MyCare

The challenges facing young carers of parents with a severe mental illness

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2. Foreword

The emergence of the 'young carers' concept has helped to frame the children of parents with severe mental health needs as a specific group with the right to access appropriate services. Conceptualising this group in this way allows us to shift away from a preoccupation with risk and to focus on the particular needs and strengths of these children and young people. However, these children can become invisible to services. This report seeks to ensure that these children and young people do not vanish from sight. It brings together their experiences and perceptions with those of professionals in children's mental health services, adult mental health services, education and voluntary sector services to deliver some key messages about young carers' needs and how services are meeting them.

A central theme emerging from this research is that young carers want to be provided with clear information about their parents' mental health needs. However, there appears to be uncertainty about whose task this is. This uncertainty may reflect a lack of practitioner confidence and skills in talking to children and young people about parental mental illness, but it also worryingly conveys professionals' belief that young carers are someone else's business.

The report's emphasis on the need to develop appropriate responses to young carers in Black and Minority Ethnic (BME) communities is extremely useful. Practitioners need to avoid making assumptions about how caring is conceptualised in BME communities as well as recognising that parent and child's views and expectations on both caring and mental illness may differ.

A focus on the role of education professionals in relation to young carers is welcome, since little is known yet about what support may be offered to young carers in the school setting. Yet school is where the impact of young caring may be most readily discerned; it also offers opportunities for distraction and achievement which young carers in this study identified as key to resilience. However, offering support to young carers in the school setting will require careful attention to issues of stigma, trust and confidentiality. These are questions which schools are becoming increasingly confident in handling with relation to a number of issues. The report includes some positive examples of the ways in which schools and colleges could support young carers including innovative suggestions for extending the young carers' opportunities to access education and offering accreditation for the caring skills they have accumulated.

This report throws down a range of challenges to all professionals encountering children and young people who are carers. It charges them to improve their recognition of and sensitivity to the needs of young carers whose parents have severe mental health needs, to co-ordinate their work more effectively and to work more creatively. It is published at a time when Government and other agencies are increasingly urging services to 'Think Family' and its recommendations provide some concrete examples of the means of realising that goal.

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3. Executive Summary

"I only realised my Mum wasn't the same as other mums when I was six and we had to do this thing at school and say why you love your mum... Others said stuff like, 'I love my Mum because she tucks me up in bed,' and I was like... 'I love my Mum because she says thanks when I cook her dinner,' and everyone just looked at me..."

Adults with severe and enduring mental health problems are amongst the most marginalised and vulnerable people in our society. In providing care for these individuals, mental health professionals may potentially overlook the fact that many of these people are also parents:

- There are an estimated 50,000 – 200,000 young people in the UK caring for a parent with mental health problems.
- Many of these young people will provide help and support for a parent.
- Some of these young people will be providing care beyond a level that is appropriate for their age. They will be 'young carers'.
- This inappropriate level of care puts young carers' own physical and mental health at risk.

These children and young people may come into contact with a variety of professionals in their daily lives, and some will be known to mental health professionals, but the majority will be unknown either to statutory or voluntary services. Education professionals may come across many of these individuals, but may not recognise them. The young carers may not self-identify as young carers, and may not wish to identify themselves to others. Nevertheless, some degree of intervention is required, since young carers are likely to suffer problems with school, such as:

- regular lateness or absence;
- difficulty completing assignments on time;
- disruptive behaviour;
- difficulty developing friendships;
- being bullied; and
- leaving without any formal qualifications.

Away from formal mental health and education settings, many young carers are able to find help and support in one of the many young carers' services that operate across the UK. These services may play an important part in providing young carers with an opportunity to find:

- respite from care duties;
- leisure time activities;
- one-to-one support; and
- the chance to socialise with peers.

However, many statutory and voluntary services coming into contact with these carers may not feel confident in providing advice or support on mental health and mental illness. Hence, MyCare is an investigation of the experiences and needs of young carers aged 9-25 whose parent or parents may suffer from severe mental illness. It is an explorative investigation of the experiences of young carers of parent(s) with severe mental illness, their needs, and how professionals from a variety of disciplines respond to these needs.

The study reviewed past research and collected information from young carers, young carers' service workers, mental health professionals and education professionals. We were particularly interested in service provision for young carers, how they learnt to best cope with their situation, and the strategies they use to do so. The study involved obtaining information through a mixture of surveys, interviews and focus groups.

The findings showed that young carers are a varied population and that many are carrying out their duties with a great deal of resilience. However, they did feel as though they needed respite from their caring role, at least for a period of time. Young carers wanted someone to talk to, who would listen and not judge them. They wanted consistency and dependability from workers. They wanted to be visible to their parent's care team, and to be included in discussions about their parent's treatment. Some wanted to be free of their caring role but others were able to find some benefits in the maturity and life skills they felt they gained from their responsibilities. Some also felt that they had a better, closer relationship with their parent(s) than they would otherwise, because of their caring role.

Nevertheless, there is a need to ensure that young carers do not become too socialised to their role, and it is important to recognise that the responsibilities young carers adopt are often inappropriate for their age. Caring for someone with severe and enduring mental health problems may affect the carer's own physical and mental health. Young carers, service workers and professionals alike should be aware that assuming substantive care roles at a young age does not represent an ideal scenario for the continued mental well-being of these young people. It may interfere with the child's normal development, restricting the young carer's ability to take part in socially and emotionally important developmental activities. Adopting mature roles and responsibilities may deprive young carers of the opportunity to enjoy childhood, which in turn can impact on the rest of their lives.

Young carers of parents with severe mental health problems are a frequently overlooked and poorly served group. The views and experiences of the young carers and professionals reported here reinforce the findings in the literature as to the need for specialist support if these young people are to achieve their full potential. The report makes the following recommendations:

For policy and practice:

1. More age-appropriate information about mental health and mental illness should be made available to young carers, and for those who work in young carers' services and the education sector. This information should be focused on the causes and effects of parental behaviour patterns that may arise from mental illness.

2. Effective co-ordination between staff of various disciplines is required, including social workers, mental health professionals, young carers' service workers and teachers. There may be a need to identify a lead professional who will take primary responsibility for working with the young carer, and link with all the relevant agencies. Ideally, this lead professional should be selected by the young carer themselves.

3. A greater priority given to funding for young carers' support services, to ensure optimal geographical coverage of services around the country.

4. Further promotion of existing online resources for young carers and professionals. A centralised hub of resources might include the following websites:

    a. www.youngcarer.com (information about young carers' services)

    b. www.youngcarers.net (direct support for young carers)

    c. www.carers.org/professionals/young-carers (support and advice for young carers and professionals)

For young carers' services:

5. Conduct specialist sessions within the young carers' service, aiming to teach young carers about mental health, mental illness and how to build resilience against it. This could include visits from people who work for local statutory or voluntary mental health organisations.

6. Encouraging young carers of parents with mental illness to meet with other young carers who may have a similar situation, either within the young carers' service or with other nearby young carers' services. This could be achieved through peer support sessions.

7. Make links with different minority communities to understand the specific needs of young carers within these communities, and to find culturally sensitive ways of meeting them.

8. Continue offering young carers the opportunity for respite, with the chance to do activities that others of their age are able to do, including working with schools to help ensure that young carers are able to access after-school activities.

9. For services to be flexible around their entrance criteria, specifically around minimum and maximum ages.

This will require adequate funding and support from statutory funders, other donors and local mental health services.

For mental health services:

10. Identify young carers; ascertain the level of care provided by the young carer and to enter negotiation with the parent about how to discuss parental mental health with the young carer.

11. Liaise with local young carers' services about the types of activities that the services provide, and to signpost and refer where appropriate.

12. Work in partnership with children's and other services to ensure that the parent has adequate support in their parenting role, in the context of recognising and addressing the whole family's needs.

For schools:

13. A school lead for young carers and their families (or other nominated staff member) to create and maintain active links with young carers' services within the local area. If there are no young carers' services within the local area, then the nominated staff member should seek advice and information from a remote information hub, such as the websites mentioned above.

14. If a staff member identifies a young carer, the staff member should speak to the School Lead and ask them for confidential advice. The staff member should not disclose the identity of the pupil against the pupil's wishes. The staff member should then speak to the young carer directly to seek more information about their situation, and signpost them to necessary support networks, possibly including local young carers' services.

15. Provide sensitive and confidential support in the school environment, providing pupils with a space to discuss their problems with teachers, school counsellors or peers.

16. Teachers and other school-based professionals to provide known young carers with understanding and flexibility regarding coursework and attendance.

4. Introduction

4.1 Background

Adults with severe and enduring mental health problems, such as schizophrenia, bipolar disorder, severe depression and schizoaffective disorder, are among the most vulnerable people in society. They are just as likely to become parents as those who do not have mental health problems (Mowbray & Mowbray, 2006). Estimates indicate that between 50% and 66% of people with severe mental illness live with one or more children under the age of 18 (Gopfert et al, 1996). Past authors have argued that the NHS mental health system has largely ignored the fact that many people with mental illness in its care are also parents, resulting in children with unmet needs (Mordoch & Hall, 2002). It is estimated that around 30% of adults with a mental illness have dependent children (Department of Health, 1999).

Children of parents with severe and enduring mental illness can experience greater levels of emotional, psychological and behavioural disturbance than their peers (Mowbray et al, 2006; Mowbray, et al, 2004). In fact, the relationship between psychiatric disorder in parents and the well-being of their children has been recognised for more than 30 years, and it is suggested that between 25% and 50% of children will experience some form of psychological disorder during their childhood or adolescence, and between 10% and 14% will be diagnosed with a psychotic illness during their lifetime (Devlin & O'Brien, 1999). Setting aside genetic factors, these children are likely to face considerable psychological and social stress; poverty, unemployment, increased familial stress, or decreased social support (Mowbray & Mowbray, 2006; Tebes et al, 2001).

Official statistics indicate that there are 175,000 young carers in the UK (Office of National Statistics; Singleton et al, 2001), with one study estimating that 29% of young carers are caring for someone with a mental illness (Dearden and Becker, 2004). However, a recent report places the number of young carers at 700,000 nationally (BBC, 2010), by extension there could be over 200,000 young carers who are caring for someone with a mental illness. These young carers may be:

> *"carrying out significant caring tasks and assuming a level of responsibility for another person which would normally be undertaken by an adult."* (The Princess Royal Trust for Carers).

According to Roberts et al (2008), the two main types of care given by a young carer of a parent with severe mental illness are:

- Emotional care (77%); providing support, helping the parent to cope better, providing empathy, support and compassion

- Domestic care (59%); household support in tasks such as cooking, cleaning, shopping

A much smaller minority, usually female, also provide personal, intimate care, such as washing, toileting and dressing. There is evidence to suggest that this may be distressing for both carer and parent (Centre for Child and Family Research, 2005). The amount of domestic care-giving is likely to increase as the child gets older and is physically more able to provide it, but the amount of emotional care-giving is likely to be similar across young carers of any age (Dearden & Becker, 2004).

Becoming too socialised into an inappropriate caring role may cause problems. Caring at a young age interferes with the child's normal development, restricting the young carer's ability to partake in socially and emotionally important developmental activities (Pakenham et al, 2006). The strain of living in an 'ill' environment may increase the potential for neglect, conflict, stress and abuse. Young carers may feel responsible for their parent, which may lead to isolation through lack of support.

They may develop a sense of 'false maturity', where taking on mature roles and responsibilities may deprive them of the opportunity to enjoy childhood. They may also feel concern for the welfare of their parent, resentment about having to provide care, guilt when they do not provide care, or embarrassment about their parent's behaviour. In addition, these children may lose many social and educational opportunities (Aldridge & Becker, 1999), which in turn can impact on the rest of their lives.

There may however be positive aspects of the caring role: it is not always an unrewarding, negative experience (Grant et al, 2008). Aldridge (2006) argues that not all young carers are at risk of harm or development delay. A Social Care Institute for Excellence (SCIE, 2005) research briefing on young carers found that, for many, caring has given them feelings of maturity, a closer family bond and practical life skills. Young carers may perceive themselves to be more independent, tolerant and helpful than their peers (Johnston et al, 1992, cited in Pakenham et al, 2006). Clarkson et al (2006) reported that nearly half the young carers they interviewed felt pride in their role.

Whatever a person's age, caring for someone with severe and enduring mental health problems may affect the carer's own physical and mental health. Living in such an environment can lead to a considerable 'burden of care' (Faddon et al, 1987). Accordingly, the Department of Health (2008) has published guidance highlighting the need for further investment in helping young carers of parents with mental health problems:

> *"additional funding will be invested in an expanded programme of local and regional training on whole-family working for staff in local services. Teams within adult mental health and substance misuse services will be particularly targeted."*

Young carers of people with severe and enduring mental health problems therefore face difficulties from two sides; they may experience the difficulties of being a young carer, coupled with the stigma and confusion surrounding complex mental health problems. Roberts et al (2008) suggest that the stigma commonly associated with mental illness increases the pressures on the young carer, who may feel less willing to seek support or participate in social activities with peers. They may be afraid to ask for help or information for fear that they may be placed into care (Centre for Child and Family Research, 2005; Underdown, 2002), and when they do come into contact with mental health services, their own mental health needs may be overlooked (Evans & Fowler, 2008; Grant et al, 2008; Roberts et al, 2008).

4.2 How do young carers cope?

Although there may be numerous difficulties, as outlined above, Aldridge and Becker (2003) found that young carers of parents with severe mental illness were often providing care willingly, with great resilience and resourcefulness. Professionals who focus solely on family problems may overlook these strengths and coping capacities. Interventions that seek to build on these capacities will enhance a young carer's resilience (Parrott et al, 2008; Roberts et al, 2008; Clarkson et al, 2006). According to Masten et al (1990), there are three main types of resilient children:

- those who do not succumb to adversities, despite being at high risk (for example, babies with a low birth-weight)

- those who develop coping strategies in situations of chronic stress (for example, the children of parents who may be addicted to drugs and alcohol)

- those who recover from extreme trauma or disastrous life events (for example, the sudden loss of a close relative)

The young carer benefits from seeing themselves as separate from the parent's illness (Mordoch & Hall, 2002); however, external factors such as inequality and poverty compound any difficulties they experience. The young carer must navigate access to resources that are relevant and responsive to their needs (Ungar et al, 2008). They need additional support aside from that given by the 'ill' parent; of particular importance is the young carer bonding with the 'well' parent, if possible (Parrott et al, 2008). Likewise, support from other adults such as teachers (Daniel & Wassell, 2005; Eley, 2004), or from holistic family care services (Dearden & Becker, 2004) can be helpful.

Specifically in relation to young carers of parents with mental health problems, one study interviewed six children aged between nine and eleven, and reviewed the written stories of seventeen adult children of parents with mental health problems (Pölkki et al, 2004). Those who coped best had an awareness of the mental health problems of the parent, were able to put their thoughts into words, and able to separate themselves from the emotional experiences of the parent. These children tended not to feel guilty in relation to their parent. The key building blocks for developing resilience in children are likely to include; a sense of security, a recognition of self-worth, and having the experience of control over one's immediate environment (Parrot et al, 2008).

Action for Children (formerly National Children's Home, 2007) argues that the interplay of vulnerability, protective factors and coping strategies determines children's outcomes in distressing situations. Many young carers will experience physical, emotional, relationship or other psychosocial problems, but may not experience difficulties in school, or in other aspects of their lives (Dearden & Becker, 2004). In adult family carers of people with enduring mental illness, three coping styles were identified (Kartalova-O'Doherty and Doherty, 2008):

- Active behavioural, such as; seeking support from others, being open about the illness, taking control, getting information, studying, household chores, exercise and relaxation.

- Active cognitive, such as; accepting caring as a family duty, thinking positively, applying previous experience or knowledge to manage the caring role, taking each day at a time, and religious beliefs.

- Avoidant, such as; avoiding discussions about illness, denial, blocking it out, using prescribed and non-prescribed medication.

Active behavioural coping strategies were most commonly reported. However, the youngest carers were also likely to report using avoidance strategies. What is likely to help young carers most was either an active behavioural strategy such as talking to someone, or an avoidant strategy such as spending some time alone or going somewhere quiet (Clarkson et al, 2006). Avoidance may appear to work in the short-term but can have a negative effect on psychological well-being. Young carers who address their problems, use positive problem-solving approaches and seek support from others tend to have better outcomes than those who deny that they are experiencing difficulties (Pakenham et al, 2006).

The Young Carer of Parents Inventory (YCOPI; Pakenham et al, 2006) measures seven coping strategies commonly used by adolescents: problem-solving coping, seeking social support, positive reinterpretation, acceptance, denial, distraction, and wishful thinking. They found that young carers made less use of active problem-solving than did non-carers. Avoidance may also be common in this group (Earley et al, 2007). However it would seem that young carers also used active cognitive strategies, such as cooking a meal or taking their parent on an outing. Various other strategies were mentioned, although less frequently, these included spending time with a friend, playing music or singing, going to the young carers' service, writing or drawing, and screaming (Clarkson et al, 2006). These strategies may help to reduce the young carer's anxiety about their parent's well-being and so providing a way to manage distressing feelings associated with the caring role.

Cultural differences may impact on young carers' ability to cope with their caring role. Religious beliefs may be helpful by carers of relatives with mental health problems (Rammohan et al, 2002); but there is no research that has identified specifically the role of religion for young carers. BME families may be more vulnerable to poverty and unemployment, which undermine a family's ability to cope with mental illness (Greene et al, 2008). Furthermore, they may be less well served by mental health services, or more reluctant to seek help from statutory services (Parrott et al, 2008). Across cultures, the experiences of young carers from different cultures are likely to be broadly similar; the 2004 UK survey of young carers (Dearden & Becker, 2004) found no significant differences between ethnic groups according to the type of care that was being provided. However, discrimination and language barriers may sometimes prevent families from BME backgrounds from receiving appropriate support (Jones et al, 2002). Where there are language barriers, children may also be expected to interpret for the person for whom they are caring, regardless of whether or not they understand the problems.

4.3 Appropriate support

One of the most important of all coping strategies that young carers can use is to seek support from others. Research by the National Children's Bureau (Earley et al, 2007) found that what young carers found most helpful was informal support from members of the extended family, peers, neighbours and informal mentors or role models. Some found it supportive to have family members who shared and understood their situation. Others found it helpful to be able to get away from their family problems by seeing people outside the family who were unaware of, or did not discuss, the difficult situation at home. However, social support is important, such as that which may be provided by grandparents, other adults in the family and/or siblings (Pakenham et al, 2007; Mowbray & Mowbray, 2006).

The internet is also an increasingly useful tool for children and young people who are seeking information on topics that are potentially embarrassing or stigmatising (Naked Flame Research, 2004). As many as 92% of young people have access to the internet at home, school, college or youth centres (Livingstone & Bober, 2005). One survey found that 60% of young people would go to the internet to access information before using telephone helplines or face-to-face services (YouthNet, 2005).

Young carers' groups are also a rapidly increasing and important source of support for young people and can often provide an outlet for carers to meet peers, establish friendships and take part in activities (The Education Network, 2005). Young carers' services initially offered mainly respite care and leisure activities in recognition that young carers had little opportunity for socialising outside the home. More recently, these services have begun to offer support such as one-to-one befriending, homework clubs and family support (Aldridge, 2006). Grant et al (2008) interviewed ten young carers of parents with mental health problems attending a Barnardo's young carers' service. They found several ways in which services commonly fail young carers (inconsistency, failure to recognise their role, feeling out of control), and suggested how these could be addressed:

- family-centred work; specifically 'interdependencies, such as multiple care-giving demands, mediating family conflict and providing help for the ill parent;

- building and valuing relationships of trust; with an emphasis on 'absolute trust' in service workers, and being given time to tackle issues at their own pace;

- one-to-one work; with an emphasis on consistency, dependability, continuity, problem-solving, and fun activities;

- group work; opportunities to form friendships, respite from caring responsibilities, recognition by others of the difficulties faced, and peer solidarity.

It is ten years since the Mental Health Foundation's (1999) Bright Futures report recommended investigation of the mental health needs of vulnerable young people, including the children of parents with mental illness. As demonstrated above, there have been a good number of previous research studies on the needs of young carers; a minority of these have investigated young carers of people with mental illness. However, what appears to be lacking is a national, comprehensive perspective of how young carers engage and cope with their situation, and what could be done to better support them. The MyCare project was born from an awareness of the need to draw together sources of evidence to inform policy and practice improvements.

4.4 Aims of MyCare

This project is an explorative investigation of the experiences and needs of children and young people between the ages of 9 and 25 years whose parent or parents have severe mental illness. It is also an investigation of current service responses to those needs. The project was established by the Mental Health Foundation in association with The Princess Royal Trust for Carers, to uncover the views of young carers, service workers and professionals from a variety of interconnected disciplines. The main aims of the project are to explore:

- the needs of young people who care for a parent or parents with severe mental illness;
- the factors that offer these young people a chance to build resilience against mental ill health;
- how staff and services could best support these young carers.

5. Method

5.1   Design

The study adopted a mixed methods design, using qualitative and quantitative methods to obtain comprehensive data. The study was split into two phases, in Phase 1 we collected surveys from professionals working in three different contexts:

- Child and Adolescent Mental Health Services (CAMHS);

- Adult Mental Health Services (AMHS), to explore whether young carers are identified through their parents, and to discover any evidence of collaborative working with CAMHS;

- Teachers and other professionals from the education sector, to explore if and how educational institutions identify and support young carers.

In Phase 2, we conducted a small number of semi-structured interviews with a sample of the professionals who were recruited through the surveys in Phase 1. We also did focus groups with young carers, who were recruited through young carers' services, and through professionals who were working with them. According to Aldridge (2006), it may be more appropriate to explore young carers' issues through qualitative rather than quantitative methods.

5.2 Participants

Phase 1
During Phase 1 a total of 79 professionals returned completed questionnaires, most of whom worked within Child and Adolescent Mental Health Services (46%, n=39), 32% of respondents (n=25) worked within an Adult Mental Health Service, and 19% (n=15) worked within education.

Of the professionals who worked within CAMHS, 54% (n=21) worked within statutory services, and 46% (n=18) worked within the voluntary sector. Respondents had a wide range of professional roles including young carers' service workers, psychologists, psychiatrists, social workers, support workers and team managers. The vast majority of AMHS professionals worked within statutory services (n=22), two worked within voluntary services and one worked in the private sector. Professional roles included service managers, nurses, psychiatrists, psychologists, social workers and support workers. Most of the educational professionals worked within state schools (n=11) with only one from universities and two from other educational services. Professional roles included head teachers, teachers, lecturers, specialist education needs workers, and educational psychologists.

Phase 2
In Phase 2 a total of nine professionals, one male and eight female, were interviewed. In Phase 1, they had identified their willingness to be interviewed further. Six of these interviewees worked in the voluntary health and social care sector, two worked in the education service and one was in private practice.

Professionals were from a variety of locations in the UK; including England, North Wales, and Scotland. The majority of participants identified themselves as British (n=6), and the other three identified themselves as British/Welsh, South African and Pakistani.

Five focus groups with young carers were conducted with a total of 37 young carers. These young carers attended young carers' groups, which were identified with the help of organisations such as Barnardo's and the Princess Royal Trust for Carers. The geographical spread of the groups included England, Scotland and Wales.

Twenty six of the young carers interviewed were female, and 11 were male. The majority were from a British ethnic background (n=31), 4 identified themselves as Pakistani, 1 as Indian and 1 as Caribbean. Their average age was 15 years, and ranged from of 9 – 24 years (Figure 1).

Figure 1: Age range of young people participating in Phase 2
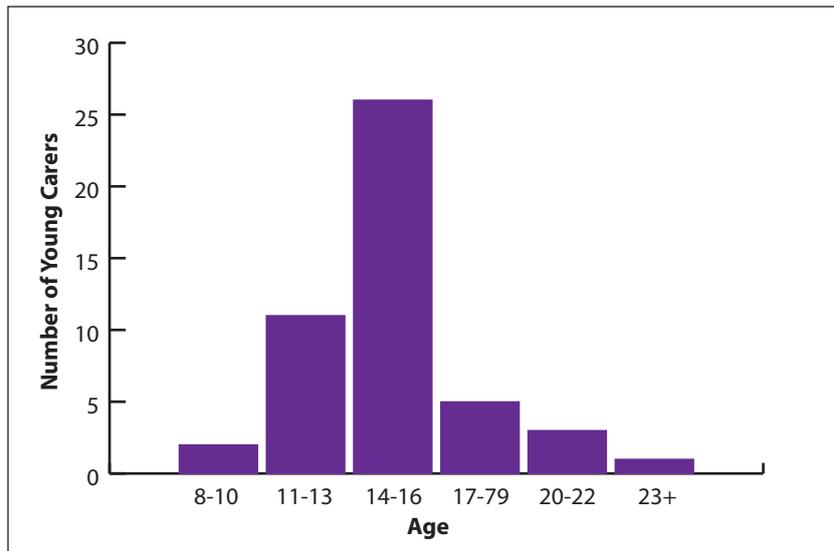
The vast majority were caring for their mothers (n=26), one was caring for a father, three were carers for both parents, three looked after a grandparent and four looked after several family members (including extended family). Twenty seven of the young carers specified how long they had been caring for, the average time spent caring was seven years and three months, with a range from one year and five months to more than 22 years. Figure 2 shows the distribution of how long the young carers had been in a caring role.

Figure 2: Young carers; length of time spent in a care role
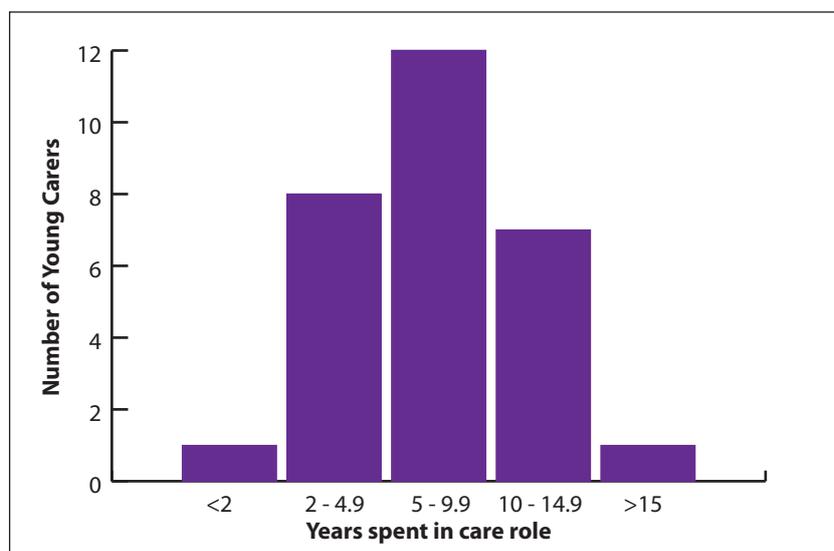
5.3 Measures

For Phase 1, we developed separate survey questionnaires for each of the three professional groups (see Appendices 9.1, 9.2 and 9.3 for CAMHS, AMHS and Education professionals respectively). These surveys covered the following areas:

- areas of met and unmet need;
- barriers to better services and support;
- perceived strengths and limitations of existing practices;
- recommendations for future practice and policy developments.

For Phase 2, we designed schedules for interviews with professionals and for focus groups with young carers (see Appendices 9.4 and 9.5 respectively). The schedule was modified for use with the different groups; young carers, professionals from a variety of different backgrounds (CAMHS, AMHS and education sector), it included the following topics:

- needs;
- resilience and coping strategies;
- service models and interventions.

Young carers contributed to creating the young carers' interview schedules. This was done through an online consultation, and through piloting with the Young Carers' Advisory Panel. This panel met once prior to the data collection phase in order to discuss the relevance and importance of the questions on the interview schedule.

5.4 Process

Prior to carrying out the study, the research team gained ethical approval from the Joint UCL/UCLH Committee on the Ethics of Human Research (Committee A).

A steering group was set up to guide the project. This group comprised representatives from the lead organisations and service providers for young carers and adults with mental health problems, and individuals at the forefront of the development for young carers' services. A Young Carers' Advisory Panel (YCAP) was set up to ensure the views of young carers were fed into every aspect of the project. The panel comprised 16 young carers aged 16-21 and one 23 year old who was able to share personal experience of the challenges around making the transition from a young carer support service into adult support services.

An event was organised to promote the project and to recruit services and practitioners to take part in the research. The event took place at the National Council for Voluntary Organisations in London on 10 February 2009 and was attended by over 100 delegates from three target professional groups; CAMHS, AMHS, and the education sector. The event was successful in recruiting many participants who would complete surveys and/or take part in interviews. It also offered a chance to recruit young carers for the focus groups.

A database was created of young carers and related services, CAMHS and AMHS services and educational institutions across the UK. The questionnaires were then sent to contacts on the database with an email asking that they be distributed throughout the service.

Participants were given the option to complete the survey electronically or by downloading a copy from the MyCare website. An option at the end of the questionnaire invited respondents to contact us to take part in a further in-depth interview, either face-to-face or on the telephone.

Interviews with professionals typically lasted between 30-45 minutes and covered the topic areas outlined in the interview schedule. Participants who agreed to participate in the study were asked to read an information sheet and sign and return a consent form.

Focus groups with young carers typically lasted between 60-90 minutes and were facilitated by two members of the research team. Recruitment to the focus groups was assisted by the local young carers' groups in each of the areas. Information sheets and consent forms were sent to the participants prior to the focus group. The groups were run pragmatically based upon the time and venue limitations in each area. In some of the groups there was a large variation between the ages of the young carers, and often it was more practical to run two groups for the older and younger participants. The two facilitators monitored the dynamics of the focus group. If necessary the group was split into smaller groups to make the young carers feel more comfortable and to improve the chances of getting accurate, rich information. The participants were given the option of responding verbally or by writing on sticky notes and passing them to one of the facilitators.

5.5   Data analysis

Responses to the questionnaire survey were subjected to statistical analysis using SPSS Version 16 for Windows (SPSS, 2007) and key findings are reported. Responses to open questions were recorded and analysed thematically under the question headings to provide qualitative examples of attitudes, beliefs and practices.

The responses from the individual interviews and focus groups were compiled and subjected to thematic analysis. One researcher went through the transcripts and identified themes and sub-themes, which were then matched against the aims of the project. A second researcher validated the process by randomly selecting five of the transcripts, identifying themes, and then comparing them with those identified by the first researcher. Any disagreement in the themes was discussed between the two researchers until an agreement was reached. The study findings are reported in the following section.

6. Results

A number of key themes emerged from the analysis of the young carer focus groups, the interviews and surveys with professionals. These themes have been organised into discrete sections and will be presented in turn. However, it is noteworthy that there is considerable cross-over between the different themes.

6.1 Caring for a parent with mental illness

Knowledge around mental health and mental illness was a key issue. Young carers felt that they lacked information to understand mental health, and needed more information to help them cope better with the situation.

"Getting information will make it easier to come to terms with." (Young carer, Lincoln)

"I would prefer to have more information on mental health." (Young carer, Wales)

"I was two when my mum became ill so I grew up with it so it's never really been explained. There isn't exactly a telephone line you can call to ask for advice or information." (Young carer, Lincoln)

There was general agreement among the professionals that young carers, while very knowledgeable about what was happening at home, could have limited understanding about mental health and mental illness. Among the CAMHS workers surveyed (n=39), just over half (n=21) felt the young people had 'moderate' understanding; seven felt young carers had 'substantial' understanding, eight felt they had little understanding. There was a realisation of the gap between practical knowledge of their situation and broader knowledge of mental health. However, professionals sometimes felt that parents would prefer children not to have the information. One raised the point that there was, perhaps, too much anxiety among non-mental health colleagues and teaching staff about needing to be an expert on mental health issues.

"The young carers are absolute experts in what happens in their house….but they don't have knowledge about mental health and mental illness when we have come across them, and they desperately want to have that." (Professional #1)

"I think sometimes families want to protect their children, they don't want to talk about mental illness too much because they think it is too much for the children to cope with but actually children are living in those families, they need some information." (Professional #1)

"Any information we give needs to be age-related as to how much they are able to take on and whether you are going to actually frighten a child more by telling them." (Professional #3)

"I think there are many professionals who feel that they need more information about mental health and mental illness in order to be talking to children and families about those issues. Now I don't think that it is necessarily true because… it's not the diagnosis that matters, it's the parent's behaviour that matters. That's the impact on the child… I think professionals have an anxiety around it, they do not feel equipped." (Professional #1)

Professionals identified a number of problems raised because the parent had a mental, rather than physical health problem. The often unpredictable, fluctuating nature of the illness meant that professionals found it hard to assess the burden of caring. Children may have been unsure of what to expect from one day to the next, and parents may be less likely to recognise the impact of their illness, not seeing their child as a 'carer'. Chronic mental illnesses were thought to be especially harmful for the children because of a perceived risk of them becoming too socialised into a caring role.

"The parents don't necessarily understand the extent of their own illness…We will take all sorts of referrals nowadays where the referrer is not able to clearly tell us what the caring responsibilities are and the reason we do that is because when we get to know the young people very well and we have a really good, trusting relationship with them then they begin to talk about their caring responsibilities." (Professional #3)

"With mental health conditions it fluctuates… Not knowing from one day to the other or one week… how the parent is going to be… I think that can cause quite a lot of lack of security." (Professional #7)

"With schizophrenia… they were much better able to say there is something wrong here. Whereas with depression, you don't necessarily know that the mother has been depressed when she is being very critical and negative." (Professional #5)

"Schizophrenia particularly and personality disorder, I do think that that's where children deal with a lot more of the stigma. Certainly we have seen that…they tend to talk a lot more about their fears…Long-term chronic depression to me feels much more damaging than a short, sharp, severe episode of mental illness, which can be very scary at the time but if it is managed doesn't necessarily put the young person into a long-term caring role…" (Professional #1)

6.2   Specific issues for young carers compared with adult carers

There was an understanding that young carers would be likely to be less visible to services than adult carers. They are less likely to be included in discussions about their parents' care, and may be overlooked in policy-making and service planning. Some of the younger carers believed that becoming older would lend them increased independence. Others believed that their caring responsibilities would increase since their parent would also become older and more dependent. Feelings of powerlessness may arise for young carers who are too young to leave home, which may cause tension with older siblings who have left. Older young carers were more experienced and aware of their situation, but needed to deal with the increased peer and academic pressure of adolescence.

"It is difficult enough to identify adult carers but they are far more likely to be recognised than children who are carers. The National Service Framework for Mental Health… is about caring for carers. It is written completely with adult carers in mind." (Professional #1)

"When other professionals come to the house… they treat you like you're invisible." (Young carer, Liverpool)

"It'll be ok because I'm going to get older and I'm going to get my own house and then I won't have to look after her." (Young carer, Milton Keynes)

"I have an older sister but she left when I was six, as soon as she could... I resented her at the time but now I realise I would have done the same if I could…When you are younger you seem to get more support... they seem to think when you are older you don't need it as much." (Young carer, Liverpool)

"For young adult carers… because they are very aware that mum or dad has a mental health issue I think it can affect their confidence and self-esteem…they are very much more aware of how society looks upon people like this." (Professional #7)

6.3   Negative impact of providing care

Young carers and professionals identified a range of emotional responses to the burden of care. Amongst young carers, professionals described anxiety about their parent's mental health as well as their own. Anger, frustration, guilt and resentment were common responses. Young carers often felt that they needed to contain their anger in order to avoid upsetting their parent or siblings. However, stress and frustration could sometimes lead to negative strategies in managing their feelings, and this could cause difficulties at school. Young carers may also feel guilt about going out and having a good time with their friends because of the feeling that something bad may happen to the parent in their absence.

There was no sense that boys or girls coped better with their feelings, though males may be less easy to identify as young carers, or less willing to be identified. Certainly some of the boys (but no girls) interviewed described how they tried not to let anyone know they were a carer, and suggested they didn't need the support available to them.

> *"I thought a few times that I'm going to end up depressed like my mum."* (Young carer, Liverpool)

> *"I always get suspended from school because of fights, because of anger."* (Young carer, Glasgow)

> *"I feel guilty going out… it stops me enjoying myself."* (Young carer, Liverpool)

> *"I just keep quiet and don't tell anyone about being a carer."* (Young carer, Lincoln, male)

> *"Carers are very sensitive to parents' slight change in mood; they feel responsible or stuck in the house and daren't leave in case the parent does something."* (Professional #2)

On a more positive note, many young carers described the emotional rewards from caring. They felt it gave them important life skills, a socially valued role, and a sense of self-efficacy. They also appreciated the special connection they enjoyed with their parent.

> *"I only realised my Mum wasn't the same as other mums when I was six and we had to do this thing at school and say why you love your mum… Others said stuff like, 'I love my Mum because she tucks me up in bed,' and I was like… 'I love my Mum because she says thanks when I cook her dinner,' and everyone just looked at me."* (Young carer, YCAP)

> *"The responsibility might not be what you want when you're young but it really benefits you when you're older."* (Young carer, Lincoln)

There were also references to the social impacts of caring. Interviewees spoke about young carers' restricted social networks. Sometimes the parent might not want or be able to take the child out, or the child might not want friends to visit because of their parent's illness. The stigma attached to mental illness may compound young carers' circumstances. They may refrain from telling others about their situation due to shame or embarrassment. They may also feel that they are betraying their parent by informing others, or even that they may be taken into care. It may also prevent the parent from explaining their illness to their child.

> *"Young carers can have fears about being taken away from their parents or parents being deemed as bad parents."* (Professional #1)

> *"I think their taboos prevent them from talking to their children about it. I think a lot of the children just find it quite a sort of unknown mystery, a serious area, and I don't think they understand it, unlike when you have a broken arm or if their parent is in a wheelchair [when] you can see what's wrong…There is a lot of isolation with mental health because the parent doesn't want to go out…and doesn't take the children out."* (Professional #3)

"People look at you differently because you don't fit in the same... Your mates are like, 'we were out on Friday night, where were you?'… You're like, 'Erm, I had to do the washing!'" (Young carer, Liverpool)

"It's difficult to keep friends, but at least you realise who your real friends are. You lose friends but you make stronger friends who you can confide in." (Young carer, YCAP)

6.4   Support in the school environment

According to the education professionals' survey (n=15), just over half of the respondents (n=8) said that young carers were identified in their school. Asked what policies and provisions were in place to support young carers, respondents offered answers ranging from 'little awareness' and ad hoc 'talking opportunities' through to a young carers' group that met at the school in lunch hour. Asked what they would do when a young carer did come to their notice, the majority said they would contact the educational psychologist (n=13) or social services (n=12). Nine said they would talk either to the child's parent, to counsellors, or to a young carers' service.

Some education professionals said that parents discouraged the children from revealing their carer status, but others felt that school staff did not listen or act because they did not feel equipped to deal with the problems that might emerge; stigma or lack of understanding. For these reasons, young carers may not be brought to the notice of education professionals. Respondents highlighted the need for teaching staff to listen to what young carers were telling them, encourage them to speak about it, and to be able to offer solutions.

"Young carers sometimes want to keep school separate and 'normal' like everybody else." (Professional, Education survey)

"Students regularly will not disclose that they are a young carer as this may be seen to not be cool by peers. Likewise the attendance at meetings can be low due to students not wanting to let peers know that they are looking after a parent with a mental health problem. I am unaware of whether any official systems are in place to identify young carers officially from the young carers' service." (Professional, Education survey)

With a few exceptions, most young carers had low expectations of what the school would and could do for them. Young carers reported a range of positive and negative responses from school staff. Some of these responses were helpful, but often the school only began to notice when the situation had reached a real crisis point, such as attempted suicide. Education staff often stated that young carers themselves did not want to be identified for fear of stigma and discrimination, or concern about parental criticism. Young carers often reported other problems in the school environment, such as bullying, which may have been linked with the stigma associated with mental illness or of being a young carer.

"Teachers have low expectations, have a label that sticks with you and it gets me down loads." (Young carer, Wales)

"I left at 14 years old to take on a full responsibilities of caring. But then all of a sudden the school took an interest… but they didn't help in giving me any sort of alternative, like I asked for work to be sent home because I did want to carry on with my education." (Young carer, Liverpool)

"I was only offered a learning mentor when I tried to kill myself." (Young carer, Liverpool)

"Schools don't want to learn about needing to give extensions or be more flexible." (Young carer, Lincoln)

"They offered to let me go to a group. School's cool." (Young carer, Glasgow)

"I got bullied in years 9 and 10 and was never the same after that... I tried to kill myself because I didn't want to be there so I couldn't learn and now I can't get a job". (Young carer, Liverpool)

6.5   Coping and building resilience

Young carers identified a range of coping strategies. The main overarching theme of the coping strategies employed was that the young carer was attempting to remove themselves from the situation, or distract themselves. In some cases the young carer engaged in an active hobby or activity; these included sports, music, or subscribing to a belief system:

> *"We act like other kids... we slam doors, run away, play loud music, because we are kids and don't know how to deal with it…I do sports to get out of the house, also to release anger and rage that could possibly build up."* (Young carer, Liverpool)

> *"I need to keep busy and take myself away from the situation when I can, I go to a swing in the park when I feel stressed, I play my guitar which sometimes works but it depends on my level of stress. Doing activities with the young carers' service really helps."* (Young carer, Lincoln)

> *"Coming to the young carers' group helps, or doing sports to get out of the house. Also it is useful to realise when anger and rage could possibly build up."* (Young carer, Glasgow)

> *"I started going to church when things got really bad and I've kept it up."* (Young carer, Lincoln)

> *"I always carry gem stones in my pockets – I don't believe in God or anything religious but I do believe these stones help."* (Young carer, Liverpool)

These coping strategies appear positive because they allow the young carer to get into an external space where they can act more freely, and possibly act more appropriately for their age. The mention of faith-related strategies such as churchgoing is interesting; the young carer is placing trust in an institution that lies outside of the home environment. Aside from hobbies and external visits, young carers described much more negative actions, which they may have used to remove themselves from their situation:

> *"I go to my bedroom, switch off the lights, hide in my bed, put a pillow over me and cry and scream. This makes me feel better. I do cry for… 24 hours."* (Young carer, Milton Keynes)

> *"I used to lie to friends if they asked I was upset... I would make up this fantasy world where I would pretend my life is perfect... It was my way of being normal, my way of coping."* (Young carer, Liverpool)

> *"I tried to kill myself."* (Young carer, Liverpool)

In contrast to the more externalised strategies outlined above, these actions appear to be more internalised. The young carers here are also describing their attempts to escape to another place. However, this may have potentially disastrous consequences. There may be another form of coping that does not involve escaping the situation, but embracing and analysing it:

> *"I thought a few times I'm going to end up depressed like my mum... I got a book instead and started writing things down, which really helped."* (Young carer, Liverpool)

Professionals understood the importance of identifying and building upon the factors in young carers' lives that helped them survive their situation. Many talked about the importance of there being another stable adult figure in the young person's life, a possible role model. They described the ways in which they tried to strengthen the resilience of the young carers with whom they worked, by boosting their self-esteem, providing them with information to dispel myths and fears, equipping them with coping skills and introducing them to peer support. This could provide more lasting, ongoing help in

the future. One professional felt it was important for young carers to know that services were aware of them and were trying to help them. Another stressed the need to ensure there was support available in the community to the young carers once they had outgrown the young carers' service.

"Somebody who has got a normal functioning significant other, whether that's parent or step-parent or friend or whoever, will have more of an opportunity to go out and meet with other people." (Professional #2)

"I have done a lot of self-esteem and confidence building by doing drama and things like this but after that we are going to go into more peer support." (Professional #6)

"We run a myth buster session… the two facilitators are CAMHS trained, so they can clarify for the young people the misinformation that they pick up. Those kinds of things help them in becoming more resilient. They can challenge their own beliefs and also challenge the beliefs of other people, kids at school that are bullying them…We ensure that…once the group has gone they have got somebody within school or within the extended family…there is somebody that they know they can talk to. That is hugely important." (Professional #1)

"… feeling that someone gives a damn about what you think as well. I think that is really empowering." (Professional #3)

6.6   Barriers to accessing support

Numerous barriers were identified for young carers accessing services and support. Age was mentioned several times, with young carers either being considered too young or too old to receive support. Young carers preferred age-appropriate support, rather than all ages being put together and defined by their overall caring role. Furthermore, support needed to continue beyond the official eligibility age limit for children and young people's services.

"Help stops at 16 even if you are still in your caring role… but when you do leave school you can't just walk into a job - I missed loads of school because I was caring." (Young carer, Liverpool)

"You start being a young carer when you are 9, and you are only a young carer in the eyes of the services for 10 years." (Young carer, Milton Keynes)

"They need to go at their own pace until they are comfortable and able to move on. They won't be able to let go of family commitments all of a sudden just because they have turned 18 or 16…" (Professional #9)

"They have asked specifically to do things with their own age group rather than be mixed with everybody all the time." (Professional #6)

There were hurdles to overcome in providing holistic, integrated support across service boundaries. Survey responses from AMHS professionals' surveys (n=25) highlight this in particular. Only nine of the respondents said that their service met whole family in cases where the parent or parents had severe mental illness. A small number (n=5) said they offered counselling, and even smaller numbers said they liaised with schools (n=1), offered group work (n=2), family therapy (n=1) and one-to-one support (n=1). One CAMHS professional talked about how they wished the AMHS would help the parents talk to their children about mental health. Difficulties in communication and collaboration across organisation boundaries could lead to young carers failing to access appropriate support.

"There are different cultures and working practice; different remits, rather than a focus for all on the whole family. There are time pressures on the workloads of practitioners in all services. There is a lack of trust, between families and services and between different services." (Professional, AMHS survey)

"Not always the correct or relevant information is shared. There are issues around confidentiality when sharing with relatives and significant others if the client does not want them to know about his or her alcohol use." (Professional, AMHS survey)

"There is an awareness from adult mental health that children in families need to be recognised and supported but I think it then becomes very dependent on how good the worker is, whether they actually do that piece of work, whether they will talk to the children about mental health and better still whether they will talk to a parent about helping the parent to talk to their children… that whole family bit about opening communication, that for me is a really important way to be talking to children…We have a lot of issues around communication with families where there are mental health needs… it is those families that we can't get a response from where we feel that the children are most vulnerable… Those children can and do become very, very isolated. Often people hide behind confidentiality, and very often if we were able to work with parents to work out what it was that they wanted to remain confidential and what it was that might be helpful to share with their children, that is the way forward." (Professional #1)

In professional services, there may be issues around which agency takes lead responsibility for the young carer. When we asked CAMHS professionals (n=39) who they thought was responsible for providing young people with information about their parent's mental health problem: the majority said it was the job of the social worker (n=30), GP (n=30), parent (n=29) psychiatrist (n=27) or young carer service (n=27). We asked if, as part of a young person's assessment process, professionals routinely asked about the young person's understanding of their parent's mental health problem: 29 said yes, six said no but would at a later date, one said that they never asked and the remaining three were unsure. Of the 25 AMHS professionals surveyed, most (n=20) said that they routinely asked adults who accessed their service if they had dependent children. Most (n=16) felt this was the responsibility of the psychiatrist or social worker. Half also felt the GP should be asking this question. The sheer number of agencies who may work with young carers appears to serve to confuse the issue.

Access to culturally sensitive provision presented another significant barrier for some young carers to receive support. Professionals were aware of the challenges of balancing the needs of young carers with sensitivity to cultural practices of those from BME communities. AMHS professionals cited several barriers to providing culturally sensitive provision for young carers including differing cultural understandings of mental illness, stigma in BME communities surrounding mental illness, and difficulties establishing relationships of trust with BME communities. Nearly three quarters of CAMHS professionals surveyed felt that young carers from BME groups perceived the role of caring for a parent/guardian(s) differently from white British young carers.

Services were not always offering culturally appropriate support, thereby excluding young carers from certain faith and ethnic groups. One respondent mentioned practical arrangements that needed to be made in order to accommodate particular religious events. Language was another barrier, and young carers may take on the role of interpreter for their parents. There was a need to produce culturally relevant information rather than simply offering translations of existing literature. Therefore there may be a need for outreach work; one service had taken steps to reach out to local minority ethnic families, recognising there may be some suspicion of statutory intervention.

"It's important to get support workers that don't judge you or treat you differently because of your ethnic background." (Young carer, Glasgow, of South Asian ethnicity)

"We very much had to have a worker who became part of the community, got involved in the groups that they were running and then put a young carer element into their group rather than saying, 'Hey, come along to our group'… Although that particular worker left and few months ago and we have recognised that there was a massive trust in her, rather than the organisation… we have taken a bit of a backward step at the moment but we have a good history to build on again." (Professional #1)

"To encourage BME communities to access support we have got three volunteer interpreters and we are trying to reach these people but we realise it is a much bigger job… and we have got an inclusion officer." (Professional #6)

"I think there is a general lack of information within the communities about what these services are all about and what are the underlying issues that they are trying to address… Maybe in the communities they don't really see the benefits of it. I think it is about doing the groundwork, it's that active outreach…When it is Ramadan we have had to change the group because some of the children are fasting…Within the service it's more about accepting your cultural diversity than making a big deal out of it… this is a group and it's made up of a huge range of people from different backgrounds, from different areas, and we are going to accept everybody for the differences that they have." (Professional #9)

"We have had a couple of traveller families, the professionals were much more concerned about them because they weren't getting an education but visiting those families the girls both appeared to be very happy with their caring responsibilities… it was a different sort of cultural background." (Professional #1)

6.7   Good practice

Professionals and young carers spoke positively of informal support, such as peer support and mentoring within young carers' services. Being flexible was valued, such as offering both group and individual support for young carers who may find group situations daunting. Young carers benefited from specialist support services that had good understanding of mental illness. One adult mental health service had employed a specialist professional to work with children of parents with a mental illness. CAMHS professionals described practical courses and interventions to support young carers, of those CAMHS professionals surveyed, the majority offered face-to face counselling and support (n=37), or information (n=29). Some said they provided a website (n=24), and smaller numbers offered peer support (n=17) or telephone helplines (n=13). Other services mentioned less frequently included referral to other services, groups, liaison with schools and young carers' groups.

Some schools did make an effort to provide support for young carers. One school had a designated pastoral care teacher with responsibility for supporting young carers. Another had a private room and a member of the teaching staff available for one-to-one time. Another said young carers were put on list of potentially vulnerable people, and it was discussed with parents/teachers if they were late for school. Some offered a generic counselling service to all pupils; others had made allowances to relieve the pressure of academic work. One young carer described a system adopted by their school that meant they did not have to explain every time they had to leave school early, or if they needed to keep their mobile phone on in class. Participants were asked to give examples of effective specialist support services for young carers of adults with mental health problems. The examples offered included one-to-one support, group work, coping skills training, creative expression groups such as music, dance and drama workshops, peer support forums and websites for young carers, and individual talking therapies.

"This service gave me cards when I was in year 11 that I could hand out to teachers which could let them know I'm a young carer. They had boxes I could tick that tells them things like sometimes I will need to keep my phone on in class or I might need to leave a lesson early to go home – they're a really good idea and really helped." (Young carer, Lincoln)

"We always have a male and female facilitator and we run a multi-cultural girls' group." (Professional #1)

"One little boy I know, we have noticed that in the mental health group he seems to be behaving a lot better than when he gets out into other groups that don't have the mental health component." (Professional #6)

"We actually set up some groups specifically for young carers that were in a situation where their parent has a mental health problem. We didn't mix them with any other young carers… worked really, really well." (Professional #7)

"They have built some good relationships at the service; peer support, doing and sharing things together not just sitting round talking about our problems but actually sharing experiences." (Professional #6)

"At school we offer what we can, free child care, free breakfast club, don't worry about homework that week. We try to take the pressure off." (Professional #2)

6.8   Suggested improvements

Clearly, the young carer should be seen within the wider context in which they live, and this should extend to the care and support that they will receive. Several respondents mentioned the need for whole family support or for teachers to be more aware of the issues that young carers face. There may benefit from a formalised process, as indicated with reference to the Common Assessment Framework (CAF). This is a standardised approach to assessing support needs, designed for use by practitioners across children's services in England. This, it was thought, would ensure a more collaborative, holistic approach to assessing and meeting the needs of the whole family where a parent has a mental health problem.

"What we are really missing is the ability to do family support. We would love to engage far more with Common Assessment Frameworks. We would love to do far more family support." (Professional #1)

"Whole family interventions would be really helpful… it would help if there was a consistent professional that had a good relationship with the whole family." (Young carer, YCAP)

"Teacher training should incorporate stuff about young carers so they know how to deal with the situation and are aware of what we're going through." (Young carer, Liverpool)

Another suggested improvement was to improve and extend young carers' experiences of education. Professionals and young carers were aware that not finishing school would restrict lifelong opportunities. There may be some simple practical difficulties that discourage young carers to continue with education after school.

"To go to college you need to take transport but you can't always afford it. You are only entitled to a student pass if you're full time so studying part time rules you out – they need to change that." (Young carer, Lincoln)

One professional suggested that the young people's caring role should be acknowledged in some form of recognised qualification, like a National Vocational Qualification (NVQ). The same professional felt that some kind of supported employment programme could be introduced for young carers. Others suggested specific training and skills that young carers may find helpful both in their caring role and in finding employment.

"They already have skills and I think it is about utilising those skills and recognising those skills… they have already got something that's of value… they are in a caring situation, they have an awareness of mental health and how can we package that and they come out with something, almost like a certificate or something…Like you have with adults, you have the supported transition employment placements; there isn't that kind of thing for young carers. I think it would be a great opportunity… employers to give young people opportunities so that we can build transitional employment." (Professional #9)

"As get older, services could help you with qualifications; the service doesn't give much career advice." (Young carer, Wales)

"Education and training such as in first aid so it would help caring role but also skills that could help in a work place or professional careers" (Young carer, Lincoln)

There appeared to be a need for additional resources for specialist staff and support services. Some felt there was need for dedicated advocacy support to help young carers voice their views and needs, highlighting specific problems compared to those reported by young carers of parents with physical disabilities. Those professionals with little or no specialist mental health knowledge (including some young carer support workers) felt ill-equipped to talk to young carers about mental health issues; there was a lack of appropriate information for staff.

"Services don't advertise because they don't have the funds to support everyone who would want to come." (Young carer, Lincoln)

"Advocacy for the young carers of parents with mental health problems… to recognise that their needs are very different to young carers of parents with other illnesses." (Professional #2)

"The booklet we have done has been fantastic in opening up dialogue with families but also for professionals who don't feel that they know enough about mental illness to use with young people… We want to do our own one for young people." (Professional #1)

"I am not sure if there is anything really good out there that measures how well they are doing, confidence, people's resilience as they go through from a young carer… making that transition into adulthood, through within the service. If there was an adequate toolkit to measure that it would be great…" (Professional #9)

7. Discussion

The experiences of the professionals and young carers corroborate the findings from the literature in relation to young people who care for a parent with a severe mental illness. Young carers' capacity to cope with the emotional demands of their role will depend upon their ability to take respite from their caring role, at least for a period of time. There were various active behavioural coping strategies in which young carers took this distance; other hobbies, taking time out, talking to friends/family, taking active steps to sort out problems, asking for help, or attending young carers' groups. Some more negative actions were identified (such as denial, aggression, violence and suicide attempts). The young carers were able to see why some behaviours were not useful (acting out their anger, for example, or getting into trouble at school), but explained that these were necessary ways of letting out some of the stress and emotions that would otherwise stay bottled up.

Professionals identified that one of the most important ways in which young carers could be supported was through the presence of another, trusted adult figure who the young carer could confide in. The presence of a more objective voice can help young carers to relate to their situation. Professionals working with this group talked of the importance of building up young carers' self-esteem and reinforcing their separate identity from that of their parent.

Young carers wanted consistency and dependability from services, particularly at key transition periods such as when they were reaching the upper age limit to qualify for attendance. For their parent, they wanted better care, treatment and practical support in the home, so that they would spend less time worrying about them. They wanted to be 'visible' to their parent's care team, and to be included in discussions about their parent's treatment. Some wanted to be free of their caring role but others did not question their role and were able to find some benefits in the maturity and life skills they felt they gained from their responsibilities. Some also felt that they had a better, closer relationship with their parent than they would otherwise, because of their caring role.

The data produced some examples of good practice in supporting young carers of parents with severe mental illness. Young carer support groups were seen by young carers as a very helpful response to their needs. This finding is perhaps unsurprising, since the majority of the young carer interviewees were choosing to attend such groups. Young carers valued the benefits of informal opportunities offered by young carers' services: peer support, the chance to make friends and build social networks, simply having fun and escaping from their carer roles to enjoy ordinary pursuits enjoyed by other children and young people, and having workers who would listen to them and give them time. The young carers' group also offered recognition of their difficulties, and the young carers felt encouraged by the fact that their difficulties were considered important; they perhaps felt validated by this concrete demonstration of concern.

Peer support from other young carers was an important benefit derived from young carers' groups. Partly for this reason, professionals noted that specific groups for young carers of parents with mental health problems may be helpful. Many young carers wanted more information around mental health and mental illness, as it was more difficult to find for mental health than it was for physical disabilities and illnesses. However, by going to young carers groups, they felt understood by their peers, and did not have to explain their circumstances. For many young carers, their parent's perhaps bizarre behaviour could be a source of embarrassment and stigma, and meant that they were reluctant to take school friends home, still further isolating them from their non-carer peers. In a young carers' group there was a sense of group solidarity in a world where they otherwise faced bullying and exclusion.

Young carers and professionals alike showed the worth of providing young carers with accurate information about their parent's mental illness, and of its impact on behaviour. Professionals without a mental health background often felt ill-equipped to explain these issues to young carers; there was a need for accessible information about the various mental illnesses and their impact that they could give to young carers. Ideally, the level and format of this information would be pitched to the age of the young carer. A child under the age of ten would require a simpler explanation than someone in their teenage years, perhaps focusing more on parental behaviours and how to respond appropriately.

While there was some disagreement about how old a young carer should be before they were able to take on the full implications of their parent's mental health problems, young carers were adamant that they did not want anything kept from them; the consensus seemed to be that it was better to know than to live in a state of not-knowing, or half-knowing. Knowledge, it was felt, was empowering for young carers. Previous studies have noted the need for more age-appropriate, easily digestible information for children about parental mental illness (Evans and Fowler, 2008; Becker, 2005). Clarkson et al (2006), in their report for The Children's Society, recommend that more open discussion about parental mental illness should be encouraged, including the use of family-friendly literature where necessary.

Schools have a recognised responsibility for promoting the mental health of all pupils, including young carers, as it is fundamental to the requirements of Every Child Matters (Department for Education and Schools, 2004). There was a need for more support and more sympathetic responses from schools. Few took active steps to identify and provide support to the young carers among their pupils, many young carers said they did not get any help from their schools, and that they were penalised for falling behind with their work due to caring responsibilities. Some young carers also released their frustrations through disruptive behaviour at school, as they were temporarily removed from their caring duties.

Those who work in schools face a sensitive issue, since professionals observed that young carers did not always want to be identified in school; they wanted to be seen as no different from their peers, many were already experiencing bullying and stigma, creating a dilemma for teaching staff. Some schools had introduced simple procedures to alleviate young carers' worries, such as an agreement with teaching staff that the young person could leave class when they needed, or keep their mobile phone on. Some had even established young carers' groups in the lunch hour, providing support without disrupting classroom attendance. Teachers need to be aware of how to potentially identify young carers within the school environment, be able to speak to the pupil in a non-confrontational, confidential manner and to encourage the young carer to stay in education. Furthermore, young carers may benefit from some recognition of the skills they have been using in their caring role, and how these skills could potentially benefit them in employment. This is especially important since young carers will often be disadvantaged upon leaving school due to lack of formal qualifications.

It was noticeable how often the responses from professionals seemed to suggest that doing something for young carers was someone else's responsibility. Respondents were aware that young carers had support needs, but were perhaps too ready to refer them (and their problems) on to some other professional or service who, they felt, would be better qualified to help them. What matters most is the impact of the mental health problem on the parent's behaviour and how that, in turn, affects the child and the family. Moreover, there was scant acknowledgement of family-oriented approaches; an approach that the literature suggests is better suited to building on the strengths of family members and establishing constructive relationships of trust.

Young carers from BME groups do not necessarily face different pressures or have different support needs from young carers in the majority population. Nor does the fact that the caring role may be more culturally accepted in their community mean they do not need support. The professionals in the survey were clear that more efforts need to be made to reach out to BME communities and ensure that the interventions offered are sensitive to their cultural needs, but without losing sight of the needs and rights of the children in these families. It was readily acknowledged that services need to do much more to reach out to and win the trust of their BME communities if young carers in these families are to be identified and offered relevant and acceptable support. In some services only mixed sex activities or activities led by men were on offer, which would not be acceptable for some girls and young women of South Asian ethnicity.

In terms of the resources professionals would find helpful in reaching out to and supporting young carers, information about mental health in various youth-friendly media came top of their lists: leaflets, books or DVDs. One professional described how their service had produced a book written by a young carer that had been extremely successful and had been published and distributed widely, beyond his or her immediate service locality.

Conclusion

Young carers of parents with severe mental health problems are a frequently overlooked, poorly served group. Moreover, they are a specific group with different experiences and different needs from young carers of parents with a physical illness or disability. The views and experiences of the young carers and professionals reported here reinforce the findings in the literature as to the need for specialist support if these young people are to achieve their full potential.

What is needed is clear, factual, young people-friendly information about mental health and mental illness, its impact, and how young carers can be helped to cope with their situation. Alongside this greater knowledge and awareness, specialist peer support groups for young carers of parents with mental health problems provide by far the most acceptable and effective ways of supporting these young people. However, importantly, there would be less need for such intervention if children's services, education and mental health services were better able to work together with the whole family, so that the needs of the whole family, as well its individual members, could be met.

Young carers do not cease to have caring responsibilities at age 16 or 18; the emotional and physical commitments remain. In finding employment, these young people are likely to be further disadvantaged in comparison with their peers because of interrupted schooling or poor attendance. Support that starts earlier and extends beyond the age of 18 would greatly improve these young carers' prospects in adult life. Nor should the support end if, tragically, the parent dies; these young carers will continue to carry emotional baggage, and will continue to need specialist support that recognises the particular demands of their role.

Recommendations

For policy and practice:

1. More age-appropriate information about mental health and mental illness should be made available to young carers, and for those who work in young carers' services and the education sector. This information should be focused on the causes and effects of parental behaviour patterns that may arise from mental illness.

2. Effective co-ordination between staff of various disciplines is required, including social workers, mental health professionals, young carers' service workers and teachers. There may be a need to identify a lead professional who will take primary responsibility for working with the young carer, and link with all the relevant agencies. Ideally, this lead professional should be selected by the young carer themselves.

3. A greater priority given to funding for young carers' support services, to ensure optimal geographical coverage of services around the country.

4. Further promotion of existing online resources for young carers and professionals. A centralised hub of resources might include the following websites:

   a. www.youngcarer.com (information about young carers' services)

   b. www.youngcarers.net (direct support for young carers)

   c. www.carers.org/professionals/young-carers
   (support and advice for young carers and professionals)

For young carers' services:

5. Conduct specialist sessions within the young carers' service, aiming to teach young carers about mental health, mental illness and how to build resilience against it. This could include visits from people who work for local statutory or voluntary mental health organisations.

6. Encouraging young carers of parents with mental illness to meet with other young carers who may have a similar situation, either within the young carers' service or with other nearby young carers' services. This could be achieved through peer support sessions.

7. Make links with different minority communities to understand the specific needs of young carers within these communities, and to find culturally sensitive ways of meeting them.

8. Continue offering young carers the opportunity for respite, with the chance to do activities that others of their age are able to do, including working with schools to help ensure that young carers are able to access after-school activities.

9. For services to be flexible around their entrance criteria, specifically around minimum and maximum ages.

   This will require adequate funding and support from statutory funders, other donors and local mental health services.

For mental health services:

10. Identify young carers; ascertain the level of care provided by the young carer and to enter negotiation with the parent about how to discuss parental mental health with the young carer.

11. Liaise with local young carers' services about the types of activities that the services provide, and to signpost and refer where appropriate.

12. Work in partnership with children's and other services to ensure that the parent has adequate support in their parenting role, in the context of recognising and addressing the whole family's needs.

For schools:

13. A school lead for young carers and their families (or other nominated staff member) to create and maintain active links with young carers' services within the local area. If there are no young carers' services within the local area, then the nominated staff member should seek advice and information from a remote information hub, such as the websites mentioned above.

14. If a staff member identifies a young carer, the staff member should speak to the School Lead and ask them for confidential advice. The staff member should not disclose the identity of the pupil against the pupil's wishes. The staff member should then speak to the young carer directly to seek more information about their situation, and signpost them to necessary support networks, possibly including local young carers' services.

15. Provide sensitive and confidential support in the school environment, providing pupils with a space to discuss their problems with teachers, school counsellors or peers.

16. Teachers and other school-based professionals to provide known young carers with understanding and flexibility regarding coursework and attendance.

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9. Appendices

Appendix 9.1 – CAMHS survey

First we'd like to find out a bit about you before we get on to the main part of the questionnaire, please tell us a bit about you and your situation. All data is kept securely and anonymously.

A.   Organisation/Service Information

1.0   Please state your full job title: _____

2.1   Organisation/Service Sector:

Statutory ☐   Non-Statutory/Voluntary ☐   Private Sector ☐

2.2   Please state which specific type of service you are in (e.g. CAMHS. youth group, young carers service, family services, social service, primary or secondary school, college etc..).

_____

3.0   Geographical Location of Service (please state the area and post code):

_____

4.0   Where does your organisation/service receive referrals from? (Please tick all that apply)

Schools ☐   Extended family/friends ☐

Self referral ☐   GP ☐

Parent/guardian ☐   CAMHS ☐

Social Services ☐   Other (please state):_____

B.   Characteristics of Young People

1.0   Does the service cater for young people who are/have? (Please tick all that apply)

Mental health problems ☐   Black minority ethnic groups ☐

Special educational needs ☐   Drug and/or alcohol use ☐

Refugees and asylum seekers ☐   Other:_____

2.0   Do you provide a service to:

Siblings ☐   Parent with mental health problem ☐

Extended family ☐   Other parent ☐

Friend/s of young carer ☐   Other:_____

2.1   If Yes, please briefly describe the major elements of provision for other family members:

_____

_____

3.0   What is your target client group? (Please tick all that apply)

10-12 years old ☐   16-18 years old ☐

13-15 years old ☐   19-21 years old ☐

**4.1   Do you work with young peoples' schools/colleges/universities?
(Please tick one answer)**

Always   ☐   Often ☐

Occasionally ☐   Never ☐

**4.2   What percentage of your caseload involves working with young people's schools/
colleges/universities? (Please tick one answer)**

Less than 20% ☐   21- 40 % ☐   41-60% ☐   61-80% ☐   81-100% ☐

**5.0   Does your service record the following types of service user characteristics?
(Please tick all that apply)**

Ethnicity ☐   Refugee/asylum status ☐   Sexual orientation ☐

Religion ☐   Mental health problems ☐   Drug and/or alcohol use ☐
                         and emotional well-being

Other:_____

We'd really like to explore young people's understanding of their parent's mental health and how that information is accessed. So the next section is based around the understanding of mental health.

C. Understanding of Parental Mental health

1.0   What does the term 'mental health' mean to you/your organisation/service?

_____

_____

**2.0   Who do you think is responsible for providing young people with information on
their parent's mental health problem?**

Parent ☐   Social worker ☐   School ☐   Other:_____

GP ☐   Psychiatrist ☐   Young carer service ☐

3.0 **Below are a number of possible sources of where young people get their information on their on parent's mental health problem, please rate them according to which source you feel is most used (please rate 1 to 5, 1 being the least used and 5 being the most used).**

Parent ☐   Professional ☐   Your service ☐

Media ☐   Extended family/friend ☐   Internet ☐   Other:_____

4.1 **As part of a young person's assessment process do you/your service ask about the young person's understanding of their parent's mental health problem?**

Yes ☐   No, we don't ☐

No, at a later date ☐   Not sure ☐

4.2 **If Yes, what is asked?**

_____

_____

5.0 **To what extent do young people understand their parent's problem and how it affects their parent?**

No understanding   ☐   Moderate understanding   ☐   Not sure ☐

Little understanding ☐   Substantial understanding ☐

6.0 **What types of information and support (if any) do you provide to young people about their parent's mental health problem?**

Face- to face counselling/support ☐   Literature ☐   Peer support ☐

Telephone support service ☐   Websites ☐   Other:_____

D.   The needs of young carers looking after parents with mental health problems

A young carer is a child or young person under the age of 18 carrying out significant caring tasks and assuming a level of responsibility for another person with a mental health problem which would normally be undertaken by an adult.

1.0 **In your experience, do young carers experience mental health problems of their own? (Mental health problems can range from mild to moderate and include severe and enduring illnesses.)**

Yes ☐   No ☐

2.0   Do you monitor the mental health needs of the young carers that access your service?

Yes ☐   No ☐

3.0   What types of information, support and advice (if any) do you provide in response to young carers own mental health needs of young carers accessing your service?

Face- to face counselling/support ☐   Literature ☐   Peer support ☐

Telephone support service   ☐   Websites ☐   Other:_____

4.1   If your organisation/service does not provide mental health support to the young carers, do you liaise with other organisations/services that do provide mental health provision?

Yes ☐   No ☐

4.2.   If Yes, who?

_____

_____

We are really interested in how culture can influence choices, and we'd like to ask you a few questions about how you feel culture influences the young carers you see.

E.   Culture and ethnicity

1.0   Do you think that young carers perceive the role of caring for a parent/guardian(s) differently, depending on their culture and ethnic background?

Yes ☐   No ☐

1.1   If Yes, please provide examples of how young carers' perceptions differ in relation to culture and ethnicity?

_____

_____

2.0   What successes has your service had in providing culturally sensitive provision to young carers?

_____

_____

3.0   What barriers/constraints has your service found when providing culturally sensitive provision to young carers?

_____

_____

F.   Resilience

"A resilient child can resist adversity, cope with uncertainty and recover more successfully from traumatic events or episodes." (Newman, 2002)

1.0.   What type of support, intervention and provision (if any) does your organisation/ service offer to build the resilience of the young carers? Please provide examples:

_____

_____

2.0.   What outcomes for young carers would demonstrate that these interventions are successful?

_____

_____

3.0   How does your organisation address resilience in young carers?

_____

_____

G.   Coping strategies

Coping strategies can be positive or negative and refer to behavioural and psychological efforts that people employ to master, tolerate, reduce, or minimize stressful events. We are interested in coping strategies which safeguard young carer's mental well being.

1.0.   In your experience, what types of coping strategies do these young carers use? Please tick the boxes of the strategies that young carers use most.

Talking to others ☐   Leisure activities ☐   Positive thinking ☐

Seeking information ☐   Religious beliefs/Practice ☐   Avoidance ☐

Drug abuse ☐   Self-harm ☐   Other/s:_____

2.0   **What types of support, interventions and provision (if any) does your organisation/ service offer in terms of helping young carers develop effective coping strategies?**

_____

_____

3.0   **What outcomes for young carers would demonstrate that these interventions are successful?**

_____

H.   Next Steps…

Your views are important to us and we'd really like to hear more about what you've got to say on this topic.

1.1   **Are you willing to be contacted if we have any questions about the answers you have provided? (We will not use your information for any other purpose and it will be kept confidential and secure.)**

Yes ☐   No ☐

1.2   **If Yes, please provide your name, direct dial and email within your organisation/service:**

_____

_____

Thank you for completing this survey

Appendix 9.2 - AMHS Survey

Demographics Sheet

First we'd like to find out a bit about you before we get on to the main part of the questionnaire, please tell us a bit about you and your situation. All data is kept securely and anonymously.

A   Organisation/Service Information

1.0   Please state your full job title:

_____

2.0   Organisation/Service Sector:

Statutory ☐   Non-Statutory/Voluntary ☐   Private Sector ☐

3.0   Geographical Location of Service (Please state the area and post code):

_____

4.0   Where does your organisation/service receive referrals from? Please rank from 1 to 5, 1 being the place you receive the most referrals from, and 5 being the least.

Self referral ☐   Extended family/friends ☐   GP ☐   Social Services ☐

Acute ward ☐   Other:_____

5.0   Does your service record the following types of service user characteristics? (Please tick all that apply)

Ethnicity ☐   Refugee/asylum status ☐   Sexual orientation ☐

Religion ☐   Mental health problems ☐   Drug and/or alcohol use ☐
                and emotional well-being

Now we'd like to ask you about your service and provision of care.

B   Service Provision

1.0   Do you ask adults who access your service if they have children?

Yes ☐   No ☐

2.0   Whose responsibility is it to enquire if service users have dependent children?

GP ☐   Psychiatrists ☐   Parent should tell ☐

Social Worker ☐   Other:_____

3.1   Does your service meet with the whole family?

Yes ☐   No ☐

3.2   If yes, what family interventions do you provide to the children?

None ☐   Referral ☐

Information/advice ☐   Counselling ☐   Other: ☐

4.0   Do you liaise with any of the following services in relation to the children of the service users? (Please rate from 1 to 5, 1 being the place you feel you liaise with the most, 5 being the least)

Schools ☐   Social Workers ☐   Inpatient wards ☐   GPs ☐

Voluntary ☐   Counselling/Psychiatrists ☐   Other: _____

5.0   Are there any barriers/constraints in working with other agencies? If yes what are these?

_____

_____

6.0   What successes have you had in your partnership working?

_____

_____

We are really interested in how culture can influence choices, and we'd like to ask you a few questions about how you feel culture influences the service users you see.

C   Culture and Ethnicity

1.0   Do you feel that parents view the needs of their children differently due to their culture and ethnic background, if so how?

_____

_____

2.0   What successes has your service had in providing culturally sensitive provision to service users?

_____

_____

3.0   What barriers/constraints has your service found when providing culturally sensitive provision to young carers?

_____

_____

D   Next Steps…

Your views are really important to us and we'd really like to hear more of what you've got to say on this topic.

1.1   Are you willing to be contacted if we have any questions about the answers you have provided? (We will not use your information for any other purpose and it will be kept confidential and secure.)

Yes ☐   No ☐

1.2   If yes, please provide your name, phone no. and email in your organisation/service:

_____

_____

Thank you for completing this survey

Appendix 9.3 – Education professionals' survey

First we'd like to find out a bit about you before we get on to the main part of the questionnaire, please tell us a bit about you and your situation. All data is kept securely and anonymously.

A.   Organisation/Service Information

1.0   Please state your full job title:_____

2.0   What type of institution do you work in?

Private school ☐   College ☐   State school ☐

University ☐   Other:_____

3.0   Geographical location of education institution (Please state the area and post code):

_____

B.   Understanding of Mental Health

We are interested in your views on the children you are in contact with and their social and emotional well being.

1.0   How do you understand mental health in relation to your workplace?

_____

_____

2.0   Does your institution help raise awareness and increase young peoples understanding of mental health? And if so, how?

_____

_____

3.1   Does your institution work to address stigma and discrimination around mental health?

Yes ☐   No ☐

3.2   If yes, how is this achieved?

_____

_____

A young carer, in this instance, is a child or young person under the age of 18 carrying out significant caring tasks and assuming a level of responsibility for another person with a mental health problem which would normally be undertaken by an adult.

4.1   Are young carers identified in your school?

Yes ☐   No ☐

4.2   If yes, what policies/provisions are in place when a young carer is identified?

_____

_____

5.0   What do you think are the barriers/challenges in identifying young carers?

_____

_____

6.1   Which other external agencies do you liaise with in the voluntary or statutory sector? (Please tick all that apply)

Social Services ☐   Young carers services ☐   Educational Psychologists ☐

Counsellors ☐   Parent ☐   Other:_____

6.2   If Other, please state why type of agency

_____

_____

7.1   Do you refer young carers to other services?

Yes ☐   No ☐

7.2   If yes, which?

_____

8.0   What training is provided for teachers on the topic of mental health?

_____

_____

9.0   What things do you think schools/you need to help support young carers?

_____

_____

10.0 **Please provide us with details of any experience you have had of dealing with children of parents with mental health problems.**

_____

_____

C. Next Steps

Your views are important to us and we'd really like to hear more about what you've got to say on this topic.

1.1 **Are you willing to be contacted if we have any questions about the answers you have provided? (We will not use your information for any other purpose and it will be kept confidential and secure.)**

Yes ☐   No ☐

1.2 **If yes, please provide your name, direct dial and email:**

_____

_____

Thank you for completing this survey

Appendix 9.4 – Professionals' interview schedules

CAMHS

1. **What do you think are the issues facing young carers of parents with mental health problems?** Probe- similar to above? as opposed to young carers of parents with physical health problems? Harder/easier to deal with?

2. **Are there different issues for young carers compared to adult carers?**
    Probe- life experience, more detrimental to life? Less appropriate?

3. **What is your experience of young carers' understanding of parental mental health?**
    Probe- much understanding? Much difference between YC's? What understanding? Where from? Want more understanding? What are the benefits/drawbacks to young carers understanding a parent's mental illness?

4. **Does the specific diagnosis/condition of the parent have a bearing on the likely effects on the young carer? (Depression, Schizophrenia, Bi-polar)?** Probe-different needs, reactions, care they have to give. -if so, is different support provided?

5. **How have you found young carers cope with their caring role?** Probe- do they cope? what helps them to cope? do you identify coping strategies? How? which do you find they use? Positive/negative- which do you think safeguards their own MH in the L/T?

6. **What have you found to be successful in helping YC's to better deal with their role as a YC?**
    Probe- What can we do-what coping strategies? What services? How much support? How would you try to build resilience? Are there drawbacks in building resilience? If so, what?

7. **Do the needs of young carers vary according to: Ages? Cultures? Gender?** Probe- In what way? How should practice address this?

8. **Do you feel your service takes the religious and cultural needs of young carers into consideration?** What does your service do to address the needs of religious YC's? What do you think could be improved?

9. **Do you have any guidelines/policy that you have to work within/follow in your service?**
    Probe- Do they help facilitate work or act as barriers to your work/support? How could they be improved?

10. **What's out there already tool wise?** Probe- DVD's/activity packs/information leaflets for young carers? where are the gaps?

11. **What can we do to help you and your service?** Probe- what do you need? What do you find helpful? What do you not find so helpful? From us, from voluntary sector, from wlocal government and NHS, from national government

12. **Anything else that I haven't asked you that you'd like to tell me about that concerns young carers?**

AMHS

1. **How is your working relationship with CAMHS?** How often do you communicate? How can communication and working across services be improved?

2. **What happens when you notice a young carer?** Probe- Whose responsibility do you think it is to enquire if service users have dependent children?

3. **Does your service meet with the whole family?** Probe- if so what interventions do they offer them?

4. **Do you refer children of the service users to child services if you find out the service users are parents?** Probe- where? How often? Is this a policy or at a workers discretion?

5. **What do you think are the issues of parents with MH problems?** How can they be better supported by your service?

6. **What do you think are the issues facing young carers of parents with mental health problems?** Probe- similar to above? as opposed to young carers of parents with physical health problems? Harder/easier to deal with?

7. **Whose responsibility is it to inform children about their parent's mental health?** AMHS/CAMHS/both? What should be in place to ensure someone does?

8. **Do you feel your service is culturally sensitive?** Probe- for service users from different ethnic backgrounds/genders/religions? What do you think could be improved?

9. **Do you have any tools that you use for young carers?** Probe- DVD's/activity packs/ information leaflets for young carers? where are the gaps?

10. **What can we do to help you and your service improve lives of Young carers?** Probe- what do you need? What do you find helpful? What do you not find so helpful? From us, from voluntary sector, from local government and NHS, from national government

11. **Anything else that I haven't asked you that you'd like to tell me about that concerns young carers?**

Education sector

1. **Do you have mental health training at your school/institution?** Probe- For teachers? For pupils?

2. **Do you have any guidelines/policy that you have to work within/follow in your school about YC's?** Probe- identification? Do they help facilitate work or act as barriers to your work/support? How could they be improved? Do you know of any YC's in your school?

3. **What do you think are the issues facing young carers of parents with mental health problems?** Probe- similar to above? as opposed to young carers of parents with physical health problems? Harder/easier to deal with? Are there different issues for young carers compared to adult carers? life experience, more detrimental to life?

4. **What is your experience of young carers' understanding of parental mental health?** Probe- much understanding? Much difference between YC's? What understanding?

Where from? Want more understanding? What are the benefits/drawbacks to young carers understanding a parent's mental illness?

5.   **How have you found young carers cope with their caring role?** Probe- do they cope? what helps them to cope? do you identify coping strategies? How? which do you find they use? Positive/negative- which do you think safeguards their own MH in the L/T?

6.   **What have you found to be successful in helping YC's to better deal with their role as a YC?** Probe- What can we do-what coping strategies? What services? How much support? How would you try to build resilience? Are there drawbacks in building resilience? If so, what?

7.   **Do the needs of young carers vary according to: Ages? Cultures? Gender?** Probe- In what way? How should practice address this?

8.   **Do you feel your school takes the religious and cultural needs of young carers into consideration?** What does your service do to address the needs of religious YC's? What do you think could be improved?

9.   **What can we do to help you and your school regarding YC's?** Probe- what do you need? What do you find helpful? What do you not find so helpful? From us, from voluntary sector, from local government and NHS, from national government

10.   **Anything else that I haven't asked you that you'd like to tell me about that concerns young carers?**

Appendix 9.5 – Young carers' focus group schedule

1.   **What is your understanding of your parents/guardians illness**
      - Do you know much about it- how it affects them?
      - What is your understanding of mental health/well being?
      - What is your understanding of mental health problems?

2.   **When were you first offered any advice/info/help about your parents mental health problem?**
      - How did you find out about this help? Did you do this yourself or didsomeone help you?
      - Was this helpful? If yes- what was helpful about it? What difference did it make to your life? If it wasn't helpful why not?

3.   **Do you have anyone else that helps/supports you such as family, friends, GP, school?**
      - Are your school aware of your situation? If so how understanding are they?
      - Is there anyone at school you talk to about being a young carer?
      - Does your school talk about young carers such as in classes like PSHCE?
      - Do they help other young people and teachers have a better understanding of mental health?
      - Does your school offer support to young carers?
      - Do you access this support at school to help manage being a young carer? Do you find this positive? If so, what is helpful about it? If not, why not?
      - Ideally would you want your situation to be confidential in school, or for teachers/pupils to know?

4.   What does the word 'stigma' mean to you?

5.   How do you feel about talking about mental health?
- What do you think your friends/peers/teachers feel about talking about mental health?

6.   How is your relationship with the parent/guardian you care for?

7.   Are there things about being a young carer that feel difficult? How do you cope with these things?
- What are the positive things about being a young carer?
- What emotions do you find difficult to manage when you are caring/helping?
- What helps you to manage these emotions better? (Such as art, sport, writing a diary, seeing friends)

8.   Do you have any brothers or sisters? Are they younger or older than you? Do they help you out at home?
- Who would take on your role if you went on a holiday/a school trip/left home?
- Do other people in your family see you as a carer? What do other people in your family think about you being a carer?
- Do you feel you are expected to help out? If so, why?
- How did you cope with helping/caring when you were younger?
- If you are religious/spiritual, does practicing your faith help you with your care role? Reading Bible/Koran/ meditating/praying.
- Do you feel the service you attend takes your faith into consideration?
- How could this be improved?
- Do you think your role will change when you are older? Do you want it to change? If so how would you like it to change?
- If you live in the country, do you feel this has an affect? Do you have problems with transport or access to shops that are close by or the internet?

9.   What things would make your life easier?

10. What are the best things about this young carer's services and why?
- What things could you suggest to improve the service/help young carers receive?
- Would you like more information about your parent's mental health problem?
- What do you think young carers services could do to encourage other young carers to come along?
- Why do you think some young carers don't seek support? What do you think we could do to encourage them to get support? (either from services, or other people)
- Overall, what do you feel are the most important aspects are for a service to have in order to meet the mental health and emotional well-being need?

Mental Health Foundation

Founded in 1949, the Mental Health Foundation is the leading UK charity working in mental health and learning disabilities.

We are unique in the way we work. We bring together teams that undertake research, develop services, design training, influence policy and raise public awareness within one organisation. We are keen to tackle difficult issues and try different approaches, many of them led by service users themselves. We use our findings to promote survival, recovery and prevention. We do this by working with statutory and voluntary organisations, from GP practices to primary schools. We enable them to provide better help for people with mental health problems or learning disabilities, and promote mental well-being.

We also work to influence policy, including Government at the highest levels. We use our knowledge to raise awareness and to help tackle stigma attached to mental illness and learning disabilities. We reach millions of people every year through our media work, information booklets and online services. We can only continue our work with the support of many individuals, charitable trusts and companies. If you would like to make a donation, please call us on 020 7803 1121.

Visit www.mentalhealth.org.uk for free information on a range of mental health issues for policy, professional and public audiences, and free materials to raise awareness about how people can look after their mental health.

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