

Experiences of children and young people caring for a parent with a mental health problem

By Diane Roberts, Mim Bernard, Gabriela Misca and Emma Head

Key messages

- The total of 175,000 young carers identified in the 2001 UK Census is likely to be a substantial underestimate.
- Over one third of young carers provide care for someone with a serious mental health problem who is their parent or holds a parental role.
- Mothers are more likely to suffer mental health problems than fathers, and care for mothers is most often given by a female child.
- The unpredictable nature of some mental health problems can create difficulties for young carers whose behaviours are not always correctly attributed.
- The high level of stigma attached to mental health problems may lead young carers to exclude themselves from social involvement.
- The needs of young carers could often be better met by validating their input, concerns and skills.
- The education system can play a major role by recognising the impact of the caring role on children and young people's experience of education, and making appropriate onward referrals.

What is the issue?

Children and young people with caring responsibilities are often referred to as 'young carers' and this is the term used throughout the briefing. This briefing focuses on the experiences of children and young people under 18 years of age caring for a parent or parents defined as having mental health problems that are 'serious' or 'severe', and 'enduring'.¹ It does not consider 'dual diagnosis' or 'substance misuse', as these topics are scheduled to be the subject of future SCIE briefings. A number of issues also arise from notions of 'safeguarding' children and young people but 'safeguarding' is not the primary focus of this briefing and is therefore discussed only briefly and from the perspective of the young carer. In addition, the nature and effectiveness of interventions or services are outside the scope of this briefing. These are currently the subject of a systematic review being conducted for SCIE by the Social Policy Research Unit at the University of York. Comments on interventions and services are, therefore, confined to the practical and emotional impacts of services as they are experienced by young carers.

It is important to note that the definition of 'young carer' varies across the literature and is contested for a number of reasons. These include:

- the fact that an all-encompassing definition of a young carer as someone 'under 18', includes very young children as well as teenagers
- whether, in principle, a child can or should care for a parent
- whether those under 18 should be *allowed* to adopt the role
- whether the definition is sufficiently inclusive, as some caring roles are difficult to define
- whether 'formal' social care provision is better placed to provide the necessary services
- whether labelling care activity in this way intrinsically diminishes its value.²

The 2001 Census³ highlights the existence of some six million carers in the UK, with 175,000 being defined as 'young carers'. This figure is likely to be a substantial underestimate, not least because for many children and young people their caring role is hidden^{4,5} and they are not identified as 'carers', either formally or by their own self-definition.⁴ Moreover, the 2004 report on Young Carers in the UK shows that nearly a third provide care for someone with a mental health problem, usually a parent and, most commonly, a mother.⁶ This report also reveals that 114,000 young carers are between the ages of five and 15, raising important practical and ethical questions about the competency of the child as carer, and the age-appropriate nature of the caring tasks being undertaken.

Why is it important?

The nature of social care provision in the UK means that a high proportion of care is delivered by 'informal carers' who are often

family members.⁷ Carers' rights and needs, as distinct from those for whom they care, have attracted increasing interest and concern and are now more widely acknowledged by practitioners, academics and policy makers.⁸ Key legislation has included the Carers (Recognition and Services) Act 1995, and the Carers (Equal Opportunities) Act 2004. Young carers, however, combine the role of 'child' and 'carer' and the interest in carers' rights now includes a specific focus on the potentially different, or additional, rights and needs of young carers. Important factors include the age of the carer, their relationship to the recipient of care, the reason for the need for care, and the nature of the care provided. Consequently, potential tensions exist between the rights of the person in receipt of care, the rights of the 'child' (as enshrined in the UN convention), and the rights of the 'carer'.⁹

Differences in the concepts underpinning various pieces of legislation and guidance also produce anomalies, particularly where young carers are concerned. For example, the guidance published alongside the 2004 carers' legislation states quite clearly that young carers, as legally-defined 'children in need', have rights which should primarily be assessed under the Children Act 1989.⁷ This legislation places emphasis on young carers' status as 'children' who have rights as 'non-adults', including the right to receive care from parents rather than the reverse. In addition, and in stark contrast, young carers are, as carers, entitled to an assessment for service provision under the Carers (Recognition and Services) Act 1995 or the Carers (Equal Opportunities) Act 2004, both of which have primarily been drafted with adult carers in mind.

Underlying these legal measures is an ongoing debate on the value of 'informal' caring roles in maintaining the stability of the social care system and providing acceptable

forms of care.¹⁰ Care provided for parents with mental health problems may, however, differ in key ways from that provided for other care recipients. Sophisticated drug regimes and the replacement of institutionalised, custodial care with community-based care, for example, mean that increasing numbers of people with mental health problems are co-resident parents.⁵ They therefore live in the same household as their children, who often act as carers³ but remain potentially vulnerable, making it necessary to consider who is providing 'informal care' and on what basis. Despite a growing realisation of the importance of the connection between child care and mental health care, services which use whole-family approaches remain the exception.¹¹ This therefore constitutes a significant issue for both child and adult mental health services.

What does the research show?

In line with increasing awareness of the needs of young carers, the 2004 report on Young Carers in the UK shows that there has been a considerable expansion of support projects – from 36 in 1995 to over 200 in 2003⁶ (and now reported to be more than 350). Through better identification, the numbers of young carers known to such projects has increased from 641 in 1995 to over 6,000 in 2003 and, in half of all care-giving situations examined, parental mental health issues are the trigger for care need.⁶

Furthermore, in over half of these cases, it is the mother of the family who is in need of care and, if she is the lone parent, this ratio rises to nearly three-quarters. In addition, this research provides statistics relating to how care-giving is split between boys and girls, the type of care each gender provides, who is in receipt of care, the age of the carer relative to their siblings, and the hours spent on each type of care task over the course of a week.⁶

While quantitative surveys and evaluations are important, they do not take account of 'hidden carers' and/or those who do not involve themselves with support groups.^{12,4} They have also tended to overshadow examination of the nuances of lived experience,^{13,14,15} issues which are now beginning to be addressed through qualitative studies focusing on young carers.^{16,17,18} Qualitative studies may, however, be criticised for their small sample sizes, their potentially unrepresentative research populations¹⁹ or for the questionable priority given to the caring role over the impact of other social factors.²⁰ By contrast, defenders of such small-scale studies maintain that the findings provide valuable evidence for addressing the wider needs of young carers.²¹ Combining evidence from both surveys and interviews thus allows more accurate conclusions to be drawn about the factors present in care-giving by children or young people, and the ways in which these can differ depending on the condition which gives rise to the need for care.⁸

Who cares and how?

The 2004 report on Young Carers in the UK⁶ is, to date, the most comprehensive source of information about the caring responsibilities of those under 18 years of age. It includes over 6,000 responses (though it is limited to participants drawn from young carers' projects). Despite its size, however, the sample is unlikely to be fully representative of all young carers because substantial numbers of children and young people in caring roles do not appear in 'official statistics' as they cope without support, or wait a long time for it to become available.⁴ The issue of support is crucial and, even where young carers are involved with a project, nearly 25 per cent have no other form of support available to them.⁶

The report also shows that young carers from minority ethnic groups are under-represented in

the survey figures and are less visible to projects.⁶ The likely reasons for this include the stigma attached to mental health problems in black and minority ethnic (BME) communities.²² However, once identified, they are more likely to have received a formal assessment and be in receipt of services.⁶ Current research therefore leaves unanswered questions about the lived experience of children and young people from minority backgrounds.⁴ A joint project involving both study and consultation with young people, family members, agencies, practitioners and managers, indicates a number of areas worthy of further investigation in the context of BME families.²² These include cultural differences in the perception of the caring role, the impact of professional assumptions and discrimination, and recognition of needs around interpretation.

The national survey on which the 2004 report is based shows that the involvement of girls is higher than boys in all aspects of care, but that this also increases with age, particularly for domestic care (cooking, cleaning, laundry) and intimate care (bathing, dressing, toileting). The amount of time spent caring and the 'age-appropriate' nature of domestic tasks also changes across age groups, with the result that an older boy or girl is likely to be more heavily involved with caring activity than a younger child who may be physically, emotionally or intellectually unable to undertake certain tasks.

The provision of domestic and emotional care (observation, supervision, support) is the most common, while intimate care (toileting and dressing/undressing) is undertaken by a minority of young carers of parents with mental health problems. The data also show that levels of emotional care-giving remain very similar for both boys and girls in all age groups.⁶ Parents may, for example, be routinely depressed and, as a result, be unable to perform the household tasks necessary to support the family

effectively.²³ In other instances, their condition may produce unpredictable but critical points at which their ability to function and complete various tasks is compromised or negated.²⁴ In both of these scenarios the young carer must, of necessity, have strategies for dealing with the situation. Whether this is providing physical and emotional support for a parent going through a psychotic episode, fitting regular domestic tasks or sibling care around a full day at school, or providing emotional support on a preventive basis, is a matter for family negotiation.²³ The 2004 report concludes that the impact of additional domestic care duties is likely to be greater for girls and young women because:

- more female parents are affected by mental health problems than male parents
- girls are more likely to provide emotional and domestic care than boys
- girls are more likely to care for a female parent at any age.⁶

What other research also clearly shows is that young carers need their experiences and input to be validated by appropriate acknowledgement and support.^{24,8}

Stigma and social exclusion

The nature of caring is often such that young carers can disappear from the 'normal' social radar to the extent that they become a 'seldom heard' group within the overall population.²¹ If they continue to fulfil the caring role and do not demand interventions in their own right, there is often little likelihood that they will come to the attention of anyone outside their immediate domestic circle.⁴ Children and young people caring for a parent are, for example, less likely than other carers to be offered a carer's assessment.⁴⁹ In addition, parents with mental health problems and their children face particular barriers in accessing support to meet their needs.²⁵

Mental health problems themselves are often not 'overt' or obvious, and can be intermittent rather than constantly present, thus becoming invisible in a way that physical or sensory disability is less likely to be. This invisibility can create difficult situations for young carers when the existence or dynamic of the caring relationship is misunderstood by observers.⁵ There is also a sufficiently high level of stigma attached to mental health problems that a child or young person caring for a parent with these difficulties may deliberately disengage from social involvement because they associate with their parent's illness.²⁶ This may be as simple as not taking friends home, but lack of social involvement may also be the result of an inability to include social activity in their daily routine or because they feel unable to leave their parent.¹⁸ It can therefore be difficult for young carers' needs to become visible and, in order to encourage effective identification and assessment, the Cabinet Office has emphasised the value of 'whole-family approaches' that cross boundaries between children's and adult's services.²⁷

Other research indicates that mental health and other practitioners have not always acknowledged clients as parents, or their children as carers, in a positive and supportive way.²⁸ The Every Child Matters agenda,²⁹ coupled with the Common Assessment Framework,³⁰ change the approach that is demanded from professionals. They are now expected to achieve particular outcomes and the Framework for the Assessment of Children in Need and their Families³¹ specifically includes a section on young carers. This latter policy clearly directs attention to the balance between parenting capacity, environmental factors and child development.

Duty, freedom and interdependence

A recent SCIE review also shows that many young carers are not only at greater risk of

disadvantage in a number of areas ranging from educational attainment to general health and wellbeing, but that much of the research examined makes negative assumptions about the effects of the caring role.³² The term 'young carer' is, for example, often assumed to imply an inappropriate level of duty or obligation to the parent or family group, though this may be disputed by young carers themselves.¹ Some young carers acknowledge that while care-giving tasks can appear onerous or restrictive, the caring role is an accepted family role and, often not a burden but a source of pride.^{33,34}

Research indicates that the caring role can be a major factor in causing disadvantage, but is less clear about the direct impact of caring compared to wider social disadvantage such as unemployment and living in poverty.¹⁹ There is also the potential that risks could be minimised through better support for parents and through forms of carer support such as 'befriending'.³⁵ However, because of their age or lack of access to transport, young carers are not always able to use facilities and services to their best advantage. Befriending schemes therefore use adults as companions to facilitate young carers of all ages in using their 'free time' to pursue hobbies, study or other activities. Providing the opportunity to pursue leisure interests can reduce the physical and emotional stresses of caring and, thus, potentially, enhance young carers' ability to improve educational achievement.^{28,26,36}

While professional ideas about the effects of caring on children and young people regularly place a high emphasis on risk associations such as potential aggression, inappropriate access to medicines, or the inclusion of children in delusions, this perception is not commonly shared by the children and young people concerned.^{20,28} Despite a tendency for professionals to perceive parents with mental health problems as having a questionable level of

parenting capacity, most young carers maintain a clear sense of their position as 'child'. This applies even where the tasks undertaken are unusual for children of their age and despite modern notions of 'childhood' which lead to the caring role being identified as 'parentification' and, thus, a role reversal,³⁷ or of 'growing up prematurely'.¹⁷ In other research, the caring role has been shown to provide not only obligations, but also the opportunity for the child or young person to develop and mature in positive ways in terms of their confidence levels, organisational abilities or in approach to family discipline.³⁸

These contrasting viewpoints are increasingly being overtaken by notions of *interdependence* in which care-giving tasks are constructed as a contribution to the family or parent/child relationship, equalled by the contributions made by the parent. On this basis, the delivery of care for those with mental health problems may become one which is regularly, if informally, negotiated to reflect the changing needs of the parent but where the young carer retains the role of 'child' in the overall relationship.²³ While there is some evidence to show that this can present difficulties with becoming independent of the parent when older, it is not inevitable.³⁹ The 'real world' skills acquired in the caring role, particularly where it is well-supported in appropriate ways, can also facilitate the transition to adulthood and lead to very positive outcomes for young carers.³⁹

Education, training and work

However, research also shows that some young carers are known to be at risk of lower educational attainment because of interrupted school attendance, reduced performance, or inability to participate in school activities alongside their peers.⁴⁰ Many young carers find the balance between home and education extremely difficult and, although some go on to

further education, it is more common for young carers to have poor qualifications or none at all.³⁹ This is often exacerbated by the high emotional support element of caring for a parent with a mental health problem, which is unpredictable and prevents forward planning.²³ Reduced levels of academic achievement, despite what is often greater maturity and coping ability within the individual, tends to restrict young carers to lower paid jobs and occupations that utilise the skills acquired in the caring role.³⁹

Children of parents with mental health problems will also often hide their caring role from their peers, as they feel they are at increased risk of bullying if the nature of their parent's disability is known.⁴⁰ Interview evidence from young carers indicates that school rarely provides an environment in which professionals accurately and routinely observe and identify behaviours that may indicate need on the part of the child or young person.²⁶ Young carers attribute this to a lack of awareness about the realities of caring on the part of education professionals. As a result they cite bullying, fatigue, lateness and inability to meet deadlines as points at which their needs could have been better investigated and responded to. They also clearly identify a need for the education system to provide more flexibility, to allow them to balance their participation with care needs. Examples include negotiable deadlines, access to additional support with curriculum content, access to pastoral support at times of stress, and a general willingness to treat the realities of their care-giving role as a legitimate reason on occasions when they are unable to comply with the demands placed on them at school.⁴¹

Many of the above points are, of course, applicable to young carers in any capacity but, for those caring for a parent with a mental health problem, they can be exacerbated by the increased need for emotional care-giving. This

emotional care can range from a simple, upbeat conversation to trying to prevent a parent from committing suicide or inflicting self-harm.⁴ Children are also not always conscious of the level of support they provide simply due to their co-residency. Its importance may be hidden by parents who do not wish to frighten them with the extreme alternatives they would have considered, had children not been available to them at difficult times.¹ In addition, where levels of care fluctuate as a result of mental health problems which are intermittent or unpredictable, this poses a further obstacle to the establishment of a successful home-school routine.²⁸

Information and input

A key area that research highlights is the need for young carers to receive age-appropriate information and for their input to be validated through appropriate acknowledgment.^{2,42} Interviews with young carers consistently include references to 'not being listened to' and 'not really understanding what was going on'.²⁸ Research in the US, Australia and the UK confirms the importance of accurate and age-appropriate information about parents' conditions.⁸ This helps young carers to understand their parent's reactions to them, which may appear bizarre or even cruel, and to reduce what are often unfounded fears that they may develop the illness themselves.^{8,13} Although there is evidence to show that some young carers develop mental health problems in adolescence or adulthood, this is by no means a universal outcome.^{16,43,44}

Understanding what is happening around them, or the myths and realities of what is likely to occur in the future, helps young carers to make sense of what can be a very complicated world: one in which they not only have to respond to their parent's need but also to balance the other requirements of the household. For example, they may undertake household administration

like bill-paying, but find this particularly difficult where they are trying to conceal their parent's condition from those in authority.²⁸ This may be because, as minors, they do not have the legal authority to implement the actions needed, or from fear of unwelcome child protection measures. One area cited is the reluctance of some professionals to accept or recognise a young carer's input to discussions about parental treatment, despite the fact that they may know more about their parent's health status than others around them.¹⁸ (This has been addressed by the Children Act 2004, which includes the provision for children to be involved in decision-making.) This is particularly important as exclusion may also contribute to a fear of separation where the parent is hospitalised.⁴⁵

Implications from the research

For organisations

When addressing perceived need and setting up appropriate responses, organisations need to consider the areas that young carers themselves identify. Young carers most appreciate the provision of facilities which enable them to understand what is happening in their families and which allow them to manage those demands.^{28,20} They identify the provision of practical responses such as:

- information about their parent's condition and any proposed care or treatment plan as it relates to either the parent or the rest of the family^{1,45}
- inclusion in planning so that they are able to provide their observations about their parent's health status¹⁸
- flexibility from education professionals to provide the time and a suitable environment to complete schoolwork if needed^{40,46}

- befriending schemes which provide access to an adult who is not an 'authority figure' and enable them to follow a personal interest or simply enjoy time outside the home without guilt³⁵
- support groups where young carers can pursue social opportunities amongst others who share and understand their circumstances,²⁶ in addition to gaining access to a variety of services including information, advocacy and accurate, timely advice.

For the policy community

Guidance should continue to encourage a more holistic view of family assessment which would acknowledge not only the capacity of the parent to 'parent', but the resilience present within the family unit.²⁴ This should also facilitate a move to a less negative and more supportive response to people with mental health problems as parents, rather than as clients who, coincidentally, have children. The current inconsistency in recording whether clients/patients are also parents, should also be addressed so that it becomes a compulsory part of record-keeping. This would better enable statutory authorities in both health and social care to acknowledge and address the needs of the whole family.⁴⁷

For people with mental health problems, their role as parent remains important even though it may be difficult to fulfil on all occasions or in all ways.⁴² Flexible and creative ways of providing parenting support have the potential to relieve young carers of some of the tasks which they currently undertake. For many parents, the flexibility and emotional support provided by their children is key to their health and wellbeing. Young carers should therefore be seen as a part of the solution and supported accordingly.⁵ Some of the other practical difficulties young carers have in undertaking their role, such as operating household bank accounts when parents are

unable to provide suitable authorities, could also be addressed by the policy community.¹⁸ A legal power with some similarities to the Power of Attorney that can be granted to adults would be useful in such situations.

For practitioners

The importance of a holistic perspective on family assessment is fundamental to providing appropriate services to both parents and children in families dealing with mental health problems. This is not to deny that some children will be at risk from parents with mental health problems, either as carers or as members of the family, or to minimise the importance for practitioners of adherence to the requirements of the Children Act. The child's welfare is paramount within the requirements of the Act and issues of 'safeguarding' pose undoubted challenges to practitioners, but the potential for the caring role to provide benefits to parent, family and child should not be ignored.

In considering the ability of a family to cope with their situation the value of co-resident children in providing both reactive responses and preventive support should not be underestimated.^{18,5} The care a child is able to provide for a parent may, for example, underpin the implementation of a successful treatment regime where the child, acting as carer, monitors medication. The term 'mental health problems' also covers a variety of diagnoses, some of which pose a greater risk than others to children and carers because of potential aggression or the inclusion of children in delusions. Recognising this, alongside the age and capacity of the young carer, is fundamental to practitioners' assessment of risk and resulting responses. Assumptions of risk should, however, be avoided as research indicates that children are not automatically at risk and may have better specific knowledge about how to deal with the situation.¹⁸

Although this briefing does not explicitly consider interventions targeted at parents, the provision of such interventions is of potential benefit to all children in the family, including those who are young carers. In addition, providing young carers with relevant information about their parent's condition, treatment regimes or ways of coping with difficult situations has also proved to be a very positive part of the practitioner–family relationship.^{1,16,24,45} Sharing of information in multi-disciplinary settings is therefore strongly indicated to ensure that factors of concern in one discipline are adequately acknowledged and addressed across the team.⁴⁸ Policy guidance also reflects the value placed on this approach, despite an acknowledgement that inter-disciplinary working can be difficult to achieve.⁴⁹ Carers (of any age) should also be made aware that they have the right to an assessment of their needs in addition to any assessment of the person in receipt of care. The nature and outcome of the assessment will, of course, depend on the age of the carer and the specific circumstances, but should be considered automatically when assessing the family.⁷ Research shows very clearly that the provision of timely and appropriate information and support is key to achieving the best outcome for all members of the family, including the young carer.

For service users and carers

There is no specific legislation directly addressing the needs of children and young people as carers, although they have legal rights both as 'children' and as 'carers'. Primarily, provision for young carers is made under Section 17 of the Children Act 1989, where they are designated as 'children in need' by virtue of the potential effects of caring on their 'ability to thrive'. The UN definition of the 'rights of the child' also clearly indicates the moral and legal need to

acknowledge the human rights of children and young people as 'non-adults'. Both can be problematic, however, as the definitions may not adequately provide for the needs of children and young people as 'carers'.⁷ The Carers (Recognition and Services) Act 1995 and the Carers (Equal Opportunities) Act 2004 apply to all carers, irrespective of age, and provide the statutory framework for an individual assessment of carers' needs in addition to an assessment of the needs of those in receipt of care.

Lack of information about a parent's condition or available support facilities can lead to young carers experiencing increased fear about their parent's illness; fear of possible separation; and the adoption of inappropriate care tasks.^{16,50,18} For those in the youngest age groups, the identification of an appropriate care-giving role may be impossible to achieve without support. This has been addressed to some degree by the Children Act 2004, which incorporates the wishes of the young person into the decision process and allows the provisions of other legislation to be used more effectively on behalf of the young carer.⁷ Young carers should also be encouraged to seek advice and information about rights or mental health issues, from the many sources of information available outside social work or mental health teams. Young carers' needs legitimately include the need to socialise with peers, including those of their own age and to gain respite from the caring role without guilt or fear. Support projects for young carers therefore provide a valuable resource in achieving this where 'normal' social networks are either damaged or non-existent.^{8,50} There are now over 350 of these projects in the UK; these often fulfil a valuable role in the provision of information, advocacy, advice and guidance for young carers.⁴ The 'Useful Links' section of this briefing provides information about organisations which offer support for young carers.

Useful links

Barnardo's – A UK children's charity, Barnardo's works directly with children, young people and their families. It runs projects across the UK, including counselling for children who have been abused, fostering and adoption services, vocational training and disability inclusion groups.

www.barnardos.org.uk

Carers UK – (formerly Carers National Association) Campaigns for carers' rights and for these to be recognised and actively involved as partners in the design, delivery and provision of health and social care services.

www.carersuk.org

Children's Society – Works in partnership with local authorities and other organisations to provide services including training and consultancy to deliver unique local solutions to local needs.

www.childrenssociety.org.uk

CSIP – Commissioned by the Department of Health and other agencies the Care Services Improvement Partnership (CSIP) was created in 2005 by the integration of a number of initiatives supporting the development of services. Works with communities and organisations working to meet a variety of health and social care needs.

www.csip.org.uk

King's Fund – Independent charitable foundation working for better health, especially in London, through policy development, research and analysis.

www.kingsfund.org.uk

National Children's Bureau – A charitable organisation acting as an umbrella body for organisations working with children and young people in England and Northern Ireland, and in partnership with Children in Scotland and

Children in Wales. Young NCB is a free membership network for all children and young people aged under 18, enabling them to speak out on issues they feel are important.

www.ncb.org.uk

NSPCC – A registered charity working mostly with children, young people and their families. It also seeks cultural, social and political change by influencing legislation, policy, practice, public attitudes or behaviours and delivery of services for the benefit of young people.

www.nspcc.org.uk

Parental Mental Health and Child Welfare Network (coordinated by the Social Perspectives Network) – A national network for social care and health workers who work with parents with a mental health problem or their children, offering information about local and national policies, services, publications and events.

www.pmhcnw.org.uk

www.pmhcnw.org.uk

Princess Royal Trust for Carers – Provider of comprehensive carers' support services in the UK and working to influence policy, the Trust currently provides quality information, advice and support services to over 300,000 carers, including over 15,500 young carers, through a unique network of carers' centres, young carers' services and websites.

www.carers.org

Sainsbury Centre – The Sainsbury Centre for Mental Health works to improve the quality of life for people with mental health problems through research, policy work and analysis to improve practice and influence policy.

www.scmh.org.uk

YoungMinds – A national charity committed to improving the mental health and emotional well-being of children and young people.

www.youngminds.org.uk

Related SCIE publications

Research briefing 23: Stress and resilience factors in parents with mental health problems and their children (2008)

Resource guide 09: Working together to support disabled parents (2007)

Web resource: Research Register for Social Care (2007)

Position paper 06: Supporting self-advocacy (2007)

Consultation Care Matters (DfES) (2007)

Consultation Joint policy review: children and young people (HMT/DfES) (2006)

Knowledge review 12: Teaching and learning and assessing communication skills with children and young people in social work education (2006)

Knowledge review 11: Supporting disabled parents and parents with additional support needs (2006)

Systematic map 01: The extent and impact of parental mental health problems on families and the acceptability, accessibility and effectiveness of interventions (2006)

Practice guide 06: Involving children and young people in developing social care (2006)

Practice guide 05: Implementing the Carers (Equal Opportunities) Act 2004 (2005)

Report 06: Managing risks and minimising mistakes in services to children and families (2005)

Web resource: Social Care Online (2005)

Research briefing 11: The health and well-being of young carers (2005)

Research briefing 06: Parenting capacity and substance misuse (2004)

Resource guide 01: Families that have alcohol and mental health problems: a template for partnership working (2003)

Report 02: Working with families with alcohol, drug and mental health problems (2003)

Acknowledgements

The Keele Editorial Board: Prof. Peter Jones (Pro Vice-Chancellor, Research and Enterprise, Keele University); Tom Owen (Research Manager, Policy, Help the Aged); Dr Sara Scott (Independent Consultant, previously of Barnardo's) and Prof. Nick Gould (Professor of Social Work, Department of Social and Policy Sciences, University of Bath).

The Keele Project Steering Group: Prof. Richard Pugh (project co-ordinator and Professor of Social Work); Prof. Miriam Bernard (Director, Keele Research Institute for Life Course Studies and Professor of Social Gerontology) and Prof. Steve Cropper (Director, Keele Research Institute for Public Policy and Management and Professor of Management)

References

1. Aldridge, J., Becker, S., and Dearden, C. (2002) *Children Caring for Parents with Severe and Enduring Mental Illness*. Loughborough: Centre for Child and Family Research.
2. Thomas, N., Stainton, T., Jackson, S., Cheung, W. Y., Doubtfire, S., and Webb, A. (2003) "Your friends don't understand": Invisibility and unmet need in the lives of young carers', *Child & Family Social Work* 8(1), pp3546.
3. Office for National Statistics (2003) *UK Census 2001*. London: Office for National Statistics.
4. Barnardo's (2006) *Hidden lives: unidentified young carers in the UK*. London: Barnardo's.
5. Armstrong, C. (2002) 'Behind closed doors – living with a parent's mental illness', *YoungMinds Magazine* 61 (Nov/Dec 2002).
6. Dearden, C. and Becker, S. (2004) *Young Carers in the UK: the 2004 report*. London: Carers UK.
7. Clements, L. (2007) *Carers and their rights – the law relating to carers*, 2nd edition. London: Carers UK and the Action for Carers and Employment National Development Partnership.
8. Becker, S. (2005) *Young carers: evidence and messages from UK and Australian research*. (Goodwood SA, Carers Association of South Australia).
9. Carers UK (2007) *Carers and their rights*. London: Carers UK and Action for Carers and Employment (ACE).
10. Department of Health, Social Services and Public Safety, N. Ireland (2006) 'Caring for carers: recognising, valuing and supporting the caring role', Belfast: Department of Health, Social Services and Public Safety.
11. Social Exclusion Task Force (2007) *Reaching out: think family*. London: Cabinet Office.
12. Banks, P., Cogan, N., Riddell, S., Deeley, S., Hill, M., and Tisdall, K. (2002) 'Does the covert nature of caring prohibit the development of effective services for young carers?', *British Journal of Guidance & Counselling* 30(3), pp229–246.
13. Becker, S. (2007) 'Global perspectives on children's unpaid caregiving in the family: research and policy on "young carers" in the UK, Australia, the USA and Sub-Saharan Africa', *Global Social Policy* 7(1), p23.
14. Aldridge, J. and Becker, S. (1999) 'Children as carers: the impact of parental illness and disability on children's caring roles', *Journal of Family Therapy* 21(3), pp303–320.
15. Aldridge, J., Becker, S. and Dearden, C. (2002) Children caring for parents with severe and enduring mental illness. Loughborough: Centre for Child and Family Research.
16. Cree, V. E. (2003) 'Worries and problems of young carers: issues for mental health', *Child & Family Social Work* 8(4), p301.
17. Underdown, A. (2002) 'I'm growing up too fast: messages from young carers', *Children & Society* 16(1), pp57–60.
18. Aldridge, J. (2006) 'The experiences of children living with and caring for parents with mental illness', *Child Abuse Review* 15(2), pp79–88.
19. Olsen, R. (1996) 'Young carers: challenging the facts and politics of research into children and caring', *Disability & Society* 11(1), pp41–54.
20. Newman, T. (2002) "Young carers" and disabled parents: time for a change of direction?', *Disability & Society* 17(6), pp613–625.

21. Aldridge, J. (2003) 'We didn't know they cared', *Mental Health Today*, July/August 2003, pp31–33.
22. Jones, A., Jeyasingham, D., and Rajasooriya, S. (2002) *Invisible families: The strengths and needs of black families in which young people have caring responsibilities*. Bristol: The Policy Press.
23. Riebschleger, J. (2004) 'Good days and bad days: the experiences of children of a parent with a psychiatric disability', *Psychiatric Rehabilitation Journal* 28(1), pp25–31.
24. Barnardo's (2005) *Keeping the family in mind: a briefing on young carers whose parents have mental health problems*. London: Barnardo's.
25. Office of the Deputy Prime Minister (2004) *Mental health and social exclusion: Social Exclusion Unit report*. London: ODPM.
26. Butler, A. H. and Astbury, G. (2005) 'The caring child: an evaluative case study of the Cornwall Young Carers project', *Children & Society* 19(4), pp292–303.
27. Cabinet Office: Social Exclusion Unit Task Force (2008) *Think family: improving the life chances of families at risk*. London: Cabinet Office.
28. Aldridge, J. and Becker, S. (2003) *Children caring for parents with mental illness: perspectives of young carers, parents and professionals*. Bristol: The Policy Press.
29. HM Treasury (2003) *Every child matters*. London: TSO.
30. Department for Education and Skills (2005) *The Common Assessment Framework*. London: HMSO.
31. Department of Health, Department for Education and Skills, and Home Office (2000) *Framework for the assessment of children in need and their families*. London: TSO.
32. Social Care Institute for Excellence (2005) *The health and well-being of young carers*. London: SCIE.
33. Cooklin, A. (2006) 'Children as carers of parents with mental illness', *Psychiatry* 5(1), pp32–35.
34. Warren, J. (2007) 'Young carers: conventional or exaggerated levels of involvement in domestic and caring tasks?' *Children & Society* 21(2), pp136–146.
35. Aldridge, J. and Becker, S. (1996) *Befriending young carers: a pilot study*. Loughborough: Young Carers Research Group.
36. Aldridge, J. and Becker, S. (1993) *Children who care: inside the world of young carers*. Loughborough: Department of Social Sciences, Loughborough University.
37. Earley, L. and Cushway, D. (2002) 'The parentified child', *Clinical Child Psychology and Psychiatry* 7(2), pp163–178.
38. Barnett, B. and Parker, G. (1998) 'The parentified child: early competence or childhood deprivation?' *Child Psychology and Psychiatry Review* 3(4), pp146–155.
39. Dearden, C. and Becker, S. (2000) *Young carers' transitions into adulthood*. York: Joseph Rowntree Foundation.
40. Dearden, C. and Becker, S. (2003) *Young carers and education*. London: Carers UK.
41. Eley, S. (2004) "'If they don't recognize it, you've got to deal with it yourself": gender, young caring and educational support', *Gender & Education* 16(1), pp65–75.
42. Young Minds (2006) *Mental illness in your family?* Available from Young Minds website www.youngminds.org.uk

43. Mayes, K., Diggins, M., and Falkov, A. (1998) *Crossing bridges – training resources for working with mentally ill parents and their children*. London: DH/Pavilion.
44. Gopfert, M., Webster, J., and Seeman, M. (2004) *Parental psychiatric disorder: distressed parents and their families*. Cambridge: Cambridge University Press.
45. Scott, S., Robinson, B., and Day, C. (2007) *Parents in hospital: how mental health services can best promote family contact when a parent is in hospital*. Barnardos; CSIP; MHAC; FWA.
46. Moore, T. (2005) 'Young carers and education'. *Youth Studies Australia* 24(4), pp50–55. Hobart, Tasmania: Australian National Clearinghouse for Youth Studies.
47. Olsen, R. and Clarke, H. (2003) *Parenting and disability: disabled parents' experiences of raising children*. Bristol: The Policy Press.
48. Sainsbury, M. (2005) 'Parental mental health problems: messages from research, policy and practice', *Health & Social Care in the Community* 13(5), pp491–493.
49. Stanley, N., Penhale, B., Riordan, D., Barbour, R., and Holden, S. (2003) 'Working on the interface: identifying professional responses to families with mental health and childcare needs', *Health and Social Care in the Community* 11(3), pp208–218.
50. Arksey, H., O'Malley, L., Baldwin, S., Harris, J., Mason, A., and Golder, S. (2002) *Services to support carers of people with mental health problems*. London: National Co-ordinating Centre for NHS Service Delivery and Organisation R & D.

About SCIE research briefings

This is one of a series of SCIE research briefings that has been compiled by Keele University for SCIE. SCIE research briefings provide a concise summary of recent research into a particular topic and signpost routes to further information. They are designed to provide research evidence in an accessible format to a varied audience, including health and social care practitioners, students, managers and policy-makers. They have been undertaken using the methodology developed by Keele in consultation with SCIE, which is available at www.scie.org.uk/publications/briefings/methodology.asp. The information upon which the briefings are based is drawn from relevant electronic bases, journals and texts, and where appropriate, from alternative sources, such as inspection reports and annual reviews as identified by the authors. The briefings do not provide a definitive statement of all evidence on a particular issue.

SCIE research briefings are designed to be used online, with links through to document and other organisations' websites. To access this research briefing in full, and to find other publications, visit www.scie.org.uk/publications

SCIE research briefings

- 1 Preventing falls in care homes
- 2 Access to primary care services for people with learning disabilities
- 3 Communicating with people with dementia
- 4 The transition of young people with physical disabilities or chronic illnesses from children's to adults' services
- 5 Respite care for children with learning disabilities
- 6 Parenting capacity and substance misuse
- 7 Assessing and diagnosing attention deficit hyperactivity disorder (ADHD)
- 8 Treating attention deficit hyperactivity disorder (ADHD)
- 9 Preventing teenage pregnancy in looked-after children
- 10 Terminal care in care homes
- 11 The health and well-being of young carers
- 12 Involving older people and their carers in after-hospital care decisions
- 13 Helping parents with a physical or sensory impairment in their role as parents
- 14 Helping parents with learning disabilities in their role as parents
- 15 Helping older people to take prescribed medication in their own homes
- 16 Deliberate self-harm (DSH) among children and adolescents: who is at risk and how it is recognised
- 17 Therapies and approaches for helping children and adolescents who deliberately self-harm (DSH)
- 18 Fathering a child with disabilities: issues and guidance
- 19 The impact of environmental housing conditions on the health and well-being of children
- 20 Choice, control and individual budgets: emerging themes
- 21 Identification of deafblind dual sensory impairment in older people
- 22 Obstacles to using and providing rural social care
- 23 Stress and resilience factors in parents with mental health problems and their children
- 24 Experiences of children and young people caring for a parent with a mental health problem

Social Care Institute for Excellence

Goldings House
2 Hay's Lane
London
SE1 2HB

tel: 020 7089 6840
fax: 020 7089 6841
textphone: 020 7089 6893
www.scie.org.uk