

CARERS look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

POLICY BRIEFING

Children and young people who have caring responsibilities

Carers UK's definition

Children and young people who have caring responsibilities (often referred to as young carers) are young people, aged under 18, whose lives are in some way restricted because of the need to take on inappropriate or excessive responsibilities for the care of a person who is ill, has a disability, is experiencing mental distress or is affected by substance misuse.

This situation often arises because of a lack of good quality, appropriate, affordable and accessible health and community care services and a lack of information about how to get assistance.

Having a parent or a sibling with an illness or disability does not mean that a young person would necessarily be a 'young carer'.

The current position

Research indicates that there could be anything between 19,000 and 51,000 young people who undertake some caring responsibilities.¹ Accurate figures are difficult to obtain due to the hidden nature of caring. Young people and their parents are often silent about the extent of the support a child provides, through fear of separation, guilt, pride and a desire to "keep it in the family". The failure services to recognise racial, cultural and religious differences can make the identification of young people with caring responsibilities from black and minority ethnic groups even more difficult.²

The most extensive research on young people with caring responsibilities to date, carried out by the Young Carers Research Group³ at Loughborough University, found that:

- * 1 in 5 young people with caring responsibilities are missing out on school
- * 1 in 3 young people with caring responsibilities who are secondary school

¹ Walker (1996) *Young Carers and their Families* HMSO

² Shah R & Hatton C (1999) *Caring Alone* Barnardos

³ Deardon C & Becker S (1998) *Young Carers* CNA

pupils have educational difficulties such as persistent lateness and lack of time to do homework

- * 1 in 5 young people with caring responsibilities are providing intimate care to another family member, usually a parent
- * 12% are caring for more than one person
- * 1 in 4 young people with caring responsibilities and their families are receiving no other forms of support other than contact with a local young carers project
- * only 11% of young people with caring responsibilities have ever been assessed by their local social services department.

In many cases, no one outside the family seems to be aware that the young person has these responsibilities. This means that these young people often go unnoticed and the family rarely receives much needed services and support.

Legislation

There is no legislation that specifically refers to young people who have caring responsibilities. Guidance has, however, been issued by the Social Services Inspectorate (the earliest of which was CI(95)12). The duties and powers of local authorities to assist young people with caring responsibilities and their families are established in three key pieces of legislation, and further developed in the Department of Health's Policy Guidance and Practice Guidance to the Carers (Recognition and Services) Act 1995.

The Carers and Disabled Children Act 2000

The only group of young people who have caring responsibilities who can benefit from the Carers and Disabled Children Act are those over the age of 16 years who care for someone over the age of 18 years. The Act enables these young people to ask for an assessment of their own needs from their local authority, and for the local authority to provide services to meet those needs. Young people (16+) caring for people over 18 can also receive vouchers and direct payments to help them to have more choice and control over the services they use.

Children Act 1989

The Children Act places specific responsibilities upon Social Services Departments in respect of children in need. Section 17(10) of the Act states that a child should be taken to be "in need" if:

- * he is unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority...; or
- * his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or
- * he is disabled.

Given this definition, in many cases children and young people who have the responsibility of caring for someone will be considered 'children in need'. The annex to the letter to Directors of Social Services from the Chief Inspectorate (1995) states that "many young carers with significant caring responsibilities should therefore be seen as children in need".

Once a child or young person has been assessed as being "in need", the Children Act specifies that a range of support services must be made available. Section 17(1) refers to a general duty to provide a "range and level of services appropriate to those children's needs". For young carers in Scotland and Northern Ireland please refer to the Children in Scotland Act and Children Northern Ireland Order.

Framework for the Assessment of Children in Need and their Families

This guidance produced by the Department of Health, Department for Education and Employment (now the Department for Education and Skills) and the Home Office (2000) specifies how assessments should be carried out. The Guidance has a companion volume of Practice Guidance, which contains detailed material on the way in which the *Framework* should be applied according to principles of best practice. The practitioner is required to look at any child in the context of the whole family.

The *Framework* states: "An assessment of family circumstances is essential. Young carers should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances. It should not be assumed that children should take on similar levels of caring responsibilities as adults. Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities."

Carers (Recognition and Services) Act 1995

This Act came into force in England, Scotland and Wales on 1st April 1996. The Act gives rights to a large group of people, including children, who provide a substantial amount of care and support to relatives or friends on a regular basis. It builds on existing community care legislation, formally bringing carers into the local authority assessment process.

The Act places a duty on local authority Social Services and Social Work Departments to assess the ability of a carer to provide and continue to provide care to the person being cared for. This definition includes young people under the age of 18 and enables them to request an assessment when the person they are caring for is being assessed. However, if a young person does not request an assessment, social services should still consider whether there is a need to assist or relieve the child either through the provision of community care services for the user or through the provision of services to promote the welfare of the child.

NHS and Community Care Act 1990

Although this Act relates primarily to adult services, if it can be proved that services provided would benefit the person being cared for, then services can be provided to that person. Such services might also enable the child or young person to be relieved of some of their caring responsibilities.

The NHS and Community Care Act emphasises consultation and negotiation, and encourages cross-agency collaboration:

“The Children Act 1989 and the NHS and Community Care Act 1990 together provide the necessary powers and duties for local authorities to respond to the needs of young carers. Where the disabled person is a parent, it is essential that the community care assessment focuses on the family and considers how to support the parent and recognises the needs of any young carers. Services for the family can be provided under children’s or adult legislation.

Extract from letter to Directors of Social Services from Herbert Laming, Chief Inspector. Social Services Inspectorate (1995)

Disabled Persons (Services, Consultation and Representation) Act 1986

Section 8 of the Act states: (1) Where:

- * a disabled person is living at home and is receiving a substantial amount of care on a regular basis from another person (who is not employed to provide such care...), and
- * it falls to a local authority to decide whether the disabled person’s need calls for the provision of any services under any welfare enactment, - the local authority shall in deciding that question, have regard to the ability of that other person to continue to provide such care on a regular basis.

The Act does not define “carer” and carers of any age are therefore entitled to benefit from it.

What is Carers UK doing about these issues?

Carers UK has been awarded a three year grant from the Carlton Trust, to progress work around the issue of children and young people who have caring responsibilities. Two important initiatives have come from this to date:

1) Alliance of key voluntary and research organisations

This has enabled us to:

- * assess and review the spectrum of responses to children and young people who have caring responsibilities from the voluntary and statutory sector
- * unpack many of the complex issues around work in this area
- * provide advice and information to families where the young person is carrying out caring responsibilities
- * commission research on specific areas of policy and practice e.g. education

- * make policy recommendations to the Department for Education and Skills (DfES), the Department of Health (DoH), and the NHS etc. that will have lasting impact on families who at present have to rely on their children to provide care for sick or disabled members

Members of Carers UK's alliance of key voluntary and research organisations include:

- * Joseph Rowntree Foundation (JRF) www.jrf.org.uk
- * Young Carers Research Group (Loughborough University) www.lboro.ac.uk/departments/centres/YCRG
- * Disabled Parents Network www.disabledparentsnetwork.org.uk
- * Children's Society www.the-childrens-society.org.uk
- * Barnardos www.barnardos.org.uk
- * NCH www.nchafc.org.uk
- * National Family and Parenting Institute www.nfpi.org.uk
- * Princess Royal Trust for Carers www.carers.org
- * Carers UK www.carersonline.org.uk

2) Advocacy

Carers London Advice and Representation Unit (CLARU) has been able to extend its service for adult carers to young people who have caring responsibilities and their families. Carers London also liases with 'young carers' projects throughout London, via London Young Carers Workers Network meetings. CLARU is able to accept referrals for cases (in London) that need expert support and legal advice to resolve. They can be contacted on: 020 7566 7847/ 7848/ 7849 or carerslondon@ukcarers.org

3) Reaching out to young people with caring responsibilities

- * www.carersonline.org.uk

Carers UK wants to ensure that young people who do have caring responsibilities have access to information about their rights and the support that is available to them, as well as enabling them to engage in the debate. To this end, Carers UK's new website - *Carersonline* - will provide a gateway for young carers seeking this information.

Emerging policy solutions

- * Social services, health, education and the voluntary sector all have a responsibility to ensure that the provision of support and services is both early and positive, and focuses on the needs of the family as a whole. Carers UK believes that supporting either the parent or child in isolation is not

sufficient; support for whole families is essential.

- * The parental role of parents with an illness or disability must be fully recognised and properly supported.
- * The receipt, quality and timing of professional services and support, and the level of family income, are critical to the ability of any family to manage.
- * A delicate, but important, balance must be found between the rights of children under children's legislation, the rights of disabled parents under disability and family legislation, and every family member's rights under the Human Rights Act.
- * Young people who have, or have had, caring responsibilities must be encouraged to maintain contact with appropriate sources of education, careers and employment support during their transition to adulthood. Where young people may have had a difficult, or truncated, experience of education in the past, due to their caring responsibilities, it is vital that they are given a second chance, and their career choices are in no way restricted.

Carers UK's view

Carers UK recognises that some young people will continue to take on caring responsibilities for a disabled parent or family member, as long as there is inappropriate insufficient services and support offered to the family. Carers UK will continue to assist and support children's organisations and organisations of disabled parents in developing appropriate policy and support to lessen the impact of disability, illness or mental health difficulties on the whole family.

Carers UK calls for:

- * Increased practical, financial and emotional support for families in order to minimise the impact of disability on the family.
- * Recognition of the right of children not to provide high levels of care for family members.
- * Increased awareness of the impact of disability on a family amongst all agencies e.g. central government, social services, health authorities, education authorities, GP's etc.
- * Training for social workers, youth workers and teachers about the impact of disability on a family, and the support available locally.
- * More comprehensive assessments of disabled parents and families where there is a disability to ensure that young people do not have unacceptable levels of caring.
- * The inclusion of provision for young people with caring responsibilities when planning future services. This is vital so that support can be provided to enable these young people can take part in 'ordinary' childhood activities, e.g. after school clubs, brownies, sporting clubs etc.

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