal support, only a handful could identify a service for their family that was ongoing and that they could access more than once a month.

Practice

A range of services is available to support young carers in the United Kingdom and in a few other countries, including respite care and short breaks of various forms, information and training, social work and counseling, and dedicated young carers projects and young adult carers projects. A "whole family approach" has become the "official" discourse in terms of working with young carers and their families as advocated by the UK government and the National Young Carers Initiative. Prilleltensky 2004 shows that ill or disabled parents do not stop being parents even when their children are providing care to them. Jenny Frank (Frank 2002, Frank and McLarnon 2008, and Frank and Slatcher 2009) sets out the principles and procedures for working in a "whole family" way. Frank advocates the need for formal services to assess and meet the (interdependent) needs of all family members. Frank and McLarnon 2008 sets out key principles of practice to underpin all interventions with young carers and their families. Becker and Becker 2008 provides a statement of recommendations which should guide all interventions and developments in policy and practice for young adult carers. Byng-Hall 2008 sets out the implications for family therapy. Grant, et al. 2008 outlines some of the issues for identification and assessment of young carers. Butler and Astbury 2005 provides an evaluation of the benefits of a young carers project.

Becker, F., and S. Becker. *Young Adult Carers in the UK*. London: Princess Royal Trust for Carers, 2008.

Sets out a clear set of recommendations for the development of future policy and practice with young adult carers and their families.

Butler, A. H., and G. Astbury. "The Caring Child: An Evaluative Case Study of the Cornwall Young Carers Project." *Children and Society* 19 (2005): 292–303.

In meeting and exceeding its original targets—namely, the identification of young carers, the assessment of young carers' needs, the direct service provision, and partnership working—this project has made significant progress.

Byng-Hall J. "The Significance of Children Fulfilling Parental Roles: Implications for Family Therapy." *Journal of Family Therapy* 30 (2008): 147–162.

The article points out that family therapy techniques help to redress "role reversal" and enable the parents to take "appropriate responsibility" in the family. It also focuses on how to prevent transmission of "parentification" in future generations.

Frank, J. *Making It Work: Good Practice with Young Carers and Their Families*. London: Children's Society and The Princess Royal Trust for Carers, 2002.

Offers guidance on assessments, service provision, and interventions to support young carers. The online version offers a comprehensive list of organizations that may offer support to young carers in the United Kingdom, including Young Carers Projects and relevant government and nongovernment organizations.

Frank, J., and J. McLarnon. *Young Carers, Parents and Their Families: Key Principles of Practice*. London: Children's Society, 2008.

The principles mentioned in this report give clarity, direction, and purpose to professional practice and are helpful for measuring success. They build further improvements in the delivery of services and should underpin all support for young carers and their families.

Frank, J., and C. Slatcher. "Supporting Young Carers and Their Families Using a Whole Family Approach." *Journal of Family Health Care* 19.3 (2009): 86–89.

A proactive practice will enable families to feel able to ask for support; therefore, the "Whole Family Pathway" is a helpful online resource directing practitioners to support for young carers and their families, and the "Children's Society Include Project" provides training and resources for professionals.

Grant G., J. Repper, and M. Nolan. "Young People Supporting Parents with Mental Health Problems: Experiences of Assessment and Support." *Health and Social Care in the Community* 16.3 (2008): 271–281.

The study reflects on what can be done to identify, assess, and support young people who are looking after parents/relatives with mental health problems. The findings signal the importance of any allied assessment activity not being viewed as a one-time event, but rather as a continuous process interwoven into project activity.

Prilleltensky, O. "My Child Is Not My Carer: Mothers with Physical Disabilities and the Well-being of Children." *Disability and Society* 19.3 (2004): 209–223.

Although the idea of child as carer and parent as care recipient may appear unidirectional, this qualitative study finds that parents, as care recipients, do not cease to be parents. They continue to provide emotional, social, and other forms of support and are perceived so by their child, demonstrating the reciprocity of both providing and receiving care.

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