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**Global Perspectives on Children's Unpaid Caregiving in the Family:  
Research and Policy on 'Young Carers' in the UK, Australia, the United States  
and Sub-Saharan Africa**

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## **Global Perspectives on Children’s Unpaid Caregiving in the Family: Research and Policy on ‘Young Carers’ in the UK, Australia, the United States and Sub-Saharan Africa**

**ABSTRACT** This article provides the first cross-national review and synthesis of available statistical and research evidence from three developed countries, the United Kingdom, Australia and the United States, and from sub-Saharan Africa, on children who provide substantial, regular or significant unpaid care to other family members (‘young carers/caregivers’). It uses the issue of young carers as a window on the formulation and delivery of social policy in a global context. The article examines the extent of children’s informal caregiving in each country; how young carers differ from other children; and how children’s caring has been explained in research from both developed and developing countries. The article includes a review of the research, social policy and service developments for young carers in each country. National levels of awareness and policy response are characterised as ‘advanced’, ‘intermediate’, ‘preliminary’ or ‘emerging’. Explanations are provided for variations in national policy and practice drawing on themes from the globalisation literature. Global opportunities and constraints to progress, particularly in Africa, are identified. The article suggests that children’s informal caring roles in both developed and developing nations can be located along a ‘caregiving continuum’ and that young carers, globally, have much in common irrespective of where they live or how developed are their national welfare systems. There is a need in all countries for young carers to be recognized, identified, analyzed and supported as a distinct group of ‘vulnerable children’.

**KEYWORDS** *children, informal care, young carers, young caregivers, children’s welfare, vulnerable children, cross-national social policy, HIV/AIDS*

## **Conceptualising informal caregiving**

In the United Kingdom, Australia, the United States, as well as other developed (advanced) countries, researchers, policy makers, social welfare agencies and professionals in health, social care and education have taken a growing interest during the last decade in the extent, nature and outcomes of children's informal (unpaid) caregiving within the family. A research interest is now also emerging in other regions, particularly sub-Saharan Africa, where the HIV/AIDS pandemic has led to millions of children being drawn into unpaid caring that goes beyond their routine labours and responsibilities within the family (Robson, 2000; Robson and Ansell, 2000; Robson, Ansell, Huber, Gould and Van Blerk, 2006). While there is sparse recognition by policy makers and limited dedicated service development or professional support targeted specifically on African children who provide substantial and regular care, the policy and service delivery responses to the needs of young caregivers in the UK, Australia and the US also vary considerably.

In the UK, Australia and the United States, as in almost every other developed industrialised nation, unpaid caring within the family is rarely conceptualised or discussed as care *work*, rather it is referred to as informal or unpaid caring (or caregiving in the United States; see National Alliance for Caregiving, 2005). The understanding that care is given free of charge is at the heart of informal caring relationships, in contrast to professional, paid-for caring arrangements. Informal caring activities are often hidden, part of the private domain of the family, founded on love, attachment, duty and reciprocity, not on monetary exchange (Becker and Silburn, 1999). However, unpaid caregiving is labour; it is care work (Brown and Stetz, 1999). Recognising these activities as care work is to politicise and to make public the activities, roles, value and outcomes that characterise unpaid and family-hidden caregiving, and to identify these issues as concerns for social and public policy, and for social development. Carers UK has calculated that the annual cost of the 'hidden' contribution by the UK's six million adult family carers is £57 billion, a similar cost to the National Health Service itself (Holzhausen, 2002). In Australia, the replacement value of the care provided by informal carers with the purchase of formal services to deliver care in the home has been calculated at \$30.5 billion per annum (equivalent to 3.5 percent of the forecast GDP and 62.2 percent of other formal health care) (Access Economics Ltd, 2005: i). In the USA, in 2004, family carers contributed

an estimated \$306 billion worth of unpaid caregiving. This dwarfs the costs of US formal home health care (\$43 billion) and nursing home care (\$115 billion) (Arno et al., 1999; Arno, 2006). No estimates have yet been made in any country of the hidden economic or social costs of children's unpaid care work. This caregiving does not fall into the International Labour Organization definition of 'children at work in economic activity', which the ILO is trying to eliminate (Robson et al., 2006: 97). Unpaid care work by children is thus not recognized as child labour and, as a consequence, is rarely identified in UNICEF or other publications as a specific cause for concern. This is a theme we return to at the end of the article. The aim here, however, is not to discuss young caring as a new (or older, not recognized) manifestation of child labour. Rather, the aim is to develop the first analysis of children's informal caring roles and responsibilities, and the policy responses, in a global context. The UK, Australia, United States and sub-Saharan Africa have been chosen because they each represent a different level of awareness and response to the needs of young carers. The article uses the 'issue' of young caregivers as a window on the formulation and delivery of social policy in a global context and uses the emerging research on young carers from sub-Saharan Africa as a lens through which to make some comparisons and observations between developed and developing countries.

### **Children's caregiving**

While there is a high degree of acceptance and legitimacy when adults take on unpaid caring roles, we know from official statistics and other sources of research evidence and experiential knowledge that many children in the UK, Australia, the US, and sub-Saharan Africa are involved in caregiving within the home (Becker, Aldridge and Dearden, 1998; Robson, 2004). In Western constructions of childhood, children are not expected (or encouraged) to take on substantial or regular caregiving responsibilities. In theory at least, 'childhood' is viewed as a 'special' or 'protected' phase, with adults, state agencies and social welfare professionals charged with safeguarding and protecting children and young people until they make the transition into adulthood (Dearden and Becker, 2000; Frank, Tatum and Tucker, 1999).

While some level of attachment and caring by children would be viewed as necessary for 'healthy' psycho-social development in most societies, it is now known that many children who undertake substantial or regular caring can experience

significant restrictions in their development, participation and opportunities, educational attainment, even when there may be some ‘positives’ associated with caring – such as enhanced coping mechanisms, the development of life, social and other skills, maturity, a sense of purpose and closer attachments (Dearden and Becker, 2000; Aldridge and Becker, 2003). Becker suggests that the term ‘young carer’ (or ‘young caregiver’ in US diction) needs to be employed precisely and deliberately to refer to a specific group of children who take on a quantity or quality of caring roles that are substantial and/or significant to families themselves, and which are different to, and go beyond, not only what we (as adults) would normally expect of children but also what many children would expect routinely to do within the home:

Young carers can be defined as children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision. (Becker, 2000: 378)

While there are some variations in the operational definition of young carers across the UK, Australia and the US, and within countries (see for example Frank, 2002: 6-8 for UK definitions and Oreb, 2001: 27 for Australian definitions) the basic ingredients of Becker’s definition are in common currency and have informed conceptualisations in all three developed countries (Moore, 2005b: 65) and in recent research on young carers in developing countries where it has been suggested that young carers in Africa fall within this definition (Robson et al., 2006: 96). The definition allows a distinction to be made between those children (young carers) who are involved in ‘significant, substantial or regular care’, many of whom will take on these responsibilities at very early ages, and those children who, as part of their routine family lives and roles, may be involved in some aspects of caring but at a level which is neither substantial or regular, nor are the outcomes unduly negative, damaging or restrictive to children themselves. Thus, caregiving can be viewed along a continuum, with all children being involved in some aspects of caring throughout childhood, but with a much smaller proportion taking on substantial, regular or significant roles often from an early age, and which in some cases are associated with serious negative outcomes. This concept of a ‘continuum of caregiving’ is a theme we return to later.

## **The extent of children’s caregiving**

Because young carers have been a ‘hidden’ group in all countries, reliable and comparative indicators of the extent of children’s caring roles are seriously underdeveloped. In this section we review the most reliable data that are currently available for each of our countries.

In the UK, almost three million children under the age of 16 (equivalent to 23 percent of all children) live in households where one family member is hampered in daily activities by a chronic physical or mental health problem, illness or disability (Becker et al., 1998: xii). However, as we shall see, the large majority of these children do not become young carers. An early study by the UK Office for National Statistics (ONS) suggested that there were between 19,000 and 51,000 children in Britain in the mid-1990s who took on ‘substantial or regular care’ (Walker, 1996).

The 2001 Census provides a more up to date estimate and shows that there are 175,000 children and young people aged under 18 in the UK who provide some level of unpaid care to other family members (Office for National Statistics, 2003). This is approximately 6 percent of children who live in families with illness and disability. Table 1 shows the number and proportion of children who provide unpaid care in the four nations of the UK. So, for example, there are 29,142 children in the UK who provide more than 20 hours of care per week, and 13,029 of these provide more than 50 hours of unpaid care work per week – that is 8 percent of all young carers. Analysis elsewhere shows that there are 13,299 children who are carers in England and Wales under the age of ten (Becker, 2004: 6).

[Table 1 near here]

**TABLE 1** *Number and proportion of children aged 5-17 who provide informal family care in England, Wales, Scotland and Northern Ireland, by hours caring per week (2001 Census<sup>a</sup>)*

	Number caring for 1-19 hours	Number caring for 20-49 hours	Number caring for 50+ hours	Total number caring	Proportion who provide informal care
England	116,823	12,284	10,092	139,199	1.7%
Wales	8,854	1,029	861	10,744	2.2%
Scotland	13,511	1,826	1,364	16,701	2.1%
N Ireland	6,666	974	712	8,352	2.5%
Total number of young carers in UK	145,854	16,113	13,029	174,996	2.1% (UK average)
Total number as % of all young carers in UK	83%	9%	8%	100%	

<sup>a</sup> Calculated from Office for National Statistics (2003) *Census 2001 data*. London: ONS.

The 2001 Census figure for the total number of children who provide care is more than three times higher than the previous ‘official’ estimate of 19,000–51,000 young carers because the Census data include children who provide any level of self-reported caring within the family. In contrast, the earlier ONS figures (Walker, 1996) only included children who were providing ‘substantial or regular care’. However, the Census figures are themselves likely to under-represent the prevalence of children’s caring because they rely on parents’ self reporting their children’s caring roles, and the data are not likely to adequately identify or count children in some caring situations, for example those who may be caring for parents who misuse alcohol or drugs or where there is enduring parental mental ill health or HIV/AIDS. Up to 1.3 million children in the UK are affected by parental alcohol problems and there are

around 360,000 children under 16 who have parents who are problem drug users (Gorin, 2004: 4). This is in addition to the estimated 2.5 million children in the UK who are affected by their parent's mental health problems (Tunnard, 2004: 6). Most of these children and young people will be 'affected' in some ways by their parent's conditions, some adversely, but only a small proportion will become caregivers to the extent or nature captured in the definition provided by Becker (2000: 378).

Secondary analysis of Census 2001 data shows that 1.6 percent of all children under 18, or a UK average of 2.1 percent of children aged 5-17 (because there are no young carers recorded in the Census as aged 1-4; see Becker, 2004) are providing informal care in the UK (Table 1). There are small variations between the four UK nations, with the highest proportion of children who are carers to be found in Northern Ireland, with 2.5 percent of all children aged 5-17 being involved in caring (Table 1). These proportions are minimums rather than maximums because of the limitations inherent within the Census questions and methodology outlined above. However, these estimates are supported by National Society for the Prevention of Cruelty to Children (NSPCC) data from a nationally representative sample of 3,000 young people aged 18-24. This survey found that 4 percent of all young people in this age group had regularly cared for an ill or disabled relative during their own childhood (Cawson, Wattam, Brooker and Kelly, 2000; Cawson, 2002; Aldridge and Becker, 2003: 16-20).

The earliest estimate of the number of young carers in Australia, by the Australian Bureau of Statistics (ABS), shows that in 1993 there were 33,800 carers aged under 15 in Australia. Because of the administrative categories used in the survey these early Australian statistics only 'count' young carers as being children under the age of 15 (ABS, 1995; see also Carers Association of Australia Inc., 1997: 22-23). A decade later, following changes in operational definitions, ABS data show that there are 169,900 young carers aged under 18 in Australia, that is 3.6 percent of all people under 18 (ABS, 2003). This proportion is approximately double that of children of the same age identified in the UK Census as carers. The variation may have more to do with the wording of survey questions and how the data were collected than evidence of a significant difference in the extent of young caring between the two countries.

In some parts of Australia, researchers and policy makers have broadened the definition of young carers to include carers under the age of 25. Consequently, the



ABS figure rises to 347,700 carers under 25, or 5.2 percent of all people in the age group (ABS, 2003). Carers Australia (2001a, 2001b) and Carers New South Wales continue to define young carers as children and young people up to the age of 25. However, recent research in Australia has argued that the definition of young carers should be restricted to those under 18, similar to the UK (Moore, 2005b: 63-64), and particularly because carers over the age of 18 are no longer children and many are caring for partners or their own ill or disabled children, a situation very different to the profile for children who care (Dearden and Becker, 2004). In the UK and US there is growing research interest in the 18-24 year old group of young adult carers, of which there are 229,309 in the UK according to the Census (ONS, 2003), and between 3.6 to 5.5 million in the US (Levine et al., 2005).

The first (and, to date, only) US survey of young caregivers, drawing on a random sample of 2,000 households and funded by the US Administration on Aging, asked whether any child 8 to 18 years of age in the household provides unpaid help or care to any person. The findings show that there are approximately 1.3 to 1.4 million young caregivers who are between the ages of 8 and 18, or put another way, 3.2 percent of all US households with a child aged 8 to 18 in them include a young caregiver (National Alliance for Caregiving, 2005). A clear limitation of this research, however, is that the age band for inclusion starts at eight. The UK Census data, in contrast, show that 4 percent of all young carers in the UK are aged between 5 and 7 (Becker, 2004), but the US calculations exclude carers in this age group.

Despite the differences in survey methodologies and age bands included in the UK, Australian and US data sets, the statistical evidence shows a degree of uniformity in the proportion of children in these three developed countries who are young carers. While the data from all countries is likely to underestimate the extent of young caregiving because of definitional and methodological limitations, these official or quasi-official sets of statistics (all undertaken or funded by government) show that only a small proportion of children in particular age groups, between 2 to 4 percent, will take on informal caring roles in the UK, Australia and the US. While this is an important finding on the proportion of children *providing* care, it tells us nothing about the proportion of people *demanding* or *requiring* informal care in each country. In sub-Saharan Africa, given the HIV/AIDS pandemic, there is evidence to show that larger proportions of the population will require informal care compared with our

three developed countries, especially in the context of restricted access to, and availability of, formal health and social care support.

There are no official figures for the number of children involved in caring in sub-Saharan Africa (Ogden, Esim and Grown, 2004; Robson et al., 2006: 97). Robson et al identify a large survey in Tanzania in the early 1990s which found that about 4 percent of 7-14 year olds were reported to have engaged in caring for sick relatives in the previous seven days (Ainsworth et al., 2000: 22, cited in Robson et al., 2006: 97). However, since then an increasing number of children have become affected by the AIDS/HIV pandemic. Children aged 0-14 constitute on average 43 percent of the population in sub-Saharan Africa, while up to 34 percent of the adult population aged 15-49 in countries such as Zimbabwe are HIV infected, with a sub-Saharan average of 7.4 percent of all adults infected (Robson et al., 2006: Table 1: 95). According to UNICEF/ UNAIDS more than 14 million children under the age of 15 have lost one or both parents to AIDS globally, the vast majority of them in sub-Saharan Africa. It is estimated that by the year 2010 in sub-Saharan Africa, in excess of 18 million children – more than all the children in the UK – will have lost at least one parent to AIDS. Less than 10 percent of children orphaned and made vulnerable by AIDS are receiving some kind of public support (UNICEF, 2006).

Within the extensive literature on the impacts of the HIV/AIDS epidemic in Africa, most of the emphasis to date has been on ‘orphans and vulnerable children’ affected and infected by HIV/AIDS (Foster et al., 2005), rather than on the impacts of children’s caring roles during their parents’ and relatives’ illness. According to UNAIDS, anecdotal evidence from various African countries suggests that children who care are often young – between 8 and 11 years old, as older siblings tend to leave home to find work or seek survival on the streets as family poverty deepens (UNAIDS, 2000). However, international governmental organizations such as UNICEF, and international non-governmental organizations such as Save the Children, have not focused explicitly on the caregiving roles of children affected by AIDS, or the impacts of these roles on children’s health and welfare and their access to education. However, there is creeping use of the ‘image’ of the AIDS-affected child as a caregiver, with Save the Children, for example, issuing a 2006 Mother’s Day appeal which described how ‘millions of children...have had to become “mums” themselves, giving up their own childhoods to care for younger brothers and sisters’ (Save the Children, 2006).

## **How young carers differ from other children: A continuum of children's caregiving**

Despite assertions by some UK commentators that there are no scientifically 'proven' differences between what young carers do within the family compared with other groups of children (Parker and Olsen, 1995; Olsen, 1996; Olsen and Parker, 1997; Newman, 2002) there is now research evidence from all three developed countries and from sub-Saharan Africa which shows that young carers *do* differ from other (randomly selected) children in both developed and developing countries, and across cultures. The differences center on the extent of their caregiving, its nature, the time involved and the outcomes for children's development, social and economic participation.

In Australia, Morrow (2005) suggests that a way of differentiating what young carers do from other children is to examine tasks as Instrumental Activities of Daily Living (such as taking out the rubbish or cleaning), and as Activities of Daily Living (such as moving relatives around the house, dressing, toileting, showering and bathing, getting them in and out of bed). Morrow argues that 'non-carers will not bath, shower and toilet a sibling or parent' (p. 58). Carers Australia (2001b: 9) found that unlike non-caring peers, young carers spend most of their time either providing care or thinking about the person with care needs. Gays (2000) suggests that Australian young carers take on caring tasks and levels of responsibility not found among other (non-caring) children and young carers report more injuries, start housework from a younger age and perform a wider range of jobs around the house and do these tasks more often and on a regular basis. Moore's (2005a: 5) study of fifty Australian young carers found that their caring responsibilities 'are more intense than their non-caring peers and are most often provided without supervision or support'.

In the UK, Warren (2005, 2006) addresses this issue head on by comparing the caring tasks of 'known' young carers with a group of almost 400 children selected at random. She found that 'what sets young carers apart from their peers is the nature, frequency and time spent each week on domestic and caring tasks' (p. 6). Young carers perform a wider range of domestic, emotional, general nursing-type care, and intimate care tasks and they spend longer on these activities than other children. Warren's study also found that young carers were more likely than other children to

have restricted opportunities for social, recreational and extra-educational participation. Warren found that young carers are more likely than other children who are not young carers to identify a range of barriers that might prevent them from fulfilling their future ambitions. In order of priority these include a lack of money, a need to look after a family member and a lack of qualifications, In contrast, children who are not young carers report that their future ambitions may be restricted primarily by a lack of money (Warren, 2006).

The only US research to examine specifically the differences between young caregivers and other children compared the experiences of 213 young caregivers with 250 child non-caregivers as part of a national prevalence study (National Alliance for Caregiving, 2005). The researchers suggest that ‘child caregivers who provide significant amounts of care have life experiences different from those of their non caregiving peers’ (p. 2). So, for example, young caregivers in the US are more likely than other children to spend more time doing a wide range of household and caring tasks, shopping, doing laundry, making dinner, looking after siblings and are more likely to show anxious or depressed behaviour and behave anti-socially particularly at school.

This pattern of findings is reinforced by research on young carers in sub-Saharan Africa. As Laird has observed, in the absence of public utilities, welfare services or social security, households in Africa are dependent on children to perform many time-consuming and strenuous household labours and productive activity to enable the household to meet its survival needs (2005: 462). Many children, from an early age, will also be caring for sick or disabled family members, particularly those with HIV/AIDS (Robson et al., 2006; Robson and Ansell, 2000: 185). This form of social organization, Laird observes, ‘is underpinned by a value system which emphasises the obligations owed by children to their parents in terms of contributing to the household and providing care during sickness or old age. Failure to fulfil these responsibilities will attract censure and probably penalty both from kin and the wider community’ (2005: 462).

Research across a number of sub-Saharan African countries confirms that there are differences between what young carers do and other children, including those who have routine caring responsibilities as part of the social organization of the family: ‘Even within an African sociological and anthropological context, what young people like Doris do, can be considered more than a child’s “normal” range of tasks

and burdens of responsibility' (Robson et al., 2006: 96). Robson et al go on: 'It is the intimate care...that most clearly distinguishes the labour of young caregivers from the usual work young people do in Africa with respect to household chores' (p. 100). Additionally, 'As caregivers, young people do more domestic work and have greater responsibility for tasks like cooking, fetching water and wood than other young people, because they live in a household with a sick grandmother, parent or sibling' (p. 100).

The evidence from both developed and developing countries indicates that many young carers have to perform more tasks (and spend longer on them) that are Instrumental Activities of Daily Living (such as shopping and housework) *in addition* to the more care-related Activities of Daily Living (such as intimate and personal care). These tasks can start at a very early age and continue for many years. In the UK, for example, one fifth of young carers in a large survey had been caring for more than six years even when the average age of the group was just 12 years old (Dearden and Becker, 2004). In Australia, research has found children who had been caring for fourteen years (Morrow, 2005).

It is possible to conceptualise children's informal caring in developed and developing countries as a continuum along which *all* children's caregiving can be located. Young carers would be placed at the 'heavier', more substantial and regular caregiving-end of the continuum, and many would also be doing a significant amount of tasks associated with Instrumental Activities of Daily Living (Diagram 1). Warren's (2005, 2006) research in the UK also found, unexpectedly, that around a tenth of her randomly selected group of children also had considerable caring responsibilities, sometimes as substantial and significant as the *known* young carers in her study. This suggests that there is a 'hidden' group of young carers within the general population of children, and this group can be located at the 'heavier' end of the continuum. This group, however, are not recognized or identified as young carers nor are they likely to be in receipt of any dedicated support services or interventions.

The evidence presented here suggests that some children are drawn into substantial, regular and significant caring roles and Instrumental Activities of Daily Living irrespective of the degree of social development or the sophistication of the welfare regime or welfare mix that characterises the country in which they live. In every group of 100 children in our three developed countries, at the minimum up to four children will be young carers. In Africa, while there are no reliable figures for the

proportion of children who are young caregivers, the actual number is likely to run into the millions, primarily because of the HIV/AIDS pandemic, the extent of demand for informal care, and the lack of available and affordable care alternatives. These are themes we develop in the next section.

[Diagram 1 near here]

**DIAGRAM 1** *A continuum of children’s caregiving*

‘Light end’ (low levels of caregiving and responsibility)	◇ ◇ ◇	◇ ◇ ◇	‘Heavy end’	‘Very heavy end’ (high levels of caregiving and responsibility)
‘Routine’ levels and types of caregiving including some help with Instrumental Activities of Daily Living	<p style="text-align: center;">◇ ◇ ◇</p> <p style="text-align: center;">Caregiving tasks and responsibilities increase in amount, regularity, complexity, time involved, intimacy and duration</p>			‘Substantial, regular and significant’ caregiving including considerable help with Instrumental Activities of Daily Living
Household tasks and caregiving tasks can be considered age and culturally appropriate for the child’s age				Household tasks and caregiving tasks can be considered age and culturally inappropriate for the child’s age
Most children				Few children
	Young carers providing 0-19 hours of care per week	Young carers providing 20-49 hours of care per week	Young carers providing 50+ hours of care per week	
Many ‘hidden’ young carers (unknown to service providers)				

## **Explanations for children's global participation in informal caregiving: Choice and income**

The reasons why a particular child becomes a carer within any family in any country will be multifaceted and complex. Becker and colleagues have suggested a framework for understanding the 'push and pulls' into caring, grounded in their own and others' research findings. Factors such as the nature of the illness/condition, love and attachment, co-residency, family structure, gender, socialisation, low income, a lack of choice and alternatives, have all been shown in UK quantitative and qualitative enquiries to push or pull children into caregiving (Becker et al., 1998: 21-26; see also Becker, 2005). Researchers investigating young carers in Zimbabwe have confirmed that these same factors can explain equally as well why some children become young carers in the global South as much as they do in developed countries (Robson and Ansell, 2000: 187). However, as yet, the research evidence base does not allow a more sophisticated understanding of the relative strengths of these factors and how they combine and interact. Studies have not been able to control for the influence of one variable over another.

Nonetheless, research from the UK, Australia and sub-Saharan Africa indicates that a number of inter-related factors from Becker et al's (1998: 21-26) framework have strong explanatory power for explaining children's participation in caregiving at the global level. The evidence suggests that the interactions between financial resources and matters of choice are especially important. In most families, young carers are drawn into caring because there is no alternative. Their caregiving is an outcome of the interplay between the demands for, and availability of, informal care within any family, community or society; a lack of available or affordable health and social care provision, particularly home-based care for people with care and supervision needs; and the lack of recognition and support available to meet the parenting needs of ill or disabled parents.

In the sub-Saharan context, Robson et al (2006: 107) have argued that the existence of young carers may be seen in part as an outcome of reduced state healthcare provision and the promotion of policies advocating home care for individuals with HIV/AIDS. Charges for healthcare, and for education, imposed by Structural Adjustment Programmes (Laird, 2005: 459) also reduce families'

disposable income and choice and push many with care needs into relying on informal carers – their children. In an Australian context, it has been argued that ‘It is largely in the absence of other support that young people become carers of an adult with a disability’ (Price, 1996: 26), while Dearden and Becker have suggested that in the UK ‘The receipt, quality and timing of professional services and support, and the level and adequacy of family income, are critical’ (2000: 46).

In the UK, Australian and African research there is often explicit reference to the fact that low income distinguishes most of the families where children are known to be caregivers (and in Africa, very low income/chronic poverty). The major US study also confirms that young caregivers live in low-income households (National Alliance for Caregiving, 2005: 15). Globally, these families lack the financial and other resources to be able to command affordable and good quality care alternatives which could prevent children from having to undertake caregiving in the first place and which could reduce the amount of caring that they have to perform currently. In particular, higher disposable income could help to reduce or limit the quantity and intimacy of caregiving – the type of caring that can cause most distress for children and for the person with care needs (Becker et al., 1998; Wates, 2002; Newman, 2002; Aldridge and Becker, 1994, 2003). For many young carers globally, participation in informal care is thus not a positive choice but is rather a necessity borne out of no real alternative (Becker, 2005). Taking on these levels and types of caregiving, including other tasks that are Instrumental Activities of Daily Living, can move some children in developed and developing countries along a continuum of children’s caregiving, where they are subsequently involved in substantial, regular and significant care that distinguishes the extent, nature and outcomes of their caring from that of other children (Diagram 1).

### **Social policy and service developments at the national level: The importance of research evidence and ‘organizations of influence’**

The earliest studies of young carers in the UK can be traced back to the late 1980s (O’Neill, 1988; Page, 1988) although more academic and focused qualitative research examining the specific experiences of young carers started four years later (Bilsborrow, 1992; Aldridge and Becker, 1993). The dozens of studies and publications by Becker, Aldridge and Dearden are significant here, in that, as the



Young Carers Research Group, their work forms a body of qualitative and quantitative research evidence that spans more than a decade and which has informed academic thinking and policy developments in all three developed countries and the research enquires of those now investigating young carers in Africa. This body of research ‘remains a fundamental cornerstone of literature on the subject’ (Oreb, 2001: 10). In the UK, social policy, law and professional practice on young carers has evolved and developed in a symbiotic relationship with the growing research evidence (Aldridge, 2004: 22). Prior to the 1990s, academics, policy makers and welfare professionals failed to recognise, account for and respond to children’s informal caring within the family.

This growing research base was critical in raising awareness among UK policy and practitioner networks of the experiences and needs of young carers and their families, and the outcomes of caring when families have few options or resources to purchase alternative forms of care. Many qualitative studies gave depth and voice to young carers’ experiences and the outcomes for children of caregiving (see Aldridge and Becker, 1999, for a review of the evidence on outcomes in the UK research, and Carers Australia, 2001a, for a review of Australian findings on outcomes). Four quantitative studies in the UK (Dearden and Becker, 1995, 1998, 2004; Brook Chen and Baker, 2001) provided statistical profiles of known young carers, including their characteristics and care roles within the family. The largest and most recent study, by Dearden and Becker (2004) reports the findings of a survey of over 6,000 young carers in contact with dedicated projects. This confirmed statistically what a body of other in-depth studies had shown qualitatively.

Media interest in research outputs and the general experiences of young carers, particularly half a dozen television documentaries, helped to fuel public awareness and interest and further academic enquiry. But a critical role in developing the UK research agenda, and then the policy and practice agendas, was played by national non-governmental organizations, namely Carers UK (formerly Carers National Association), the Children’s Society, Princess Royal Trust for Carers and Crossroads, all of which funded research and helped to inform and influence the development of law and policy guidance, sometimes directly by drafting the documentation. Key individuals within these organizations, and a few Members of Parliament, all with an interest in and commitment towards young carers, also played an important part. Young carers themselves took a role in lobbying MPs and policy makers, politicised

and helped by these carers and children's organizations. One manifestation of this in the UK is the annual Young Carers Festival which has been organized by the Children's Society and which has attracted over 1000 young carers and government and policy makers since 2000.

Between the early 1990s and 2005 young carers in the UK were 'well and truly placed on the map of child welfare services' (Newman, 2002: 614). From just a handful of young carers projects in the early 1990s there are now over 350 dedicated projects across the UK in contact with around 25,000 young carers and employing hundreds of workers as well as many volunteers. Young carers in the UK have legal rights to an assessment of their own needs and of their ability to provide and continue to provide care, and they have rights to services and in some cases cash in lieu of services ('direct payments') under UK carers legislation. Many young carers would also be considered as 'children in need' under children's legislation and they and their families would have rights to appropriate support. The UK government's National Carers Strategy (HM Government, 1999) has a chapter dedicated to young carers. Additionally, young carers are referred to in much social care and health-related guidance, in education circulars, in inter-professional guidance, and in various National Service Frameworks (see Aldridge and Becker, 2003: 175-198, and Bibby and Becker, 2000, for a review of relevant UK policy and law). However, despite these established rights and a relatively comprehensive legal and policy framework, there are still gaps and weaknesses that have been identified through research. For example, most young carers have never had a formal assessment of their needs or ability to care and the vast majority are not in contact with any dedicated support provision (Dearden and Becker, 2004). Moreover, the legal framework, by comprising of carers and children's legislation and a wide range of guidance, is complex and confusing to many social welfare professionals and can serve to exclude some young carers (for example, those under the age of 16 have no legal right to services in their own right *as carers*).

Australian research on young carers can be traced back to the early 1990s, just a few years 'behind' the research in the UK. The Alzheimer's Association of South Australia reported that some children in families with dementia had caregiving roles (Alzheimer's Association, 1995:7) and the Association developed and continues to run retreats and camps for these children. The Alzheimer's Association study is primarily one of children affected by a parent's dementia, rather than a study of young

carers *per se*. The Carers Association of Australia produced two reports (1996, 1997) that were the first substantive attempts to research specifically young carers in Australia and which also contained policy and service recommendations. The later report (Carers Association of Australia Inc., 1997: 9) outlines some of the long-term consequences of children taking on care responsibilities and these findings mirror those reported in the multitude of published UK studies.

Price's study of 93 'children and young people living in New South Wales, aged 18 years or under or still in secondary school, who provide significant care to an adult with a disability in their household' (1996: 7) found that most young carers were providing care for between ten and 20 hours each week, although some were on call for 24 hours per day. One in eight were caring for more than one person (the same proportion as reported in UK studies – see Dearden and Becker, 2004). Many Australian welfare professionals had not identified young carers and had thus failed to engage with their particular needs. The professional focus remained on the adult with the disability, without reflecting how the disability may impact on the functioning of the household or children (Price, 1996: 11; see also Aldridge and Becker, 1999, 2003), or for that matter the disabled person as a parent.

At the end of 2000, the Carers Association of Australia was successful in gaining funds from the Commonwealth Department of Family and Community Services to undertake national research on young carers: 'The funding of this research project is a recognition of the need to establish an authoritative reference base to be used to inform future policy and funding decisions' (Oreb, 2001: 11). The reports from this project (Carers Australia, 2001a, 2001b) are comprehensive documents that review the available Australian and international research evidence and report findings from focus group interviews with Australian young carers *up to age 25*. Moore (2005a, 2005b, 2005c) reports the findings of in-depth research conducted with 50 young carers and outlines a series of strategies for future policy development. Morrow (2005) provides a breakdown of young carers' roles by whether they are Instrumental or other Activities of Daily Living. Gray et al (2006) identify the education issues for Australian young carers. These studies confirm the pattern of findings from UK enquiries and suggest that the experiences of young carers, and the nature of their caregiving, are identical in the UK and Australia.

The earliest Australian policy and service initiatives specifically for young carers originate from the mid-1990s. Most dedicated services have been developed

through regional Carers Associations or Carers Groups and in 2005 the national Government pledged an additional \$26.6 million to be made available for respite and information services for young carers (Carers Australia, 2005: 2). The support available to Australian young carers includes young carers programmes operated by Carers Associations, camps, buddy and mentoring programmes, websites, newsletters, drama and arts groups, counselling, teleconferencing and breaks. Carers Australia (2001a) argues that better coordination of services across regions and by providers is required.

All Australian states now have dedicated projects or initiatives for young carers. The Carers Association of New South Wales, for example, has developed a programme of work for young carers and their families, including an information pack for young carers and a training package for service providers and teachers. The Association also piloted other forms of support, including local support groups and group counselling over the telephone. Now, Carers New South Wales has an established Young Carers Project with distinct and clear aims and methods and it has published research and other reports, including guides for professionals and parents. Oreb (2001) and Carers Australia (2005: 30-33) describe the range of services and programmes available to young carers across Australia. In 2004, the first National Young Carers Summit was held in Sydney, attended by 60 young carers, government representatives and policy makers, which produced a series of recommendations and strategies for the future (Carers Australia, 2005).

Despite a growing network of dedicated projects and services for Australian young carers, many of these initiatives, like those in the UK, are provided by voluntary and community sector organizations (NGOs), notably Carers Associations, and are founded on precarious funding arrangements. More restrictively, unlike the situation in the UK, Young carers in Australia to date have no specific legal rights to recognition, assessments or to support services. While the needs of some Australian young carers are being recognized and responded to through direct services and interventions provided by state Carers Associations and other one off, ad hoc regional young carers programmes delivered through the community sector, most young carers counted in Australian official statistics will not be receiving any recognition or specific support at all (just like the UK), but nor would they have a legal right to assistance.

In both UK and Australian research, and policy developments, there is growing recognition of the importance of a ‘whole family approach’ to meeting the needs of young carers *and* the person(s) with care needs (Becker et al., 1998; Aldridge and Becker, 2003). UK policy makers, particularly those in the Children’s Society (Frank, 2002), the Princess Royal Trust for Carers and the Disabled Parent’s Network have played a major role in developing the model for this holistic approach to service delivery, and this is largely a response to criticisms made by some UK researchers and disabled people themselves of existing young carers services (Keith and Morris, 1995; Olsen, 1996; Newman, 2002; Wates, 2002).

Researchers and policy makers in the US have been slower in engaging with the research and policy agendas for young caregivers. Gates and Lackey (1998) have examined the impact of caregiving on young people looking after adults with cancer and chronic physical illness (Lackey and Gates, 2001), while Beach (1994, 1997) has focused on the impact of family caregiving 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) add to the US research base on children’s caregiving experiences and outcomes. 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. This research (National Alliance for Caregiving, 2005) provides the first estimate of the prevalence of young caregivers in the US (1.3 - 1.4 million children) and those attending the 2005 conference hoped that this study would provide the ‘tipping point’ from which services might be developed.

The US research evidence base on young carers is less developed than it is in the UK and Australia. Moreover, 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. By 2006 there was only one dedicated initiative, the Caregiving Youth Project, in Boca Raton, Florida, compared with over 350 projects in the UK. The American Association of Caregiving Youth, also based in Boca Raton, is in formation. Some disease-specific organizations,

notably the National MS Society and Cancer Care, have information and programmes aimed at young caregivers. The National Alliance for Caregiving is planning to establish a National Coalition for Young Caregivers, to try and move the research and policy agenda forward drawing on the impetus of the 2005 Washington conference. However, for most of America's young caregivers, there is little recognition of their roles and no dedicated support available.

Despite an extensive literature on orphans and vulnerable children affected by the HIV/AIDS pandemic, there is little recognition of the role of young carers in sub-Saharan Africa, and there are few services specifically designed to meet their needs. Policy directed at children's welfare in sub-Saharan Africa is 'situated between grim human development indices and an impoverished public sector' (Laird, 2005: 459). The small body of research evidence on African young carers originates largely from UK-based academics (Robson et al, 2006), rather than from indigenous researchers. However, there are important lessons to be learnt from ongoing research in Africa that can inform future research and policy initiatives for young carers in developed and developing countries. For example, the research on children affected by and caring for parents and other relatives with HIV/AIDS in Africa is informing a new approach to young carers research in the UK, with a growing emphasis on the concept of resilience as a way of understanding and responding to the experiences and outcomes of young carers. The UK-based Economic and Social Research Council are funding the first cross-national study of the experiences, needs and resilience of children caring for relatives with HIV/AIDS in Tanzania and the UK which will report in late 2007 (Becker and Evans, 2005). If the focus of research turns away from the 'vulnerability' of young carers to one concerned with 'resilience', then researchers may be better equipped analytically to explain *differences* in experiences and outcomes *between* young carers within and across countries. Indeed, such a focus would challenge researchers and policy makers to consider new ways of understanding children's caregiving, as not so much an example of vulnerability, but as an active expression of resilience (Evans, 2005; Newman, 2002).

## **Discussion: Young carers in a global context**

### ***Levels of response: Advanced, intermediate, preliminary and emerging***

The United Kingdom, Australia and the United States, despite each being developed and industrialised nations with established mixed economies of welfare, all recognise and respond in different ways to children's participation in informal caregiving. Each nation has its own country-specific research evidence base and official or quasi-official estimate of the number of young carers. This article shows that around 2-4 percent of all children in each of these developed countries can be referred to as young carers, although in all of these countries this is likely to be an underestimate. This article also demonstrates, through the analysis of country-specific responses, that local context is critical in determining social policy and service development responses at the national level, but that there is also policy transfer across geographical boundaries.

The UK can be characterised as relatively *advanced* in terms of awareness of young carers, research, law, social policy, government guidance and service delivery (Diagram 2). 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. However, despite these legal and policy advances most young carers do not access the available support initiatives and so remain hidden. However, if all UK young carers were to make demands on existing services and projects, then it is unlikely that these providers could meet that demand.

Australia inhabits an *intermediate* position between the UK and the US. There is a growing Australian-specific research evidence base, partial rights in some regions and a smaller distribution of young carers projects and initiatives. As with the UK, many of these projects and initiatives have been promoted and developed by the community and voluntary (NGO) sector and most are precariously funded. There is little reference to young carers in Australian government policy documents or guidance from health, social care and education authorities. There appears to be a time-lag of two to three years between the UK and Australia in terms of services and practice developments, although this is longer with regards to the establishment of legal rights for young carers in Australia.

The United States occupies a *preliminary* position, characterised by a small country-specific research base, no specific legal rights for young caregivers, and virtually no dedicated projects. There is little public or Federal recognition of the experiences and needs of young caregivers. The time-lag between the US and the UK, in terms of awareness, the research evidence base and the development of dedicated support services, is already greater than ten years. However, this does not mean that the US could not ‘catch-up’ if there was the political will and commitment, by researchers, policy makers and service providers, to recognise and engage with the issue and needs of young caregivers in the US.

In all three developed countries it appears to be the existence of a country-specific research evidence base that lays the foundation for policy developments and service responses. The more developed and country-specific is the research base, the more advanced is the policy and legal framework. This suggests, with regard to young carers at least, that policy makers prefer to have a home-grown research evidence base to inform their local and national decisions rather than drawing on or relying on research from other countries, even when research findings are similar.

However, other influences are important in the development and transfer of policy. Non-governmental Carers Associations have played a key role in all three countries in advocating for young carers and moving policy forward. These organizations have also met at international carers conferences and have shared ideas and research, thus facilitating policy and practice transfer. The stronger and more influential is a country’s carers organization and carers policy network (or ‘carers lobby’) the more advanced that country is in their level of awareness, research, and policy and service developments for young carers. It would not be disputed that the UK has the most established and influential carers lobby.

Awareness of, and responses to the specific needs of young carers in sub-Saharan Africa have not developed to the point where they could be characterised as *preliminary*. There is virtually no official, professional or public recognition of the specific role and position of young carers, despite potentially millions of children being drawn into caring and other roles that go beyond ‘normal’ expectations of children’s labour within these societies. In recent years, however, there has been a growing level of official, professional and public recognition about the broader category of orphans and vulnerable children who are affected by HIV/AIDS and interventions targeting this group are increasingly seen as a policy priority (see for



example, DfID, 2004; UNICEF, 2005). Research is however only just starting to explore the extent to which the specific needs of young carers in sub-Saharan Africa are being addressed by such interventions (for example, Becker and Evans, 2005). This situation in Africa can be termed *emerging* (Diagram 2). Furthermore, researchers and policy makers in developed nations can learn from the experiences of young carers in the global South. These experiences point us in new directions for research, utilising the concept of resilience as well as vulnerability. The experiences of young carers in sub-Saharan Africa can provide an analytical lens through which researchers can understand and explain children's caregiving in both developed and developing countries, and through which policy makers globally can build new frameworks and service responses for young carers and their families.

[Diagram 2 near here]

**Diagram 2** *Levels of awareness and response to young carers at the global level – a typology*

Level	Characteristics	Country/ Region example
Advanced	<ul style="list-style-type: none"> <li>• Widespread awareness and recognition of young carers amongst public, policy makers and professionals</li> <li>• Extensive and reliable research base</li> <li>• Specific legal rights (national)</li> <li>• Extensive codes and guidance for welfare professionals and national and local strategies</li> <li>• Multiple dedicated services and interventions nationwide</li> </ul>	United Kingdom
Intermediate	<ul style="list-style-type: none"> <li>• Some awareness and recognition of young carers among public, policy makers and professionals</li> <li>• Small research base</li> <li>• Partial rights in some regions</li> <li>• Small but developing body of professional guidance</li> <li>• Some dedicated services and interventions nationwide</li> </ul>	Australia
Preliminary	<ul style="list-style-type: none"> <li>• Little public or specialist awareness and recognition of young carers</li> <li>• Limited research base</li> <li>• No specific legal rights</li> <li>• Few, if any, dedicated services or interventions at national or local levels</li> </ul>	United States
Emerging	<ul style="list-style-type: none"> <li>• Embryonic awareness of young carers as a</li> </ul>	Sub-

	distinct social group within the ‘vulnerable children’ population	Saharan Africa
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### ***Global opportunities and global constraints***

While this article has focused on the UK, Australia, the US and sub-Saharan Africa, the awareness of young carers and policy and service responses among most other developed and developing countries can be classified as *preliminary* at best or *emerging* (Diagram 2). In developing nations the specific issue of young carers has not been identified as a concern for public or social policy, even though the image of the child as carer is beginning to permeate into descriptions of children affected by HIV/AIDS. In Africa, the international governmental and non-governmental children’s organizations such as UNICEF and Save the Children are spearheading awareness and responses to children affected or orphaned by AIDS (see Laird, 2005 for an analysis of UNICEF’s Country Programmes). These children’s organizations’ constructions (or non-constructions) of young caregivers are effectively those of vulnerable *children* affected by AIDS, not as *carers*. While UNICEF’s (2005) *State of the World’s Children* identifies many groups of children who are invisible and excluded, including ‘children in adult roles’, ‘child-headed households’, ‘children who are exploited’ and ‘children without parental care’, it has little to say about young carers who can be in all of these groups simultaneously. Similarly, while there is considerable focus on child labour, including children in domestic service, there is little recognition of the invisible children in unpaid caring roles and the barriers and outcomes that they experience. Given the importance of UNICEF’s role, analysis and publications, it becomes critical that UNICEF itself recognizes, analyzes and highlights the role of informal young carers.

In contrast, in the three developed countries it has been national non-governmental carers organizations that have played a decisive role in determining the level of awareness and response to young carers, although in the UK the Children’s Society Young Carers Initiative must also be mentioned for its influence on practice developments (Frank, 2002).

If the specific needs of young carers are to be identified in developing countries this will require existing national and international *children’s* organizations

to reconceptualize the vulnerable child to include identification and concern for young caregivers. It will require the key issue of schooling and universal educational participation, so central to the discourse and policy agenda for children affected by AIDS and the UN Millennium Development Goals, to be identified as an issue for young carers in sub-Saharan Africa.

While there are international governmental and non-governmental children's organizations, there are no international governmental and non-governmental *carers* organizations. This is not to say that the carers organizations of individual countries are not internationalist (in that they communicate with each other across geographical boundaries), but there is no *dedicated* international or transnational carers organization. Progress for young carers may therefore require the evolution of a new Global Issues Network (GIN) which identifies the nature of the issues that affect young caregivers, the problems to be worked on, and which encourages good practice through knowledge exchange and monitoring in individual countries and transnationally (Deacon, 2005: 441). Such a GIN for young caregivers could be developed through bringing together the relevant children's *and* carer organizations, and the key researchers, all of which have played an important role in developing awareness and responses to young carers at the national level.

The development of such a GIN will be an important step for promoting young carers' interests and rights under international frameworks such as the Convention on the Rights of the Child. National laws must match international commitments to children, to ensure that young carers, like other vulnerable children, have a right to education, health and participation.

In developing countries, progress in the formulation of national policy and service developments for young carers will be constrained by existing global institutions and policy prescriptions. Many developing countries are subject to international policy conditions attached to the receipt of debt relief and financial aid (Room, 2004). A consequence, As Laird observes, is that 'highly indebted African governments presiding over impecunious public sectors are essentially unable to provide social services or social assistance' (2005: 458-9). The introduction in the 1980s of charges for health and education under the Structural Adjustment Programmes for developing countries also serves to reduce the available disposable income and choices of communities, families and young carers. As we have shown, it is this lack of choice and income, particularly in the context of few affordable or

available health and social care services, which forces many children in low income families into substantial and regular care, both in developing and developed nations. This is exacerbated by global contractions in state-provided welfare and precarious funding for non-governmental provision. Moreover, Western conceptions of children's rights, as enshrined in the UN Convention, can be problematic for societies whose notion of rights is founded on interdependence and reciprocity, where children have responsibilities and duties towards their parents and families as much (if not more so) than they have any rights (Laird, 2005: 460).

UNICEF, Save the Children and other children's organizations in sub-Saharan Africa need to identify, analyze and respond to young carers as a distinct group of vulnerable children who take on adult caregiving roles often to the detriment of their own childhood, education, psycho-social development, health and economic well-being. Governments all over the world, by ratifying the Convention on the Right of the Child (except in the US), have pledged to safeguard children from harm, abuse, exploitation, violence and neglect. Making young carers visible to governments and populations, and developing more coherent, comprehensive and right-based responses, requires as a necessary first step that young caregivers be identified as a distinct group with distinct needs in *all* countries. This is the immediate, global, challenge. Thus, at the moment, young carers in London, Canberra, Washington DC and Dar es Salaam, and their brothers and sisters throughout the world, may have more in common than that which separates them.

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### **BIOGRAPHICAL NOTE**

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