

CARERS UK

Young Carers and Education

by Chris Dearden & Saul Becker, Loughborough University

Contents

Section 1

Young carers - an introduction	1
Defining young carers	1
The extent of young caring in the UK	1
Why do some young people become carers?	1
What do young carers do?	3
Summary of key points in Section 1	3

Section 2

What research tells us about young carers' educational experiences	4
Why do some young carers experience educational difficulties?	6
Cause and effect	6
Concentration/anxiety	6
Absence/poor attainment	6
Bullying	7
Longer term consequences?	7
Summary of key points in Section 2	8

Section 3

Using education and related policies to support young carers	9
Connexions	10
Inclusion policies	11
PHSE	11
Education welfare services	12
Sure Start	12
Mentoring	12
Education maintenance allowances	12
Moving forward	13
Identifying and supporting young carers in school	13
Examples of good practice	14
Summary of key points in Section 3	15
Resource 1: References	16
Resource 2: Selected reading and useful addresses	17
Resource 3: Legislation and policy	18

Boxes and tables

Box 1 The incidence of illness/disability and young caring	2
Tab 1 Percentage of young carers performing caring tasks	3
Tab 2 Key educational difficulties identified through research on young carers	5
Tab 3 Proportion of school age children experiencing educational difficulties 1995 & 1997	6

Published in 2002 by Carers UK - 20/25 Glasshouse Yard, London, EC1A 4JT

Copyright Carers UK 2002

All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system without permission in writing from the publishers.

SECTION 1

Young caring: an introduction

It is only during the past fifteen years that young caring has gradually become recognised and accepted as a social issue. Early studies of the phenomenon attempted to establish the extent of the 'problem' (see for example O'Neill, 1988; Page, 1988) and, while failing in this aim, acted as a catalyst to further research. Throughout the 1990s and beyond research has enabled us to learn more about young caring, why it happens, what young carers do and some of the actual and potential outcomes of caring with limited support. This research has also helped to raise the profile of the needs and rights of parents with physical or mental impairments.

Defining young carers

Many researchers and organisations have attempted to offer a working definition of young carers. For example, The Blackwell Encyclopaedia of Social Work defines 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 which 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).

Other common definitions include:

A young carer is anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of a person who is ill, has a disability, is experiencing mental distress, is affected by substance use (Carers National Association, 1998).

A child or young person who is carrying out significant caring tasks and assuming a level of responsibility for another person, which would usually be taken by an adult

(Chief Inspector of Social Services, quoted in Walker, 1996).

While the Carers Act defines all carers as those who are:

Providing, or intending to provide a substantial amount of care on a regular basis (The Carers Act, 1995).

Common factors in all definitions of young carers are that they are children, i.e. under the age of 18 and therefore considered to be the dependants of adults; that they undertake *significant* caring tasks, i.e. tasks that are important; and that these tasks would usually be associated with and performed by adults. Thus, young carers are not children who happen to have an ill or disabled parent, sibling, grandparent or other relative, but are children who provide a significant, often inappropriate (for their age), level of care to that relative. Most children with disabled relatives will not be young carers because their families will have adequate support services from private, statutory and voluntary agencies and from other informal sources such as wider family members and friends.

The extent of young caring in the UK

While there are no exact figures on the number of young carers nationally, some data do exist that give us an idea of the extent of the issue. Box one contains some of the findings from research. So, for example, official statistics (Walker, 1996) suggest that up to 51,000 children in Britain may be providing substantial and regular care to another family member. NSPCC data (Cawson, *et al.*, 2000; Cawson, 2002) suggest that four per cent of all 18-24 year olds will have regularly cared for an ill or disabled relative during their own childhood. This would mean that there is a four per cent likelihood that young people aged 18-24 will have been young carers.

Why do some young people become carers?

There are many factors that influence whether children become carers, but the most significant is the availability and effectiveness of health and social care support for their ill or disabled relative. Where support services and family income are adequate children will not

Box 1 The incidence of illness/disability and young caring

Source: Aldridge and Becker, 2003

Findings (%)	Numbers involved	Source
23% of children aged under 16 live in families with one family member 'hampered in daily activities by any chronic physical or mental health problem, illness or disability'	Approximately 3 million children under 16 live in families with illness/disability in the UK. Most will not be young carers	Eurostat, 1997 (Becker et al, 1998)
Between 0.27% and 0.72% of all 8-17 year olds will be young carers	19,000 - 51,000 young carers (aged 8-17) in Britain	Office for National Statistics (Walker, 1996)
4% of all 18-24 year olds will have regularly cared for an ill or disabled relative during their own childhood	173,040 young people aged 18-24	NSPCC (Cawson et al, 2000; Cawson, 2002)
17% of carers aged 16-35 had caring responsibilities before their 16th birthday	212,000 adult carers (aged 16-35) cared during their own childhood	1985 General Household Survey (Parker, 1994)
1% of all family carers in Scotland are young carers	6,000 young carers aged under 16 in Scotland	The Scottish Executive (2001)

usually adopt a caring role. However, many families lack the necessary resources - financial and practical - to enable disabled or ill people to remain independent and to prevent children from caring. Other important factors are the nature of the illness/disability of the relative, family structure, the number of children 'available' to care, their ages and their gender.

The nature of the illness/disability of family members requiring support dictates, to a large extent, the type and level of care provided by children. Thus, family members with a physical disability or chronic illness are more likely to need practical, physical support, sometimes including personal, intimate care (see below for the types of care provided by children). Those with mental health problems may also require practical assistance but are much more likely to need emotional support and encouragement (Dearden and Becker, 1998; Aldridge and Becker, 2003).

Family structure is very important in influencing whether children become carers

and the extent to which they are involved in care provision. Research suggests that most young carers live in lone parent families where there is only one adult, usually (although not always) a mother (Dearden and Becker, 1998). If a lone parent becomes ill and requires support there is no adult partner and caring often falls by default to children within the family. This does not mean, however, that in two parent families children do not become carers. In some cases the other adult in the home will continue in paid employment to provide the family with an income and in other families an adult will choose not to become a carer. In a survey of 2303 young carers, 54 per cent were living in lone parent families. Overall the majority (58 per cent) of all care recipients were mothers and this was more marked in lone parent families where 76 per cent were mothers (Dearden and Becker, 1998).

In families where there is more than one child, care may be shared or one particular child may become the carer. Aldridge and Becker (1993) suggest that sometimes a child is

'elected' into the caring role by other family members and that this role then becomes established. Gender and age can also be factors in determining which child adopts the carer role. For example, some families may be uncomfortable about cross-gender care when that care is of a personal nature. Religion can also play a part - cross-gender care is unacceptable to many Muslims for example. Age can be a significant determinant in some families, with older children providing most of the caring tasks. Nevertheless, younger children may learn to do more as they grow and may become more involved when their older siblings are socialising and perhaps leaving the family home. In the survey mentioned above, Dearden and Becker (1998) found that the likelihood of involvement in most caring tasks increased with age. They also found that girls were more involved in all aspects of care and that this was especially marked in relation to domestic chores and intimate caring tasks.

What do young carers do?

The type and level of support provided by young carers is, to a large extent, dictated by the availability or otherwise of other support services. The care provided ranges from basic domestic tasks through to personal care. Dearden and Becker (1998) identified five main types of care provided by young carers and Table 1 shows the incidence of the different caring tasks in their 1995 and 1997 surveys of young carers supported by projects around the UK (Dearden and Becker, 1995, 1998).

Table 1 shows that most young carers provide domestic support - cleaning, cooking, shopping, washing dishes etc. Over half provide general, nursing-type care such as assisting with mobility, giving medication.

Emotional support is most commonly associated with caring for someone with mental health problems (62 per cent of those caring for someone with mental health problems provides this type of care) and can include giving support to a relative with suicidal or self-harming tendencies, staying with someone who is anxious or depressed and observing for any changes in mental state. Intimate care - usually associated with physical health problems and disability (26 per cent of those caring for someone with physical health problems, compared with nine per cent of those caring for other types of illness) - refers to assisting with washing, bathing etc. Child care refers to caring for younger siblings, in addition to other caring tasks for their ill/disabled relative, and 'other' includes a variety of additional tasks, for example administration, translating for non-English speaking or hearing impaired relatives, financial management etc.

Research clearly indicates that young carers provide similar types of care as adult carers. The major difference is the hitherto 'hidden' nature of young caring and the fact that it transgresses social norms - children are expected to be 'dependants' rather than 'care providers'.

In section 2 we will examine what research tells us about the educational experiences of young carers.

Summary of key points in Section 1

- Young carers are children (under the age of 18) who undertake significant caring tasks that are often inappropriate for their age and are usually associated with and performed by an adult.
- Official estimates put the number of young

Table 1 Percentage of young carers performing caring tasks

Caring tasks	1995	1997
Domestic	65%	72%
General	61%	57%
Emotional support	25%	43%
Intimate care	23%	21%
Child care	11%	7%
Other	10%	29%

carers at between 19,000 and 51,000 at any one time. Other research suggests that four per cent of young adults (aged 18-24) will have been young carers during their own childhood.

- Children become carers because of a lack of, or inadequate health and social care for disabled/ill adults. Other factors that influence what they do are the nature of illness/disability of the care recipient, family structure, age, gender and cultural considerations.
- Caring tasks undertaken include domestic chores, general caring (giving medication, assisting with mobility) intimate care and emotional support. In some families, as well as one or more of these caring tasks, young carers will also perform child care for younger siblings.

SECTION 2

What research tells us about young carers' educational experiences

Early research into young caring was, of necessity, small scale. This was because as young caring began to emerge as a social issue, young carers were hidden: there were no support services available to them until the early 1990s and these were initially small pilot projects set up in the north of England. Thus, while some early studies did identify young people who had missed school and experienced educational difficulties as a result of their caring roles (Aldridge and Becker, 1993; Frank, 1995), others did not (Bilsborrow, 1992). However, as the number of young carers projects began to grow, anecdotal evidence from project staff suggested that many young carers were experiencing educational problems. An evaluation of three of the first young carers projects to be developed showed educational difficulties to be widespread (Mahon and Higgins, 1995).

One of the first studies to focus on young carers and education was conducted in the London borough of Enfield (Marsden, 1995). In common with some of the earlier studies of young caring (see for example O'Neill, 1988; Page, 1988; Elliott, 1992), young people were not contacted directly, but information was

obtained from professionals in education and other services. The findings indicated a high level of concern regarding young carers and education. For example, from 38 young carers identified by schools, 15 were thought to be definitely restricted in their educational progress as a result of caring and 20 were considered to possibly be restricted. In only three cases did respondents say that educational progress was unaffected. Of the 28 young carers identified by other services, 17 were considered to definitely be restricted and 11 were possibly restricted in their educational progress. The major educational difficulties identified were punctuality, attendance and problems with homework/coursework. Additional problems cited were difficulties joining in extra curricular activities, low attainment, anxiety and fatigue (Marsden, 1995). These were very similar to the difficulties identified in other qualitative research. Table 2 outlines the key difficulties identified through research.

It is important to note that not all young carers will experience all of these difficulties; indeed some will have no educational problems at all. Educational disadvantage can be viewed as a continuum ranging from 'severe' at one end, through 'moderate' and 'occasional/less severe', with 'no obvious impact' at the other end.

Nationally, five per cent of the total school population are absent on any given day, while two per cent of Year 11 pupils truant for several weeks at a time, two per cent for several days at a time, and 34 per cent occasionally (DfEE, 1999a). Ten per cent of all school absence is due to 'home responsibilities' (Fox, 1995), although not all of this will be the result of caring.

The findings from Enfield (Marsden, 1995) reflected what young carers project staff had been reporting for some time. By the time this report was published, there were 36 designated young carer projects around the country. The existence of such projects made it possible for the first larger scale survey to be conducted. Data obtained from the projects related to 640 young carers - the largest data set at that time. Far from being unusual,

Table 2 Key educational difficulties identified through research on young carers

Difficulty	
Absence	May be regular, protracted or occasional May result in referral to educational welfare services
Lateness	May be persistent or occasional
Tiredness	May be identified by lack of concentration, lack of attention, falling asleep
Difficulty joining extra curricular activities	Due to time constraints as a result of caring
Bullying	May be a direct result of caring/family disability but may be unrelated
Restricted peer networks in school	May have little in common with same age peers, may be mature beyond their years, may be a result of time constraints due to caring
Poor attainment	May be reflected in lack of qualifications, low grade qualifications or underperformance
Homework/coursework	May be poor quality, not submitted on time or at all This may be persistent or occasional
Anxiety	Concern over ill/disabled relative
Behavioural problems	May result in referral to educational psychologist or child and adolescent psychiatrist

educational difficulties were found to be common, with one quarter of young carers of compulsory school age missing school as a *result of their caring responsibilities* (Dearden and Becker, 1995). Furthermore, when other indicators of educational difficulties, such as receipt of educational welfare services, educational psychology services, or additional educational support, or referral to young carers projects by educationalists were taken into account, the ratio was one in three. Even allowing for the anecdotal evidence from professionals working with young carers, this figure was much higher than anyone had anticipated.

In 1997 the survey of young carers supported by projects was repeated (Dearden and Becker, 1998). By this time there were many more projects and data were collected and collated relating to more than 2,300 young

carers. Although there had been some improvements in the proportion that were experiencing educational difficulties, the numbers remained high. Table 3 shows the percentages for each of the two surveys.

Children's rights to education are enshrined within Article 28 of The UN Convention on the Rights of the Child, ratified by the UK in 1991. Article 29 states that one of the aims of education should be for children to develop to their fullest potential. While educational disadvantage is a matter of degree, onerous, time-consuming and extensive caring - whether or not it falls within the definition of 'regular and substantial' - can deprive a young carer of making the best of their educational opportunities and attaining their true potential. When children experience educational disadvantage as a result of caring and fail to achieve their potential they may well be

Table 3 The proportion of school age children experiencing educational difficulties 1995 and 1997

Age group	1995	1997
5-10	20%	17%
11-15	42%	35%
All 5-15	33%	28%

deemed children in need (see Resource 3 for a discussion of the 1989 Children Act, children in need and the UN Convention on the Rights of the Child).

Why do some young carers experience educational difficulties?

Cause and effect

As it has become apparent that many young carers have educational problems, research has sought to establish how their caring roles result in such problems. Where children are missing school as a result of their caring roles, or are persistently late due to, for example, waiting for homecare services to arrive, it is easy to see cause and effect. However, regarding other examples of educational disadvantage we cannot be certain that caring itself is responsible. No other research has looked at variables that may have an impact on young carers' educational disadvantage in addition to caring, such as IQ, distance from school, poverty and social exclusion, personal interest, parental interest and stimulation etc. Thus, we do not know whether young carers are any more likely than any other group of vulnerable children or children in need, for example, children looked after, to suffer educational disadvantage as a direct consequence of their specific status (as young carers, children in need, etc.). We do know that not all young carers experience educational disadvantage and, again, the research is unable to demonstrate categorically why this is so. With this caveat it is possible to examine some of the research and identify examples where caring has had an impact on education.

Concentration/anxiety

In some cases anxiety about their ill/disabled relative leaves young carers unable to fully concentrate:

I just worry when I've got to go to school ... I ring him [father] up at break and dinner to see

how he is ... I can't concentrate at school, even when I am there, there's no point in going really.

When I was at school I would worry about him, whether he was OK, whether he'd fallen, because if he fell he couldn't get up, so I did used to worry about that ... I often used to phone him from school to make sure he was OK, but I'd make an excuse, 'I'm just phoning to see if the catalogue stuff has come', or something.

(Dearden and Becker, 1995)

Absence/poor attainment

In more extreme situations, absence from school is a result of caring responsibilities or the nature of relatives' illness. For example, children may be afraid to leave parents, especially when they have a history of self-harm or suicide (Aldridge and Becker, 2003). Some physical illnesses are marked by periods of exacerbation and remission and during acute phases children stay at home to 'be there' in case they are needed. This can lead to low educational attainment if regular or persistent:

I'm not really sure [how often I miss school] it just depends how bad my dad is. If he's too bad I won't go and he says 'Go' but I won't, I say 'I'm staying here'.

(Dearden and Becker, 1995)

The problem that I had was that mum used to be really ill and I used to take her to hospital every so often and sometimes we used to end up in casualty and we had to wait there all night, you know. And then during the day, obviously she was admitted, and then I would be with her in hospital, and then making sure that my brothers were at school, and then coming back home and running around everywhere really. So I missed out a lot of school and the work.

(Dearden and Becker, 1998)

I missed a lot of school because he [dad] wasn't well and I didn't like leaving him in case he fell over and couldn't reach a phone or pull the cords ... I went to it [school] twice a week, that was it... until Year 11 and then I just drew the line and told them to give me home tuition or I don't come at all. And I got my home tuition.

When she [mum] got ill it was at the time of my mocks [GCSEs] and I didn't want to leave at all, me and my sister, so we didn't ... we used to miss days off school and everything ... I didn't do my GCSEs. After my mocks I went back for a year.

(Dearden and Becker, 2000a)

Bullying

Bullying is another problem although it is not always associated with caring. Crabtree and Warner (1999) found that 71 per cent of young carers were bullied, only slightly higher than Kidscape figures of 68 per cent of all school age children being bullied. Many young carers acknowledge that being bullied is part of 'normal' school life and would not divulge their home situations for fear of the bullying worsening. However, in some cases bullying is due to young carers' 'difference' in relation to their peers, whether this is because they have to do more in the home or because they have a relative who is 'different' in some way. Thus it is not caring that results in bullying, but the family situation.

I got kicked in the ribs once and I've been called names, also I was followed on my way home from school and I've been tormented.

I have experienced name-calling from my peers and others, who perceived my dad's mental illness as being different. It makes me feel hurtful when I hear people making derogatory comments about dementia or Alzheimer's - I take it personally.

(Crabtree and Warner, 1999)

Anyway, she [friend] found out about my mum from her mum and spread it around, so then I was getting skitted about my mum. I just heard little things behind my back, I sort of knew. Then it got physical.

(Dearden and Becker, 1995)

Although it is important to stress that young carers are only slightly more likely than other children to be bullied, when that bullying and name calling is directed towards a family member, particularly one who is ill/disabled or who has a terminal illness, this adds to the stress already felt by many children and exacerbates any existing educational difficulties.

What are the longer-term consequences of educational difficulties?

As young carers are partially defined by age, i.e. under the age of 18 and legally deemed children, it has been difficult to ascertain the longer term consequences of their often negative educational experiences because research has only concentrated on those aged 18 and under. However, in 1999 two pieces of research were undertaken, one a study of former young carers, now adults and reflecting on their previous experiences (Frank *et al.*, 1999) and the other a survey of young carers' transitions into adulthood, concentrating on young people aged 16-25 (Dearden and Becker, 2000a).

The findings of these two pieces of research confirm that missed education is a critical factor for many young carers. In Dearden and Becker's (2000a) study, 20 out of 36 16-18 year olds had missed some school and 10 had no GCSEs. In the 19-24 age group 11 out of 24 had missed some school and five had no GCSEs. In some cases, schools had not entered the young people for formal examinations although it was not absolutely certain why. The imposition of school 'league tables' and the pressures on teachers to get ever improving grades from their students may have been a factor. In other cases, young people had effectively excluded themselves as a result of very poor attendance or of dropping out of school before examinations were taken. It was also clear from both pieces of research that professionals often colluded with young people in their school absences - what Frank *et al.* termed 'sanctioned exclusion' (Frank *et al.*, 1999; Dearden and Becker, 2000a). Although we would not advocate an unnecessarily punitive approach towards such children, education and formal qualifications are becoming increasingly important, therefore

a more balanced approach to supporting families and ensuring children receive the education to which they are entitled is required.

Educational difficulties, a poor school record in relation to absenteeism, time-keeping etc. and no or low grade qualifications can all impede entry into the labour market. In Dearden and Becker's (2000a) research two thirds of the 16-18 age group were still in some form of education - either at school or in further education. For some this was because jobs were hard to find and education offered a second chance of either re-sitting GCSEs, progressing to A levels or gaining vocational qualifications. Of the 24 young people in the 19-25 age group, only 10 were in employment and of these, two were hoping to go to university and one was employed part-time. Five of the younger age group and four of the older group were unemployed and actively seeking work, while four of the older group were in receipt of invalid carers allowance (now known as carers allowance) and classed as full-time carers. (For more information on carers allowance see Resource 3.)

Frank *et al.* (1999) and Dearden and Becker (2000a) found that caring influenced decisions in relation to employment. Frank *et al.* state that half of their sample attributed their choice of career in caring professions to their earlier experiences of caring during childhood. However, while Dearden and Becker also found evidence of childhood caring influencing employment decisions, they also discovered that educational difficulties restricted employment choices, so some young people were unqualified for the type of work they wanted. Dearden and Becker were concerned that caring during childhood, coupled with a history of educational disadvantage, should not push people into low paid caring roles in the labour market because of a lack of alternatives.

The research findings raise some important questions, the key one being whether it is the level of educational disadvantage or the impact such disadvantage has on a child that is significant. To frame the question differently, could minimal educational disadvantage, i.e. a

young carer who is a regular school attender who keeps up with coursework and homework and attains reasonable results for these, result in significantly negative outcomes, as severe as, or worse than extreme educational disadvantage? Or, conversely, could a young carer who has extreme educational difficulties overcome these and have a good outcome? Clearly children's resilience will play a factor in outcomes as will any educational support they receive. One of the respondents in Dearden and Becker's (2000a) study, for example, left school at 15 to care for her dying father. After he died she entered the labour market with no qualifications but found work (of a caring nature with children) and was slowly gaining vocational qualifications and putting together a portfolio of her experience. Another respondent had missed school regularly to care for her mother but was resilient enough to catch up on missed work and to submit coursework. However, her mother became ill again at the point at which she would have been sitting GCSE examinations and she missed most of these, leaving school with no qualifications.

Assessment of young carers is central in both determining the level of educational disadvantage and also its potential impact. Assessment issues parallel the debates around defining carers by the quantity of support that they offer, i.e. should it have to be 'regular and significant' for them to receive support? We would argue that while quantity is important, outcomes/effects are equally important and young carers should not miss out on assessment and support because the level of care they provide is considered to be low. These young carers can still remain at risk of negative outcomes that may be severe. The Children Act 1989 (see Resource 3) places considerable emphasis on outcomes, so children who risk impaired psychosocial development or health problems - even if they have no or little in the way of educational difficulties - should be assessed and supported as children in need.

Summary of key points in Section 2

- Research, both quantitative and qualitative, suggests that at least a quarter and probably a third of young carers experience

educational difficulties. The rest do not report problems although qualitative research often finds evidence of some of the indicators of educational difficulties (identified in Table 2) even in young carers who attend school regularly.

- Educational disadvantage is experienced in many forms.
- Educational difficulties will range from severe, to moderate, to low.
- While the research indicates that caring can result in educational disadvantage for some young carers, in other cases caring will be only one factor within a child's life that may lead to educational difficulties. The existing research is not robust enough to seek out other specific causes of educational disadvantage among some young carers, such as poverty, isolation, social exclusion etc.
- Educational disadvantage as a result of caring during childhood can have knock-on effects in later life in relation to career choices and opportunities.
- While the level of care provided by children is important, outcomes - including educational ones - are equally important and should be considered by professionals working with young carers, especially during the assessment process.
- Future research will need to focus as much on young carers who experience little or no educational disadvantage, as it will on those young carers with educational problems. We need to know the reasons why many young carers seem free of educational difficulties so as to be able to identify the circumstances or factors that might help reduce educational disadvantage for other young carers. Future research will also need to determine whether it is the level of educational disadvantage experienced by young carers, or the impact such disadvantage has on children that is significant.

SECTION 3

Using education and related policies to support young carers

Given the educational problems experienced by many young carers and widely documented in research, it is perhaps surprising that they have only very recently been acknowledged in education policy; as a group they yet remain to be mentioned in education legislation.

The 1944 Education Act reaffirmed the government's commitment to compulsory education. Although education had been compulsory from the late nineteenth century onwards, there was a lot of non-compliance from working class families who needed their children's earnings. The 1944 Act was intended to offer equality of opportunity, with free education provided by local education authorities and based on age, aptitude and ability. This led to the tripartite system of grammar, technical and secondary modern schools, although in reality most parts of the country operated a bipartite system, as there were few technical schools. The 1944 Act underpins all subsequent Education Acts.

All children are entitled to a free education - in fact all children must be educated in some way. Education is currently compulsory from the age of five until the academic term in which a child's sixteenth birthday occurs. While most children are educated within the state system, parents can opt for private education or may educate their children at home. However, parents have a duty to ensure that their children receive an education and can be prosecuted for not sending them to school or making alternative, acceptable provisions. Equally, local authorities have a duty to make provision for children in their locality to receive a place in a school. Although parents can express a preference, children may not always go to the school of their choice. Although compulsory, education is viewed as a right, something denied to many children in previous generations and still denied to children in other countries and cultures. It is one of the rights enshrined not only within UK law, but also within the UN Convention on the Rights of the Child (see Resource 3). It is also one of the rights that some young carers are denied.

The National Carers Strategy, *Caring for Carers* (see Resource 3), outlined provisions that would help to meet young carers' needs and reduce their often negative experiences of education. The government indicated that they would:

- aim to ensure that children whose parents or other relatives have specific needs arising out of disability or health conditions enjoy the same life chances as all other children in the locality. This requires local authorities to identify children with additional family burdens and to provide services that are geared to ensure these children's education and general development do not suffer;
- do more to make health, education and social services work together on children's services plans, as set out in the White Paper Modernising Social Services;
- continue to emphasise the need for cooperation between adults' and children's services within social services departments. This means, for example, that the community care assessment of a disabled parent must pay attention to that disabled person's role as a parent;
- improve awareness training about young carers for General Practitioners, primary health care teams, social workers and teachers at the time of their initial training and subsequently, through providing opportunities for young carers to share their experiences with professionals;
- promote awareness of young carers within schools by ensuring that teaching on Personal, Social and Health Education (PSHE) includes references to young carers;
- encourage schools to designate someone to act as a link for young people who are carers, with social services, the health service and any young carers' project;
- ensure that local authorities recognise, within a general objective to increase community support for carers, the need to sustain and enhance the number of young

carers' projects, and especially to ensure that young carers have access to leisure and recreational activities;

- enhance counselling services and promote the independence of young carers. Older teenagers who have been caring for some time can find it difficult to move on and gain their independence. Emotional ties, a sense of duty and a lack of accessible housing can be very restricting. Underachievement in education and lack of confidence can mean that financial independence is difficult. In some ways there are parallels with children leaving care, and local authorities need to ensure that their counselling and housing services are responsive to the needs of young carers.

The majority of the points outlined above make reference to young carers' educational experiences or to how young carers can be supported within schools. Some current policies within education may be used to help to support young carers. *The aim should be to try and ensure that young carers receive the education to which they are entitled and also to make the most of their opportunities in order to achieve their full potential, both in the classroom and outside.*

Connexions [www.connexions.gov.uk]

Connexions is a support service for all 13-19 year olds in England. It offers integrated advice, guidance and access to personal development opportunities and aims to help young people to make a smooth transition to adulthood and working life. All young people will have access to a personal adviser who will identify barriers to learning and find solutions, arranging access to more specialist support if required. While Connexions is for all 13-19 year olds, certain groups who are known to experience educational difficulties and disadvantages will be actively sought and supported. Young carers are among these groups. Connexions may prove to be particularly helpful to those young carers who are currently experiencing educational disadvantage or to those who have recently left school with low grade qualifications. A personal adviser will be able to advise on a

range of options, such as work-based training, further education etc. to try and ameliorate some of the negative impacts of caring. In some areas, such as West Sussex, there are specialist posts for Connexions advisers working with young carers. However, Connexions is only for 13-19 year olds, whereas the average age of young carers supported by specialist projects is just 12 (Dearden and Becker, 1998).

Inclusion policies

Official guidance on social inclusion within education (DfEE, 1999b) recognises young carers as a group at particular risk and in need of support. Like the Carers Strategy, the guidance suggests that schools consider appointing a designated member of staff to have responsibility for young carers and that they work with other agencies that support them. It also acknowledges young carers' fears of family separation and suggests that referral to outside agencies is done sensitively and in a way that recognises such fears.

A multi-agency approach to inclusion is recommended to include, for example, social services, police, health and local education authority staff, youth offending teams, probation and youth justice. It is clear that staff from local young carers projects could also be included in such a multi-agency approach where the child concerned is a young carer. The guidance points to social services for assessment of children in need (under the Children Act, 1989 - see Resource 2). Whatever strategy is adopted to prevent exclusion, families should be involved, preferably using an action plan agreed by school staff, parents and pupils. Where children are carers, it is worth noting that: 'In a genuine crisis, a school can approve absence for a child to care for a relative until other arrangements can be made. The school should set a time limit for the absence and set some school work so the pupil does not fall far behind while at home' (DfEE, 1999b: 14). For some families this knowledge may ease parental guilt and children's anxiety relating to occasional absences where crises in family care provision arise and alternative arrangements cannot be made immediately. One of the obvious advantages that inclusion

policies have over Connexions is that they apply to all children, rather than those over the age of 13. This means that any young carer demonstrating signs of educational disadvantage or disaffection can be identified early and receive support before they are covered by Connexions. This may reduce educational difficulties earlier and then Connexions personal advisers can be made aware of earlier and potential problems once the child is aged 13.

PSHE

Personal, social and health education is taught at all of the key stages in education and therefore applies to all children. PSHE was recognised in the Carers Strategy as one of the ways of educating children about young carers. By doing so it is hoped that young carers will self identify and seek support should they require it; and that other children will become aware of some of the issues and not be negative in their dealings with young carers, thereby reducing bullying and social isolation. Schools can use a variety of resources for PSHE, including inviting guest speakers to some classes. This would offer the opportunity to not only discuss young carers' issues, but also issues around illness and disability, including mental ill health. Carers Lewisham (Baker, undated) produce a pack designed for schools that includes information on young carers and their responsibilities, mental ill health and disability and support for young carers [www.carers.org]. From 2002 citizenship must also be taught as part of PSHE. Since citizenship includes social and moral responsibility and community involvement, young caring may also be included to the extent that respect for others regardless of illness/disability is part of social responsibility and that 'community' involvement may provide opportunities to work with or learn about a range of organisations including disability organisations, those for mental ill health, carers groups etc. While teaching children about illness, disability and caring is a good start, PSHE lessons could be used to teach the social model of disability, making pupils aware of some of the disabling barriers and attitudes within society. Children whose parents have mental illness are often bullied and victimised because of the ignorance surrounding mental

health issues, therefore the lessons concerning mental illness need also impress upon children the fact that one in four of us is likely to experience mental ill health at some point and that people with mental illness are not 'nutters', 'psychos', 'loonies' etc. Equally, issues of drug and alcohol misuse should be taught in a non-judgemental manner, impressing upon children the dangers but also pointing out that these are illnesses, like any other, that require support and understanding rather than judging.

Education welfare services

[www.dfes.gov.uk/a-z/EDUCATION_WELFARE_SERVICE_ba.html]

Schools can refer children to the education welfare services for persistent non-attendance when other attempts to resolve the issue have failed. Such attempts should include action by form tutors, the involvement of other staff within the school, e.g. head of year or head/deputy head teacher and contact and discussion with parents. An Education Welfare Officer (EWO, sometimes known as education social worker) will be allocated to the child and work with the child and family to improve attendance and other related problems. Although attendance issues are EWOs' main responsibility, they also undertake duties related to child protection issues, child employment, alternative provision for excluded pupils, and reporting on children with special educational needs. Many young carers who experience educational difficulties are in contact with EWOs, although educational support and education welfare services only account for five per cent of all services received by young carers and their families (Dearden and Becker, 1998). When supporting young carers, EWOs could instigate home-school contracts, thereby involving parents and maintaining and strengthening a positive home-school relationship.

Sure Start [www.surestart.gov.uk]

Sure Start is part of the government's strategy to reduce child poverty and social exclusion. As such, it is not really an educational policy but one intended for pre-school children up to the age of four. It aims to promote the physical, intellectual and social development of babies and young children. Provision is made within

Sure Start programmes for the support of parents and children with 'special needs'. Parents with illness or disability may resent the label, but if it is applied sensitively they and their children may benefit from the support of a Sure Start programme. However, Sure Start should not be used to support children who may become carers in the absence of any other type of support. All policies should now be looking to prevent young caring from occurring in the longer term by supporting disabled and ill adults, including in their parenting role. Nevertheless, where older children within a family have adopted caring roles in the past, younger children may benefit from the support offered by a Sure Start programme. There should be no assumption, however, that the children of disabled parents will become carers; this only happens when services and support are inadequate.

Mentoring [www.nmn.org.uk]

The National Mentoring Network is supported by the DfES and has many schools, colleges and universities as members. Mentoring can be used within education to improve achievement, self-confidence, personal and social skills, and can be used with children who are, or have the potential to be, disaffected and socially excluded. Not all schools will use mentoring but it is another form of support that might benefit young carers and other children who may be experiencing educational difficulties. Schools in Manchester, Oxford and Bournemouth, for example, operate peer mentoring schemes.

Education maintenance allowances

[www.dfes.gov.uk/a-z/EDUCATION_MAINTENANCE_ALLOWANCES_ba.html]

Education maintenance allowances (EMAs) are designed to help young people from less well off families stay on at school or college. The cost of post-16 education is believed to act as a disincentive to young people from more disadvantaged backgrounds, and research has shown that they are more likely to gain fewer or no qualifications, more limited horizons, and unskilled jobs. The allowance is conditional on a signed learning agreement outlining what is expected of the young person in terms of attendance and homework. Many young carers

live in, or on the margins of poverty and such allowances will prove invaluable to many families where disability and ill health reduce the family income making it difficult for children to remain in education beyond the age of 16. At the time of Dearden and Becker's (2000a) study EMAs were being piloted in specific areas and few of the respondents were entitled to them. As a result many were experiencing severe financial hardship by remaining in post-16 education.

Moving Forward

The above policies are some that may be used to support young carers within education and to try to reduce the often negative outcomes associated with providing care with little or no support. The research evidence suggests that for the third of young carers who experience educational disadvantage, transitions into adulthood, independence and the labour market may all be adversely affected (Dearden and Becker, 2000a). Support within education is therefore essential for current young carers who may already be experiencing difficulties, in order to prevent knock-on effects in the future. In the longer term we should be aiming to prevent young caring from starting in the first place and should certainly prevent it from becoming established if it has already started. This requires not only support within education, but also, as the Carers Strategy suggests, much more multi-agency working, to include health and social services, education and voluntary groups. A designated person within schools who has responsibility to liaise with other agencies and who has good knowledge of the issues and up to date research evidence is a useful first step.

Identifying and supporting young carers in school

As all children between the ages of five and 16 should be in school, teachers are well placed to identify young carers. However, this has not been happening, partly because of a lack of knowledge and understanding of the issues on the part of teachers, and also because many young carers go to extreme lengths to hide their home and caring situations from their peers and teachers. A knowledge of the educational difficulties experienced by many young carers, coupled with knowledge of the

types of caring tasks performed by children with caring responsibilities may make it easier for teachers to question why some children are experiencing problems and to identify and support young carers within their schools. This information should not be restricted to teaching staff - school nurses and school counsellors will also need this information if they too are to be aware of and support young carers.

It should be possible for schools to collect information on family illness and disability for their own records. This could be done when children first begin school. A standard form with the usual questions about a child's personal details, could also ask about any long-term illness or disability, including physical and mental ill health, learning difficulties etc., within the family. A note could explain that some children who have an ill/disabled relative worry about them during school hours and find it difficult to concentrate. The same form could also ask whether parents have any special requirements for school visits, e.g. wheelchair users who need a fully accessible building, hearing impaired parents who may require a signer, parents whose first language is not English etc. This standard form could then help teachers to identify potential young carers and also parents who may find it difficult to attend meetings at school. School staff would then be in a better position to support young carers and their families. Such information would need to be updated, at least annually as a child progresses through school.

When school staff notice a child who is exhibiting any of the indicators of educational problems outlined in Table 2, they should always check whether this is in any way connected with the illness/disability of a family member. Schools should have a designated person responsible for young carers and this person should have the necessary knowledge and information to inform and advise other members of staff. However, while this is strongly recommended by the Department for Education and Skills, it is not yet a requirement. In the absence of such a person the following checklist for teachers should help, although it is recommended that a

person be designated for this responsibility.

1. Speak to the young person in private - do not confront them in front of their peers. Establish if their problems are connected with the illness/disability of a family member.
2. Establish what caring tasks they are performing and why.
3. Speak to parent/s and ascertain whether they have any/sufficient help and support for themselves and to reduce their children's caring roles and ensure their children can make the most of their education.
4. Explain to parents and children that they may be entitled to an assessment of their needs from social services - this could include a community care assessment and a carer's assessment. Discuss their rights and help them to contact social services if necessary.
5. With the family's permission, be prepared to refer to other agencies if necessary. This may be the local social services department for an assessment of the family's needs, a local young carers project to support the child, or the family GP who can advise on what may be available within the local health services.
6. Discuss what support the school can offer. A balance must be struck between condoning school absences and a more punitive approach (the threat of court proceedings for non-attendance). Explain the importance of regular attendance, but acknowledge that family circumstances may mean there could be times when this may be difficult. Support from Education Welfare Services may be sought.
7. Find out about local organisations such as disability groups, play schemes, Citizens Advice Bureaux, carers groups etc. School staff can play an important role in putting families in touch with other agencies without formally referring them. Make your school a local information resource for children and families who need information.
8. Be flexible in your support for children and parent/s. For example, allowing the child to telephone home if they are worried, arranging to visit parents at home who may find it difficult to attend parents' evenings

etc.

9. Throughout any interventions always respect the family's right to privacy and treat all family members with respect and in a non-judgemental manner.

Although this checklist is not comprehensive, it should assist school staff in beginning to support young carers in their schools. Other examples of good practice are outlined below, to provide some ideas of the kinds of services and interventions that can be helpful to young carers. Ill or disabled parents invest as much in their children's education as any other parents, but their circumstances may make it difficult for them to attend school meetings, and those who lack adequate support services may rely on their children much more than they would wish. A supportive response from school staff is essential if they are to feel included in their children's education. Furthermore, support from within education can help to ensure that their children's particular needs as carers, in addition to their educational needs are not overlooked. The Children's Society has produced a good practice guide for professionals working with young carers. Information about the guide and the Executive Summary can be found on their website (www.childrensociety.org.uk/youngcarers).

The Children's Society and The Princess Royal Trust for Carers have examples of good practice

- One of the major aims of the Sheffield Young Carers Project is to increase young carers' opportunities and in particular their opportunities in education, training and employment. To this end, there has been a careers adviser (now a Connexions adviser) seconded to the project on a part-time basis since 1997. The adviser has worked with young people in a variety of ways. For example, arranging interviews and visits to local colleges and places of employment; assisting young people to use computer packages to see the types of employment they may be suitable for; obtaining literature for young people about colleges, universities, specific careers etc; assisting young people to choose subjects for GCSE study; liaising with education welfare

officers and teachers; and assisting one young woman - whose caring responsibilities for both of her ill parents and several younger siblings severely restrict her time available to study - to enrol on a distance learning programme. In addition to ongoing careers advice, the project also used to run a homework club where young people could work in a quiet place and have access to a computer and internet resources. Although the homework club no longer operates, project staff can still help young people to proof read schoolwork before submission. Project staff have also worked within local schools in PSHE lessons, raising awareness of some of the issues associated with young caring (Dearden and Becker, 2000b). The project has produced a video resource pack for schools and the Connexions adviser has done training sessions within local schools. The pack can be obtained from the project (see Resource 2 for information).

- Carers Lewisham, part of the Princess Royal Trust Carers Centre, runs a Schools Development Project. The history of the project can be traced back to 1992 when carers Lewisham worked with school nurses to highlight the issue of young carers. School nurses then asked about illness within the family and children's caring responsibilities when they conducted yearly health checks. As a result they identified over 50 young carers. Between 1992 and 1997 Carers Lewisham worked with several individuals who had an interest in young carers' issues and, in 1997, made a successful bid for funding for a schools development project to carry out in-depth work in just two schools, rather than to try and cover all of the schools in the borough. The project has produced a secondary teaching resource pack, Supporting Young Carers in School (Baker, undated) which contains lesson materials, resource sheets, information for teachers and strategies for schools to adopt in order to successfully identify and support young carers in their schools. A report on the Schools Development Project is also available (Baker, undated) and can be downloaded from the internet [[www.carers.org/about-](http://www.carers.org/about-the-trust/publications.asp)

[the-trust/publications.asp](http://www.carers.org/about-the-trust/publications.asp)] as can a Good Practice Guide for working with young carers.

- The Liverpool young carers project, part of Barnardos, has strong links with Connexions. A connexions adviser is seconded to the project for one day a week. Although the adviser will work with any of the young people aged 13-19, they are specifically interested in any young people who have 'slipped through the net' and, as a result of missed education, have missed out on careers advice and about whom they have little or no knowledge. As part of the secondment, the adviser will share his knowledge and raise awareness among his colleagues in Connexions. The standard Connexions form in Liverpool has a category for young carers as they are acknowledged to be at risk of experiencing educational problems. In addition to this secondment, Connexions also funds a young carers worker within the Barnardos project who will also train as a Connexions personal adviser. This post has been funded because there was a perceived gap in supporting young carers aged 16 and over, particularly those who were experiencing or had experienced educational difficulties. Although this post is specifically for post-16s, the worker will support 15 year olds who have educational difficulties.

Summary of key points in Section 3

- Education is both compulsory and a right, protected by education legislation and the UN Convention on the Rights of the Child.
- The National Carers Strategy recognises the educational impact caring can have on children and indicates what the government intends to do about this.
- A variety of policies can help young carers to get the most out of their education and to achieve their full potential.
- Schools should identify young carers and put in place mechanisms to support them. There should be a person designated in all schools who has a sound knowledge of the issues and relevant literature.

- Schools should have good mechanisms for including all parents, including disabled parents, in school life. They should also hold information about local organisations and agencies and have an important role in the provision of information.
- Supporting young carers in education will help to make their transitions into adulthood, employment and independence more positive. It will also make their experiences of education more rewarding here and now. The aim should be to try and ensure that young carers receive the education to which they are entitled and also to make the most of their opportunities in order to achieve their full potential both in the classroom and outside.

Resource 1

References

- Aldridge, J. and Becker, S. (1993) *Children who Care: Inside the World of Young Carers*, Loughborough: Young Carers Research Group, Loughborough University.
- Aldridge, J. and Becker, S. (2003) *Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals*, Bristol: Policy Press.
- Baker, G. (undated) *Supporting Young Carers in School: A secondary Resource Pack*, London: The Princess Royal Trust, Lewisham Carers Centre.
- Baker, G. (undated) *Unseen and Unheard: The Invisible Young Carers*, London: The Princess Royal Trust, Lewisham Carers Centre.
- Becker, S. (2000) 'Young Carers' in Davies, M. (Ed) *The Blackwell Encyclopaedia of Social Work*, London: Blackwell.
- Becker, S., Aldridge, J. and Dearden, C. (1998) *Young Carers and Their Families*, Oxford: Blackwell Science.
- Bilsborrow, S. (1992) 'You Grow up Fast as Well...' *Young Carers on Merseyside*, Liverpool: Carers National Association, Personal Services Society and Barnardos.
- Carers National Association (1998) *About Young Carers*, London: Carers National Association.
- Cawson, P. (2002) *Child Maltreatment in the Family: The Experiences of a National Sample of Young People*, London: NSPCC.
- Cawson, P., Wattam, C., Brooker, S. and Kelly, G. (2000) *Child Maltreatment in the United Kingdom: A Study of the Prevalence of Child Abuse and Neglect*, London: NSPCC.
- Crabtree, H. and Warner, L. (1999) *Too Much to Take On: A Report on Young Carers and Bullying*, London: Princess Royal Trust for Carers.
- Dearden, C. and Becker, S. (1995) *Young Carers - The Facts*, Sutton: Reed Business Publishing.
- Dearden, C. and Becker, S. (1998) *Young Carers in the United Kingdom: A Profile*, London: Carers National Association.
- Dearden, C. and Becker, S. (2000a) *Growing up Caring: Vulnerability and Transition to Adulthood - Young Carers' Experiences*, Leicester: Youth Work Press.
- Dearden, C. and Becker, S. (2000b) *Meeting Young Carers' Needs: An Evaluation of Sheffield Young Carers Project*, Loughborough: Young Carers Research Group, Loughborough University.
- Department for Education and Employment (1999a) *Tackling Truancy Together*, London: DfEE.
- Department for Education and Employment (1999b) *Social Inclusion: Pupil Support*, London: DfEE.
- Elliott, A. (1992) *Hidden Children: A Study of Ex-Young Carers of Parents with Mental Health Problems*, Leeds: City Council Mental Health Development Section.
- Fox, N. J. 'Professional models of school absence associated with home responsibility', *British Journal of Sociology of Education*, 16:2:221-42.
- Frank, J. (1995) *Couldn't Care More: A Study of Young Carers and their Needs*, London: The Children's Society.
- Frank, J., Tatum, C. and Tucker, S. (1999) *On Small Shoulders: Learning from the Experiences of Former Young Carers*, London: The Children's Society.
- Keith, L. and Morris, J. (1995) 'Easy targets: a disability rights perspective on the "children as carers" debate' *Critical Social Policy*, 44/45: 36-57.
- Mahon, A. and Higgins, J. (1995) '...A Life of Our Own' *Young Carers: An Evaluation of Three RHA Funded Projects in Merseyside*, Manchester: University of Manchester, Health Services Management Unit.
- Marsden, R. (1995) *Young Carers and Education*, London: Borough of Enfield, Education Department.
- O'Neill, A. (1988) *Young Carers: The Tameside Research*, Tameside: Metropolitan Borough Council.
- Page, R. (1988) *Report on the Initial Survey Investigating the Number of Young Carers in Sandwell Secondary Schools*, Sandwell: Metropolitan Borough Council.
- Parker, G. (1994) *Where Next for Research on Carers?* Leicester: Nuffield Community care Studies Centre, University of Leicester.
- Parker, G. and Olsen, R. (1995) 'A sideways glance at young carers' in Department of Health, *Young Carers: Something to Think About*, London: Department of Health.

The Scottish Executive (2001) *Men and Women in Scotland: A Statistical Profile*, Edinburgh: The Scottish Executive.

Walker, A. (1996) *Young Carers and Their Families*, London: The Stationery Office.

Wates, M. (2002) *Supporting Disabled Adults in their Parenting Role*, York: York Publishing Services.

Resource 2

Selected reading, useful addresses and internet sources

Selected reading

Aldridge, J. and Becker, S. (2003) *Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals*, Bristol: Policy Press.

Baker, G. (undated) *Supporting Young Carers in School: A Secondary Resource Pack*, London: The Princess Royal Trust, Lewisham Carers Centre.

Baker, G. (undated) *Unseen and Unheard: The Invisible Young Carers*, London: The Princess Royal Trust, Lewisham Carers Centre.

Becker, S., Aldridge, J. and Dearden, C. (1998) *Young Carers and Their Families*, Oxford: Blackwell Science.

Blyth, E. and Milner, J. (1997) *Social Work with Children: The Educational Perspective*, Harlow: Longman.

Dearden, C. (1998) 'The social and educational impacts of caring on children', *Primary Practice*, 13: 41-5.

Dearden, C. and Becker, S. (1995) *Young Carers - The Facts*, Sutton: Reed Business Publishing.

Dearden, C. and Becker, S. (2000) *Growing up Caring: Vulnerability and Transition to Adulthood - Young Carers' Experiences*, Leicester: Youth Work Press.

Department of Health (1999) *Caring about Carers: A National Strategy for Carers*, London: DH.

Frank, J. (2002) *Making it work: good practice with young carers and their families*, London: The Children's Society and The Princess Royal Trust for Carers.

Frank, J., Tatum, C. and Tucker, S. (1999) *On Small Shoulders: Learning from the Experiences of Former Young Carers*, London: The Children's Society.

Wates, M. (2002) *Supporting Disabled Adults in their Parenting Role*, York: York Publishing Services.

Useful addresses and internet sources

Barnardos Action with Young Carers

24 Colquitt Street
Liverpool L1 4DE
0151 708 7323

Carers Lewisham

The Princess Royal Trust
Lewisham Carers Centre
Waldram Place
Forest Hill
London SE23 2LB
020 8699 8686

Carers UK

20-25 Glasshouse Yard
London EC1A 4JT
020 7490 8818
www.carersonline.org.uk

The Children's Society

Young Carers Initiative
Youngs Yard
Finches Lane
Twyford
Near Winchester
Hampshire SO21 1NN
01962 711511
www.childrenssociety.org.uk/youngcarers

Department for Education and Skills

www.dfes.gov.uk

Department of Health

www.doh.gov.uk

Disabled Parents Network

PO Box 5876
Towcester
NN12 7ZN
0870 241 0450
www.disabledparentsnetwork.org.uk

The Princess Royal Trust for Carers

142 Minorities
London LC3N 1LB
020 7480 7788
www.carers.org

Sheffield Young Carers Project

Venture House
103 Arundel Street
Sheffield S1 2NT
0114 281 6151

Young Carers Research Group

Centre for Child and Family Research
Department of Social Sciences
Loughborough University
Loughborough
Leicestershire LE11 3TU
01509 228355
www.ycrg.org.uk

Resource 3

Legislation and policy for disabled people, carers and vulnerable children

In this section we outline some of the relevant laws and policies that provide the practice framework for professionals working to support disabled people, carers and vulnerable children, and the legislative basis for the 'rights' of these groups. The definition of disability is inclusive, to encompass physical disability and illness, mental health problems and learning difficulties. Legislation from the past 30 years that specifically refers to disabled people, carers or children has been included. There is, inevitably, some overlap as some pieces of legislation and policy documents relate to both disabled people and carers, while others relate to both children and young carers. For ease, we have included some of these policies or laws in each relevant category

Legislation and policy for disabled people (Source: Aldridge and Becker, 2003)

1970 Chronically Sick and Disabled Persons Act

Section 1 requires local authorities to identify the needs of disabled people (including those who have mental disorder of any description). Under Section 2, local authorities have a duty to provide a range of services to these people where this is necessary to meet their needs.

1983 Mental Health Act

Specifies procedures for the compulsory admission of patients to hospital; defines the position and rights of patients while in hospital; the circumstances of their treatment; procedures for their continued detention and discharge. Also creates the Mental Health Act Commission.

1986 Disabled Persons (Services, Consultation and Representation) Act

Section 4 states that local authorities should decide whether the needs of a disabled person call for the provision of services under the 1970 Act. Under Section 8, the assessment of services must take into account the ability of carers to continue to provide care.

Community Care: Agenda for Action (Griffiths Report) 1988

Local authorities are to act as organisers and purchasers of services, but not necessarily providers. The report acknowledges the role played by carers, but young carers are not specifically mentioned.

Caring for people: Community care in the next decade and beyond White paper 1989

Outlines the six primary objectives of community care policy: to promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible; to ensure that service providers make practical support for carers a high priority; to make proper assessment of need and good care management the cornerstone of high quality care; to promote the development of a flourishing independent (private) sector alongside good quality public services; to clarify the responsibilities of agencies and so make it easier to hold them to account for their performance; and to secure better value for taxpayers' money by introducing a new funding structure for social care.

1990 NHS and Community Care Act

Section 47 places a duty on local authorities to assess people's needs for community care services. Section 46 requires local authorities to publish community care plans.

1991 Care Programme Approach (CPA) to be implemented by health authorities together with social services. CPA is the cornerstone of the government's mental health policy. The essential elements include a systematic assessment of health and social care needs, an agreed care plan, allocation of a key worker and regular review of the patient's progress.

1995 Disability Discrimination Act

Deals with discrimination in the provision of goods, facilities and services. Since December 1996 it has been illegal for service providers to refuse to provide a service to a disabled person on the same terms available to others. From 2004, service providers will have to take reasonable steps to remove, alter or provide reasonable means of avoiding physical features that make it impossible or unreasonably difficult for disabled people to use a service.

1995 Mental Health (Patients in the Community) Act

Provides (by amending the 1983 Mental Health Act) for supervised discharge orders for certain patients discharged from hospital following detainment under the 1983 Act. Also establishes a new category of patients who are subject to compulsory after care in the community, including powers for health and social services authorities to require patients to live at a specified place and attend for medical treatment.

1996 Community Care (Direct Payments) Act

Empowers local authorities to provide cash payments for some clients assessed as needing community care services. They can then use the money to purchase their own services.

1999 National Service Framework for Mental Health

The framework sets national standards, based on clinical evidence, and sets out best practice for promoting mental health and treating mental illness. The framework recognises that family carers may have their own needs and specifically mentions young carers.

2000 Care Standards Act

Establishes the National Care Standards Commission in England and the Care Standards Inspectorate for Wales, to regulate and inspect services against national minimum standards. Also establishes Social Care Councils to regulate the social care workforce including social work.

A Jigsaw of Services 2000

A report on parenting support for disabled parents, which concludes that professionals' focus tends to be on either the child in the family or on the impact of disability on parents' own needs. A family approach is rarely adopted.

Legislation and policy for carers (Source: Aldridge and Becker, 2003)

Caring for people: Community care in the next decade and beyond White Paper 1989

One of the six primary objectives of community care policy is to make practical support for carers a high priority. Young carers are not specifically mentioned.

Young carers: Something to think about 1995

This was the first document specifically on young carers by the Social Services Inspectorate (SSI), Department of Health. It emphasises a whole family approach, recognising the need for adequate services for ill or disabled parents and a focus on their children's needs. It also acknowledges families' legitimate concerns about professionals' attitudes.

1995 Carers (Recognition and Services) Act

Gives carers of any age, including young carers, the right to an assessment of their ability to provide and continue to provide care. Social services are required to carry out a carer's assessment, if requested, at the same time that they assess or re-assess the person requiring care.

The Act applies to carers who provide a substantial amount of care on a regular basis, but local authorities are left to decide what counts as 'regular' and 'substantial'.

1995 Carers (Recognition and Services) Act: Policy Guidance and Practice Guide

The guidance recognises that 'regular' care should be distinguished from frequent care. It also clarifies the importance of assessment for those who intend to provide care, as well as existing carers. Where young carers are concerned, the guidance acknowledges that the impact of caring may affect a child's health and development and limit educational and leisure opportunities. It also acknowledges that assessment of an ill or disabled parent should focus on how best to support the parent's ability to parent their child. It also states that a young carer may be a 'child in need' as defined under the Children Act 1989 and, as such, will be able to access services under this Act.

Young carers: Making a start 1996

A second SSI report that further acknowledges the need for flexible and coordinated services that cross the boundary between community care and children's services. It also signifies the importance of coordination between social services, health and education professionals, who may be the first to identify the problems faced by young carers and their families.

National Carers Strategy: Caring about carers 1999

The strategy commits the government to improve the situation and support of all carers. A separate chapter on young carers recommends that local authorities should identify young carers; that respite care services should be developed; that professionals need awareness raising and improved training; that the national curriculum should contain relevant material; that there should be a designated link person in every school; that enhanced counselling services for young carers should be developed; and that there should be more young carers projects. The parenting needs of ill or disabled parents are also acknowledged.

National Service Framework for Mental Health 1999

The framework recognises that the needs of those caring for someone with mental health problems are especially high and that they are not receiving adequate services. Once again there is an acknowledgement that parents with mental health problems should be supported in their parenting role and that young carers should be offered services to ensure they have the same life chances as other children. All carers of someone on the Care Programme Approach should have an assessment at least annually and have their own written care plan.

2000 Carers and Disabled Children Act

This Act gives carers over the age of 16 (and caring for someone over the age of 18) the right to request an assessment of their own needs even if the person receiving care does not wish to be assessed. Local authorities may provide services for carers in their own right; carers may receive vouchers for short-term breaks; and carers may receive direct payments in lieu of services for which they have been assessed. Carers under the age of 16 will need to access assessment and services through the 1995 Carers Act or the 1989 Children Act.

Legislation and policy for vulnerable children Source: Aldridge and Becker, 2003

1989 Children Act

Under Section 17 of the Act, social services have a duty to safeguard and promote the interests of children 'in need'. Many young carers may, and have been considered to be children in need. Children are considered to be in need if: they are unlikely to achieve or maintain, or to have the opportunity to achieve or maintain a reasonable standard of health or development without the provision of services by a local authority; their health or development

is likely to be significantly impaired or further impaired without the provision of services; they are disabled. A range of services can be offered to children in need to safeguard and promote their welfare. Local authorities will promote the upbringing of children within the family by providing services appropriate to their needs.

Quality Protects 1998

Quality Protects was launched in 1998 and was a three-year programme (now extended) to transform the delivery and management of children's services. It emphasises better outcomes, with several key changes and eight national objectives. Although the emphasis is on looked after children, its objectives cover all children and families in receipt of services or support from social services. Thus, many young carers will be included. One of the key objectives is to ensure that children whose parents have specific needs arising out of disability or health conditions enjoy the same life chances as other children in the locality.

Working together to safeguard children 1999

Sets out how all agencies and professionals should work together to promote children's welfare and protect them from harm, abuse and neglect. The document acknowledges that parental illness, physical or mental, may result in young caring and that children's social and recreational activities may be restricted.

Government's Framework for the assessment of children in need and their families 2000

The framework provides a basis for collecting and analysing information to support professional judgements about how to help children and families. It specifies how assessments of children should be carried out, concentrating on the child's developmental needs, parenting capacity and environmental factors. The accompanying reader, *A Child's World* (Horwath, 2000), contains a chapter on how the framework should be applied to young carers.

Building a strategy for children and young people Government consultation document 2001

Sets out the government's vision for all children and young people, how they can best achieve their full potential and what support they require. Specialist workshops with young people, including young carers, are held across England.

In addition to the specific legislation and policy for vulnerable children, there is also the UN Convention on the Rights of the Child. Ratified by the UK government in 1991, the Convention consists of 54 Articles relating to children's rights and the implementation of these rights. Although the Convention is binding, there is no judicial machinery to enforce it and no right of individual complaint. Nevertheless, the Convention is useful for professionals working with children where rights are thought to be being neglected. Box 5 outlines the Articles that are particularly relevant to young carers.

The UN Convention on the Rights of the Child

Article 2 covers non-discrimination, protecting children's rights without discrimination on the grounds of race, sex, religion, origin, disability etc. of both children and their parents. Research indicates that many young carers suffer discrimination, in terms of access to information, services and education, as a result of their parents' disabilities.

Article 3 adopts the welfare principle, i.e. the best interest of the child is paramount.

Article 4 relates to the duties of States to implement the rights to the maximum extent *within the available resources*.

Lack of resources should not be used as an excuse for neglecting vulnerable children.

Article 5 relates to parental roles; States to respect the responsibilities, rights and duties of parents.

The lack of support to disabled parents in their parenting role undermines this Article.

Article 17 requires that a child has access to information, especially information that will promote his/her well being and physical and mental health.

Many young carers do not have access to such information and care unsupported because they and their families do not know what help may be available.

Article 24 covers children's right to the highest attainable standards of health.

Young carers can suffer poor health, both physical and mental, as a result of caring.

Article 27 covers children's rights to an adequate standard of living.

Most young carers live in or on the margins of poverty and social exclusion, with illness or disability reducing family incomes and standards of living.

Article 28 promotes children's rights to education.

Article 29 states that one of the aims of education should be for children to develop to their fullest potential.

Research suggests that many young carers experience educational difficulties, miss school and do not achieve their full potential.

Article 31 recognises the child's right to rest and leisure and to engage in play and recreation.

Young carers carry responsibilities not usually associated with children and may therefore have limited time for play and recreation.

The first three boxes briefly outline some of the major laws and policies relating to each of the three groups and it becomes apparent that, along with some overlap between categories there are also some contradictions and tensions. For example, while children are seen as the dependants of adults, and childhood a discrete phase when they should be developing and achieving their full potential, young caring goes against such societal norms. Furthermore, while legislation has been in place for over 30 years entitling disabled adults to assessments and service provision, they are still not receiving adequate services that meet their needs - including their parenting needs - which results in some cases in children becoming carers.

For any young carer there may be a particular combination of laws required to assess their needs and make service provision. This will depend on their age, since although any carer may be assessed under the Carers Act, only those over the age of 16 can receive services in their own right under the 2000 Carers and Disabled Children Act. For under-16s the Children Act will be the correct route to take and, via this route, services can be provided to the family if they will benefit the child. The same caveat applies to the receipt of benefits. Full-time carers caring for someone in receipt of disability living allowance (DLA) may claim carers allowance (formerly invalid carers allowance) provided they are over the age of 16. While under 16s cannot make a claim regardless of the regularity or substantial nature of their caring, their parents will be eligible for child benefit as their children are considered 'dependants'.

As a result of research raising awareness of young caring, specialist support services have been developed to support young carers. However, parenting needs have continued to be overlooked by providers. Some academics and disabled parents (see for example Parker and Olsen, 1995; Keith and Morris, 1995) have argued that this undermines disabled parents and leads to their parenting capacity being questioned. Wates (2002), in a review of social services policies and protocols for supporting disabled adults in their parenting role, found that few departments included parenting roles and responsibilities in eligibility criteria. This results in some disabled

people, who do not meet thresholds for support, having their parenting needs neglected. For some families this will inevitably mean that a whole family approach to assessment and service provision, as preferred by the government and the Department of Health, cannot take place and children are more likely to become young carers. Paradoxically, such children may then be deemed to be vulnerable and 'in need', thus triggering an assessment under the Children Act. This further undermines disabled parents who cannot themselves receive adequate support and services unless their children are judged to be in need of these.

Although legislation and policy have, increasingly over the past few years, recognised the particular needs of young carers, there has been less policy development for ill or disabled parents. While support for existing young carers remains necessary, in the future professionals should be working across agency and departmental barriers to adopt a whole family approach and prevent young caring from becoming established in the first place.

Summary of key points in Resource 3

- There are a variety of laws and policies designed to protect and meet the needs of disabled people, carers and vulnerable children. Sometimes there are tensions within and between these policies and laws.
- Many young carers are denied rights enshrined in the UN Convention on the Rights of the Child.
- Disabled parents' parenting needs are often overlooked, even where their needs for health and social care services have been assessed. This tends to result in them finding some aspects of parenting difficult and may also lead to some children taking on inappropriate caring roles.
- Sometimes it is only when young caring has become established that families can access support from statutory agencies.
- The policy and legal framework for young carers and their families is well developed, if a little complex and at times confusing, although disabled parents' parenting needs have been neglected in the past. Nevertheless, it does provide a useful and fairly comprehensive framework for the support of young carers. Major problems arise, however, in implementation.

Carers UK - registered and head office

20/25 Glasshouse Yard
London
EC1A 4JT
Telephone: 020 7490 8818
Email: info@ukcarers.org

CarersLine 0808 808 7777

(open Monday-Friday 10-Midday, 2-4pm)

Mincom 020 7251 8969

Website www.carersonline.org.uk

Carers Training Unit

The Training Unit at Carers UK is committed to providing courses that reflect real training needs and current issues faced by professionals who work with carers. Research into carers' experiences, the impact of legislation both on carers and on service providers, and other policy analysis carried out by Carers UK ensures that our courses are relevant and up to date.

For further information, or to book online visit www.carersonline.org.uk, or contact the Training Unit Administrator on 020 7566 7632. For details of courses in Scotland please contact Carers Scotland's Training Unit on 0141 221 9141.

Our Training Unit brochure gives full details of courses available. To receive a copy by email contact: training@ukcarers.org.

Are you a professional or carers group?

Do you want to be kept in touch with the latest developments on carers and caring issues? We can send you regular policy and campaign updates, a monthly mailing and two quarterly newsletters.

Why not become an Associate of Carers UK?

For more details please phone our membership hotline on 020 7566 7602.

To receive a form by email contact: janice@ukcarers.org.

YCRG - Contact Details

Young Carers Research Group
Department of Social Sciences
Loughborough University
Loughborough
Leicestershire
LE11 3TU
Administration: 01509 223383
Fax: 01509 223944

ISBN: 1 873747 24 X

Cost: Free - available as a pdf document only

Researched and written by: Chris Dearden & Saul Becker, Loughborough University, Centre for Child and Family Research

Designed by: Rhiannon

Produced: April 2003

Copyright: Carers UK 2003

Registered and Head Office: 20-25 Glasshouse Yard, London EC1A 4JT

Telephone: 020 7490 8818 Fax: 020 7490 8824

Registered in England and Wales as Carers National Association number 864097. Registered charity number 246329