The Health and Well-being of Young Carers

Key messages

- Young carers do not form an homogenous group with clearly defined or uniform responsibilities. The amount and type of care they provide can vary greatly, and does not predict how far the health or well-being of each young carer may be affected.

- Several pieces of legislation and guidance formally recognise young carers and define service provision and the responsibility of agencies with reference to this group.

- Only small numbers of young carers are currently being identified or assessed for support. The reasons for this include blurred boundaries of responsibility between adults and children’s services; a lack of awareness among many professional groups of young carers’ needs and concerns; and young carers’ own lack of awareness of their entitlements, and their reluctance to seek formal help.

- The research has found that young carers can experience substantial physical, emotional or social problems, and encounter difficulties in school and elsewhere.

- Many of the studies examine the experiences of young carers who are in touch with Young Carer Projects; they do not report the views of “hard to reach” young carers who are not in touch with either services or projects, or perhaps do not see themselves as young carers at all. The research therefore principally offers general findings on the experiences of young carers who see themselves as such, and who seek help and support.

- Social workers and teachers have been recognised as the people potentially most capable of identifying and supporting young carers, but young carers’ report that they consider themselves to be stigmatised by teachers and their peers, and feel that little support is forthcoming from schools.

- The research consistently reports positive feedback from young carers about Young Carers Projects. In this setting many young carers consider their problems and experiences to be valued, understood and recognised. They prefer support that is non-intrusive and provided by individuals and organisations other than statutory services.
Introduction

This section introduces and defines the scope of the briefing and the topic.

A SCIE briefing provides up-to-date information on a particular topic. It is a concise document summarising the knowledge base in a particular area and is intended as a ‘launch pad’ or signpost to more in-depth investigation or enquiry. It is not a definitive statement of all evidence on a particular issue. The briefing is divided into the different types of knowledge relevant to health and social care research and practice, as defined by the Social Care Institute for Excellence (SCIE) (1). It is intended to help health and social care practitioners and policy-makers in their decision-making and practice.

The topic of this briefing is the health and well-being of young carers. There is no standard definition of the term “young carer”. The National Strategy for Carers defines young carers as “persons under the age of 18 who have caring responsibilities for another family member who is either unwell (from either mental or physical illness) or disabled”. A more detailed definition is provided by the Blackwell Encyclopaedia of Social Work: “Children or 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 normally be associated with an adult” (2). The definition and classification of a young carer is recognised as very important because it carries with it certain rights to services, such as an assessment of needs (3). This briefing considers young carers performing a caring role for parents only, rather than for siblings or other family members. The group of parents considered for this briefing include the physically disabled and chronically ill, and parents with learning disabilities, mental health problems or problems of addiction (3-6).

The term and concept of a “young carer” may be considered controversial because of the possible implication of dependence for disabled or ill parents (7,8). However, young carers is an accepted term in the policy and research literature, and it is not the function of this briefing to examine the debate surrounding the validity or appropriateness of young carers as a term or concept. This briefing is “child-centred”, but may be read in conjunction with the briefings on the issues faced by disabled parents, and what they find helpful, which are “parent-centred” (9,10). In combination, the briefings hopefully offer a balanced examination of the topic.

The nature of the care provided by young carers can be very broad. It can include household tasks beyond what would normally be expected, including sibling care; general care, such as administering medication or lifting a parent; interpreting / translating and helping a parent to learn English; emotional support; or intimate care, such as toileting and bathing (3,11-18). The amount of time a young carer spends in these tasks can vary depending on the nature of the help or support required by their parent. This may be basic physical or intimate care for a parent with physical disability, or emotional support for a parent with a mental health problem or some form of addiction (3,11,14). Young carers do not therefore form an homogenous group with clearly
defined or uniform responsibilities. Also, the amount or type of care does not predict how far the health or well-being of the young carer may be affected. This can depend on other variables such as family structure and support from relatives and other sources (17). Issues considered by this briefing include physical and mental health, psychological well-being, education and social development.

Why this issue is important

This section summarises research findings relating to the prevalence of children and young people as carers in the UK and the key characteristics of this group.

Large numbers of children and young people in the UK are involved in some kind of care for members of their families, often a parent. The most frequently-cited estimate gives a range of 19,000 to 51,000, but this does not define the extent or nature of the care involved (19). Thirty percent of young carers are supporting parents with mental health problems, and more than fifteen percent of young carers are from ethnic minorities (14). However, the actual numbers may be significantly higher because the definitions that may be applied to the concept of young carers and the impact of providing care can be made justifiably very broad and inclusive (5,6,14,20). Young carers can also often be reluctant to disclose their situation either to professionals or to other children and young people (4,21-24), especially if the parent has some form of mental illness (14). An analysis of the 2001 UK census data for all households reported that 114,000 (1.4% of all) children aged 5-15 were providing "informal" care for family members, with 18,000 (6.3%) providing 20 or more hours care a week, and 9000 (3.1%) providing 50 or more hours care a week (25). A further analysis of this data generated slightly higher percentages, identifying a figure of 150,000 young carers in England and Wales (13). The health of 773 of the children aged under 16 who provided more than 20 hours care a week was reported to be "not good" (25). These percentages are broadly comparable with the findings of a recent, large, national survey of young carers supported by specialist young carers projects, although this survey did also record considerably more young carers providing care between 20 and 49 hours every week (13). The average age of young carers in three large surveys was 12 years (13-15). Young carers have been found to provide more care as they grow older, and older children are also less likely to utilise the support of young carers’ projects (13). Typically, caring can be a long-term commitment (13). Research also suggests that more girls than boys act as young carers (4,13,14,16,24). A recent survey found the number of hours caring to be comparable between white carers and carers from black and ethnic minorities (13).

Not all children with ill or disabled parents become young carers: the family may receive all the practical, emotional and financial support that they may need from a range of other sources (3,4,12). Young carers are more common in single-parent families, families suffering social exclusion and enjoying little
support from other family members, and families with unemployed parents or on low incomes (3,5,6,13-15,18,26). Lack of employment can in turn contribute to a family’s poverty (13). In the absence of a second parent, the likelihood of a child performing some form of care for a parent with care needs is increased; in two-parent families a young carer’s responsibilities have been shown to involve looking after siblings more than the parent (13). The presence of a second, non-disabled or ill parent does not necessarily mean a child will not have caring responsibilities, however. For example, young carers may also have to take on caring responsibilities because a second parent has to go to work (5,27). Children are therefore more likely to become young carers for an ill or disabled parent if their family lacks sufficient means of personal or financial support.

Research findings are equivocal on the long-term effects on young people of caring. Being a young carer, especially where personal and practical support is lacking, can affect elements of a child’s transition to adulthood (5,20). The further / higher education and employment opportunities of young carers may also be adversely affected because this group are more likely to experience problems with school work and attendance (5,23). However, there is no evidence of long-term emotional or mental health problems as a result of caring (28). Teachers, social workers and professionals working within primary care, who are in a position to identify and help young carers, reportedly may lack awareness of this group’s responsibilities and needs (17,18,20,21,27,29).

What do the different sources of knowledge show?

Organisational Knowledge

This section lists and briefly summarises documents that describe the standards that govern the conduct of statutory services, organisations and individuals in relation to young carers. The following documents all formally recognise young carers and define service provision and the responsibility of agencies with reference to this group. However, there are no “national standards for the quality and quantity of health and social care support to young carers and their families” (3).

This guidance aims “to assist local councils in making direct payments”. It replaces the passages on direct payments in the Carers and People with Parental Responsibility for Disabled Children Practice and Policy Guidance.
The Carers and Disabled Children Act 2000
This Act gives carers aged 16 and over (and caring for someone over 18) an entitlement to an assessment of their needs and ability to continue to provide care (independently of the care receiver), and a right to services and direct payments in lieu of services (but young carers under 16 have no right to services or support under this Act). Policy Guidance, Practice Guidance, and A Practitioner's Guide to Carers' Assessments, are all available to aid the implementation of this legislation.

This document describes a framework for assessing children’s and families needs to identify "whether the child being assessed is in need . . . and which services would best meet the needs of this child and their family”. The needs of disabled family members must also be considered when assessing needs. Explicit reference is made to the needs of young carers.

Caring About Carers. The National Strategy for Carers 1999
http://www.carers.gov.uk/
This document sets out government policy and seeks to raise awareness of young carers among professionals and promote services to support this group. The strategy makes recommendations for practice but does not define standards. The need to raise awareness of young carers, their needs and responsibilities, is also a major recommendation of the research in this field (17,20,21,24,27,29,30). This strategy also advocates more multi-agency working to help support young carers. Chapter Eight of the Strategy focuses exclusively on young carers.

Human Rights Act 1998
This Act requires that there should be no discrimination in access to services on grounds on disability, the right to marry or have a family, and that cultural and linguistic differences should be taken into account in the provision and delivery of services.

Carers (Recognition and Services) Act 1995
All informal carers are entitled to an assessment of their needs, including young carers, separate from the needs of the person for whom they are caring. This is a duty of local authorities. The assessment must be requested, however. For this to work, young carers and their families have to be aware of services and be willing to approach them.

National Health Service (NHS) and Community Care Act 1990
This Act aims to enable people with physical or other needs to live in their own homes as a result of an assessment of their needs and the delivery of services to support those needs. The Act only relates to people aged 18 or over, but the provision of support to the cared-for parent may indirectly benefit young carers. Local authorities are required by this Act to carry out assessments of the needs of anyone who appears in need of community care services. If the person being assessed is disabled then, according to related legislation cited in the Act, their practical needs for “greater safety, comfort or convenience” must be assessed.

Children Act 1989

If a child does not have the opportunity or is unable to achieve or maintain a “reasonable standard of health or development”, then they are regarded as being “in need”, which in turn means they are eligible for a range of support services. Under section 17 of this Act young carers may be regarded as children in need, although the “reasonable standard of health or development”, is not clearly defined (3). However, the Act does not assume that young carers suffer significant harm simply because they are performing a caring role, and also assumes that children are best cared-for within their own family, and any intervention taken must be beneficial to the child and take account of the child’s wishes. This is important given the frequently reported concerns of both young carers and their parents that the involvement of social services may lead to the child being removed from their family (14,29,31,32).

UN Convention on the Rights of the Child
http://www.unicef.org/crc/crc.htm

This Convention was ratified by the UK in 1991, although there are currently issues relating to enforcement (14). The rights of children cover physical and mental health, education and social welfare. According to the Convention no child or young person should suffer discrimination on the grounds of race, sex, religion or disability, either of the children themselves or of their parents. Young carers may experience such discrimination in relation to access to services and education (14).

Policy Community Knowledge

This section summarises documents and guidance describing proposed structural models for the delivery of policy and improved practice. These documents are published by public policy research bodies, lobby groups, think tanks and related organisations.

Teachernet. Young Carers. Department for Education and Skills
This resource summarises the legal and policy framework for teachers and other educational professionals with regard to young carers, as well as defining best practice in this field.

http://www.carersuk.org/Policyandpractice/Research/yceduc.pdf
This document summarises research findings relating to young carers and education and provides a number of resources for professionals with a role to play in this field. This includes a checklist of questions for teachers or a designated member of staff to ask in order to assess the needs of young carers.

http://www.communitycare.co.uk/articles/article.asp?liarticleid=40748&liSectionID=3&liParentID=2
This book contains a chronology and guide to relevant law and policy affecting young carers, and particularly those children and young people caring for parents with severe mental illness.

http://www.childrenssociety.org.uk/youngcarers/professionals/prof_guide.htm
The hard copy version of this document offers guidance on assessments, service provision, and interventions to support young carers. The online version offers a comprehensive list of organisations which may offer support to young carers in the UK, including Young Carers Projects and relevant government and non-government organisations.

The problem of the boundaries between adult and children’s services is a constant theme of much of the policy and research literature. Research and guidance literature currently advocates the “whole family” approach, which seeks to support young carers and their parents together, rather than focusing exclusively on either the child or the parent (3-8,14). This approach is advocated by both sides in the young carer debate. Identification and assessment of young carers is also a key recommendation of much of the research and policy literature (4,14,17,18,29,31).

Practitioner Knowledge

This section describes studies carried out by health and social care practitioners, documents relating their experiences regarding the topic, and resources produced by local practitioner bodies to support their work.

http://www.lampdirect.org.uk/information/carers.asp
This list of resources has been produced by Leicester, Leicestershire and Rutland councils to define practice with reference to carers, including young carers, and is informed by the National Strategy for Carers. The resources include Carers Practice Guidance. This guidance provides a framework for a joint approach by health and social care to attend to the needs of carers.

Young Carers Resource Pack for Schools
This document aims to “give teachers an overview of young carers’ issues that will supplement their existing skills and expertise”. It includes a summary and description of classroom materials for key stages 2 and 3 relevant to children and young people who are carers. The pack is the result of a collaboration between local authorities, schools and Young Carers Projects in Surrey.

The Young Carers Research Group provides a list of Young Carer Projects in the UK
Title link:
http://www.lboro.ac.uk/departments/ss/centres/YCRG/ycProjects/ycProjects.html

Research Knowledge

This section summarises the best available research literature. The focus is on studies undertaken in the United Kingdom, so that the findings are as relevant as possible to the intended audience of the briefing.

The limitations of the research
The research covers all levels and types of care performed by young carers, and the problems of recruiting young carers for research are acknowledged by some authors (24,29). Consequently, research examines the experiences of young carers who are in touch with Young Carer Projects, and do not report the views of “hard to reach” young carers who are not in touch with either services or projects, or perhaps do not see themselves as young carers at all. The research therefore principally offers general findings on the experiences of young carers who see themselves as such, and who seek help and support, and the impact of caring on their lives and well-being. Not all young carers will experience physical, emotional or social problems, or encounter difficulties in school or elsewhere as a result of their caring responsibilities (7,8,12,17,28,33,34). Adolescence and low socio-economic status creates its own anxieties and problems, so it is difficult to establish how far any adverse effects on health or well-being relate directly to performing a caring role (7,8,12,33,35). Some researchers have pointed out that this limitation applies in particular to studies which focus exclusively on the views of young carers and do not compare the results with control groups of non-carers (7,8,33). However, some studies have utilised such groups and have generated similar findings to the non-comparative studies (6).
What are the positive and negative aspects of caring?
Young carers and their parents report both positive and negative elements to providing care. Many young carers report that caring gives them feelings of maturity, and a sense of closeness to both parents and family; they also value their responsibilities and consider them to be a source of practical life skills (5,6,11,16,18,23,29). These findings have been echoed by parents and service providers (6). Young carers are often happy to perform their role (21,24,29,36) and can see it simply as providing support to the family, rather than something more onerous or distinct (17). Possible negative aspects can exist, however, and these are discussed below.

What is the impact on physical health?
Some young carers say they can become tired as a result of their caring responsibilities (6,12,22,27). They also may experience some physical problems as a result of lifting parents with physical disabilities (23,37). There is no evidence of any other direct effect of caring on the physical health of young carers.

What is the impact on education?
Research findings are mixed about the impact of young carers’ responsibilities on their attendance at school and their performance in education. Some studies have found that young carers report no adverse affect on their schoolwork (6,24). However, many other studies report that young carers experience difficulties in attending school and finding the time or energy to do homework (5,12,13,18,22,23,29,31,36,38). However, none of these studies controls for socio-economic status, which is an important factor in school absences (33). A recent survey reported a decrease in the number of educational difficulties experienced by young carers generally compared to previous surveys, possibly as a result of a growing awareness in schools of young carers’ problems. At the same time it reported an increase in reported problems with school among the sub-group of children who cared for parents with drug or alcohol problems (13). Teachers may be either unsympathetic or can sanction the absence of young carers, rather than seeking to identify support for the child (5,18,21,23). Schools generally do not provide any counsellors or other means of support to help young carers (24,29,36,39,40).

What is the impact on psychological health?
Surveys of young carers found substantial numbers reporting stress, anxiety, low self-esteem and depression (5,6,14,18,23,26). This has also been found in a study comparing young carers with children who are non-carers (6). Several research studies have found that young carers often feel concerned and anxious about their parent’s welfare when they are not there to help look after them (4,29,35), especially if their parent has mental health problems and is at risk of self-harming (11,12,26). Other studies also found that substantial numbers of young carers reported mental health and related problems, such as eating problems, difficulty in sleeping, and self harm (23,35). One study has also made the point, however, that it is not possible to determine how far it is their role as a young carer that is contributing to these problems, or whether other mental health and socio-economic variables are playing the principal role (35).
What is the impact on social development and exclusion?

Many young carers have reported feeling isolated from their peers. They also feel that they lack the time and opportunity to socialise, and can also be reluctant to do so (5,6,14-16,18,23,26,29,31,35,36,40). Young carers also report bullying and anxiety about bullying (21,35,36). This has also been found in a study comparing young carers with children who are non-carers (6). The research has also found that young carers are often reluctant to disclose their situation to professionals or other children or young people (4,6,14,18,21,23,24), although girls have been found to be more willing to share their feelings and experiences than boys (35). Possible reasons for this secrecy include a fear of intrusion into family matters by social services, loyalty to parents, or a fear of ridicule or bullying (11,14,18,22,24,26,31).

The length of time a child performs a caring role may determine how many problems they have with their health, education, social development and well-being. Children and young people who have been caring only for a very short time report few worries or problems, and those who have been caring for “as long as they can remember” report a similar lack of anxiety, possibly because they have developed coping strategies (35). The “middle” group, who have been caring “for quite a long time”, report the most anxiety, possibly because they have increasing responsibilities but are yet to develop adequate coping mechanisms or knowledge of their role (35).

What interventions have been found to be successful?

The research consistently reports positive feedback from young carers about Young Carers Projects: this was the only setting where many young carers considered their problems and experiences to be valued, understood and recognised. Young Carers’ Projects provide support that young carers perceive to be voluntary and non-intrusive (18,22,29). Social workers have been found to be the main source of referral to Young Carers’ Projects (13). However, many of the projects are concentrated in the south-east and north-west of England, with the result that there are large numbers of young carers who have little or no access to this form of support (14). Most of these projects are provided by the voluntary sector with only short-term statutory funding and are therefore vulnerable to closure (3).

What services are provided for young carers?

The Carers (Recognition & Services) Act 1995 and the Carers and Disabled Children Act 2000 both require Social Service Departments to assess all informal carers in their locality as long as they are providing or intend to provide “a substantial amount of care on a regular basis”, and to provide services to support these carers, as long as they are aged 16 or over. It is unclear what constitutes the level of “substantial” or “regular” care required by the Acts; details of the definition remain at the discretion of local authorities (14,41). For example, the Acts do not distinguish or prioritise between intimate care and general care, and children who provide emotional and other support to parents with mental health problems can be missed by this criteria (20,38). Assessment requires social workers who are trained specifically to assess the needs of young carers (30). However, the research has found that few young
carers are actually assessed (4,13,14,17,18,29,31), although numbers are increasing (13). Where young carers are assessed, the assessment is most often conducted under the Children’s Act (1989). Young carers from black and ethnic minorities were found to be more likely to be assessed, and also tended to be assessed under the Carers Act (1995) (13). Young carers who fail to attend school, have only one parent, or have a parent with drug or alcohol problems, are also more likely to be assessed than others (13,38). In the case of parents with problems of drug or alcohol addiction, the larger numbers of assessments may be due in part to potential child protection issues (13).

One study reported that the majority of support or assistance for young carers and their parents came from members of their extended family or neighbours (6). A study assessing the support for young carers in black families found that they were receiving no external support at all, including from Young Carers Projects (17). As many as a quarter of young carers and their families rely entirely on Young Carers Projects for support (13,14). This reflects in part issues surrounding the definition of the term young carer, and also the failure to identify possible beneficiaries of the available services. A lack of awareness among health and social care professionals and teachers of the nature and possible implications of caring by young people was a possible reason for this (4,17,21,30,42). Young carers themselves can also be unaware of their right to be assessed (39,42). However, social workers and teachers have been recognised as the people potentially most capable of identifying and supporting young carers (29). The lack of assessments may also be due to problems created by vague boundaries of responsibility: children’s services may consider that funding for care should be provided to the parent rather than the child, and so be the responsibility of adult services (17,18,41). Parents may also be reluctant to seek support because they fear their children may be classed as “in need”, and services may focus on the child alone rather than the family as a whole (17). Studies have also found that services did not take sufficient account of the cultural and religious needs of the family and young carer (17,18).

User & Carer Knowledge

This section summarises the issues raised by service users and carers in relation to this topic, both as described by the literature and as defined through local consultation.

How do young carers view their role?
Young carers’ views about their role and needs are diverse. A consultation with twelve young carers conducted for this briefing reported both positive and negative experiences of caring. They felt that their role caused them anxiety, and imposed social and practical limitations. However, they also reported that their role taught them tolerance, independence and increased self-awareness.
How do young carers view statutory services?
Young carers and their parents have reported that they would like more shared care and respite care, and more counselling and emotional support (6,17,18). This was also echoed in the consultation with young carers conducted for this briefing. One study also found that they wanted easier access to information about disability and medical conditions (6). In another study, however, young carers reported that they preferred not to know too many details of certain conditions, and parents were also reluctant to divulge too much information to their children (26).

Several studies report that young carers and their families consider the support provided by social services to be intrusive and of limited value (5,17,18,22,24). The consultation with young carers conducted for this briefing also found that they thought social services were not a good source of support. Young carers also say that services tend to be slow and rigid in their delivery (39). The same study also reported cases where adults’ and children’s services worked in isolation and failed to communicate or collaborate effectively, with the result that appropriate services failed to be provided for children who were carers (39). Studies have also found that young carers felt that professionals and others had little understanding of what was happening within their family, and that their own knowledge and concerns about their parents’ situation were often ignored or dismissed (11,14,16,18,23). Also, young carers often did not seek help or support because they feared being taken into care or losing their parent to hospital (14,17,29,31,32). The consultation with young carers conducted for this briefing also found that these young people valued confidentiality from support services, and wanted services designed specifically for them, and separate from the support provided to their parents.

How do young carers view their schools?
A survey of young carers’ views found that they considered themselves to be stigmatised by teachers and their peers, and felt that little support was forthcoming from schools (39). Once again, the consultation with young carers conducted for this briefing confirmed that these young people thought schools could be more understanding of their situation, and offer them more support. Some also felt that homework and schoolwork was relatively unimportant because they had so many other things going on in their lives. Where schools offered mentoring services, however, these were considered to be helpful. In terms of the future, these young carers wanted get a job and earn money, but thought they needed help in doing so, such as support in gaining work experience.

How do young carers view Young Carers Projects?
The research consistently reports positive feedback from young carers about Young Carers Projects (18,22,29). This was the only setting where many young carers considered their problems and experiences to be valued, understood and recognised; and where they felt accepted and not judged. These findings were also reported by the young people consulted for this briefing, not only in relation to Young Carers Projects, but also for NSPCC support services.
Useful Links

This section lists sources of information relevant to services users and professionals who work within this field.

Carers UK
http://www.carersonline.org.uk/
This organisation provides information and training for professionals working with young carers.

Caring about Carers
http://www.carers.gov.uk/Index.htm
The government website on carers. It makes available copies of much of the legislation, as well as summaries of and frequently asked questions about government policy.

Children and Families. Department for Education and Skills
http://www.dfes.gov.uk/childrenandfamilies/
This document provides links to a range of government and non-government bodies and organisations. This was formerly Quality Protects.

Connexions
http://www.connexions.gov.uk
This is a support service for young people aged 13-19, especially those who experience disadvantage or emotional difficulties. This includes young carers. The service offers personal advice and guidance to young people.

Princess Royal Trust for Carers
http://www.carers.org/home/
This organisation aims to offer information and support to all unpaid carers throughout the UK. The “Help for Carers” section has pages specifically for young carers.

Social Exclusion Unit
http://www.socialexclusion.gov.uk/
The Social Exclusion Unit works mainly on specific projects, chosen following consultation with Ministers and interested groups. The Unit forms part of the Government's strategic multi-agency approach to tackling social exclusion.

YC Net
http://www.youngcarers.net/
This is a website recently launched by the Princess Royal Trust for Carers specifically to provide advice, information and support to young carers on their responsibilities, concerns and anxieties. The site also includes sections for health, social work and education professionals, as well as parents.

Young Carers Initiative. The Children’s Society
http://www.childrenssociety.org.uk/youngcarers/info/index.htm
This initiative aims to provide advice, information and support to young carers. The site includes a list of young carers projects in the UK with their contact details, as well as other relevant organisations.
Young Carers Research Group (YCRG). Loughborough University and the Institute of Applied Social Studies, University of Birmingham.
http://www.ycrg.org.uk
The aim of the YCRG is to conduct high quality research, evaluation and consultancy on all matters relating to young carers, and to advance knowledge and inform the development of policy and good practice.

Young Minds. Young Carers.
http://www.youngminds.org.uk/youngcarers/
This is a brief section with resources and links relevant to young carers.

Related SCARE briefings

Helping parents with a learning disability in their parenting role
http://www.elsc.org.uk/briefings/briefing13/index.htm

Helping parents with a physical disability or impairment in their parenting role
http://www.elsc.org.uk/briefings/briefing14/index.htm

Parenting capacity and substance misuse
http://www.elsc.org.uk/briefings/briefing06/index.htm

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Thank you also to the other reviewers and service users for their contributions to this briefing.
Reference List


This document analyses and defines the different types of knowledge and information which may inform social care research and practice.


This entry defines the term and concept of young carers.


This article reviews the main research studies on young carers in the UK, examines the services available to support young carers, and identifies the implications for future policy and practice, particularly in social care.


This book reviews the literature on young carers and other groups in relation to parents with mental illness, and offers a guide to relevant law and policy. It reports the findings of an in-depth qualitative study looking at the experiences and needs of children who care for a parent with mental illness. It also gives the perspectives of both parents and professionals.


This study examines the extent to which caring can influence young people's decisions and activities in relation to education, training and employment, leaving home and becoming an adult. It also looks at the impact of community care policies and services on these young people.

disability. Disability and Society, 16 (6), 797-814.

This paper reports on two studies examining the nature of the role performed by young carers and its impact on their lives. A Critical Appraisal of this article is available


This paper reviews and critically examines research on young carers.


This paper challenges the construction of the concept of 'young carers' employed by researchers and policy-makers.


This is a research and policy briefing describing the issues faced by parents with learning disabilities and what they find helpful.


This is a research and policy briefing describing the issues faced by parents with physical disabilities and what they find helpful.


This is a brief report of a two-year study looking at the needs and experiences of young carers who have parents with severe mental health problems.


This report looks at the effect of caring on young people's education.

Report of the third national survey of young carers who are being supported by Young Carers Projects in the UK.


Second of a series of extensive surveys of young carers.


First of a series of extensive surveys of young carers.


This article offers an overview of the experiences and characteristics of young carers with reference to the findings of a small-scale qualitative study.


This study investigates the experiences and needs of young black people caring for disabled or ill family members and their access to services.


This study examines the experiences of young carers in South Asian communities who were in contact with two Young Carers Projects. A Critical Appraisal of this article is available


This is a survey for the Department of Health carried out by the Social Services Division of the Office of National Statistics.

This book examines the background to young carers, their situation, their rights and their needs. It uses case studies to illustrate experiences, relationships and dynamics. It also discusses the effects of caring on the young person’s health and psychosocial development, and considers the policy and legal context for young carers and their families, offering guidance on how best to implement policy.


This is a study on the prevalence and effects of bullying on young carers.

(22) Banks P., Cogan N., Riddell S., Deeley S., Hill M., Tisdall K. (2002). Does the covert nature of caring prohibit the development of effective services for young carers? British Journal of Guidance and Counselling, 30 (3), 229-246.

This paper discusses the implications of the findings of reference 6 for the field of guidance and counselling.


This survey reports on the experiences of former carers. A Critical Appraisal of this article is available.

(24) Eley S. (2004). 'If they don't recognize it, you've got to deal with it yourself': gender, young caring and educational support. Gender and Education, 16 (1), 65-75.

This article discusses the findings of a small-scale, localized, qualitative study on the views of children and young people who are acting as young carers. A Critical Appraisal of this article is available.


This article provides a brief analysis of the caring responsibilities of young and elderly carers in the UK based on the 2001 census. Full text available: http://bmj.bmjournals.com/cgi/content/full/327/7428/1388

This article reports the findings from a Young Carers Project in Glasgow, set up specifically for children caring for parents with mental health problems.

A Critical Appraisal of this article is available


This book examines the needs of young carers, and considers the impact this responsibility has on their social, personal, emotional and educational development.


This US study investigates the mental health of adults who were previously young carers.


This paper is a small-scale qualitative study seeking the views of young carers about their role and experiences.

A Critical Appraisal of this article is available


This article reports on the need for training for health professionals and teachers in the needs of young carers.


This paper highlights the "common experience" of two groups of young people, especially with reference to social exclusion.


This article reports on a Young Carers Project in Wales.

This paper reviews and critically examines research on young carers.


This study explores the experiences of children brought up in a family headed by a parent or parents with learning difficulties.


This paper reports on a research study exploring the worries and problems of young carers in Edinburgh. A Critical Appraisal of this article is available


This book describes the views and experiences of young carers and their relationships with adult professionals.


This article briefly examines some of the effects of caring on the physical health of young carers.


This article presents the results of the survey reported in reference 14 and places them in the context of current policy and legislation.

Underdown A. (2002). "I'm growing up too fast": messages from young carers. Children and Society, 16 (1), 57-60.

This paper provides a general overview of the reported views of a survey of young carers.

This article profiles a case where a school nurse was able to offer support to a young carer.

(41) Leece J. (2002). Extending direct payments to informal carers: some issues for local authorities. Practice, 14 (2), 31-44.

This article discusses the practical issues involved in the implementation of the Carers and Disabled Children Act (2000).


This article discusses the lack of awareness of young carers' entitlements among professionals and young carers themselves.