

**Typescript version of a chapter which was published as follows:**

Becker, S., Dearden, C. and Aldridge, J. (2001) 'Children's labour of love? Young carers and care work', in Mizen, P., Pole, C. and Bolton, A. (eds) *Hidden Hands: International Perspectives on Children's Work and Labour*, Falmer Press, Brighton, pp. 70-87.

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**Phil Mizen, Chris Pole and Angela Bolton (editors)**  
*Hidden Hands: International Perspectives on Children's Work and Labour*,  
Falmer Press, 2001

## **Children's labour of love? Young carers and care work**

by

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## 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. Indeed, *learning* to care, and *showing* and *providing* care, are part of a child's socialisation and are a prerequisite for healthy psycho-social development.

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, their psycho-social development and their transition from childhood to adulthood? It is this group of children - those who undertake significant unpaid care work within the home - who are the focus of this chapter. 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, p. 378). 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.

Young carers provide similar levels of support to adult carers but their experiences differ because those under the age of 18 are legally defined as children and, as such, are not expected to take on significant or substantial caring roles. However, community care policy and legislation in the UK assume that family members will provide, unpaid, the bulk of care in the community with the state stepping in to fill the gaps (Griffiths, 1998; Department of Health, 1989). In some families this results in children and young people adopting caring roles, often, although not exclusively, in the absence of another adult in the home. While adult carers can be seen to be conforming to societal norms in supporting family members, when children act as carers they transgress such norms. In theory at least, childhood is viewed as a protected phase, with adults, and the state, supporting and protecting children and young people until they make the transition into adulthood.

There is now a considerable body of research in the UK, but also developing internationally (Becker, Aldridge and Dearden, 1998), 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 young carers experience impaired well-being, health and psycho-social development, including physical injury, stress-related symptoms, poor educational attendance and performance, restricted peer networks, restricted friendships and opportunities, and difficulties in making the smooth transition from childhood to adulthood. This chapter reviews the main research studies on young carers in the UK and identifies the implications of children's unpaid care work for future policy and practice.

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 labours of those already heavily involved in this type of work.

### **Children's unpaid care work**

Can we consider the caring tasks and responsibilities performed by young carers to be *work*? Let us answer this in a number of stages.

There are approximately one million people in England paid to work full or part-time to provide social care - as many as the number employed in the NHS. Of these, about a quarter work in local authority social services departments while the remainder are employed in the private (for profit) sector and voluntary sector. Those who provide home-based care (from all sectors) total about 170,000 people (compared with about 450,000 who work in residential or day care services for adults) (Becker, 2001 forthcoming). Home care services staff are the people who go into the homes of ill, elderly, disabled and other vulnerable adult groups, generally to provide domestic or personal care support - in other words, they are paid care workers. The vast majority of these staff (as well as the majority of all staff who work in social care) are unqualified. Most are women. And most are poorly paid.

An example of a home care worker is a Community Care Assistant. Scanning the job adverts in the social work press and especially local and regional newspapers will show that there are almost always vacancies for this kind of care work. A typical job description for a Community Care Assistant (to be employed in a social services department) goes like this:

**'Nottinghamshire County Council. Community Care Assistants (25 Posts). 20-25 Band £5.11 per hour.**

Are you a caring, reliable and flexible person? ... Community Care Assistants provide services to vulnerable people in their own homes which is a challenging but rewarding career and staff are supported through NVQs and other training by the Department's Investors in People programme. Community Care Assistants provide personal care and domestic support services to people of all ages, including families with children, and from different backgrounds and cultures and therefore an understanding of Equal Opportunities is required. Although staff work usually on a one to one basis with service users in their own homes they are supported and managed by a Senior Community Care Assistant and Home Care Manager.' (*Nottingham Evening Post*, 15 March 2000, p. 43).

Another advert states the kind of hours expected:

**'Nottingham City Council. Community Care Assistants SCP 8 £5.12 per hour.**

... You will be responsible for providing a high standard of personal care and domestic support for people of all ages, disabilities and from all sections of our multicultural community, in order to maximise service users' independence within their own homes. We expect that you will have a flexible approach to the post and will be prepared to work weekends and bank holidays on a rota basis. In addition you may be required to work occasionally in the evenings. You will be expected to participate in training opportunities relevant to the post.' (*Nottingham Evening Post*, 15 March 2000, p. 39).

These posts are for Community Care Assistants to work within two local social services departments. Staff employed to similar job descriptions within the private and voluntary sectors can usually expect poorer employment conditions, and even lower wages, with few if any opportunities for training and personal development.

As Clough argues, 'looking after other people has always been badly rewarded'. He suggests three reasons for this. First, 'such work is not thought to require skills; surely it's only what people do within their own families? Second, it is the work of women: it requires instinctive, feminine characteristics. Third, we cannot afford to pay more' (Clough, 2000, p. 71).

As we shall see later, many children perform exactly the same kinds of care work required of Community Care Assistants. The difference though is that children do this work most often with little choice or alternative; their labour and commitment is rarely recognised by professionals; they have no supervision; no opportunities for training and personal development; no specified hours or terms of employment; and they are unpaid. They do care work as 'a labour of love'.

Children are not the only people who perform this labour of love. There is an extensive literature on adults who care for other family members - informal carers - and there is comprehensive data on their characteristics. This literature is more developed in the UK than elsewhere, although there is now a growing international recognition of the role and importance of informal carers (Becker, 1997, 1999). Today, nearly six million adults in Britain provide unpaid care to other family members, that is 13% of all people aged 16 or over (Office for National Statistics, 1998). About a quarter of adult carers provide more than 20 hours of unpaid care per week, with around 800,000 people providing full-time care of at least 50 hours a week. Research has highlighted the experiences and needs of adult carers, including the effects, impacts and outcomes of caring (Glendinning, 1992; Becker and Silburn, 1999). Moreover, there is a developed literature on the gendered dimension of caring: 'in most societies at most times, the sexual division of labour has given responsibility for the care of people who are frail or vulnerable to women - within families and on the basis of love or duty' (Baldwin and Twigg, 1991, p. 117). Thus, of those caring for at least 20 hours per week, 63% are women (OPCS, 1992).

Feminist analysis of paid care work in general and informal care in particular has helped raise awareness of the sexual division of care labour. However, the literature that grew out of and which contributed to this analysis rarely if ever recognised the other power dimension around the division of unpaid care work within the family, namely the children's dimension. So, research, policy and practice throughout the 1970s and most of the 1980s failed to identify, acknowledge and respond to the 'fact'

that in many families unpaid care work was provided not by adults but by children and young people.

It would be inconceivable to employ children as Community Care Assistants or other care workers - there would be a public outcry as well as all the other ramifications. However, within the 'private' domain of the family children do provide unpaid care work - but their labour is not defined as work. Because unpaid informal care is a 'private' family matter, governed by its own relationships and rules, it is referred to in the UK as 'caring' and in the USA as 'care-giving', not care work. While this language has helped to distinguish the informal unpaid carer from the paid care worker, it has simultaneously helped to obscure and hide children's contribution to both caring *and* care work.

### **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, although even today there is little recognition that the care they provide is actually unpaid care work. Research, by focusing on the characteristics and experiences of young carers (as a group of children who are also carers) has given little attention to the significance, the social meanings, and outcomes, of children's unpaid care work. This chapter is an attempt to redress this imbalance.

Early research in Britain 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 Bilborrow (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 chapter.

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).

Young carers projects offer a range of services based on the identified needs of the children themselves. Most provide information and avenues for accessing other forms of support as well as counselling, advocacy and befriending services. Providing leisure activities for young carers is also a priority for most of the projects and is valued highly by the children themselves. Activities allow young carers some respite from caring and the opportunity for fun 'time-out' as well as the chance to meet and mix with other children in a similar situation. This also gives parents 'time off' from their children - an opportunity to have some privacy and time away from worrying about or having to deal with their children's needs.

Aside from service provision young carers projects are also involved in awareness-raising strategies in order to ensure the needs and rights of young carers are identified and met both within statutory and voluntary agencies. Projects are also keen to work in collaboration with, or advise other agencies in order to meet these needs and some aim to influence local policy and practice. Young carers projects are increasingly located within carers' centres or other carer support groups.

Research by the Department of Health (DH, 1996a, 1996b) has suggested that the services offered by young carers projects are also equally 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 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 children's care work within the family**

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'. In Europe as a whole, nearly a quarter of all children (16 million in total) live in households of this type (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 and 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 psycho-social 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 responded to and considered as 'children in need' under the Children Act (see later for a discussion of this Act).

Figure 1 illustrates the extent of care work among children. Within the children's population as a whole the number of young carers is relatively small (but no less important for that). By way of comparison with other groups of children defined as 'in need', there are more children in Britain providing substantial or regular care than there are children on the Child Protection Register (32,000), but less than the number of children 'looked after' in fostering or residential units (78,000) (DH, 2000a).

**[Figure 1 near here]**

**Figure 1. Representation of the extent of young caring**

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 2).

**Figure 2. 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	10%	29%

(translating, dealing with professionals, money management etc.)		
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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. But most young carers are also undertaking the same kinds of care work that other adults from outside the family (such as Community Care Assistants) are being paid for. Where children are concerned, this care work leads often to negative consequences, as we shall see in the next section.

### The outcomes for children of undertaking care work

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);
- poverty and social exclusion (Dearden and Becker, 2000);
- 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 3);
- 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 3. 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, 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).

### **Young carers' transitions to adulthood**

While we are now more aware of how care work affects young people still classified and (in theory) protected as *children*, we have until recently had little knowledge of whether providing significant or substantial care work influences young people's transitions into *adulthood*.

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.

Young carers' transitions to adulthood can be influenced and affected in a variety of ways. While parental illness or disability can occasionally *directly* influence their children's transitions, it is usually an indirect influence. The most obvious direct influence is parent-child separation. This can happen as a result of parental death, hospitalisation or local authority care proceedings. Sometimes young people feel they can no longer remain with their parents *because* of their illness – this is usually where a parent has mental health problems.

The indirect influences and effects are many and varied, sometimes positive, more usually negative. A large proportion of the young carers had missed school and gained no or minimal educational qualifications. This affected their transition from school into further/higher education and the labour market. Missing school was often linked to an absence of or inadequate service provision to ill or disabled parents, resulting in them often being left alone for long periods or having little support at times when help is most needed. Young people were sometimes reluctant to leave ill parents alone because they feared the consequences.

Almost all of the young carers lived in families that were in receipt of welfare benefits. Many were living in poverty. None of the parents with illness or disability were in employment. Even previously affluent families may become poor if they rely on benefits for a prolonged period of time. Half of the young carers lived with lone parents. The combination of lone parenthood and illness or disability makes entire families vulnerable to poverty and social exclusion. The absence of a second adult in the home also resulted in children and young people within families taking on additional care responsibilities. Where that lone parent had health problems, these responsibilities included the provision of care work and support. Charging policies for social care services served to exacerbate poverty and resulted in some

families cancelling services which were deemed too expensive or which were seen as poor value for money.

The emphasis on continuing education coupled with the lack of jobs for young people often exacerbated poverty. For those young people with caring responsibilities part-time work became difficult, sometimes impossible.

Care work can be stressful, particularly for young people living with parents who experience pain, mental distress, or who have a terminal or life threatening illness. In a few cases stress and depression were severe enough to lead to physical and psychological ill health for the child.

Helping to care for and support parents with ill health sometimes results in maturity, self-reliance, independence and responsibility. The young people in Dearden and Becker's study exhibited a range of skills and competencies that aided transitions into adulthood. Many viewed the acquisition of these qualities and skills in a positive way. However, at the same time, many young carers were denied educational and employment opportunities because of their caring circumstances – a 'Catch 22' situation. The skills and competencies that they acquired therefore had opportunity costs, and providing care and support to family members in the absence of professional, external, acceptable support services cannot be considered as an acceptable way for young people to acquire these skills.

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.

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.

### *The assessment of young carers*

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.

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 ill or 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.

### **Childhood and care work: issues for policy and practice**

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

The key issue here is that for healthy psycho-social development and transition to adulthood children should *gradually* increase their responsibilities within, and outside, the home. Being responsible from an early age for care work, especially intimate and personal care - those labours which would usually be associated with (paid) adult work - can seriously compromise a child's well-being and development and can lead to a number of negative outcomes, not least impairment in their transition to adulthood.

How can these negative outcomes 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.

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 inadequate or no 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, 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).

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. Additionally, the social security system does not recognise the particular needs of ill or disabled parents who have adolescent children. Assumptions are made regarding family/parental responsibilities to support their children for increasingly longer periods of time. Poverty, illness, lone parenthood and lack of support may make this difficult.

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 entrenched 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 the family as a whole. 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, young people with caring responsibilities experience educational difficulties and disadvantages. Schools can compound these by failing to recognise the specific educational, social and developmental needs of young carers. Where children and young people do miss school, there needs to be a better, more even balance between punitive interventions (such as threats of court action) and collusion (by condoning unauthorised absences).

Ninth, health, social services, education and other organisations, agencies and professionals need to consider the best way of working together, to deliver a seamless package of 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.

Tenth, employment and education policies in particular need to be better co-ordinated to recognise the specific needs of young carers and the 'Catch 22' situations that many of them face. In some families caring might make financial sense in the absence of grants and awards; the skills and competencies young carers develop (which some identified as important for transitions) go largely unrecognised and unrewarded in the labour market; access to education and paid work is impaired as a result of caring.

Eleventh, 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.

Twelfth, 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. This challenges us all to think critically about how services to ill and disabled parents, and to existing young carers, should be structured, what they should do, and how they should fit together. Such a re-think would mean fundamental change to the existing structures for young carers' services, and the emergence of new and empowering services for ill and disabled parents. It would also require a re-appraisal of what we mean and understand by terms such as 'caring' and 'care work'. To date, children's caring responsibilities within the home, by being defined as 'caring', have hidden its importance and significance as care work. But to define these caring responsibilities as work poses major challenges to how we understand, and then respond to, children's unpaid labour of love.

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