Young Carers: Evidence and Messages from UK and Australian Research

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Abstract

In the United Kingdom, Australia, the United States, as well as a few European and other advanced countries, the extent and nature of children's (informal, unpaid) care work within the family has become a growing concern for politicians, government and non-governmental agencies (carers' organisations and children's charities), and for policy makers and professionals in healthcare, social care and education. In the UK, the 2001 Census shows that 175,000 children under 18 provide care to other family members, with 7% of these caring for more than 50 hours per week. These official figures, however, underestimate the real extent of young caring in the UK. In Australia, Australian Bureau of Statistics data for 2003 show a population of 169,900 young carers under 18, while the figure for the Unites States has been calculated as 1.3-1.4 million children.

Drawing on both quantitative and qualitative research studies conduced by the author and others from the UK and Australia over the last decade, this paper examines the extent and nature of children's caring roles within the family, the factors that push and pull children into caring, and the outcomes for children when they provide care. It also reviews the main legislative, policy and practice responses that have developed in the UK during this time, and considers whether existing research findings provide a reliable and trustworthy foundation for evidence-informed policy and practice with this group of children and their families.

Children speak out about their care work in the home

Georgia, aged 17, Australia

"In March 1969, my mother turned 18 years old. It was a great year until she contracted a very bad episode of the measles. Mum never fully recovered. She stayed very weak and it was a real effort for her to walk. She was very frightened about what was happening to her and the doctor's didn't know what was wrong... Dad left mum when she was pregnant with me, so mum had me alone. It nearly killed mum having me. She was in hospital for 12 months afterwards and was paralysed from the neck down. Now, I'm 17 years old and I care for her. Mum was recently in hospital and she came home with a tracheostomy tube. I have been caring for mum for three years now. I left school at the age of 15 years. She has a gastrostomy tube and is unable to walk without help or on some bad days, using a wheelchair. She needs help on the toilet, in the shower, brushing her hair and teeth etc. I'm not normal. I don't go many places. I don't go to school. My life is very different and boring compared to my friends. Mum always tells me I'm too old."

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Jimmy, aged 16, UK

"When I think about all those years I cared for my dad it makes me angry, not because I had to care for him – I wanted to care for him – but because I was left alone to cope with his illness for so long.

I wasn't just doing ordinary tasks like other kids might do around the house. I was having to cook for him, beg for money and food parcels so I could feed him, take him to the toilet, clean him up when he couldn't get to the toilet – because he couldn't get up the stairs towards the end.

No one should have to see their parents like that, when they lose all their bodily functions. I loved my dad and I couldn't bear to see him losing his dignity – getting more ill before my eyes. But because I loved him, I wanted to be with him. I wanted to look after him. I just wish someone could have helped me and that those who interfered in our lives and made them difficult could have left us alone.

All I ever wanted was to talk to someone and someone who could have warned me about my dad's fits, caused by his brain tumour.

It's too late for me now. My dad died and I'm no longer a 'young carer', but for all those other kids out there who are in the same situation I was, then something should be done to help them. Not take them away from their mum or dad, but to help them care without worrying, without being frightened."

Alison, now aged 18, UK

"I've been caring for my mum for nine years now on my own. When my dad died suddenly my mum got ill and I had to look after her – prepare the meals, cook them, do all the housework, gardening. At first I hated it. I hated my mother because I resented having to do all those jobs – why did it have to happen to me?

I suppose I rebelled. But I shouldn't have been left to look after her on my own for so long. I know now I was rebelling but then I was just so scared. I didn't want to lose my mum as well.

Now I look upon her like any other mum – I never think of her as disabled and I don't mind as much doing all the jobs. I even love gardening now, in fact if anyone tried to help with my garden or tried to touch it I'd kill them!

And now I want to help others who are in my position. It's too late for me now – help should have come when I was a girl, but it didn't and now I don't want anyone coming in and interfering. I find it hard to express my feelings, but I really want to help – all those other young carers who might not be coping. I don't think there's much help for them at the moment and some of them are less fortunate than I was, but there should be help available.

I agreed to take part in this research because it's important everyone knows how we feel and how we've been ignored. Something has got to be done to help young carers." (Jimmy and Alison are quoted from Aldridge and Becker, 1993; see also Bibby and Becker, 2000; Georgia is quoted from Price, 1996).

Developing a research evidence base for policy and practice with young carers and their families in the UK

Since the initial research studies of the early 1990s, 'young carers' research in the UK has been concerned with both describing, understanding and improving the 'hidden world' of young carers. There has been an escalation in research interest about this group of children, most often with an explicit intention of providing a research evidence base that can inform and influence the development of policy and practice with young carers and their families.

A dilemma that policy makers and practitioners face is to determine whose evidence, and what kinds of evidence, should they value most when it comes to formulating policy or deciding on interventions. Should the experiences and testimony of an individual young carer inform policy-making or practice more than, say, the account of a disabled parent, or should it be the other way round? Should we take more notice of these forms of individual experience when there is a critical mass behind them – when, for example, we have a collective view or testimony from many young carers or many parents generated through empirical research?

Research evidence – the results or findings of systematic, robust and trustworthy empirical enquiry – unlike views, perceptions, ideology and beliefs, is the only source of evidence that provides any systematic procedure for establishing the reliability and trustworthiness of the knowledge base and for assessing the superiority of one claim over another (Becker and Bryman, 2004). Individual and collective experiences need to be checked and validated by empirical research if they are to become a reliable consideration for policy and practice. Thus, in the context of young carers and their families, research needs to gather the views and experiences of children, parents and other family members who need help and support as well as the perspectives of professionals who provide services, to check out the extent to which views and experiences are unique or common, to make sense of them, and to identify clearly the messages and implications for policy and practice.

Research findings, and the conclusions reached, need to be based on the careful application of appropriate research designs, methods and analysis. The findings can count as evidence for policy and practice if they are suitably substantial and have been collected in a rigorous, systematic and accountable way. The approaches that have been used in the last decade of UK research on young carers include surveys, interviews, focus groups and (to a very limited extent) longitudinal studies. Researchers have not used the methodologies employed by medical and healthcare researchers, such as randomised controlled trials, systematic reviews and meta-analysis. It has not been possible, or perhaps even desirable, at this stage to do so.

Quantitative approaches in UK young carers research, such as the three national surveys of young carers in contact with dedicated young carers projects (Dearden and Becker, 1995, 1998, 2004) have provided descriptive statistics that profile the characteristics of such families and provide evidence on the (statistical) associations between variables, such as gender and caring responsibilities. Qualitative methods such as in-depth interviews and focus groups with young carers have provided evidence on 'experiences and processes' – especially as understood by children and parents themselves. This kind of research evidence complements the statistical profiles from surveys and other quantitative approaches. Indeed, for research to inform policy and practice a compelling case can be made that policy makers and practitioners need research evidence from both quantitative *and* qualitative inquiries so that they have the 'big picture' as well as a more detailed and

intricate understanding and explanation of what's going on within families and communities. In other words, there is a strong case that both quantitative and qualitative research on young carers is necessary, both as separate studies *and* within mixed-methods investigations, for the development of a useful and usable evidence base for policy and practice.

Rather than seeing any research approach or method as intrinsically better than any other, researchers investigating young carers in the UK have chosen their research methods based on the specific research question(s) to be addressed in any enquiry. What we have seen over the last twelve years is the accumulation of a body of qualitative and quantitative research evidence that confirms the same pattern of findings. Successive studies have added to and built up a body of research evidence rather than delivering major challenges (or refutations) to existing knowledge. In this sense, then, the existing UK research evidence base, while in its infancy, can be considered to be relatively robust and trustworthy, even though it counts as provisional knowledge, and even though there are many new questions to be asked and answered. The sections that follow outline the main research evidence base that has developed over the last twelve years in the UK and Australia, and identify some messages for policy and practice.

Conceptualising informal caring and unpaid care work among children

In the UK, as in almost every other advanced country, unpaid care work within the family is rarely conceptualised or discussed as care *work*, rather it is referred to as *informal 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, as opposed to professional, caring relationships. Informal care-giving activities are often invisible, part of the private domain of the family, founded on love, duty and reciprocity, not monetary exchange (Becker and Silburn, 1999). Calling these activities care *work* is to politicise and make public the activities, financial and personal worth, and outcomes, that characterise unpaid care-giving. Everything that an unpaid carer does for another family member or friend, if conducted by a 'paid professional' (such as a nurse, social worker or community care assistant) would carry a monetary value and a charge. Carers UK has calculated that the annual cost of the hidden contribution by adult family carers is £57 billion, the same cost as the National Health Service itself (Holzhausen, 2002).

While there is a high degree of acceptance and legitimacy in *adults* being involved in care-giving for other family members, we also know that many *children* in Britain, Australia, the US and internationally are involved in unpaid care work within the home. These children are generally referred to in the research literature and in UK and Australian social policy and social welfare legislation as 'young carers'. However, this generic label has caused some confusion as to who should be included under its remit. All children will care *about* and sometimes care *for* family members and significant others. Indeed, this care-giving needs to be encouraged and nurtured if children are to value caring both during their childhood and later in adult life. Indeed, *learning* to care, and *showing* and *providing* care, are part of a child's socialisation and are a prerequisite for healthy psychosocial development. So, while all children are involved in some form of caring, does this make them 'young carers'?

The answer is obviously 'no'. Becker suggests that the term 'young carer' needs to be used precisely and deliberately to refer to a specific group of children and young people who take on a quantity or quality of caring tasks which are usually the responsibilities of adults and which, when conducted by children, can be associated

with negative outcomes for their own health, well-being and development: "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, p. 378). In Australia, Carers New South Wales includes children and young people up to the age of 24 in their definition of young carers (see later).

Becker's definition helps to distinguish between those children who are involved in 'significant, substantial or regular care' (young carers) and those children who, as part of their routine family lives and roles, *may* be involved in aspects of caring but at a level which is neither substantial or regular, nor are the outcomes unduly negative or damaging. As we shall see later in this paper, young carers *differ* from other children by virtue of the nature and extent of their unpaid care work, particularly intimate care (Warren, 2005), and they are *similar* to adult carers in the types of care that they provide and the outcomes reported.

However, young carers, by being under the age of 18 (in the UK definition), are legally defined as children and, as such, are not *expected* (or encouraged) to take on significant or substantial unpaid caring roles or responsibilities. When they do, and when these roles come to the attention of social care, health and education professionals, they can become a cause for concern (because, for example, of educational problems, child welfare concerns, children's poor health etc). While adult carers can be seen to be conforming to individual, societal and familial norms in supporting family members, when children act as unpaid carers they transgress, or certainly challenge such norms in the UK, Australia and other industrialised countries. In theory at least, 'childhood' in these democracies is viewed as a protected phase, with adults, and state agencies (social workers, education, healthcare workers and so on), supporting, safeguarding and protecting children and young people until they make the transition into adulthood. At this (adult) stage they will no longer be the concern of child welfare agencies, and any support they may go on to receive will usually come from (adult) carers' organisations and adult social care services.

The situation is quite different in other regions of the world. In Southern Africa, for example, many children from an early age will be undertaking unpaid care work for sick or disabled family members, particularly those with HIV/AIDS, and especially in the absence of formal social and healthcare systems (Robson and Ansell, 2000). Here, this unpaid care work is often part of the routine of family life. Until recently this has not been seen as a cause for concern, nor has it been the subject of any systematic research. However, the limited evidence that does exist suggests that "there are strong cultural expectations that young people undertake tasks within the home which extend to caring for others" (Robson and Ansell, 2000, p. 185). This 'push' into caring is reinforced by the 'pull' that in most families there is no one else available, nor are any professional alternatives actually affordable.

How many young carers are there in the UK today?

In the UK, almost three million children under the age of 16 (equivalent to 23% of all children) live in households where one family member is 'hampered in daily activities by any chronic physical or mental health problem, illness or disability'. In Europe as a whole, nearly a quarter of all children (16 million in total) live in households of this

type (Becker et al, 1998, p. xii). However, the vast majority of these children will not be young carers, as we shall explain later. An early study by the UK Office for National Statistics (Walker, 1996) suggested that there were between 19,000 and 51,000 children in Britain in the mid-1990s who took on 'substantial or regular care' and who could thus be classified as young carers.

The 2001 Census shows that there are at least 150,000 children and young people aged under 18 in England and Wales (175,000 if we include Scotland) who provide unpaid care within families. In England and Wales there are around 24,000 children who provide more than 20 hours of care per week, and 11,000 of these provide more than 50 hours of unpaid care work per week – that is 7 per cent of all caring children. There are 13,299 children who are carers in England and Wales who are under ten years of age (see Table 1).

Table 1: Age and number of children who provide unpaid care in England and Wales, by hours caring per week (2001 Census)

	1-19 hours	**20-49 hours**	**50+ hours**	**Total number**	**Total %**
0-4	0	0	0	0	0
5-7	4,161	512	792	5,465	4%
8-9	6,361	610	863	7,834	5%
10-11	13,727	1,180	1,360	16,267	11%
12-14	39,983	3,429	2,982	46,394	31%
15	18,265	1,865	1,272	21,402	14%
16-17	43,179	5,717	3,684	52,580	35%
All	**125,676**	**13,313**	**10,953**	**149,942**	**100%**
All as %	**84%**	**9%**	**7%**	**100%**	

Source: Becker, 2004, p. 6.

The 2001 Census figure for the number of children who provide care is significantly higher than the previous 'official' estimate of 19,000–51,000 young carers because the Census data include children who provide *any* caring within the family. As we have seen in Table 1, most of these children may only provide a limited amount of care per week but this will be classified as '1-19 hours per week', while 24,000 children provide more than 20 hours of care a week – the 'amount of care' that some local authorities use to operationalise 'substantial or regular' care. In contrast, the Office for National Statistics figures (Walker, 1996) only include children who are providing 'substantial or regular care'. However, the Census figures are themselves likely to under-represent the true prevalence of children's involvement in unpaid care work because they rely on parents' self reporting their children's caring roles, and the data do not identify or count children in some caring situations, for example those who may be caring for parents who misuse alcohol or drugs. Up to 1.3 million children are affected by parental alcohol problems and there are around 360,000 children under 16 in the UK who have parents who are problem drug users (Gorin, 2004, p. 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, p. 6). Not all of these children, of course, will become young carers. Most will be 'affected' by their parent's conditions, many adversely, but only a small proportion will become unpaid care-givers to the extent or nature captured in the definition offered by Becker, above (2000, p. 378).

In a nationally representative sample of 3,000 young people aged 18-24, the National Society for the Prevention of Cruelty to Children (NSPCC) found that four per cent of *all* this age group had regularly cared for an ill or disabled relative during their own childhood (Cawson et al, 2000; Cawson, 2002; Aldridge and Becker, 2003, pp. 16-20). This figure is useful in indicating the extent to which young people *in general* are likely to have had regular caring responsibilities during childhood. Put another way, young people in the UK aged 18-24 have a 4 per cent chance of being a young carer in their own childhood.

Drawing on Census 2001 and other data, Becker suggests that *at least* 1.5 per cent of *all* children under 18, or *at least* 2% of children aged 5-17, and 6 per cent of all children living in families where there is illness or disability, will be young carers in Britain (Becker, 2004, p. 7). These figures do *not* include children caring for parents who misuse alcohol or drugs because existing data are too unreliable at the moment to allow an informed estimation. While these proportions are higher than previously thought, the great majority of children living in families where there is illness or disability do not become young carers, for many reasons, including the availability of other family members to care; the family receives good quality and reliable health and social care support and services; they have adequate money to purchase alternative forms of care – to name but a few reasons (Becker et al, 1998; Aldridge and Becker, 2003). We return to these themes later in the paper.

A growing awareness of young carers in the UK

Researchers in the UK, particularly the Young Carers Research Group based at Loughborough University and now also at the University of Birmingham, have been instrumental in bringing knowledge and awareness of these hidden children and their unpaid care work to wider public attention, and to the notice of policy makers and professionals who work with children and families where there is illness, disability and care needs.

In the UK during the 1990s policy, law and professional practice on young carers evolved and developed in a symbiotic relationship with the growing research evidence which first described, and then explained, the experiences, circumstances and needs of this group of children and young people (Aldridge, 2004, p. 22). Prior to the 1990s, academics, policy makers and welfare professionals failed largely to recognise and account for children's unpaid care work within the family. However, by the end of the decade a sea change had occurred in the UK: the number of dedicated young carers' projects grew from a handful to around 250; young carers were acknowledged in policy, guidance and law; they had legally defined rights to assessments, to services, 'direct payments' and other forms of provision both under community care and children's legislation; the UK government's National Carers Strategy made a series of policy commitments designed to support them; and young carers were also identified as a priority group in other health, social services and education spheres (Bibby and Becker, 2000).

The earliest research on young carers in the UK sought to establish the extent of the 'problem' of caring among children (O'Neill, 1988; Page, 1988) and stimulated further research into the needs and experiences of such children. Small-scale qualitative studies (Bilsborrow, 1992; Aldridge and Becker, 1993) identified the experiences of around a dozen or so young carers, often drawing on their own words (see for example the quotations by Jimmy and Alison at the top of this paper). A small research team at Loughborough University was formed (the Young Carers Research Group – YCRG) under the directorship of Dr Saul Becker and this group were

awarded a series of grants and contracts from various charities and health and social services authorities to undertake local, and then national research in this field. Small-scale studies conducted by other researchers also sought to ascertain the experiences of, or effects on, children in families where a parent had a specific illness or disability, such as Parkinson's disease (Grimshaw, 1991), mental health problems (Elliott, 1992), multiple sclerosis (Segal and Simkins, 1993), and HIV/AIDS (Imrie and Coombes, 1995). Pursuing an active dissemination strategy for their research, the YCRG researchers published extensively and made dozens of conference presentations to audiences of health, social care and education professionals eager to know more about this hidden group of children. The published studies also generated considerable media attention and interest from policy makers and politicians, including Early Day Motions. Over the next two years the Department of Health prepared guidance for social services departments, and young carers were included in the remit of the first piece of UK legislation specifically for caregivers – the 1995 Carers (Recognition and Services) Act. Many organizations, particularly children's and carers' charities, the Social Services Inspectorate, social services and health authorities nationally, formed an ad hoc policy network that used research evidence to argue for further policy, procedural and legislative change (Becker et al, 1998; Aldridge and Becker, 2003; Aldridge, 2004).

The media also played an instrumental role in using research evidence to promote change. The weekly social care magazine, *Community Care*, ran a year-long campaign in 1995 – 'Young carers: back them up!' – to raise awareness among professionals. And, as awareness of young carers' issues grew, and support for them increased, it become easier to identify young carers in larger numbers and to conduct survey-based studies. *Community Care* magazine commissioned the YCRG to undertake the first national survey of young carers (Dearden and Becker, 1995), which itself became the subject of a major Television documentary seen by seven million people. This survey was replicated in 1997 and 2003 (Dearden and Becker, 1998, 2004). These national surveys enabled a *statistical* analysis of the factors that influenced children's caring roles and their receipt of assessments and services. This statistical base was hard to ignore. More qualitative and quantitative research followed. The media maintained its coverage of the 'human interest' stories as well as the policy issues, and policy makers and politicians cited research evidence during Parliamentary debates (for example, *Hansard*, 2000) and in the growing body of policy guidance and government documents issued by various departments (HM Government, 1999; Dearden and Becker, 2000). Many young carers also became more vocal and 'politicised', with delegations of children attending meetings with MPs and policy makers, facilitated by children's and carers' charities, particularly the Children's Society, Carers UK, The Princess Royal Trust for Carers and Barnardos.

The Departments of Health and Education issued separate guidance to all local authority social services and education departments regarding their duties to young carers. Other developments at the end of the 1990s, not least the government's National Carers Strategy (HM Government, 1999), helped put young carers firmly on the policy and professional agendas.

Internationally, there has been relatively slow recognition of the contribution children make to unpaid care work, with only a small number of research studies from outside the UK, although there is a growing body of evidence from Australia (Becker, 1995; Becker et al, 1998; Banister, 1995; Price, 1996; Gays, 2000). However, there are now dedicated services for young carers in Australia, New Zealand, Malta, The Netherlands, Germany, Canada, and there is a growing recognition of the role of

children as carers in southern Africa (see for example Robson and Ansell, 2000; Evans, 2005).

Characteristics of young carers and their care work in the UK

Many qualitative research studies have provided a uniform picture of the characteristics, experiences and needs of children who undertake unpaid care work within the family. Additionally, three UK-wide surveys of young carers in contact with dedicated support projects confirm the profile generated by the qualitative studies (Dearden and Becker, 1995, 1998, 2004). The 1997 survey (Dearden and Becker, 1998) provides data on 2,303 young carers aged 18 or under while the 2003 survey provides a profile of 6,178 young carers, the largest survey of its kind (Dearden and Becker, 2004). The average age of young carers supported by projects in 1995, 1997 and 2003 remains the same, at just twelve years. Over half of the young carers are from lone parent families and most are caring for ill or disabled mothers. In the 2003 survey, 56 per cent were girls and 44 per cent were boys; 16 per cent were from minority ethnic communities (virtually no change since 1997).

Half of the young carers in 2003 were caring for someone with a physical illness or disability, followed by mental health problems (29 per cent of young carers), learning difficulties (17 per cent) and sensory impairments (3 per cent). One in ten children were caring for more than one person. The 2003 study also shows that while almost half of the young people are caring for ten hours or less per week, a third of children care for between 11 and 20 hours per week and 18 per cent care for more than 20 hours per week.

An additional question asked in 2003 concerned the number of years young people had been caring. Data were collected for 4,028 cases (66 per cent of the sample). Thirty-six per cent had been caring for two years or less; 44 per cent for between three and five years; 18 per cent for six to ten years and three per cent for over ten years. Given that all of the young carers were aged 18 and under, and that the average age is just 12, the findings suggest that unpaid care work may be a long-term commitment for many children, and can start at a very early age.

The nature of the care work undertaken by children ranges along a continuum from basic domestic duties to very intimate personal care. In 2003, most young carers (68 per cent) do some level of *domestic work* within the home (Dearden and Becker, 2004). However, where young carers differ substantially from other ‘non-caring’ children in the extent and nature of the nursing and personal care work that they perform, the amount of time they spend on these caring tasks, and in the significance, and outcomes, of the adult-like responsibilities that they take on for other family members (Warren, 2005).

Forty-eight per cent of young carers known to dedicated projects in 2003 were involved in *general and nursing care work*, which included organising and administering medication, injections, and lifting and moving parents (Dearden and Becker, 2004). Eighty-two percent of children provided *emotional support and supervision*, particularly to parents with severe and enduring mental health problems (see also Aldridge and Becker, 2003). One in five provided *intimate care work* including toileting and bathing. A small proportion, about 11 per cent, also took on *child-care responsibilities* in addition to their caring roles for other family members. Around 7 per cent were involved in other *household responsibilities*, including translating (where English is not the first language), dealing with professionals, the family’s money management etc (see Table 2). Box 1 provides verbatim comments from children about the kinds of unpaid care work that they undertake.

Table 2: The percentage of young carers performing various types of care work, 1995, 1997 and 2003

	1995	1997	2003
Domestic work	65%	72%	68%
General care work	61%	57%	48%
Emotional support & supervision	25%	43%	82%
Intimate care work	23%	21%	18%
Child care to siblings	11%	7%	11%
Other household responsibilities	10%	29%	7%

Source: Dearden and Becker, 1995, 1998, 2004

Box 1: What children say about the care tasks they perform

"To help my dad out I dress him, take him to the toilet, keep him warm, listen for him in the night, give him medicines, watch him because when he smokes he drops his fags on the floor, he might set light to himself."

"I would get up, get a wash, put the kettle on, get a bowl of water, sponge, soap, give my mum a wash, get her dressed, go and get something from the shop for her, brush her hair and teeth."

"From the age of nine I was doing all the dinners and everything – I shouldn't have been doing all that."

"It's horrible having to do that sort of thing for your dad. It's degrading and it was especially degrading for my dad losing control of himself, and then having to be washed and cleaned up by me."

"I went out a couple of times once and stayed out a bit later than I normally did, come home and she's messed herself. I came in a happy mood, had a few drinks with my friends and then I've got to start stripping the beds and things like that... then I felt guilty when I realised one day what I was doing. I thought I shouldn't go out so much."

Dad will be really ill sometimes and sometimes I'll get pissed off about that. You just get so racked off... you just drop off to sleep and suddenly you hear him shouting for you. You never get two minutes on your own in this house, sometimes you think, 'Oh I've got to get some time by myself' and walk out, but I always come back."

These quotations from young carers are extracted from a range of research studies conducted by the Young Carers Research Group (www.ycrg.org.uk)

Children caring for parents with severe mental illness

Children caring for parents with severe and enduring mental health problems have much in common with other young carers, but their experiences also differ in many real respects (Aldridge and Becker, 2003). Children in these families, like other young carers, undertake both domestic and emotional care responsibilities for their parents,

although emotional support and supervision are far more common in families where there is mental illness. Many children also take on household management responsibilities. However, when it comes to being consulted by professionals about their parent's needs and their own needs as children and as carers, these young carers are often more invisible than young carers providing physical unpaid care work. Children and parents with mental health problems often fear and experience discriminatory responses from local people and from professionals, and these responses can sometimes lead to family separations or child protection procedures. These fears can also adversely affect parents' mental health and well-being over time. Aldridge and Becker's study shows that even when parents *are* supported by a range of health and social care interventions, children can still undertake significant and substantial caring responsibilities. All 40 parents in the study were on an enhanced Care Programme Approach and were receiving multi-professional mental health services and support. However, these services were often experienced by parents as inappropriate (or insensitive) to their needs, inconsistent, fragmented or unresponsive to their *changing* conditions and care needs. In these circumstances parents often had to rely on their children for immediate, flexible and continuous care – something that professionals seemed unable to provide.

Outcomes

Much of the research literature on young carers, particularly the growing body of qualitative studies, have given these children and young people a 'voice' to express their experiences, needs and wants. This body of research evidence, and the more recent quantitative studies, show that many young carers can experience one or more of the following *negative* outcomes: restricted opportunities for social networking and for developing peer friendships (Bilsborrow, 1992; Aldridge and Becker, 1993, Dearden and Becker, 1995, 1998, 2004; Thomas et al, 2003); limited opportunities for taking part in leisure and other activities (Aldridge and Becker, 1993); poverty and social exclusion (Dearden and Becker, 2000, 2005; Roche and Tucker, 2003); health problems (Aldridge and Becker, 1993; Coombes, 1997; SCARE, 2005); impaired mental health (Cree, 2003a, 2003b); emotional difficulties (Elliott, 1992; Dearden and Becker, 1995, 1998, 2004); educational problems (Marsden, 1995; Dearden and Becker, 1998, 2004; Crabtree and Warner, 1999; Carers Association of Australia, 1997); limited horizons and aspirations for the future (Becker and Aldridge, 1993; Dearden and Becker, 2000); a sense of 'stigma by association' (particularly where parents have mental health problems or misuse alcohol or drugs, or have AIDS/HIV) (Elliott, 1992; Landells and Pritlove, 1994; Alexander, 1995; Imrie and Coombes, 1995; Lewis, 2001, Aldridge and Becker, 2003; Evans, 2005); a lack of understanding from peers about their lives and circumstances (Aldridge and Becker, 1993, 1994; Dearden and Becker, 1998); a fear of what professionals might do to the family if their circumstances are known (Aldridge and Becker, 1993, 1994; Dearden and Becker, 1998); the keeping of 'silence' and secrets (again because of the fear of public hostility or punitive professional responses) (Aldridge and Becker, 1993; Crabtree and Warner, 1999, Frank et al, 1999; Aldridge and Becker, 2003); and significant difficulties in making a successful transition from childhood to adulthood (Aldridge and Becker, 1999; Dearden and Becker, 2000; Frank et al, 1999).

The growing body of research studies on young carers suggests that many young carers can and do experience one or more of the negative outcomes listed above. For example, we know from the most recent quantitative study of young carers in contact with dedicated projects that 22 per cent of these young carers experience

educational difficulties, although this proportion has dropped from 33 per cent a decade earlier (Dearden and Becker, 1995, 1998, 2004).

Two pieces of research suggest that there can be some *positive* outcomes for children associated with caring. 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. However, while the authors noted that these positives were real outcomes for some children in their sample, they also observed that *all* the children experienced some negative consequences as well, and that these were often severe. These included: stress, depression, and restricted social, educational and career opportunities. The authors suggest that young people's choices were both influenced and restricted by caring. Career and job choices were sometimes influenced by the skills gained through caring but restricted by the lack of formal qualifications (because, for example, young carers had problems at school). The authors concluded: "Maturity, responsibility, decision-making and the acquisition of practical skills were viewed as important and useful for independence and adulthood and were often gained through caring. However, opportunity and other personal costs accompanied the acquisition of these skills" (Dearden and Becker, 2000, p 3).

Another study that reports some positive outcomes is Aldridge and Becker's (2003) research in 40 families where a child was caring for a parent with severe mental illness. Here the children report that caring can allay some of the 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 work. The authors suggest that in some instances caring can actually help to enhance parent-child relationships and can make children feel *included* when often, outside the domain of the family, they are ignored or even excluded (not consulted, not recognised) by health, social care and other professionals.

Not all young carers will experience physical, emotional, relationship or other psychosocial problems, and many may not experience difficulties in school or elsewhere. While just under a quarter of young carers in the 2003 national survey had educational problems, the majority appeared not to have such difficulties (Dearden and Becker, 2004). We cannot be sure to what extent the negative (or positive) outcomes described above are common among young carers, nor do we know whether they group or 'cluster' together in some way. We cannot be certain at this stage why some young carers *do* or *do not* experience significant difficulties at school or elsewhere in their lives, nor can we be certain that for those who do, that it is their care-giving responsibilities that account solely for any problems encountered. Research, as yet, has been unable to adequately isolate 'caring' from other key factors (variables) that can impact on children's health, well-being and development, in particular factors such as low income, family poverty and other forms of disadvantage. Some have suggested that focusing on family or children's resilience may offer some explanation here (Newman, 2002). While the strength of existing young carers research has been in making visible what had hitherto been invisible, and in charting and describing the broad landscape of young carers' experiences, the research evidence base is still under-developed in terms of critical analysis on outcomes.

Young carers in Australia

Australia is one of the few other developed countries where there is a growing research evidence base on young carers and a network of dedicated service provision. The Australian Bureau of Statistics (ABS) calculated that, in 1993, there were 33,800 carers aged under 15 in Australia, of which 48 per cent were male. Because these early statistics 'count' young carers as being those children under 15 years of age (rather than under 18, as in the UK definition), the ABS figures were a serious underestimate of the 'true' number of children and young people (under 18) who would be involved in care-giving in Australia (ABS, 1995; see also Carers Association of Australia Inc., 1997: 22-23). A decade later, figures from the ABS show that there are 169,900 young carers aged under 18 in Australia, that is 3.6% of all people under 18. If the age range was extended to include all carers under 25, then the figure rises to 347,700 carers, or 5.2% of all people under 25 (ABS, 2003, cited from Carers New South Wales website). Carers News South Wales defines young carers as "children and young people, under 25 years of age, who care for and support a family member who has a long term physical illness, mental illness or disability" (Carers New South Wales website, 2005).

In one of the earliest studies that casts light on young carers in Australia, the Alzheimer's Association of South Australia received funding in 1994 from the National Action Plan for Dementia Care to run a Demonstration Project aimed at reducing the stress levels of children who had a parent with dementia and to increase their ability to 'manage' their situation. Some of these children had care-giving roles within the family even if they were not defined as the main or sole carer. The programme was evaluated and led to the publication of a modest report (Alzheimer's Association, 1995) designed to help professionals working with children in these circumstances. This study shows how dementia affects the whole family, including children who may have to take on caring roles: "For the children, after facing the anxiety generated by the ambiguous nature of the early symptoms, comes the gradual, inevitable loss of their parent. As the dementia progresses the need to provide a significant amount of the nurturing and care in the family often falls on their shoulders..." (Alzheimer's Association, 1995: 7).

The Alzheimer's Association study is of children affected by a parent's dementia, rather than a study of young carers *per se*. However, it does show how caring responsibilities among children can change and increase over time. Moreover, it was one of the first studies in Australia which intentionally set out to highlight these issues among welfare professionals, who it was acknowledged had failed to recognise the role of children in these situations: "The valuable research into the effects on the carer has been predominantly focussed on the adult caregiver, very little has specifically addressed the issues for children and adolescents and early onset dementia" (Alzheimer's Association, 1995: 7). Since the publication of this report, the Alzheimer's Association of South Australia has continued to run retreats and camps for children who are in this situation.

A later Australian study focused specifically on 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" (Price, 1996: 7). 'Significant care' was defined as "the primary provision of assistance to an adult, in areas such as cooking, cleaning, laundry, showering, dressing, toileting, shopping, banking, and caring for other children, beyond what is generally expected from a child of comparable age. The emphasis is on the impact this role may have in restricting the young person's education, leisure and friendships" (Price, 1996: 7).

Price discovered that 44 per cent of young carers whose gender was known were male, consistent with the 1993 ABS estimate for the national profile of young carers at that time. Three quarters of young carers in Price's study were from lone parent families, 20 per cent from two parent families and 5 per cent lived with a grandparent (for whom they provided care). Almost half the young carers were providing care to an adult with a physical impairment, 19 per cent to someone with a mental health problem and five per cent to someone with a sensory disability. 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. In terms of the *impacts* of caring on children, the research concluded that:

> "Some young people who live with an adult with a disability may be required to spend many hours assisting the adult with housework or the adult's personal care. The responsibilities undertaken by these young people impact upon many areas of their lives including their education, friendships, leisure options and the relationships with their family members. These [young] people receive little assistance from community support services. Young people indicated a willingness to accept extra help, but were frustrated by isolation and other barriers" (Price, 1996: 4).

Moreover, a 1997 study by the Carers Association of Australia outlines some of the long-term consequences of children taking on heavy care responsibilities:

> "Our consultation with adults who had care responsibilities as children reveals the long term damage that can be caused by heavy care responsibilities and premature 'adulthood'. Many of the responses from adults who had had care responsibilities as children were filled with bitterness, resentment and a feeling of being 'all cared out'. Children and young people's lives can be ruined by the heavy burden of family care. Too heavy responsibilities assumed too early in life can damage the lives of young Australians..." (Carers Association of Australia Inc., 1997: 9).

In terms of the *support needs* of young carers and their families, the Australian research also confirms the UK findings: "It is largely in the absence of other support that young people become carers of an adult with a disability" (Price, 1996: 26). Many Australian welfare professionals had not identified young carers, and thus failed to engage with their particular needs: "Their [the professional] focus remained on the adult with the disability, without reflecting how the adult's disability may impact on the functioning of the entire household" (Price, 1996: 11). Consequently, "services must firstly recognise not only the need of the adult but *the needs of the family* as a whole" (p. 26, emphasis in original). As a consequence of this and other local research, the Carers Association of New South Wales developed an ambitious 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 to young carers, 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 (see www.carersnsw.asn.au/projects/ycarer/ycarer.htm) and it has published research and other reports, including guides for professionals and parents. Other dedicated projects exist throughout Australia. The Carers Association of Australia has also made a number of recommendations to Government which have led to more

recognition and support for children with caring responsibilities (Carers Association of Australia Inc., 1997). More recently, Gays' (2000) survey of 180 pupils at two schools suggests that around 11% of pupils had a caring role, a proportion similar to a Princess Royal Trust for Carers survey in the UK, and which would suggest that official figures may underestimate the true extent of young caring in Australia.

Why do children become carers? The pushes and pulls

Can the existing research evidence base from the UK and Australia tell us anything about why some children become unpaid carers in families where there is illness, disability or some other need for care, support or supervision? Drawing on the research evidence base generated over the last twelve years it is now possible to identify a range of factors that research suggests are relevant here, even if we are unable to determine precisely the extent to which individual factors act as pushes or pulls on children's caring responsibilities within the home, or the extent to which they interact.

The push that draws children into a caring role in the first place is the nature of the illness or condition itself and how it relates to a need for care, support or supervision (Aldridge and Becker, 1999). What is important here is the type of illness/condition (physical, mental, a combination, and so on) its intensity, duration, stage of development, changing form, and how these factors are associated with a (changing) need for care. We know from research that where the care need is, for example, associated with parental mental illness, then children are far more likely to be involved in emotional care-giving and supervision than the provision of, say, intimate personal care.

Other factors that pull children into unpaid care work include the fact that children are co-resident (they most often live in the same household as the person with care needs, particularly if it's a parent) *and* they have strong bonds of attachment (and love) for the person who needs their help. Children are immediately available (and flexible enough) to be able to provide care that is responsive to the changing needs of the person who has a need for care. The bonds between child and parent may change as the caring relationship itself changes over time, but there is no research evidence to suggest that the attachment itself dies, even after parents themselves have passed away (Chowns, 2005). Nor is the attachment one-sided. Indeed, there is a growing body of research evidence to show that the caring relationship is characterised not by any 'dependency' of one side (parent) on another (child), but is founded on reciprocity and exchange with parent's retaining their parental roles and authority, even when there are considerable barriers to them doing so (Keith and Morris, 1995; Olsen and Parker, 1997; Dearden and Becker, 2000; Wates, 2002; Aldridge and Becker, 2003).

Family structure is an important factor that pushes some children into unpaid care work. In lone parent families, for example, where there is no other adult available to care, there is a greater vulnerability for children to become carers when the parent becomes ill, disabled or has another condition which leads to a need for care or supervision. It is not surprising, therefore, that in all UK studies to date the majority of young carers live in lone parent families. Even in two parent families, however, children can be and are unpaid carers. Sometimes this is because both parents have care needs. One in ten young carers cares for more than one person (Dearden and Becker, 1998, 2004). At other times children are drawn into caring roles in two parent families because the ('well') parent works away from home, or even declines to care. The research evidence shows clearly that this is more likely to happen where the ill

parent is a woman and the 'well' parent is a man, rather than vice versa – men (fathers) are more likely to decline to care than women (mothers). In these cases, children can be drawn into unpaid care work because there is little alternative.

The issue of the 'availability' of other family members is critical here. Where there is only one child in a family and the parent becomes ill, then the pressure on that one child is greater than, for example, where there are other children or where there are older co-resident siblings. Where there is more than one child available within a family to care, these roles may be shared or sometimes a particular child may take on more significant aspects of care. Here, some children can be socialised into unpaid caring roles from an early age (Aldridge and Becker, 1993; Robson and Ansell, 2000). Certain children within a family (usually those with less power or more transparent caring characteristics) can be pushed into a caring role by other family members and by familial expectations, so that they take on more caring responsibilities than others, including older co-resident children (Robson and Ansell, 2000). Expectations based on religion and culture can also be very powerful here, drawing some children into adult-like unpaid caring roles (Shah and Hatton, 1999; Jones et al, 2002). Thus, there can sometimes be reluctance on the part of children and parents to have caring roles 'interfered' with by professionals, even though such interventions can lead to beneficial outcomes for all family members. This is also to some extent about the distribution of power within the family. Children, as so-called 'dependants' of parents, have few options to 'walk away' from caring responsibilities, especially in the absence of any viable alternatives. The problem of 'leaving home' (and leaving caring) can delay some young carers' transition to independence (Dearden and Becker, 2000).

Whether care is shared, evenly or unevenly, will also be influenced by the gender and ages of respective children. Research suggests that girls are more likely to take on all forms of unpaid care work, and more of it, than boys. But, where there are no sisters within a household, then a boy may take on all duties, including intimate care for a mother. The research evidence suggests that as children get older, they are more likely to get involved in all forms of unpaid care work (Dearden and Becker, 1998, 2004). Young children (those under ten) are less likely, for example, to provide intimate care than older children.

Many children seem to be drawn into caring not through any informed or positive choice but rather through a series of pushes and pulls, a matter of necessity in the absence of real alternatives. Here, families lack affordable and good quality support services (which could prevent children from having to undertake unpaid care work in the first place), and most disabled parents also receive no support in their parenting roles, so they often have to rely on their children for things that they would prefer to do for themselves and for others (Becker et al, 1998; Wates, 2002; Aldridge and Becker, 2003).

The existing research evidence base thus suggests that the reasons why a particular child becomes a carer within any family will be complex and will vary from household to household and from situation to situation. Factors such as the nature of the illness/condition, love, attachment and co-residency, socialisation, a lack of choice and alternatives, low income, family structure, gender, all push or pull some children into unpaid caring roles and help to explain why a child might become or remain a carer in any household (Becker et al, 1998). Robson and Ansell (2000, p. 187) suggest that their interviews with young carers in Zimbabwe confirm that these same factors explain equally as well why some children become young carers in Zimbabwe as much as they do in the UK. Their research thus confirms (rather than refutes) the

explanatory framework provided by Becker and his colleagues (1998) for why children become carers and suggests that this has international relevance (see also Evans, 2005).

However, while the research base identifies the importance of these factors in explaining why children take on unpaid care work, it is not sufficiently developed or sophisticated to be able to show the relative strength of one factor over another, or how they interact with each other. However, it is likely that no universal truths can be asserted here, and that in any family one or other factor will have particular force depending on the circumstances of that household and its relationships with wider family and community. We do know, however, that a lack of family income to purchase alternative forms of care seems to be a common factor in families identified by researchers (in the UK, Australia and Southern Africa). Trying to establish whether low income is the *defining* factor that pushes children into caring roles is like trying to unwrap the thorny issue about 'structure versus agency'. To what extent does low income act as a structural determinant of caring roles or are individual and familial attributes, and resilience, also important here? At this stage the research evidence base has enabled the question to be identified but not yet the answer.

However, in their assessment of the factors that impact on young carers' transitions to adulthood and the outcomes of caring, Dearden and Becker (2000) suggest that their research evidence from sixty families shows that some factors exert more influence than others. They say that while the nature of parental illness or disability, and family structure, are important and inter-related influences, these only provide a partial explanation for young carers' experiences of vulnerability and transition. The authors suggest that other factors, *external* to families, play the *major* role. They argue that the receipt, quality and timing of professional services and support, and the level and adequacy of family income, are critical in determining the experience of transition for young carers. These interact with familial factors in complex ways, and in each family the various influences are likely to have different weightings. Nonetheless, the authors conclude that it is the absence of family-focused, positive and supportive interventions by education, health and social care professionals, often combined with low income, that are largely responsible for the negative outcomes associated with unpaid caring by children and young people, and the difficulties in making a smooth transition to adulthood. This suggestion, that structural (external) factors play a more significant role than individual and family attributes, requires more research to confirm or to refute it.

Linked to this is a growing interest in the concept of 'resilience' and how this might affect experiences and outcomes for young carers and their families. Resilience is the term used to explain the role that individual differences can play in helping to explain responses to stresses and adversity (Evans, 2005). Some young carers may have protective factors that help to reduce the potentially negative outcomes of their caring, familial and socio-economic situations, and these factors may center on personal attributes, family characteristics, or aspects to do with the wider community, networks and resources available to young carers and their families (Rutter, 1990; Masten et al, 1990; Schoon and Parsons, 2002; Evans, 2005). If the focus of research turns away from the 'vulnerability' of young carers to one concerned with 'resilience', then our ability to explain *differences* in experiences and outcomes *between* young carers, based on research evidence, becomes more likely. Indeed, such a focus would challenge us to consider new ways of understanding children's unpaid care work, as not so much an example of vulnerability, but as an active expression of

resilience (Evans, 2005). This must become a future focus for research on young carers and their families.

Messages for policy and practice

In response to the growing research literature on young carers and the campaigning of carers and other organisations, young carers in Britain have been 'recognised' in social policy, legislation and professional practice from the mid-1990s onwards. Various pieces of UK legislation concerning carers, community care and children have provided young carers with a complex (and sometimes contradictory) safety-net of 'rights' to assessments, services and support, and in some circumstances to cash payments in lieu of social services (see Aldridge and Becker, 2003, pp. 175-198; and Bibby and Becker, 2000). However, research studies show that only a small proportion of UK young carers (around one in five of those surveyed) actually have had a formal assessment of their own needs and their ability to continue to provide care (Dearden and Becker, 2004). Moreover, it is estimated that less than 25,000 young carers are actually in contact with the 350 or so dedicated young carers projects in the UK. This suggests that 150,000 young carers in the UK identified in the 2001 Census, and the other unidentified young carers of parents who misuse alcohol or drugs, are unlikely to access specialist (dedicated) support services or provision. We know very little about these young carers – and they remain even more invisible than the young carers who have been the subjects and participants of the research discussed in this paper.

Young carers' experiences of unpaid care work, and the impacts on their health, well-being, psychosocial development and transition to adulthood, challenges common understanding of what 'childhood' is about in both the UK and Australia. Because young carers are involved in adult-like tasks which require maturity, responsibility and often a high degree of skill and expertise (and which would, if undertaken by adults from outside the family, legitimately attract a fee or salary), there is a question as to whether it is appropriate for children to be involved in significant or substantial care work at all, or whether there are appropriate ages at which children might be reasonably expected to take on these responsibilities. So, for example, at what age should children be allowed to toilet a parent or to carry them up and down stairs? Could we define an age for these and other tasks or responsibilities? Even if it was possible to determine an 'appropriate' age, would it be desirable to do so?

The key issue here is that for healthy psychosocial development and transitions to adulthood, children should *gradually* increase their responsibilities both within, and outside, the home (Aldridge and Becker, 1993). Being responsible from an early age for care work, especially intimate and personal care – those labours which would usually be associated with (paid) adult care work – can compromise a child's health, well-being and development and can lead to a number of negative outcomes that can affect children not only in their 'childhood', but also into later, adult, life (Frank et al, 1999; Dearden and Becker, 2000).

In recognition of this, social policy in Britain, and those responsible for its implementation – social work and social care, health and education professionals in particular – have developed policy and practice guidelines which emphasise the need to take account of the needs of the whole family (not just parents or children in isolation), and have developed services and responses which try to prevent children from taking on inappropriate caring responsibilities, or which try to reduce their current level of responsibilities (Frank, 2002). This whole family approach is also

being identified in Australian research, policy and practice. An enduring message from the research evidence base is that professional involvement and positive interventions with children *and* families can make all the difference to the well-being of family members and can prevent children from having to take on unpaid caring roles in the first place. Professionals also need to ensure that young carers and their families are aware of, and understand, their rights under existing legislation and policy. Where children and families receive appropriate services and support this is almost always beneficial and can reduce or prevent children's own involvement in unpaid care work. Health, social services, education and other organisations, agencies and professionals need to consider the best way of working together, to deliver a seamless package of 'joined-up' support to parents and children within families where there is illness, disability, drug or alcohol misuse, mental health problems and so on.

The existing research evidence base also shows that it is important for children and parents that practitioners in contact with them show them respect. Disabled parents must feel that their needs and rights are being taken into account and promoted; that services are directed at them not only as *disabled* adults but also as *parents* as well; and that their parenting abilities are not being challenged unfairly. Equally, young carers must feel that their abilities as carers are acknowledged and valued and that they are not patronised or ignored in decision-making processes simply because they are children.

Linked to this need for respect, the research evidence suggests that each family must be considered and be treated as unique, with its own strengths, weaknesses and needs. Professionals must acknowledge, value and respect the reciprocal and interdependent nature of attachment and care-giving within families and support these relationships through a range of policies and services. Care must be taken to acknowledge and value the diverse cultural, religious and social expectations and experiences of families from different ethnic and religious communities whilst acknowledging the rights of children to a secure and healthy childhood, and to achieve, in the UK, the five outcomes identified in *Every Child Matters* (HM Government, 2003). Schools, as pivotal institutions within the new structure for integrated children's services in the UK, and also in Australia, can play an important role in recognising young carers and in helping to direct young carers to appropriate sources of help and support. Some young people with care-giving responsibilities experience educational difficulties and disadvantages. Schools can compound these by failing to recognise the specific educational, social and developmental needs of young carers.

We also need to conceptualise and understand caring as unpaid care *work*. To date, children's unpaid care-giving responsibilities within the home, by being defined as 'caring', have hidden its importance and significance as unpaid, and often *inappropriate*, care work. But to define these caring responsibilities as work poses major challenges to how we understand, and then respond to, children's unpaid labour of love.

A further challenge to understanding children's unpaid care work comes from a shift in research focus, away from 'vulnerability' to one concerned with 'resilience'. Here, rather than children's unpaid caring within the family being constructed as an act of vulnerability or necessity, it can be seen rather as an expression of resilience and agency.

The existing research evidence base on young carers has helped inform current policy and practice responses for young carers and their families in both the UK and Australia. A small but relatively trustworthy body of research evidence now exists

which has had a major (and quick) impact on law, policy and practice. Good dissemination and use of the media by key researchers has helped here. While the existing research evidence base is good on describing the characteristics, experiences and needs of young carers it is less developed with regards to ‘causes’ and ‘effects’. Nor has it adequately addressed the balance between structural determinants of experiences and outcomes (such as poverty and low income), and matters of agency and resilience. Perhaps this is not surprising as the evidence base in both the UK and Australia is still in its infancy and will develop and grow over the coming years. The research evidence base that we have in ten years time should look very different to that which is available today.

Acknowledgement
In writing this paper the author acknowledges that he has drawn on much of the research and analysis conducted by himself and other members of the Young Carers Research Group, particularly Jo Aldridge and Chris Dearden. These three researchers worked together for over a decade on many of the studies reported above.

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“Australian full paper October 2005 final”