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Summary

The Mental Health Foundation and The Princess Royal Trust for Carers are conducting research into the mental health of children and young people aged 10-21 who care for a parent with a severe and enduring mental illness in England, Wales, and Scotland.

The research will investigate the experiences and needs of these children and young people, specifically examining how age, gender, and culture affect their perceptions of caring, resilience, and coping strategies.

The final report of the research – due to be published in 2010 – will provide a comprehensive evidence base from which a range of policy recommendations will be drawn. These will aim to:

- promote the mental health of this group of young carers and
- improve services' awareness of, and responses to, their specific mental health needs.

This interim policy briefing and call for evidence is intended to provoke a wide-ranging debate and to gather evidence on this vital subject. Evidence is requested by **1 May 2009**, and will inform our final recommendations.

Mental health and caring: The statistics

According to data from the 2001 Census approximately 5% of adults in the UK are directly affected by severe and enduring mental illnesses, including schizophrenia, personality disorders, and bipolar affective disorder.¹

It is very common for people experiencing mental illness to receive informal (unpaid) care from their families and friends. There are estimated to be 51,000 children and young people providing care for somebody with a mental illness, making up almost a third of the 175,000 young carers in the UK.² Adults with severe and enduring mental illnesses are equally as likely to be parents as their peers, and consequently many of them rely on their children to provide them with at least some informal care.³

Caring for a parent with a severe and enduring mental illness

The responsibilities of children and young people caring for a parent with a mental illness may be largely similar to those of other young carers. These can include a wide range of domestic tasks, administering medication, translating for non-English speaking family members, and helping to care for younger siblings.⁴

But there is also a number of ways in which their caring responsibilities may differ significantly from those of other young carers. Whilst it is estimated that 82% (144,000) of young carers provide emotional support for the person they care for,

the need for emotional support among people with severe and enduring mental illness is often particularly acute.⁵

I talk to my mum or dad when they're feeling sad
young carer⁶

In some cases providing this emotional support will involve preventing a parent from harming themselves or committing suicide, or dealing with the aftermath of these actions.⁷

The fluctuating levels of mental health amongst many people with a severe and enduring mental illness can also make caring for them particularly challenging for children and young people.⁸ Their care needs are often intermittent and unpredictable, posing obstacles to their carers establishing a routine and planning for the future.⁹

Once or twice I get a bit fed up because I plan my weekends and it gets messed up because I have to look after my mum
young carer

Furthermore, the stigma surrounding mental illness often results in children and young people concealing their caring role from their peers for fear of being bullied or socially isolated. In turn, this acts as a barrier to receiving support.¹⁰ It is common for these young carers to miss social opportunities to relax and bond with their peers as a result of their caring responsibilities.

I don't have time after school and weekends. I've never been ice skating in my life and the first time I went cinema was when I was 11
young carer

The effects of caring on mental health

I tell myself that I'm going to be alright
young carer

The prevalence of mental health problems is higher amongst children and young people living with a parent with a severe and enduring mental illness than it is amongst their peers, whether or not they have caring responsibilities.¹¹ Between 25-50% of these children and young people will experience a mental health problem during their childhood and adolescence.¹² Up to 14% will be diagnosed with a psychotic illness during their lifetime.¹³ Previous research has found that 40% of former young carers said their mental health had been directly affected by their responsibilities.¹⁴ Half of those felt they needed counseling as a consequence.¹⁵ The experience of being a young carer can also have a significant effect on the development of relationships in adult life.

My carer role in childhood continued to impact my relationships with peers as a young adult... I tended to be involved romantically with people who needed a carer and could not give equal care to me. I think this is because I did not see that I could be good at other things, other than caring.

former young carer¹⁶

The emotional and physical stresses of caring itself are undeniably a factor in these trends. In addition to the typical worries of most children and young people, those caring for a parent with a severe and enduring mental illness often experience continuous worries in relation to the health of the person they are caring for.¹⁷ Many also experience major disruption and loss in their lives as a result.¹⁸ Moreover, the experience of having a parent with a severe and enduring mental illness can lead to exposure to other factors that increase a child or young person's risk of developing a mental health problem themselves, such as:

- poverty
- unemployment
- increased familial stress
- decreased social support.^{19 20 21}

The case for change

In the 21st century no child or young person should have to adopt adult caring responsibilities. Whilst it is inevitable that children and young people play a role in supporting a parent with a severe mental illness, there need to be sufficient resources in place to ensure that this role is appropriate for their age. In the meantime, there is a moral imperative to provide young carers with appropriate support to alleviate the long-term negative effects that caring can have on their mental health.

This group of young carers is particularly at risk, and protecting their mental health is first and foremost a matter of social justice. According to the Government's own analysis, the experience of mental health problems can limit opportunity and aspiration, decrease social mobility, and lead to costly social problems later in life including poverty, social exclusion, offending, anti-social behavior, family breakdown, and drug and alcohol abuse.²² It is unacceptable that a child or young person should be exposed

to an increased risk of these outcomes as a result of carrying out essential responsibilities without appropriate support.

Supporting young carers also makes long-term financial sense for the health and social care sector. Young carers are already responsible for a significant proportion of the £87 billion that carers collectively save the economy each year by reducing the demands on statutory services.²³ It is likely that meeting their mental health needs now will lead to additional savings by reducing future demands on mental health services from this vulnerable group.

The policy context

In England the over-arching policy framework for all children and young people is the Children's Plan (2007), which "aims to make England the best place in the world for children and young people to grow up."²⁴ The Children's Plan acknowledges that young carers "feel that they are missing out on their education and other opportunities and are isolated from their peers."²⁵ It sets out a requirement for services to adopt a whole-family approach:

*This means that children's and adults' services must have arrangements in place to ensure that no young person's life is unnecessarily restricted because they are providing significant care to an adult with an identifiable community care need.*²⁶

The plan also outlines the Government's proposals for Family Pathfinders to provide more effective support to families relying on young carers. There are six Family Pathfinder sites specialising in providing support for young carers across the country, focusing on developing new ways of working to improve outcomes for young carers and their families.²⁷ This is due to be increased to twelve or thirteen sites by 2010/11.²⁸

The use of the whole-family approach is endorsed by the Social Exclusion Task Force's report Think Family (2008), which argues that individual needs should be "looked at in the context of the whole family, so clients are seen not just as individuals but also as parents or other family members".²⁹ This approach is also supported by a number of good practice guides, such as The Children's Society's 'Young Carers, Parents and their Families: Key Principles of Practice'.³⁰

A detailed strategy for young carers is set out in Carers at the Heart of 21st Century Families and Communities (2008).³¹ The strategy commits to fund local and regional training on whole-family approaches, focusing in particular on teams within adult mental health services. It also sets out proposals to improve services provided to young carers in educational settings by developing specific resources to be used as part of the National Healthy Schools Programme, the Social and Emotional Aspects of Learning (SEAL) Programme, and the Personal, Social and Health Education (PSHE) syllabus. GP training on the specific needs of young carers is also pledged.

Within mental health policy, the National Service Framework for Mental Health (1999) is explicit that "where the person with

mental illness is a parent, health and local authorities should not assume that the child or children can undertake the necessary caring responsibilities".³² The Department of Health has published guidance on working with families in which a parent has a mental health problem, and the Code of Practice for the Mental Health Act provides additional guidance for working with families in which a parent is being treated under the Act.^{33, 34}

In Wales the Assembly Government is committed to reviewing its carers strategy subsequent to the publication of Carers at the Heart of 21st Century Families and Communities.³⁵ It has also requested legislative competence over carers issues and vulnerable children, including support for parents whose mental health may affect their children's opportunities and wellbeing, and over the Mental Health Act.^{36, 37, 38}

The revised National Service Framework for Adult Mental Health (2005) in Wales recognises the needs of children and young people caring for a mentally ill parent, and requires local authorities and Local Health Boards to have strategies to address the needs of children experiencing need/vulnerability as a consequence of their parent or guardian's mental health problem.³⁹ All young carers are recognised as being in "special circumstances" and in need of particular support in the Welsh National Service Framework for Children, Young People and Maternity Services (2005).⁴⁰

In Scotland, young carers' policy is split between national government and local government policies. The Care 21 research report on the future of unpaid care in Scotland published by the (then) Scottish Executive in 2006 recommended the publication of a Young Carers Strategy and the establishment of a national forum representing the views of young carers.⁴¹ In response to this report, a young carers task group has been established to review existing arrangements and the implications of acting on these recommendations.⁴²

In more general terms, Getting It Right for Every Child (2007) provides the primary context for all children and young people, and adopts a "co-ordinated and unified approach" to promoting the welfare of children and families.⁴³ The Scottish Government and the Convention of Scottish Local Authorities (COSLA) have also produced a joint policy statement prioritising the provision of support and early interventions to improve the life chances of those most at risk.⁴⁴

Within mental health policy, the Scottish Government's discussion paper Towards a Mentally Flourishing Scotland (2007) argued that emphasis should be placed on the mental health of children and young people, especially those who are at greatest risk of mental health problems – and recommended targeting interventions towards children with a parent with a mental illness.⁴⁵

Local carers strategies are in general joint activity between local authorities and NHS Boards. NHS Boards as part of an overall NHS Carer Information Strategy in relation to the provision of information, carer training and referral to local support will have strategies for young carers.⁴⁶ It is likely that, with the advent of Single Outcome

Agreements, in 2009/10 planning partnerships (NHS/local authorities) will develop more joint strategies to achieve shared outcomes.⁴⁷

Call for evidence: what do you think?

The pressures of caring for a parent with a severe and enduring mental illness on a child or young person's mental health are clear. But as recent reports from the charity Barnardo's and the Social Care Institute for Excellence demonstrate, significant obstacles for policy and practice remain including the poor adoption of whole-family approaches and poor communication between adult and children's services.^{48, 49}

We are concerned with how policy and practice can respond to the experiences and needs of these children and young people, specifically how their age, gender, and culture affect their perceptions of caring, resilience, and coping strategies.

In order to ensure that we develop a comprehensive and evidence-based range of policy recommendations we are consulting with a wide range of stakeholders. We are keen to hear your personal and professional experiences in this field.

In particular, we would welcome responses to the following questions:

- 1 What are your views on the mental health needs of children and young people who care for a parent with a severe and enduring mental illness?
- 2 How do these needs vary according to the age, gender, and culture of the child or young person?
- 3 What are the effective service responses to these needs?
- 4 How can professionals be supported to meet these needs?
- 5 What can be done to promote the mental health of these young carers, both in the short-and long-term?

If you would like to contact us with your answers to these questions, or with any other points you wish to make, please email policy@mhf.org.uk, or write to

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The closing date for comments is **Friday 1 May 2009**.

The Mental Health Foundation is the leading UK charity working in mental health and learning disability.

The Princess Royal Trust for Carers is the largest provider of comprehensive carers support services in the UK.

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