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## **Young carers in the UK: research, policy and practice**

**Dr Saul Becker**

Director, Young Carers Research Group, Loughborough University

**Chris Dearden**

Research Fellow, Young Carers Research Group

**Jo Aldridge**

Research Associate, Young Carers Research Group

All correspondence about this article to:

Dr Saul Becker

Department of Social Sciences

Loughborough University LE11 3TU

Tel 01509 223352

Fax 01509 223944

Email [S.Becker@lboro.ac.uk](mailto:S.Becker@lboro.ac.uk)

*Abstract: There is now a considerable body of research which shows that when children undertake significant care work within the home, and where they and their families lack appropriate health and social care support and adequate income, then many children can experience a range of outcomes, including impaired well-being, health and psycho-social development, poor educational attendance and performance, restricted peer networks and friendships, and difficulties in making the smooth transition from childhood to adulthood. This article reviews the main research studies on young carers in the UK; examines the policies available to support young carers; and identifies the implications for future policy and practice, particularly in social care.*

## **Introduction**

Most children will care *about* and sometimes care *for* family members and significant others. This caring needs to be encouraged and nurtured if children are to value care-giving both during childhood and later in adult life. But what of those children who take on significant, substantial or regular caring tasks and responsibilities which have a negative impact or outcome for their own well-being and psycho-social development and transition from childhood to adulthood? It is this group of children - those who undertake significant unpaid care work within the home - which are the focus of this article. These children are generally referred to in the United Kingdom as 'young carers'.

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 which would usually be associated with an adult' (Becker, 2000, forthcoming). 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.

It is important to emphasise at the outset that not all children in families where there is illness or disability will become young carers. Indeed, in the majority of such families it will be rare for children to take on significant, substantial or regular caring responsibilities. In many families another adult may provide care, support or supervision - from within or outside the family unit. The family may receive

services and support from health, social services, the voluntary or private sectors (the so-called 'mixed economy of care') - working with families as part of the state's framework and provision for health, social and community care, or as part of the welfare infrastructure which exists to protect children and support families. Good quality, reliable, and affordable professional support, especially when combined with adequate family income, can help prevent many children from having to undertake significant care work within the home and can reduce the amount of care being provided by those already heavily involved in caring.

### **The growing awareness of 'young carers'**

Since the mid-1980s there has been an increased awareness in the UK of the existence of children and young people as carers. Early research sought to establish the extent of the 'problem' of caring among children (O'Neill, 1988; Page, 1988) and, while failing to indicate potential numbers of young carers did stimulate further research into the needs and experiences of such children. Small-scale qualitative studies, such as those by Bilsborrow (1992) and Aldridge and Becker (1993a) identified the experiences of young carers, often drawing on their own words. Aldridge and Becker (1994) also conducted the first study of parents with an illness or disability who were supported by their children. Other studies have sought to ascertain the experiences of, or effects on, children in families where a parent has 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).

As awareness of young carers' issues has grown and support for them has increased it has become easier to identify them in larger numbers and to conduct more detailed quantitative studies. By contacting specialist support services it has been possible for researchers to generate statistical information about larger numbers of young carers. In 1995 the first national survey was conducted (Dearden and Becker, 1995) and information was collated on 640 young carers supported by specialist projects. This survey was replicated in 1997 and generated data on more than 2,300 young carers, including information relating to social services' assessments of young carers (Dearden and Becker, 1998). These two national surveys are discussed in some detail later in this article.

Alongside the growing body of research into young caring has come increased professional awareness and support for young carers. In 1992 the first two pilot

projects to support young carers were established. By 1995 there were 37 such projects and by the end of the decade over 115 (Aldridge and Becker, 1998). The majority of specialist support projects are located within the voluntary sector but most receive some form of statutory funding.

The projects offer a range of services and are valued highly by young carers and their families alike, especially those families who resist professional assistance or are not entitled to it. Without the support of these projects a quarter of young carers and their families would have no outside support at all (Dearden and Becker, 1998). Research by the Department of Health (DH, 1996a, 1996b) has suggested that the services offered by young carers projects are also valued by health and social care professionals for their 'specialist' response to the needs of young carers and their families, as a way of locating appropriate access to statutory services and of raising the profile of young carers.

The Department of Health (SSI, 1995; DH 1996a, 1996b) issued guidance to all local authority social services departments regarding their duties to young carers, a move which was followed by the Department of Education. Other developments at the end of the 1990s, not least the National Carers Strategy (DH, 1999), helped put young carers firmly on the policy and professional agendas. The Carers Strategy outlines a number of government policy commitments to meet the needs of young carers in Britain. Internationally too, there is growing recognition of the contribution children make to caring, with a developing body of research in the USA, Australia and elsewhere, and policy initiatives and services being developed in a number of countries (Becker, Aldridge and Dearden, 1998).

### **The extent and nature of caring among children**

In the UK, almost three million children under the age of 16 (equivalent to 23 per cent 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' (Becker, Aldridge and Dearden, 1998, p. xii). It is impossible to calculate with any accuracy the proportion of these children who take on, or do not take on, significant caring responsibilities within the family. However, Office for National Statistics figures (Walker, 1996) indicate that there are between 19,000 to 51,000 children in Britain who take on 'substantial or regular care' and who would thus be classified as 'young carers' under a Carers Act definition based on the quantity of care provided and its regularity. The 'real' figure will be higher if the definition of a

young carer is constructed more broadly, to include the *significance* to the family of the care given, and the *impacts* of care work on children's well-being and psychosocial development. Because of the negative nature of these impacts and outcomes a number of organisations, including the Family Rights Group (1991), Children's Rights Development Unit (1994) and Social Services Inspectorate (1995) have argued that young carers should be considered as, and be responded to, as 'children in need' under the Children Act (see later for a discussion of this Act).

Many small-scale studies have provided a fairly uniform profile of the characteristics, experiences and needs of young carers. The findings of these studies have provided a picture of who young carers are, what they do in terms of care work, and the outcomes that caring has for their lives. The results of these small-scale studies have also been confirmed by the two national surveys of young carers mentioned above (Dearden and Becker, 1995, 1998). The later study, *Young Carers in the UK*, provides a profile of the characteristics, needs and experiences of 2,303 young carers aged 18 or under, all of whom are supported by specialist young carers projects.

The average age of young carers supported by projects in 1995 and 1998 remains the same, at just 12 years. Over half are from lone parent families and most are caring for ill or disabled mothers. In 1998, 86% of young carers were of compulsory school age; 57% were girls and 43% were boys; 14% were from minority ethnic communities.

Most young carers (63%) in 1998 were caring for someone with a physical illness or disability, followed by mental health problems (29% of young carers), learning difficulties (14%) and sensory impairments (4%). The proportions do not add up to 100% because one in ten young carers is caring for more than one person.

The nature of care work undertaken by children ranges along a continuum from basic domestic duties to very intimate personal care. Most (72%) young carers, like other children who are not carers, do some level of *domestic work* within the home. However, where young carers differ substantially from other children is in the extent and nature of the personal care work which they perform and in the significance and outcome of the adult-like responsibilities which they take on for other family members.

Over half of the young carers in 1998 were involved in *general care*, which includes organising and administering medication, injections, lifting and moving parents etc.

About 43% provided *emotional support and supervision*, particularly to parents with severe and enduring mental health problems. Almost a third took responsibility for other *household responsibilities*, including translating (where English was not the first language), dealing with professionals, the family's money management etc. One in five provided *intimate care* including toileting and bathing. A small proportion, about 7%, also took on *child care* responsibilities in addition to their caring roles for other family members (Figure 1).

**Figure 1. The percentage of young carers performing various forms of care work, 1995 and 1998**

	1995	1998
Domestic work	65%	72%
General care (giving medication, lifting etc.)	61%	57%
Emotional support & supervision	25%	43%
Intimate care (toileting, bathing etc.)	23%	21%
Child care to siblings	11%	7%
Other household responsibilities (translating, dealing with professionals, money management etc.)	10%	29%

Source: Dearden and Becker 1995, 1998

In many families children are involved in exactly the same types of care work as other (unpaid) adult carers.

### **Outcomes for children**

Small-scale studies and the two national surveys of young carers have produced very similar findings on the impacts of caring on children and the outcomes for their well-being and psycho-social development. Taken as a whole the research literature on young carers shows that these children are likely to experience:

- restricted opportunities for social networking and for developing peer friendships (Bilsborrow, 1992; Aldridge and Becker, 1993a, Dearden and Becker, 1995, 1998);
- limited opportunities for taking part in leisure and other activities (Aldridge and Becker, 1993a);
- health problems (Becker, Aldridge and Dearden, 1998);
- emotional difficulties (Elliott, 1992; Dearden and Becker, 1995, 1998);
- widespread educational problems (Marsden, 1995; Dearden and Becker, 1998; Crabtree and Warner, 1999) (Figure 2);
- limited horizons and aspirations for the future (Aldridge and Becker, 1993a, 1994);
- 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; Imrie and Coombes, 1995);
- a lack of understanding from peers about young carers' lives and circumstances (Aldridge and Becker, 1993a, 1994; Dearden and Becker, 1998);
- a fear of what professionals might do to the family if their circumstances are known (Aldridge and Becker, 1993a, 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, 1993b);
- significant difficulties in making a successful transition from childhood to adulthood (Frank, Tatum and Tucker, 1999; Dearden and Becker, 2000).

**Figure 2. The proportion of young carers of school age experiencing educational difficulties or missing school, 1995 and 1998**

Age group	1995	1998
5-10	20%	17%
11-15	42%	35%
All 5-15	33%	28%

Source: Dearden and Becker 1995, 1998

Since 1995 there have been some small improvements in the overall position of young carers in the UK. For example, fewer are providing personal intimate care such as bathing, showering and toileting - the type of care work found most unacceptable by both parents and their children (Aldridge and Becker, 1993a); and fewer young carers are missing school or experiencing educational difficulties. However, these improvements are slight. The incidence of intimate care has reduced

by only two per cent (from 23% of all young carers in 1995 to 21% in 1998), while the overall incidence of educational difficulties has fallen by just five per cent (from 33% of all young carers in 1995 to 28% in 1998). This is in spite of a Department of Health national initiative during 1996-97 to raise awareness of young carers (DH, 1996a, 1996b).

In their study *Growing Up Caring*, Dearden and Becker (2000) investigated the ways in which care work influenced sixty young carers' transitions into adulthood. They show that children and young people who adopt significant caring responsibilities can be affected not only during their childhood, but also as they make the transition from childhood to adulthood.

Dearden and Becker concluded that a range of factors determines the quality and outcome of young carers' transitions to adulthood. While the nature of parental illness or disability, and family structure are important and inter-related influences, they only provide a partial explanation for young carers' experiences of vulnerability and transition. Other factors, external to families, have the major influence. The receipt, quality and timing of professional services and support, and the level and adequacy of family income, are critical. These interact with familial factors in complex ways, and in each family the various influences are likely to have different importance. Nonetheless, the authors conclude that it is the absence of family-focused, positive and supportive interventions by professionals, often combined with inadequate income, which cause the negative outcomes associated with caring by children and young people. The main factors that influence young people's caring experiences and transitions to adulthood are thus: service receipt, family income, the nature of parental illness or disability and family structure. In the next section we consider the legislation available to help meet young carers' needs for support and services.

## **Legislation which supports children who are also carers**

### ***The Children Act***

The 1989 Children Act proposes that children are best cared for within their own families and that intervention should only occur when necessary to safeguard the child's welfare. The emphasis is on 'parental responsibility', the combination of rights, powers, duties and responsibilities which parents have. The Act also stresses the 'welfare principle' which makes the child's welfare paramount. This principle

would be applied in any court proceedings. Furthermore, courts must listen to the wishes of the child subject to their age and understanding.

Section 17 of the Children Act (1989) states that local authorities have a duty to 'safeguard and promote the welfare of children within their area who are in need; and so far as is consistent with that duty, to promote the upbringing of such children by their families'. A child is defined as being in need if:

- (a) she/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 her/him of services by a local authority;
- (b) her/his health or development is likely to be significantly impaired, or further impaired, without the provision for her/him of such services; or
- (c) she/he is disabled.

While the Act does not specify what constitutes a 'reasonable' standard of health or development, there is some debate as to whether young carers should be considered as children in need of services and as children who may not have an equal opportunity of achieving a reasonable standard of health in relation to non-caring children. As we have already seen, the research evidence shows that many young carers are vulnerable to a range of health-related and developmental difficulties and experience a series of negative outcomes.

Many local authorities use predetermined groups to establish the numbers of children in need in their areas. These predetermined groups include children with disabilities, children from homeless families, children in low income families, children in lone parent families and children of unemployed parents. Few define young carers as a predetermined group of children in need, although this may change in the future as more authorities become aware of the needs and rights of young carers. Being defined as a child in need means that social services are able to provide a range of services and interventions, including advice, guidance and counselling; activities; home help (including laundry services); assistance with travelling to use a service provided under the Act; and assistance to enable the child or her/his family to have a holiday. These, and small amounts of cash, can be provided to the family of a child in need, rather than specifically to the child, if it will benefit the child.

### *Young Carers and the Carers Act*

Young carers may be assessed as children in need under the Children Act if they meet their local authority criteria, but their needs as *carers* may be overlooked. While the NHS and Community Care Act offers carers the opportunity to request an assessment of their needs, the Act is intended specifically for adults; young carers were not considered when the Act was drawn up. As a consequence, young carers have been unable to access this legislation but have been referred instead to social services children's sections for assessment of their needs under the Children Act. The Carers Act 1995 has closed this loophole, since it applies to all carers, regardless of age. For the first time, the needs of young carers as carers can be assessed.

The Carers Act is concerned with carers of any age who are providing, or intend to provide, a substantial amount of care on a regular basis and entitles them to an assessment of their needs when the person for whom they care is being assessed or re-assessed for community care services. The result of a carer's assessment must be taken into account when decisions about services to the user are made. The *Practice Guide* to the Act recognises that 'denial of proper educational and social opportunities may have harmful consequences on [young carers'] ability to achieve independent adult life'. Consequently, 'the provision of community care services should ensure that young carers are not expected to carry inappropriate levels of caring responsibilities' (DH, 1996c, pp. 10-11).

However, while the Act imposes a duty on local authorities to recognise and assess young carers' needs it does not oblige departments to provide any services to them. Thus, the needs of young carers may continue to be neglected, even where they are acknowledged, because of an overarching concern with budgets and the management of limited resources. Another limitation of the Carers Act is that it requires carers to request assessment, which necessitates a knowledge of their rights and entitlements.

However, the major benefits of the Act, as it relates to young carers, are in the way it gives formal recognition to this group of children and provides for an assessment of their needs as carers. Moreover, the Act allows for a wider interpretation of the definition of a 'young carer'. While the Carers Act refers to carers as people who provide a 'substantial amount of care on a regular basis' the term 'substantial' is not defined. The *Practice Guide* clarifies the definition of a young carer and acknowledges for the first time that young carers should not be defined solely by reference to the amount of time they spend caring. The guidelines state: 'there may

be some young carers who do not provide substantial and regular care but their development is impaired as a result of their caring responsibilities' (DH, 1996c, p. 11).

The needs of young carers identified under this piece of legislation will be met under local authorities' duties under section 17 of the Children Act, i.e. they will be treated as children in need. This will also be the case for those young carers who do not provide a 'substantial' amount of care but who are considered, nevertheless, to be in need of services which will promote their health and development. Thus, young carers - those who provide a substantial amount of care or those who provide less care but whose health or development is nonetheless impaired as a result of their caring responsibilities - can be defined as children in need and can expect support and assistance via the Children Act, even in the absence of resources available to deliver services under the Carers Act.

### *Assessments*

Although young carers have rights under the Children Act and Carers Act, very few have ever been assessed by social services. Of the 2,303 young carers surveyed by Dearden and Becker (1998) only 249 had received any form of assessment of their needs under the Children Act or Carers Act. These figures are particularly low considering that all of these young carers are supported by specialist projects and therefore have someone to act on their behalf (should they require it) to request an assessment of their needs. They are also low considering that one in five young carers still perform intimate caring tasks and almost a third have educational difficulties. The process of assessment by social services of young carers was found to be variable, ranging from very poor to excellent. The majority of assessed young carers were unaware that they had been assessed by social services even after the event, and few had been actively involved in the process.

While the process of assessment is variable, the outcomes tend to be positive. Of those young people assessed, services were either introduced or increased following assessment and most children and families were satisfied with these outcomes. It is the availability of such external support services which has a key influence on what young carers have to do within the family, and why.

## **The needs of ill or disabled parents**

While awareness, research and policy relating to young carers have developed there has been little development in policy or practice regarding disabled parents. This skewed development has meant that while support for young carers has increased, some local authorities feel that the 'problem' has been solved and have done little to support ill and disabled parents in their parenting roles. This has led some commentators to suggest that highlighting the experiences of young carers serves to undermine disabled parents (Keith and Morris, 1995), and that providing services to young carers deflects attention and scarce resources away from their disabled parents (Parker and Olsen, 1995). There has also been some confusion in support for young carers, resulting in a lack of clarity about what specialist support services should be providing or doing. Some of the better organised and managed young carers projects assist whole families in accessing the support services to which they are entitled, and try to ameliorate some of the more negative outcomes associated with young caring in families which do not have adequate support or services. However, others have concentrated on giving children a 'good time', providing leisure activities for young carers while doing little to support whole families and to prevent these negative outcomes (Dearden and Becker, 2000).

The government's 'Quality Protects' initiative is intended to ensure that the children of parents with disability or specific health needs enjoy the same life chances as other children (DH, 1998). However, this is unlikely to happen unless disabled adults are supported as parents. Current policy and practice initiatives are failing to *prevent* young caring from starting in the first place.

Where young caring has become established, young carers can, as we have seen, be classed as children in need, as defined by section 17 of the Children Act 1989. However, few young carers receive assessments under the Children Act and of those who do, we have no way currently of knowing whether they are assessed as children in need or children at risk (DH, 1996a, 1996b). Recent policy has improved the assessment procedure for children in need to incorporate three domains: the child's developmental needs, parenting capacity and family and environmental factors (DH, 2000a, 2000b). Future assessments of children should therefore take into account the needs of young carers, the needs and capacities of their disabled parents and environmental factors such as poverty, housing etc. This should, in due course, result in better assessments of existing young carers and support for the wider family.

## **Some issues for future policy and practice**

How can many of the negative outcomes identified above be tackled and reduced, for the benefit of young carers now and in the future? There are a number of ways forward which need to be addressed by policy makers and professionals in health and social care, education, employment, social security and elsewhere. Here though we focus on those related to social care.

First, the definition of a young carer needs to be broad and inclusive, but also as precise as we can make it. There has been considerable confusion in policy and professional circles, and also in the literature, about what constitutes a young carer. There is a compelling case that a definition should not just be based on the *amount* of care work provided by children but should also relate to the *significance* of that care to individual families, and to the *impacts* of care work on children themselves. Definitions are important. To be defined as a young carer opens the door to a set of specific rights, not least the right to a detailed assessment of need, which itself is the gateway to access services and support under children's or carers' legislation.

Second, awareness-raising and training on young carers' issues needs to be widespread and on-going. Professionals need to recognise and understand that their involvement and their positive interventions with families and children can make all the difference to the well-being of all family members and can prevent children from having to take on care work in the first place. Professionals also need to ensure that young carers and their families are aware of, and understand, their rights to assessments under the various pieces of legislation and their rights to services and support. Currently few young carers are being assessed under any Act. Where children have been assessed and have received services or support this is usually beneficial and reduces their own involvement in care work. In some cases it will prevent children taking on care work in the first place.

Third, assessment processes will need to be viewed by families as a positive step. Disabled parents must feel that their needs and rights will be taken into account and promoted, and that their parenting abilities will not be questioned. 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.

Fourth, many families receive no or inadequate social care services. This results in children and young people undertaking inappropriate care work. Even where services are provided they are sometimes seen as inappropriate, intrusive or too costly. Service providers need to examine the level and types of services available and also the point at which these are offered. Early interventions may prevent inappropriate roles from becoming established.

Fifth, services that support disabled adults in their parenting role are rare. While most local authorities now acknowledge the existence of young carers and mention them in community care or children and families service plans, the needs of disabled parents are rarely *specifically* mentioned or responded to.

Sixth, social services, health, education and the voluntary sector all have a responsibility to prevent young caring from occurring by early recognition and positive interventions which focus on the needs of the whole family. If interventions are instigated early and are positive and supportive, then young caring should not become institutionalised within families nor be condoned by professionals.

Seventh, while support of the whole family should be seen as a priority, rather than a focus on parents or children in isolation, young carers projects do offer a highly focused way of recognising, valuing and responding to the specific needs of children who undertake care work. However, there is scope for young carers projects to take a more active role in supporting whole families. Moreover, young carers projects should operate alongside and complement support services for ill and disabled people. The existence of such projects should not detract statutory organisations from their duties to arrange or provide services to ill or disabled people and to children in need as laid down by law.

Eighth, social services, health, education and other organisations, agencies and professionals need to consider the best way of working together, to deliver a seamless package of support to adults and children within families where there is illness, disability, drug or alcohol misuse, mental health problems etc. There is also a need for national standards for the quality and quantity of health and social care support to young carers and their families. There is currently no uniformity across regional boundaries in what families can expect in the way of help and support. Families should receive help that is based on their needs, rather than where they live.

Ninth, each family must be considered and treated as unique, with its own strengths, weaknesses and needs. Professionals must acknowledge, value and respect the reciprocal and interdependent nature of caring 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 minority ethnic communities whilst acknowledging the rights of children to a secure and healthy childhood.

Tenth, children and young people have rights and some may choose to become carers for their parents. In such cases they should have the right to services and benefits which will assist them in their role as carers. Children and young people should not, however, feel obliged to care because of a lack of alternatives.

Young carers need security in childhood and independence in adulthood. They need to be able to make the best of their own lives, their childhood, and the educational and other opportunities available to young people in a modern society. To secure these, the emphasis in policy and practice should be on preventing children from taking on inappropriate care work in the first place, and stopping these roles from becoming institutionalised where and when they have already begun. Policies and services which identify and respond to the needs of all family members, but in particular those which support ill or disabled parents to enable them to prevent inappropriate caring roles from developing, will offer the best way forward. But what of those children already heavily engaged in care work? Here policy and practice should try to ensure that these children have the opportunities for a healthy and happy childhood, and that their own well-being and future as adults is not compromised by their care work and family responsibilities.

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