



Commission for  
Rural Communities

Tackling rural disadvantage

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**Service needs and  
delivery following  
the onset of caring  
amongst children  
and young adults:**  
evidenced based review

Prepared for the Commission for Rural Communities by Young Carers  
International Research & Evaluation, The University of Nottingham



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## **Abstract**

This review provides an overview, synthesis and analysis of research and other evidence on 'young carers' and 'young adult carers' in the UK. There are 175,000 children under the age of 18 who are informal (unpaid) family carers – 2.1% of all children. Additionally, there are another 230,000 carers aged 18-24 – 5.3% of all people in this age group. This is the first evidence review that focuses on both young carers *and* young adult carers and their service and support needs following the onset of caring, with specific discussion of young carers and young adult carers in rural areas.

The review examines the available evidence on the number and characteristics of young carers and young adult carers; the factors that explain why they become carers in the first place and why they often have to stay in these caring roles for many years; the nature of the tasks and responsibilities that they perform within the family; the range of negative and positive outcomes that are associated with caring (and how issues of resilience may affect these outcomes); the needs of young carers/young adult carers and how they can be best supported by health, social care, education and other service providers (including details of relevant legislation and policy). Finally, the review focuses on the specific issues confronting rural young carers/young adult carers and rural service providers. An extensive bibliography lists all the evidence cited in the review.

Rural young carers and young adult carers face particular barriers in accessing and receiving services and support, compounded by distance, lack of adequate public transport, isolation, stigma and lack of privacy. There is a need for authorities and organisations to plan services and support for these carers which recognise (a) the impact of rurality and (b) that it will cost more to develop and provide equality of services in rural areas – the 'rural premium'.

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## Summary points

- There are 175,000 children under the age of 18, and 230,000 young adults aged 18-24, who are unpaid family carers in the UK. This is 2.1% of all children and 5.3% of all 18-24 year olds.
- Many young carers start caring at a very early age and can continue in caring roles for many years – often throughout their childhood (and into adulthood). Around one in ten young carers and young adult carers provide more than 50 hours of care per week.
- Children and young adults who are most heavily involved in caring are those most likely to need services, support and assistance, to help promote their own health, well-being, education, development, labour market participation, and social inclusion.
- There are various factors which push and pull children/young adults into caring roles, including family illness/disability, attachment and love, co-residency or close proximity, family structure, gender, age, expectations, poverty and few, if any, alternatives. The evidence is weak about which of these factors play the most significant role, although numerous studies are suggesting that family poverty and low income exert a strong influence.
- Many children and young adults perform a range of caring tasks and take on significant, substantial and regular responsibilities for other family members. They find it hard to balance other demands made upon them (education, work, friends, relationships etc) with their ongoing caring commitments.
- Many children and young adults report a wide range of negative outcomes associated with caring, including educational problems, difficulties in finding and keeping paid work, and personal/emotional problems to name a few. Some report positive outcomes, particularly how caring has helped them to foster even closer bonds with parents and other family members, even though these relationships can be difficult and strained at times. The evidence base is underdeveloped on which factors are most closely associated with particular outcomes.
- The needs of young carers and young adult carers are relatively modest and while there is evidence of significant recognition and service development for young carers over the last decade, the needs of young adult carers in the UK have gone largely unrecognised in terms of awareness, identification, policy, services and delivery.
- There is still a major problem (on the part of professionals working in education, health and social care) in identifying and assessing young carers and young adult carers, and in meeting their legal rights (to assessments, services and support).
- Rural young carers and young adult carers face particular barriers in accessing and receiving services and support, compounded by factors which include distance, lack of adequate public transport, isolation, stigma and lack of privacy. There is a need for authorities and organisations to plan services and support for these carers which recognise (a) the impact of rurality and (b) that it will cost more to develop and provide equality of services in rural areas – the ‘rural premium’.



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## 1 Introduction

The purpose of this review is to provide an overview, synthesis and analysis of research and other evidence on 'young carers' and 'young adult carers' in the UK. There are 175,000 children under the age of 18 who are informal family carers, with another 230,000 carers aged 18-24. This is the first publication, and certainly the first evidence review, that focuses on both young carers and young adult carers and their service needs following the onset of caring.

This review examines the available evidence on the number and characteristics of young carers and young adult carers; the factors that explain why they become carers in the first place and why they often have to stay in these caring roles for many years; the nature of the tasks and responsibilities that they perform within the family; the range of negative and positive outcomes that are associated with caring (and how issues of resilience may affect these outcomes); the needs of young carers/young adult carers and how they can be best supported by health, social care, education and other service providers (including details of relevant legislation and policy). Finally, we focus on the specific issues confronting rural young carers/young adult carers and rural service providers. An extensive bibliography lists all the evidence cited in the review.

# 2

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## 2 Defining our terms

### 2.1 'Informal care' and 'informal carers'

'Informal care' and 'informal carers' differ in a number of important respects from other types of 'formal' (professional) caregiving, for example the care provided by a social worker, nurse, care assistant or nursery worker. An official definition of informal carers is "people who look after a relative or friend who needs support because of age, physical or learning disability or illness, including mental illness" (Department of Health, 2005). More recently the Government has suggested a new definition for consultation: "A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems" (HM Government, 2008: 19). This 'looking after', 'unpaid support' or 'special help' as it is sometimes referred to can be in the forms of active support, social interaction or supervision.

Informal care, unlike formal care, is founded on an unpaid, non-professional 'caring relationship' between a family carer (for the purpose of this review, people who are children and young adults – see section 2.2) and the person for whom they care. This care is personally directed and is given free of charge by virtue of an established relationship based on love, attachment, family obligation, duty and friendship. The caring relationship has both a social element (there is a bond or attachment of some sort) as well as a physical element (certain tasks or responsibilities are undertaken by one for or with the other). While some of these elements can be found in formal (professional, paid for) relationships it is the unpaid nature of informal care and the 'caring relationship' that primarily distinguishes informal care and informal carers from other forms of caregiving or from other care providers. This is not to say that the unpaid caring relationship is always free from tension or difficulties – indeed far from it. There is considerable research evidence to show that the caring relationship can be difficult for both sides, and that the outcomes for carers can often include impaired health and well-being (including mental ill health), isolation, poverty and social exclusion. These outcomes are discussed in section 6 of this review.

It is important to acknowledge that many carers do not recognise themselves as 'carers', rather they see themselves as sons, daughters, fathers, mothers, husbands, wives, partners, brothers, sisters or friends. As such, many carers view their actions as extensions of family or personal relations rather than as a distinct type of 'caregiving'. This ambivalence about the title of 'carer' is as much the case for many children and young adults who are carers as it is for much older carers.

### 2.2 'Young carers' and 'young adult carers'

We make a distinction in this review between carers who are under the age of 18 ('young carers') and 18-24 year old carers ('young adult carers') because both groups of carers are at a different developmental stage in their lives and 'career' as carers; one group are legally 'children'

and the other are legally 'adults'; and while they have experiences and needs that are similar there are also important differences that need separate identification and discussion (Dearden and Becker, 2000; Becker and Becker, 2008). Moreover, in terms of service needs and delivery issues, young carers are generally the 'responsibility' of children's services while young adult carers fall into the remit of adult services and adult social care. This distinction has major implications for the delivery of services and interventions for young carers and young adult carers (see section 7).

In this review we define young carers 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).

We define young adult carers as people aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support or supervision (Becker and Becker, 2008).

### **2.3 Similarities and differences**

While there is a high degree of acceptance and legitimacy in older adults being involved in caring for other family members, where children are carers the situation is more challenging. Young carers, under the age of 18, are legally defined as children and young people 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 workers, or social care, health and education professionals, then they can become a cause for concern (because, for example, of educational problems, child welfare concerns, children's poor health or safeguarding issues and so on – see section 6 on outcomes). While much older adult carers (for example, the one in five of the population aged in their fifties who are carers) can be seen to be conforming to individual, societal and familial norms in supporting family members, when children act as unpaid carers they can transgress, or certainly challenge, such norms in the UK and in other developed and developing countries (Becker, 2007). However, as children get older, particularly between the ages of 18-24, then it is seen as less inappropriate for them to take on caring responsibilities, because they are now 'adults'. As we see in sections 6.3-6.5, the outcomes can still be highly negative for young adult carers just as they are for many children who care.

# 3

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## 3 Numbers and characteristics

### 3.1 Census 2001

There are a range of sources of data on the extent of informal caring in the UK, including British Household Panel Surveys (Hirst, 1999), the 1985-2000 General Household Surveys of Carers (Maher and Green, 2002), the 2001 Census (ONS, 2003) and other sources from one-off large-scale surveys conducted by organisations such as Carers UK and the Princess Royal Trust for Carers.

The 2001 Census included for the first time a question about whether people ‘looked after or gave any help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability or problems related to old age’. An advantage of using the 2001 Census over and above other sources such as the General Household Survey of Carers is that it provides data by every local authority on the number of adult and young carers, the amount of care that they provide (hours per week), and is based on a ten-yearly survey of all households in the UK. This is a source we use extensively in this review although we draw on other surveys and qualitative research findings concerning young carers and young adult carers where appropriate.

### 3.2 Young carers aged under 18

In the UK there are almost three million children (equivalent to 23% of all children) who 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). However, only a small proportion of these children and young people will become young carers to the extent or nature as captured in the definition in section 2.2 above.

The 2001 Census shows that 175,000 children in the UK provide some level of unpaid care to other family members. This is approximately 6% 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 countries 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. Analysis elsewhere shows that there are 13,299 children who are carers in England and Wales under the age of ten (Becker, 2004: 6).

Overall, across the UK, 2.1% of all children are young carers. There are small variations between the four UK nations, with the highest concentration of children who are carers to be found in Northern Ireland, with 2.5% of all children aged 5-17 being involved in caring (Table 1). These proportions are minimums rather than maximums because of limitations inherent within the Census questions and methodology, which we outline in section 3.3.

**Table 1:**

Number and proportion of children under the age of 18 who are carers in the UK, by hours caring per week

	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%
<b>Total number of young carers in UK</b>	145,854	16,113	13,029	174,996	2.1% (UK average)
<b>Total number as % of all young carers in UK</b>	83%	9%	8%	100%	

Calculated from Office for National Statistics Census 2001 data, in Becker, 2007.

Table 2, below, shows the number of young carers in the UK by age and hours per week caring. Here you can see that 6,563 young carers in the UK are aged between five and seven, and that 940 of these provide at least 50 hours of care per week. Another 9,524 young carers are aged eight or nine, and 1,055 of these are providing 50 hours of care or more each week. In total, around 35,000 young carers are of primary school age and nearly 4,000 of these are caring for more than 50 hours per week. These Census figures reveal that many children are drawn into caring roles from a very young age and that many of these young carers will have to care for very long hours each week, with one in six having to care for more than 20 hours per week and almost one in ten caring for more than 50 hours each week. It is important to remember that these are minimums rather than maximums – the true extent of young caregiving is likely to be higher, for reasons outlined in section 3.3.

**Table 2:**

Number and proportion of children who are carers in the UK, by age and hours caring per week

	1-19 hours	20-49 hours	50+ hours	Total number	Total %
0-4	0	0	0	0	0
5-7	5,015	608	940	6,563	4%
8-9	7,717	752	1,055	9,524	5%
10-11	16,120	1,433	1,615	19,168	11%
12-14	46,267	4,103	3,519	53,889	31%
15	21,024	2,282	1,494	24,800	14%
16-17	49,711	6,935	4,406	61,052	35%
<b>All</b>	145,854	16,113	13,029	174,996	100%
<b>All as %</b>	83%	9%	8%	100%	

Source: Calculated by the author from Office for National Statistics Census 2001 data, in Becker, 2008: 443.

### **3.3 Census limitations**

The Census 2001 figures are likely to under-represent the true prevalence of children's caring in the UK because they rely on parents' self reporting their children's caring roles, and the data are thus not likely to adequately identify or count children in many caring situations, and especially in circumstances where there is social stigma, for example where children are caring for parents who misuse alcohol or drugs or where there is enduring parental mental ill health or HIV/AIDS (Aldridge and Becker, 2003; Evans and Becker, 2009). 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 carers to the extent or nature captured in the definition provided in section 2.2 above.

It has been suggested that a more accurate figure of the extent of caring amongst children may be between 4-10% of all children in the UK, which would mean that anywhere between 350,000 and 1 million children could be involved in caring. These proportions are based on a number of research studies of the general 'child and young person' population. One, by the NSPCC, has shown that 4% of young adults had caring responsibilities in their childhood (Cawson, Wattam, Brooker and Kelly, 2000; Cawson, 2002). Another, based on a much smaller local population, suggests that up to one in ten children are involved in care-giving (Warren, 2007; Warren and Ruskin, 2008). However, in the absence of further reliable data to confirm these findings the official figure that is used by Government and for service delivery purposes remains at 175,000 young carers or 2.1% of all children in the UK.

### **3.4 Young adult carers aged 18-24**

Secondary analysis of Census 2001 data show the number of young adult carers aged 18-24 in the four nations of the UK (Table 3). In total, there are 229,318 young adult carers in the UK, and this is 5.3% of all people in that age group. However, this varies between the four UK nations, with the highest levels of young adult caring being in Wales (where someone aged 18-24 has a 5.7% probability of being a carer), compared to England (4.8%). This regional variation is likely to reflect different levels of illness, disability, geography and need across the four UK nations, and also differences in the availability of local health and social care services and support for ill and disabled people, and for carers.

**Table 3:**

Number and proportion of young adult carers aged 18-24 in the UK, by country and hours caring per week

	Number caring for 1-19 hours	Number caring for 20-49 hours	Number caring for 50+ hours	Total number caring	Proportion of this age group who provide informal care
England	140,903	22,547	21,571	185,021	4.8%
Wales	9,675	1,697	1,690	13,062	5.7%
Scotland	15,417	3,203	2,495	21,115	5.0%
N Ireland	7,254	1,681	1,185	10,120	5.5%
<b>Total number of young adult carers in UK</b>	173,249	29,128	26,941	229,318	5.3% (UK average)
<b>Total as % of all young adult carers in UK</b>	75%	13%	12%	100%	

Source: Calculated from Office for National Statistics Census 2001 data, in Becker and Becker, 2008

Table 3 also shows that one quarter of all young adult carers in the UK (56,069 people) are providing care for more than 20 hours per week and almost 27,000 of these (12% of the total) are providing care for more than 50 hours each week.

Table 4 provides a breakdown of the young adult carers population by two age bands available in the 2001 Census (18-19 and 20-24). These figures are important for policy and service delivery purposes, as we outline in section 3.4 below. 27% of all young adult carers are aged 18-19, and 73% are aged 20-24. Focusing down a little, the data show, for example, that there are 4,661 carers aged 18-19 in England who provide more than 50 hours of care per week, and another 16,910 carers aged 20-24 in England who provide more than 50 hours of care per week.

**Table 4:**

Number and proportion of young adult carers aged 18-24 in the UK, by age, country and hours caring per week

		1-19 hours	20-49 hours	50+ hours	Total number	Total %
Aged 18-19	England	38,341	6,053	4,661	49,055	21%
	Wales	2,784	479	338	3,601	2%
	Scotland	3,910	947	527	5,384	3%
	N.Ireland	2,112	466	275	2,853	1%
Aged 20-24	England	102,562	16,494	16,910	135,966	59%
	Wales	6,891	1,218	1,352	9,461	4%
	Scotland	11,507	2,256	1,968	15,731	7%
	N.Ireland	5,142	1,215	910	7,267	3%
All young adult carers aged 18-24		173,249	29,128	26,941	229,318	100%
All young adult carers as %		75%	13%	12%	100%	

Source: Calculated from Office for National Statistics Census 2001 data, in Becker and Becker, 2008

### 3.5 'Heavily involved' carers

The literature on informal care and informal carers sometimes makes a distinction between 'informal helping' and 'heavily involved caring'. How 'heavily involved caring' is defined varies according to different studies but a number of measures have been used as proxy indicators for this more intensive and demanding form of caring. These indicators include focusing on carers who are co-resident (in other words, living with the person with care needs as opposed to 'extra-resident' carers); focusing on those who are the sole or main carer; focusing on those providing 20 hours or more care per week (particularly those caring for 50 hours or more – see Tables 1-4 above); focusing on those who are providing help with personal and/or physical care; and those where the carers are themselves very elderly, very young (in other words, children or young adults who are carers), or those who have health or other problems of their own. In general, the 'heavily involved' carer is providing the most care (in terms of long hours each week) and the most intense and personal forms of care – help with personal and/or physical needs – as opposed to 'informal helping'.

While many young carers might not necessarily be providing the longest hours of caring, most would still be considered to be 'heavily involved' particularly where they are taking on adult-like caring responsibilities and where their caring roles impact on their own psycho-social development, health, education and well-being. In particular, young children (for example, the 35,000 young carers of primary school age and the 4,000 of these who are providing more than 50 hours of care per week – see Table 2) would be defined as 'heavily involved' by reason of their young age, the amount of caring they do and the potential impact this might have on their development/education. It is heavily involved young carers and young adult carers who are most likely to need

formal health and social care support, social work assessments and interventions and specialist support from young carers and adult carers services (see also section 7).

Thus, identifying the number and characteristics of young carers under the age of 18 and young adult carers aged 18-24 who are most heavily involved in caring (caring over 20 hours per week, and particularly those who are caring for more than 50 hours each week) is important for policy and service planning purposes. This is a reliable indicator of 'service needs' in that research on young carers and Office for National Statistics, and other research on adult carers, shows that carers who provide the longest hours of caring each week are those most likely to experience impaired physical and mental health, stress, relationship difficulties and experience restrictions in their ability to participate socially and fully in society and take advantage of education, recreational and leisure opportunities. They are also those most likely to need services and support in their caring roles and to meet their own needs (Becker, 2008).

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## **4 Why children and young adults become carers**

Drawing on the evidence base generated over the last fifteen years it is possible to identify a range of factors that research shows are relevant in explaining why children and young adults are drawn into unpaid caring roles for other family members.

### **4.1 A need for care**

The 'trigger' factor that draws these young people into a caring role in the first place is the onset of the illness, impairment or condition itself and how it's nature, duration and change relates to a need for care, support or supervision (Aldridge and Becker, 1999). 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, personal care (Dearden and Becker, 2004a; Aldridge and Becker, 2003).

### **4.2 Co-residency and attachment**

Other factors that draw children and young adults into caring roles include the fact that children are most often co-resident (they 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. Some young adult carers are not co-resident but live near to the person(s) that they support (even, for example, when they leave home to go to university), and the attachment remains very strong (Becker and Becker, 2008). Co-resident young carers and young adult carers living close to the person they support

are immediately available (and flexible enough) to be able to provide care that is responsive to the changing needs of the person who requires support. The bonds between child/young adults and parent(s) 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. 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 so-called 'dependency' of one side (parent) on another (child), but is founded on reciprocity and interdependence with parents 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; Becker and Becker, 2008; Evans and Becker, 2009).

### **4.3 Family structure**

In lone parent families, where there is no other responsible adult available to provide care, there is a greater vulnerability on children to become carers when the (lone) parent becomes ill, disabled or has another condition which leads to a need for support or supervision. It is not surprising, therefore, that in all UK studies to date the majority of young carers and young adult carers live in lone parent families. Even in two parent families, however, children can become 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, 2004a). 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 (Aldridge and Becker, 1993).

The issue of the 'availability' of other family members is also critical here. Where there is only one child or young adult in a family and the parent becomes ill, then the pressure on the young person to take on a caring role (in the absence of alternatives) is increased. 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 and young adults 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 other family members (Robson and Ansell, 2000; Becker and Becker, 2008).

#### **4.4 Expectations**

Expectations based on religion and culture can also be very powerful, drawing some children and young adults into unpaid caring roles (Shah and Hatton, 1999; Jones et al, 2002). Expectations based on age are also important. In the case of young adult carers, as they get older there are growing expectations within some families that they should provide care as they are now 'adults', and the care they give is considered less inappropriate as they get older (Becker and Becker, 2008).

#### **4.5 Gender and age**

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 personal care for a mother that contravenes gender norms. The research evidence suggests that as children and young adults get older, they are more likely to get involved in all forms of unpaid care work and this becomes normalised over time (Dearden and Becker, 1998, 2004a; Becker and Becker, 2008).

Young adult carers, especially those that are starting caring in their early twenties and who may already have some independence from the parental home, may have more choice and control over what they do or are willing to do, but even here many feel 'trapped' with little alternative but to provide care and support. The problem of 'leaving home' can delay some young carers' transition to independence (Dearden and Becker, 2000) and is also problematic for many young adult carers who find it difficult to leave home or to pursue higher education or part or full-time paid work. Others choose not to leave in order to protect siblings from assuming a caring role (Becker and Becker, 2008).

#### **4.6 Money and choice**

In UK, Australian, American and African research on young carers there is often explicit reference to the fact that low income (and in Africa, chronic poverty) distinguishes most of the families where children are known to be caregivers (Becker, 2007). There is overwhelming evidence that poverty restricts severely the abilities of families and carers to purchase alternative forms of care and support, which forces some households to rely on children and young adults for care, support and supervision (Aldridge and Becker, 2003; Becker and Becker, 2008). This is also discussed in sections 6.1 and 6.4.

In summary, many children are drawn into caring not through any informed or positive choice but rather through a series of 'pushes and pulls'. Their caregiving is a matter of necessity in the absence of real alternatives, exacerbated by poverty and low income. Here, families lack affordable and good quality support services (which could prevent children from having to undertake caring 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). Children, as so-called 'dependants' of parents, have few options to 'walk away' from caring responsibilities, especially in the absence of any viable alternative.

#### **4.7 Limitations of the evidence**

While the existing research base identifies the importance of these factors and how they interact to explain why children and young adults take on caring roles, the evidence is not sufficiently developed to be able to show the relative strength of one factor over another. It is likely that in any family one or other factor will have particular force depending on the circumstances of that household and its relationships with wider (extended) family, community and external sources of professionalised support. For example, 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 (family structure, age, gender, etc) more important?

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 report 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. These very same external factors play a critical role in explaining the experiences and needs of young carers in other countries both in the global North and South (Becker, 2007), and for young adult carers (Becker and Becker, 2008).

# 5

## 5 Caring tasks and responsibilities of children and young adults

### 5.1 Young carers

In addition to what we know from Census 2001 data (see section 3 above) about the hours that young carers and young adult carers spend involved in caring tasks each week, there are also three national statistical profiles of what young carers do in the home drawn from large samples of young carers in contact with dedicated support projects (Dearden and Becker, 1995, 1998, 2004a). The 1997 national survey (Dearden and Becker, 1998) provides data on 2,303 young carers while the 2003 survey (Dearden and Becker, 2004a) provides a profile of 6,178 young carers, the largest survey of its kind anywhere in the world. 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% were girls and 44% were boys; 16% 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% of young carers), learning difficulties (17%) and sensory impairments (3%). 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% care for more than 20 hours per week.

An additional question asked in the 2003 survey concerned the number of years young people had been caring. Data were collected for 4,028 cases (66% of the sample). 36% had been caring for two years or less; 44% for between three and five years; 18% for six to ten years and 3% for over ten years. Given that the average age of these young carers is just 12, the findings suggest that informal caring can both be a long-term commitment for many children and that this commitment can start at a very early age. The 2001 Census figures confirm this, with children from the age of five being recorded as caregivers (see Table 2 above).

The nature of the caregiving undertaken by children ranges along a continuum from basic domestic duties to very intimate personal care. Most young carers (68%) do some level of domestic work within the home (Dearden and Becker, 2004a). However, where young carers differ substantially from other 'non-caring' children is 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 (Warren, 2005, 2007; Warren and Ruskin, 2008; Becker, 2007). Warren (2005: 6) found that "what sets young carers apart from their peers is the nature, frequency and time spent each week on domestic and caring tasks". 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 (non-caring) children.

48% of young carers known to dedicated projects in 2003 were involved in general and nursing care, which included organising and administering medication, injections, and lifting and moving parents (Dearden and Becker, 2004a). 82% 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 personal and intimate care including help with going to the toilet and with bathing tasks. A small proportion, about 11%, also took on childcare responsibilities in addition to their caring roles for other family members. Around 7% were involved in other household responsibilities, including translating (where English is not the first language), dealing with professionals, the family's money management and so on (see Table 5).

**Table 5:**

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

	1995	1997	2003
<b>Domestic work</b>	65%	72%	68%
<b>General &amp; nursing care</b>	61%	57%	48%
<b>Emotional support &amp; supervision</b>	25%	43%	82%
<b>Intimate and personal care</b>	23%	21%	18%
<b>Childcare to siblings</b>	11%	7%	11%
<b>Other household responsibilities</b>	10%	29%	7%

Source: Dearden and Becker, 1995, 1998, 2004a

A growing body of research evidence from a few other developed countries, particularly from Australia, confirms this picture of the caring tasks and responsibilities of children (Becker, 2007). For example, research in Australia by Morrow (2005) suggests that a way of differentiating what young carers do from other children is to examine household tasks as 'Instrumental Activities of Daily Living' (such as taking out the rubbish or cleaning), and 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). Other research evidence from Australia (Carers Australia, 2001: 9) shows that young carers spend most of their time either providing care or thinking about the person with care needs unlike non-caring peers. 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 (2005: 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".

Thus, the existing research evidence from both the North and South (Becker, 2007) 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). All of these activities can start at a very early age and continue for many years.

## 5.2 Young adult carers

While there are many studies of young carers in the UK far less is known about young adult carers aged 18-24. Information is sparse about the issues and challenges that they face due to being carers, what would be appropriate support and the best methods and routes to reach them. As recently acknowledged in a report by the Social Exclusion Unit (2006): "The transition from childhood to adulthood is becoming increasingly complex, difficult and risky... the transition to adulthood is more difficult if you also have to deal with one or more of the following issues: poor housing; homelessness; substance misuse; mental health issues; poor education or long-term employment" (p7). The decisions made at this age, including education and employment, are some of the most important and far-reaching decisions taken at any time of life. Yet disadvantaged young adults, including young adult carers, are often least equipped with the skills required. For young adult carers in transition, especially those caring for a parent with severe mental health or substance misuse problems, some may not have the advice or guidance from within the family to help them navigate through this period of change in their lives at the same time as they continue with their caring responsibilities.

The Social Exclusion Unit's report highlights the fact that services are often age-related and are for adults or children and that: "...there are relatively few examples of public services that address the specific needs of 16-25 year olds in the round or that ensure effective transition from youth services to adult services" (p8). Indeed, The Princess Royal Trust for Carers' own Young Carers Services report that young carers start to drift away from their services around the age of 16 and upwards. However, few carers of this age group take advantage of the other services and groups offered by adult carers' services, suggesting that many young adult carers, at present, are unsupported and do not relate to the 'adult' services that are available from voluntary sector carers centres or adult social care services provided, administered or commissioned through local authorities.

Becker and Becker's (2008) study, *Young Adult Carers in the UK*, investigates the experiences, needs and service responses to the 290,000 young adult carers aged 16-24 in the UK today. Their qualitative data provides new insights into the diverse experiences and needs of what is a 'hidden' and neglected group of carers. Young adult carers are involved in a wide range of caring tasks and responsibilities and some are very heavily involved in caring. Just under two thirds of Becker and Becker's sample are providing emotional care 'a lot of the time' and this was a task that many young adult carers found particularly arduous and which restricted their participation in other life events, activities and socialising. Just under a third were providing personal and intimate care 'a lot of the time' which included helping the person being supported to wash or take a bath. Where a parent's condition deteriorated, then the amount of caring increased unless adjustments were made to care packages or support materialised from other family members. All young adult carers described having an increasing number of other demands on their time alongside their caring responsibilities, be it to do with education, jobs or personal relationships and therefore they felt pressurised by trying to meet these demands alongside their caring commitments.

# 6

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## 6 Outcomes

### 6.1 Costs

Caring can incur extra expenses for carers and for their ill, disabled or other family members, not least in terms of economic, social, health and opportunity costs. These include one-off capital costs (such as the costs of installing a downstairs toilet or shower), special aids and adaptations (making doors wider so that they are accessible to wheelchairs) and regular extra household expenditure (for example, on heating, laundry and so on). Also, caring can lead to reduced or foregone earnings, lower future earning capacity because of interruptions to work, and financial insecurity in later life. There is a strong association between being a carer and the experience of poverty and social exclusion (Howard, 2001). Charging for social care services and support will often exacerbate poverty and social exclusion for many carers. Many carers also experience isolation, loss of self-esteem and feelings of resignation or depression; their physical and mental health can also suffer (Becker, 2008).

### 6.2 Negative outcomes for young carers

As far as young carers are concerned, there is a substantial body of research evidence which shows that many young carers can experience one or more of the following negative outcomes: restricted opportunities for social networking and for developing peer friendships; limited opportunities for taking part in leisure and other activities; poverty and social exclusion; health problems; impaired mental health; emotional difficulties; educational problems (poor attendance or punctuality, underachievement and bullying); limited horizons and aspirations for the future; a sense of 'stigma by association' (particularly where parents have mental health problems or misuse alcohol or drugs, or have HIV/AIDS); a lack of understanding from peers about their lives and circumstances; a fear of what professionals might do to the family if their circumstances are known; the keeping of 'silence' and secrets (again because of the fear of public hostility or punitive professional responses); and significant difficulties in making a successful transition from childhood to adulthood (Becker et al, 1998; Aldridge and Becker, 2003; Becker, 2005; Evans and Becker, 2009).

### 6.3 Negative outcomes for young adult carers

While we know less about young adult carers than we do about young carers in the UK, there are a number of qualitative studies which show that young adult carers are vulnerable to many of the same negative outcomes outlined in section 6.2 above (for a review of these studies see Becker and Becker, 2008). Young adult carers often feel that they have insufficient time for themselves: life is constantly busy with little free time, time to be alone or opportunities for rest and relaxation and this is particularly the case for those young adult carers who are providing high levels of emotional care or where they are caring for more than one person. This also affects young adult carers' ability to look for or take on paid work (Becker and Becker, 2008). Poverty is a particular problem. Most young adult carers in Becker and Becker's study experienced significant financial hardships as a consequence of caring and living

in a family where there is physical or mental ill health, disability, and alcohol or drug misuse. Family income was very tight and there is strong evidence of poverty and social exclusion for all family members; in some instances young adult carers were using their own (limited) money to subsidise the needs of parents.

#### **6.4 Education**

There is a significant amount of research evidence which shows that caring responsibilities impact negatively on the education of many young carers. For example, in a large scale survey of over 6,000 young carers of primary and secondary school age, around one quarter had some form of educational difficulty (Dearden and Becker, 2004a). In a review document for Carers UK, Dearden and Becker (2004b) have outlined the range of educational outcomes that can be experienced by young carers of school age and have suggested ways forward for schools, including strategies for the better identification of young carers and more sensitive responses.

There is evidence that some young adult carers have done well at school although others report educational difficulties and in particular a lack of awareness in schools about children with caring responsibilities (Becker and Becker, 2008). Where school staff have been understanding and have identified children who care, and where they have offered appropriate support, then this has made a significant difference in terms of engagement and achievement for some young carers (Becker and Becker, 2008). Where young carers were not recognised or identified, then school or college could be problematic, with many young carers failing to get the best out of their educational opportunities and failing to meet their full potential.

Generally, young adult carers reported that their experience of college was more positive than school because of its flexibility, its adult-orientated focus and staff who were more understanding and supportive of young adults with caring roles. However, some young adult carers had left college prematurely without completing their intended qualifications (Becker and Becker, 2008).

Examination of 2001 Census Samples of Anonymised Records (SARs) shows that among young adults (16-24 years) caring reduces the likelihood of being a student and thus of participating in further or higher education for young men, and especially, for young women (Yeandle and Buckner, 2008). Young adult carers at university are required to balance caregiving with their academic studies and learning (Becker and Becker, 2008). Some do this by 'caring at a distance' and returning home at weekends or holidays to provide care. Others balance care and study by continuing to live at home and travelling to their local university, enabling them to maintain their regular caring roles. Young adult carers who are studying at university but return home each day to care have substantial and significant caring roles which appear to be no less time consuming than for carers living at home who are not in higher education. Of the young adult carers at university in Becker and Becker's (2008) study, none were aware of any specific carers support available for them at their university. Similarly, they were often unaware of local services for carers that might be able to support them because

traditionally those carers services have not reached out to university populations.

## **6.5 Employment**

Caring can severely restrict the ability of young carers and young adult carers to find or retain paid work. Examination of 2001 Census SARs shows that among young adults (16-24 years) caring reduces their chances of being in either full-time or part-time work (Yeandle and Buckner, 2008). Only one third of Becker and Becker's (2008) sample of 25 young adult carers had recently or were currently engaged in part-time employment as a means to getting additional money for themselves or their relatives, despite familial low income and poverty. Others found it too difficult to combine paid work with the conflicting demands of caring.

Some unemployed young adult carers feel very much alone and unsure of how to make progress in getting into the paid labour market. Low self-confidence and not having the necessary qualifications impeded their success or they simply felt that combining caring and work was not feasible. Lack of transport was also mentioned as a factor, particularly in rural locations, so that they could not search further away for work (Becker and Becker, 2008; see also section 8).

Unlike other young people whose future aspirations are often mediated by money and qualifications, young adult carers' futures are also mediated by their caring responsibilities, particularly where they are caring for a parent, rather than sibling, and where there is no other extended family support available.

## **6.6 Outcomes for the family**

Within the family unit it is not just children and young adult carers who experience a range of negative outcomes. Many of the people being supported also experience a range of outcomes, not least their own marginalization from the labour force, isolation, deprivation and exclusion, often as a consequence of the 'disabling barriers' that are inherent in society and in much social organisation and social welfare policy and practice. Thus, people with care needs and their carers comprise some of the most deprived and marginalized groups in society. Many experience disadvantage in the paid labour market and relative isolation within their own communities. They are among those most vulnerable to financial poverty and social exclusion. Their quality of life is affected not only by their impairment, and family and caring circumstances and arrangements, but also by the support that they receive from outside the family; by the level and adequacy of their income (often from social security benefits – see Silburn and Becker, 2009); and by the reactions to, and help that they can receive from, health and social care agencies.

## **6.7 Positive outcomes and resilience**

There is evidence from research that young carers and young adult carers can experience some positive outcomes 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. Aldridge and Becker's (2003) research in 40 families where a child was caring for a parent with severe mental illness shows that caring can allay some of the children's fears, concerns and anxieties that they have about their parent's condition because it gives children some control and direct involvement in the provision and management of care. 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. Becker and Becker's (2008) study of young adult carers shows how important the caring relationship is to young adult carers and how they structure their lives, relationships, choices, education, training and work around caring responsibilities and how this can help to develop their knowledge, maturity and transferable skills.

Not all young carers or young adult carers will experience physical, emotional, relationship or other psycho-social problems, and many may not experience difficulties in school, college, paid work or elsewhere. We cannot be sure to what extent the negative (or positive) outcomes described in sections 6.1-6.6 are common among young carers and young adult 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 and young adult 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 that can impact on young carers and young adult carers' health, well-being, development, education and labour market participation, in particular factors such as low income, family poverty, social exclusion, disability and other forms of (multiple) disadvantage.

Some have suggested that focusing on family or children's resilience may offer some explanation here (Newman, 2002; Evans and Becker, 2009). A 'resilience' perspective helps to explain individual differences in accessing and using support, and in coping with stress and adversity. The concept of resilience emphasises people's strengths in coping with adversity and their agency in engaging with protective factors that may help to reduce their vulnerability. Protective factors may be associated with personal attributes, family characteristics, or aspects of the wider community; however, they are likely to be context-specific and may vary cross-culturally (Evans, 2005; Evans and Becker, 2009).

While the strength of existing young carers and young adult carers research has been in making visible what had hitherto been invisible, and in charting and describing the broad landscape of these carers' experiences and differential outcomes between young people who care, the research evidence base is still under-developed in terms of critical analysis on outcomes and the protective factors which help to promote resilience.

# 7

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## 7 Service needs and delivery

### 7.1 Needs and services

In 2008 the Government published its second National Carers Strategy which outlined its vision and commitments for the next ten years. As far as young carers were concerned the vision states: “Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the *Every Child Matters* outcomes” (HM Government, 2008: 123). What are the prospects for this ambition to be met?

In most instances the needs of young carers and young adult carers are relatively modest and do not require very intensive (or very costly) interventions and services. However, each carer will have their own specific needs depending on family circumstances, the nature of the illness/disability and the need for care, family finances, who else can help provide care from within and outside the family, and so on.

It has been suggested that the best way to support informal carers is to improve the services and support offered to those who are currently recipients of their care – ill or disabled people themselves (Royal Commission on Long Term Care, 1999; Pickard, 2004). The Royal Commission, for example, proposed moving towards a ‘carer-blind’ situation where the presence of a carer did not impact on the likelihood of services being offered by the State to the person with care needs. Parker, Morris and others have argued that the best way to stop inappropriate caring by children and to support young carers is for their ill or disabled parents to receive services and support as disabled people and as disabled parents (Keith and Morris, 1995; Olsen, 1996; Olsen and Parker, 1997; Wates, 2002). This position argues that formal services provided to those with care needs should replace informal care provision by children and adults who are carers.

An alternative approach, however, is to provide services and support to young carers and young adult carers based on an assessment of need in order to support them in their caring roles, to meet their own needs and to reduce the negative outcomes of caring. There has been growing recognition in recent years of the importance of supporting carers directly in their caring role and in their personal circumstances. Indeed, the legislation discussed in section 7.2 provides young carers and young adult carers with a set of legal ‘rights’ to assessments and to support. Performance ratings for social care authorities also now include recognition of the amount and quality of local support provision for informal carers and local authority children’s services are also inspected on the quality of their services for young carers.

The Audit Commission's (2004) review of what carers can 'reasonably expect' to receive suggest that carers across the UK, including young carers and young adult carers, should be able to expect the following:

- Identification of need (by primary care staff and councils).
- Provision of information in the form of literature, websites, call centres, verbal advice and training (from both local and national sources).
- Provision of support (including breaks from caring and help for those who are working or want to return to work).
- Assessments (of both the person with care needs and the carer).

There is a range of services now available to support young carers, including respite care and short breaks of various forms, information and training, social work and counselling and a national network of over 350 young carers projects. The approach taken by the authors of this review is that young carers and young adult carers need services and support in their own right (as carers) at the same time as the people they support need dedicated services and support (Aldridge and Becker, 1996; Aldridge and Becker, 2003; Becker and Becker, 2008). A 'whole family approach' (the current approach to working with young carers advocated by Government and the National Young Carers Initiative – see Frank, 2003; and Frank and McLarnon, 2008) recognises the need for formal services to assess and meet the (interdependent) needs of all family members. In support of this approach Frank and McLarnon (2008) have devised key principles of practice to underpin all interventions with young carers and their families.

However, despite legal and policy advances for young carers, Dearden and Becker's (2004a) survey of over 6,000 young carers showed that only 18% had ever had an assessment of their needs or ability to continue to care while only two out of a sample of 25 young adult carers in Becker and Becker's (2008) study had been assessed and two thirds of their sample were unaware of their right to a carer's assessment. Moreover, research from many sources suggest that there are ongoing problems with the identification of young carers and young adult carers in schools, colleges, higher education, workplaces, health and social care settings etc. The identification of young carers and young adult carers in rural settings will be made more difficult due to a combination of factors, including: the dispersal of services over wider geographical areas; the greater costs associated with travel by carers and by professionals; the reduction in 'on the doorstep' health, social care and other facilities and their concentration in regional centres; the stigma associated with seeking help from 'local' providers and related issues of privacy. These barriers to identification are a cause for concern as identification and then a formal 'assessment' of need are often the gateway to services and interventions directed at young carers and their families (Frank and McLarnon, 2008).

The Third Joint Chief Inspectors' Report on Arrangements to Safeguard Children states that "Joint Area Reviews have found that awareness of the needs of young carers has increased across children's services and in schools. They have identified that good quality services are in place in most areas for young carers, often delivered in partnership with the voluntary sector. However, processes for identifying young carers are

less well-developed in most areas. This makes it difficult to plan the capacity to meet potential demand for services” (Ofsted, 2008, p.41).

Around 25,000 young carers in the UK make use of a network of over 350 dedicated local young carers projects. These projects provide young carers with opportunities to meet other young carers and to develop meaningful friendships, take part in ‘fun’ and therapeutic activities, have one-to-one support (including counselling), all in a safe, child-focused and confidential environment (Becker and Becker, 2008). Young carers projects are valued highly by children and by their parents. However, many of these young carers projects do not work with carers over the age of 18. New research evidence (Becker and Becker, 2008) reveals the problems that this ‘cut off’ can cause for many young carers who have been in contact with projects for some years, and who, on reaching 18, find themselves without a service or support. In theory, young adult carers could access support from adult carers services provided by the voluntary or statutory sectors. In fact, very few use an adult carers service and then not to any great degree. Adult carers services and centres are generally used by and promoted to much older carers – from around age 40 and over, rather than young adults aged 18-24.

There is a lack of recognition of the needs of young carers once they reach the age of 18, and of young adult carers who may start caring between the ages of 18-24, and there are very few services or supports available to them during this ‘transition’ between childhood and adulthood, and between children’s and adult services. Becker and Becker (2008) make a number of policy recommendations for young carers and adult carers services about the need for identification of this hidden group of carers and for the development of ‘transition’ support services for young adult carers in the UK (see Box 1). Many young carers services are now aware of the ‘gaps’ in service provision for young adult carers and questioning to what extent they have a responsibility for filling that gap. A few of Becker and Becker’s (2008) sample were accessing ‘18 plus’ or other transitions-related services that were new developments arising from the work of young carers projects. A number of models of provision are now emerging across the UK (Becker and Becker, 2008).

**Box 1:**

Recommendations for the identification and development of support for young adult carers in the UK (from Becker and Becker, 2008)

1. The key factor to be considered in the development of services and interventions for this group should be concerned with outcomes rather than types of services and models. Commissioners and service providers should identify clearly the outcomes to be achieved and delivered for young carers aged 16-17 and for young adult carers aged 18-24.
2. A key principle for the development of services should be that young carers and young adult carers, who wish to do so, are involved fully in planning services.
3. Services for young carers under the age of 18 need to prepare young carers, especially around the ages of 16+, for the next 'phase' in their life. This might include signposting or referral to other service providers.
4. Young carers projects need to develop short-focused preparation programmes for young carers in transition – this should include the issues most pertinent to them such as job/course search skills, grant applications for university, CVs, first aid, cooking, benefits, relationships, adult social care services etc.
5. Systems will need to be developed and put in place to monitor and evaluate interventions and outcomes, using robust measures, instruments and tools that enable comparison between interventions/services over time and place.
6. All agencies, but especially local authority services and carers services, should provide young carers and young adult carers with information about their legal rights, including the right to a carer's assessment from the local authority, which is a potential gateway to services and support for carers and their family.
7. Young carers projects in conjunction with adult carers and other services need to consider the best ways to provide 'seamless services' to young carers after they reach 18. Young carers projects need to build relationships and bridges with local adult carers services to help adult services recognise and become more engaged with the needs of young adult carers.
8. Universal services, such as schools and health care (including primary and secondary health care) have a role to play in supporting young carers and young adult carers alongside more specialist provision. Universal service providers need to be more alert to the specific needs of these carers and find ways to deliver their particular service to them.
9. Agencies that would not traditionally be associated with meeting the needs of carers also need to identify and engage with young adult carers. So, for example, colleges, universities, Job Centre Plus, employers, leisure services providers and others all need to be alert and sensitive to the needs and issues confronting this group of hidden carers and which affect their opportunities for further education and learning, leisure, careers and paid work.
10. Some young adult carers will be parents themselves and may need parenting support in this role at the same time as they need support because of their ongoing caring responsibilities to others.
11. The needs of young adult carers, and the outcomes that are required through service interventions, need to be integrated fully into every local authority's carer's strategy.
12. Adult carers services need to address the barriers that are inhibiting carers aged 18-24 from using their service and address their own lack of relevance to this group – as perceived by young adult carers themselves.

## 7.2 Relevant legislation

*The Carers (Recognition and Services) Act 1995* gives carers of any age – including young carers – the right to an assessment of their ‘ability to provide and to continue to provide care’. Social services are required (if so requested by a carer) to carry out this assessment of the carer at the same time as it assesses or reassesses the person for whom care is provided (the carers’ assessment is therefore linked to the cared-for persons’ assessment). The Act applies to carers who ‘provide a substantial amount of care on a regular basis’. Circular LAC (96) 7 (DH, 1996) states: “it is for local authorities to form their own judgement about what amounts to ‘regular’ and ‘substantial’ care”. Carers who do not provide substantial or regular care should also have their views and interests taken into account when an assessment is undertaken. ‘Care’ includes physical caring tasks as well as emotional care and general attendance to ensure the service user comes to no harm.

Under the 1995 Act, local authorities are legally obliged to take into account the results of this assessment when making decisions about any services to be provided for the person with care needs. However, the Act did not carry with it any additional resources for social care authorities in terms of implementation, or for meeting carers’ needs or for providing services directly to carers.

*The Carers and Disabled Children Act 2000* gives family carers over the age of 16 (and caring for someone over the age of 18) specific rights:

- Carers may request an assessment of their own needs, even if the person receiving care does not wish to have an assessment.
- Local authorities may provide services for carers in their own right.
- Carers may receive vouchers for short-term breaks.
- Carers may receive direct payments in lieu of services for which they have been assessed.

*The Practice Guidance to the Act* (DH, 2001) sets out to promote services and other provisions that are designed to sustain the caring relationship in a manner that is in the interests of all parties. Support for carers is essential to their own well-being and also to the well-being of the relative(s) they support. Carers should receive the support that they feel is most appropriate to their needs. In some cases, a cash payment in lieu of services (‘direct payments’) may be more appropriate so that carers can make their own arrangements and pay someone of their own choosing. Local authorities are able to charge for services that are provided directly to carers, subject to a test of means.

*The Children Act 1989*. Young carers under the age of 16 will need to access assessments and services through the 1995 Carers (Recognition and Services) Act or the Children Act 1989 (as ‘children in need’ under Section 17). Section 17(10) of the Children Act 1989 provides that a child shall be taken to be ‘in need’ if (a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority...; or (b) his health or development is likely to be significantly impaired, or further impaired, without the provision

for him of such services; or (c) he is disabled. The “reasonable standard of health or development” is not clearly defined. The Act provides local authorities with a power to assess children in need and specifies a range of support services that should be made available. Section 17(1) states that “It shall be the general duty of every local authority... (a) to safeguard and promote the welfare of children within their area who are in need; and (b) so far as is consistent with that duty, to promote the upbringing of such children by their families, by providing a range of services appropriate to those children’s needs”. Services that could be provided to young carers who are defined as ‘children in need’ could include advice, guidance, counselling, help in the home and other interventions designed to achieve the intentions of Section 17(1) (see also Dearden and Becker, 2001). Where there are concerns that a young carer has been or is likely to suffer ‘significant harm’ then the Act allows for the necessary enquiries and/or protective action to be taken. The Act does state that children are best cared for within their own family and that any intervention taken must be beneficial to the child and take account of his or her wishes.

*The Carers (Equal Opportunities) Act 2004* applies to adult and young carers. This Act made three main changes to the law with the objective of providing further support for carers and helping to ensure that they are not placed at a disadvantage because of the care they provide. First, the Act requires local authorities to inform carers, in certain circumstances, that they may be entitled to an assessment under the 1995 and 2000 Acts (see above). Second, when undertaking a carer’s assessment, the local authority must consider whether the carer works, undertakes any form of education, training or leisure activity, or wishes to do any of those things. Third, the Act provides for co-operation between local authorities and other bodies in relation to the planning and provision of services that are relevant to carers (HM Government, 2004, para 10). For further information on relevant legislation, guidance and policy for young carers see Aldridge and Becker (2003) and Frank and McLarnon (2008).

*The Children Act 2004* provides the legal underpinning for Every Child Matters: Change for Children – the Government programme aimed at improving children’s lives and integrating children’s services. The overall aim is to improve the five outcomes for all children (being healthy, stay safe, enjoy and achieve, make a positive contribution, achieve economic well-being) by encouraging partnerships through newly established Children’s Trusts. Children’s Trusts are local area partnership arrangements for bringing together key agencies, some of which have a duty to cooperate to safeguard and promote the welfare of children under the Children Act 2004, in order to deliver better integrated and more outcome-focused services for children, young people and their families. Effectively, Children’s Trusts were created to address the fragmentation of responsibilities for children’s services and build upon, bring together and formalise the joint work that was already taking place in many areas. Local authorities are also required, under Section 17 of the Act, to produce a single overarching strategic plan for all services affecting children and young people. The local authority

must consult widely in the plan and include children, young people and their parents, the voluntary sector, as well as the key partners within a Children's Trust. The needs and service responses for young carers should therefore be included in each local authority's plan.

### **7.3 Assessments**

Young carers and young adult carers will need a thorough assessment of their needs and of their ability to continue to provide care. When assessing young carers, however, it must be remembered that they are children and young people and their needs must be considered within a children's legislative and policy framework, not just under the law and policy that relates to adults and adult carers. Many young carers – especially those under the age of 16 – may need to be assessed as children in need under the Children Act 1989 (see section 7.2 above). It is important that professionals working with young carers know about the available specialist and universal services and resources that can help young carers locally and nationally; for example, whether there is a local young carers project, a young carers lead teacher in school (as recommended in guidance), online advice and information, health and other services.

The *Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000* makes it clear what the purpose of a carer's assessment is under the Carers and Disabled Children Act:

- To determine whether the carer is eligible for support.
- To determine the support needs of the carer (i.e. what will help the carer in their caring role and help them to maintain their own health and well-being).
- To see if those needs can be met by social or other services (DH, 2001, para 19).

It goes on to state that: "Great sensitivity on the part of the assessors may be required. It is important that the assessment process does not assume that the carer wants to continue to provide care, or should be expected to. Nor should it be assumed that the cared for person necessarily wants to continue to receive care from this carer..." (para 20).

While the term 'substantial and regular' care is not defined in any legislation, the *Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000* suggests that "the test that a practitioner should apply will relate to the impact of the caring role on the individual carer. In particular the practitioner will need to address the following questions: Is the caring role sustainable? How great is the risk of the caring role becoming unsustainable?" (DH, 2001, para 14).

The Guidance also states clearly that: "A carer's assessment should be focused on what the carer identifies as the best possible outcome. The best possible outcome will depend on the impact of caring on the particular carer. This impact is also the best test for 'regular and substantial' caring. While many carers may clearly be able to state from the beginning what it is they want to happen to make their lives easier,

others may take time to identify their own needs. . . . It is very important to make a clear distinction between 'outcomes' and services. . . . The best service to provide the outcome will depend on the individual circumstances'' (DH, 2001, paras 22-24).

The carers' assessment process is intended to determine the outcomes that carers want for themselves (and for the person they support) and the best ways in which these outcomes can be achieved through services or other forms of support. As part of the assessment of need and a carer's ability to continue to care, the social worker or other person undertaking the assessment will need to identify and draw up a carer's action plan. This will be the plan of services and interventions that are required to meet the carer's needs, to deliver the specified outcomes and to help the carer maintain their own health, well-being, social inclusion and ability to continue caring. This action plan should be agreed with the carer (as far as possible) and be communicated to the carer so that they have a record of what is proposed.

Unfortunately, evidence to date suggests that only a very small proportion of young carers and young adult carers have ever received such an assessment (Dearden and Becker, 2004a; Becker and Becker, 2008).

*The Common Assessment Framework* (CAF) was introduced as an element of the Every Child Matters programme for children and young people. Its key purpose is to shift the focus from dealing with the consequences of difficulties in children's lives to preventing circumstances from deteriorating in the first place. The CAF is intended to provide a straightforward process for a holistic assessment of a child's additional needs, taking account of the individual child, their family and community. The CAF is meant to be particularly suitable for use in universal services (health and education), as a means of identifying and tackling problems before they become serious. Young carers, just like any other child with additional needs, could receive a CAF from which additional services and support may flow.

# 8

## 8 Rural issues

As Eley (2003: 62) acknowledges, “The caring literature has not given the rural dimension the attention that it deserves”. Unfortunately, the Government’s new National Carers Strategy (HM Government, 2008) also has very little to say about carers in rural areas. Young carers and young adult carers in rural areas have the same inherent needs as carers living elsewhere. However, as with carers of any age, the “rural setting in which they live means they face extra barriers of physical and social isolation and lack of services” (Carers UK, 2003).

Carers UK (2003) have identified a number of additional problems for carers living in rural areas and these are as relevant to children and young people who are carers as they are to much older carers. In the sections below we develop the analysis of Carers UK (2003) and relate this to young carers and young adult carers in rural areas. For all these issues, poverty and social exclusion exacerbate the difficulties experienced by rural young carers/young adult carers and their families.

### 8.1 Lack of services

As Carers UK (2003) states, services in rural areas tend to cost more due to the distance needed to travel to and within these areas. Access to specialist services can also be severely restricted as they tend to be in the main town. For example, young carers and young adult carers living in rural areas who are from ethnic minority communities or who are caring for parents with severe mental health problems, HIV and AIDS or other ‘stigmatising’ conditions (such as substance misuse) can find few specialist services available to support them in their caring role or few services for the person with care needs (Aldridge and Becker, 2003; Becker and Becker, 2008; Evans and Becker, 2009). There may also be fewer facilities for short breaks for carers, and medical services may also be sparser than in urban areas. Rural carers will also rely on GPs making more home visits as distance to a hospital or surgery will often be much greater than in cities. Closure of community hospitals can generate particular difficulties for families. Additionally, there are fewer contact points for information and advice in rural areas, meaning that rural young carers and young adult carers’ access to information can be far more restricted and difficult. In the absence of good quality and reliable local services and sources of information and advice, rural young carers and young adult carers are likely to see no alternative to their ongoing caring commitments.

### 8.2 Distance and Transportation

There is evidence that often young people living in rural areas are excluded from accessing public services, further education, vocational training and jobs because of the lack of a useful or affordable public transport (Storey and Brannen, 2000). There is also evidence that young people in rural areas seem to experience a more extended transition to independent living than those in urban areas due to the structure and nature of rural housing provision. These factors will affect young

carers and young adult carers living in rural settings, further curtailing their opportunities and their move to independence where parents or relatives have high needs for support.

Becker and Becker (2008) found that young carers services in rural areas spent a high proportion of their budget on transportation (taxis, mini buses etc) – getting young carers to and from projects and transporting them to and from activities or travelling to see them at home. Developing mutual carers support (eg mentoring or befriending schemes) can also be difficult in remote rural areas, due to the distance between carers, the lack of transport and issues to do with privacy and confidentiality (see section 8.3). Additionally, many rural young carers and young adult carers report that they have to travel significant distances to accompany the person(s) they support to do the shopping, to medical appointments etc, and that the cost of using public transport and taxis can be prohibitive. Indeed, many bus services in rural areas are infrequent, and this means that those carers who do want to take the person they support out, or those who want to try to visit friends, find it difficult to do so when there may only be one or two buses a day in their area. Young carers and young adult carers in rural areas have said that getting funding for driving lessons, and/or helping them to purchase a car, would be of great assistance to their caring role, improve the quality of life for the whole family and increase their opportunities for choice, control and independence (Becker and Becker, 2008).

### **8.3 Isolation, companionship and privacy**

In small or 'close' rural areas maintaining the privacy of the young carer or young adult carer, and the person they support, can be difficult. Even making use of very local services (where they are available) can be problematic. Some young carers and young adults, especially those caring for parents with stigmatising conditions, may prefer to use services in nearby towns rather than in their own community to avoid 'everyone knowing their business'. Accessing carers' assessments (see section 7.3) can also be more difficult for many of the reasons outlined above. Additionally, where social workers are involved, the chances of keeping this 'private' can be more problematic in small communities.

### **8.4 Barriers facing service providers in rural areas**

Carers UK (2003) have identified a number of problems facing agencies serving rural carers and these are as relevant to services for young carers and young adult carers as they are to services for much older carers. These problems include: the high unit cost of providing services; the difficulties in consulting rural people; the fact that rural users and carers may be reluctant to ask for help (for reasons outlined in section 8.3); the lack of reliable data about the needs of people needing support and the young carers in rural areas; staff recruitment/retention problems; problems disseminating information; poor take up of services due to transport, privacy and other reasons mentioned above, including low income and poverty amongst many of these families (see also sections 6.1 and 6.6).

## 8.5 Ways forward

Carers UK (2003) have suggested a number of 'solutions' and examples of good practice for supporting carers in rural areas: carers in rural areas need help to maximise their income through mobile benefit/welfare rights advice sessions; they need better access to information – online and telephone helpline information can be helpful as can local directories of services; local carers' transport systems need to be developed which help carers with shopping, going to appointments etc; service providers need to get their services into local communities, especially those that are in remote areas and where transport and distance are particularly prohibitive; social care authorities, health and GPs need to work more closely (perhaps sharing premises) to minimise the distances travelled by carers and their families in rural areas; local schemes should be developed which provide a travelling handyperson and domestic support; there is a need for more volunteers/befrienders who can travel to, and help, carers and their families. These suggestions are as relevant to young carers and young adult carers as they are for the development of services and responses to older carers. Finally, there is a need to plan services and support for young carers and young adult carers which recognise first, the impact of rurality and second, that it will cost more to develop and provide equality of services for young/young adult carers in rural areas – the 'rural premium'.

# 9

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