

“There for you”: The role of parents in supporting young people with mental health problems

Results of a survey

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“It must be incredibly hard for a young person who’s in crisis themselves to then look at the one person they trust, who is sitting on the floor sobbing their heart out thinking I have no idea what to do, and nobody’s helping me. That must be quite traumatic for a young person.” Parent

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Introduction

Although there is the beginning of a sea change in the way we view mental health and the stigma surrounding it, young people and their families are still struggling to get the vital help they need. Half of all adult psychiatric disorders start by age 14¹, but a massive treatment gap still exists. Only a quarter of those referred to specialist services will be seen.² In addition only 0.7% of the total NHS budget is spent on mental health services for under 18's.³ Despite all the ongoing efforts to transform child and adolescent mental health services, things are not changing fast enough for many young people and their families.

The parents of adolescents are the most unsupported of all groups of parents, and those who have teenagers with mental health problems seem to be particularly isolated. Yet parents are likely to be a big part of the solution as far as successful outcomes for young people are concerned. Our research shows that they play a key role in supporting their children through both crisis and recovery.

AYPH has an ongoing programme of work on the challenges facing parents and their young people in navigating mental health services. This briefing presents the results of an online survey of 316 parents undertaken in the summer of 2016 and identifies emerging messages for improving information and support. The project also includes focus groups and individual interviews with parents, participation work with young people and discussions with stakeholders. A final report drawing together all the findings from these different perspectives will be published in early 2017.

“She’ll come to me and she breaks my heart: ‘help me mum’, and I say, I promise I’ll help you pet, I’ll make sure you get help. And I feel like I’m banging my head against a brick wall because it doesn’t happen, it never happens.” Parent

How we did the survey

The charity YoungMinds coordinates a parents’ network; a group of over 1000 parents with children with mental health problems who discuss issues and share information online. This is a particular group of engaged parents who are looking for support and feel they have something to say. As such they do not represent the families who have no voice at all, or those who are perhaps less engaged with their young person’s mental health problems. However, they provide an important starting point for finding out what parents think. AYPH designed a short survey and the link was circulated to the panel. Questions addressed the role that parents have in supporting their young people, the types of services that had been accessed, what had been helpful or had caused difficulties in trying to get help, and what kind of support parents would like to see available.

Of the 316 parents who responded to the survey, the majority were mothers (302). The young people they were supporting were aged from 11-15 (41%), 15-18 (27%), over 18 (20%) or under 11 (13%). Just over half of the young people were female (53%). Almost all parents indicated that their young person was feeling very depressed and/or highly anxious (91%), with a quarter of parents saying their child had a clinical diagnosis of depression (23%). Most had several difficulties at the same time. Over half of the parents said their child self-harmed (59%) and/or had behaviour problems (51%), and 43% had autism spectrum disorder. Others had a diagnosis of eating disorders (13%), personality disorder (7%) psychosis (3%) or bipolar disorder (2%).⁴

1 Kessler R et al (2005) Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry*, 62, 593-602.

2 Frith E (2016) *Children and Young People’s Mental Health: State of the Nation*. London: CentreForum.

3 Frith E (2016) as above.

4 We have also drawn on some quotations from focus groups with parents and young people. All names and potentially identifying details have been changed.

The findings – what parents say

Parents struggled with the issue of waiting times (66%), no one believing there was a problem (49%), thresholds for intervention being set too high (41%), and being excluded from the process by the agencies involved (41%). Parents commented that “it took 13 years to be listened to”, and that “No one was interested or listened until it was too late”. They also felt subject to “parent blaming”, and that they were being judged “harshly and wrongly”.

66% of parents said a big issue was waiting times

.....
49% of parents said no one believed them that there was a problem

“It’s an awful feeling, when you just want to help them and you don’t know how, you don’t know what to do” Parent

Even when the child receives services, parents often feel left alone to cope, without the information they need to provide the right kind of support at home and to deal with crises. Parents worried they aggravated the situation through their own anxiety, and described families in considerable distress. As one parent noted, “We made our daughter’s condition MUCH worse by doing the wrong thing, and no one told us”.

The practical impact on parents can be extensive. In order to care for their young people, many have to take time off work, go part-time, take unpaid leave, or resign from jobs entirely. Some face disciplinary action for missed days, and families – including siblings – face further stress.

Parents view their role in different ways, with the majority (83%) rating provision of emotional support as one of the most important things. Parents also stressed the important of “being there” by advocating for their young person to fight his or her corner and trying to get the best services. For some parents their most significant role was to keep their child physically safe, and to help to keep normal life going.

“I’ve put a photograph in all the shops on Falcon Road, I’ve put a photograph of Sophie, which is really hard...I’ve put a photograph in just saying please do not sell this child any paracetamol” Parent

Parents work hard to find help from the outset, using a wide range of contacts including primary care, school staff, local voluntary sector projects, and family and friends. Parents also mentioned receiving initial help from sources such as hospital consultants and clinical nurse specialists treating chronic physical conditions, community nurses, Local Authority youth workers and family support teams, other parents, and online helplines. However 36% said “no one helped” when problems were first identified.

36% of parents said that they had paid private counsellors, psychologists or other therapists

A full range of available services had been used by the families, from statutory child and adolescent mental health services (90%), Accident and Emergency (33%), and voluntary sector projects (31%), through to drug and alcohol teams, child sexual exploitation services and educational psychologists. A significant proportion – over a third (36%) – reported they had paid private counsellors, psychologists or other kinds of therapists.

Parents feel they have something to offer but are often side-lined in the process. They said “Build resilience in the family – you stand a better chance of helping the young person long term too”. Parents pointed out that with more guidance they could be part of the solution, helping to reduce the need for crisis intervention.

41% of parents felt excluded by the agencies involved in helping their young people

Helping parents to be part of the solution

The parents in our survey made a huge range of comments and suggestions, but we have picked out some common and reoccurring themes as a starting point for thinking about what might help to improve support for young people at home. These include:

- **Development of parent support groups**, variously referred to as “parent to parent support groups”, “group networks”, or “local community groups”. This kind of peer and group support for parents was the most common kind of help that was requested.

“It’s understandable, this service is for children, but the child is coming here for one hour a week and as parents we deal with it 24 hours a day, every single day” Parent

“I think the role of parent is something around holding that massive space that’s left by there not being services. I never thought about the fact that I was actually a carer, I just thought I was a mum doing what mums do. But actually, yeah, you become a carer” Parent

- **Provision of more practical advice for parents** to successfully navigate crises, avoid escalating the situation, and generally manage the young person at home. Some called this “carer support”. On the whole parents are not asking to be involved in the one-to-one therapeutic relationship nor do they want therapists to break their child’s confidentiality, they simply want to help.
- **Provision of mentors, advocates or liaison staff for parents** to support and assist in knowing where to go for help, ensuring parents views were taken into account. The importance of key workers, designated contacts, case workers, “a named point of contact”, “unbiased advocate”, “attached care coordinators”, “a named CAMHS worker”, “someone to stay from beginning to end” were all emphasised by many parents.
- **More consistency in how schools operate as intermediaries and supporters.** Parents acknowledged the complex issues of confidentiality and lack of resources and training in the school setting, but also suggested communication could be improved with, for example, independent Parent Support Workers to provide liaison and help with managing the school/CAMHS/home interface, and to help young people to stay engaged in education.
- **Easier access in relation to early intervention.** Parents consistently stressed the importance of acting “before parents reach breaking point”. Respondents suggested, for example “a proper triage based service for all levels of mental health issues, not just when they become severe”.
- **Provision of more consistent, widely available, reliable crisis support**, including out of hours support, telephone support lines, and information on what to do in different situations. Provision varies enormously across the country.
- **Acknowledgement that parents are important partners** in helping young people recover. Parents understood the need to balance patient confidentiality, the best interests of the young person, and their own needs, but felt that their potential to help was underplayed. More involvement of parents in service design and delivery was encouraged.

“There has to be a way of communicating something which is helpful, which may not be infringing your child’s rights or whatever. I think that’s a real issue” Parent

Conclusions and next steps

There are few families who do not encounter some kind of worrying behaviour with at least one or two of their adolescent children at some time or another. Most get by well enough with some good will and back up. But many have a harder time, the more extreme or desperate their young people become. However serious the problem may be, they have a major part to play in supporting their young people, and in finding helpful interventions. But they often feel left out of the picture, helpless at finding the right kind of support, distressed by what is happening to their adolescent child and their family, confused by what is on offer (including private and unregulated services) and unclear about how they can help.

The struggles families face can feed into a 'them and us' model of parents versus professionals, which is unhelpful for some of the young people stuck in the middle. Yet as one parent suggested, "We also know that we can be the most valuable tool CAMHS have to help our child". The parents in this survey have contributed a comprehensive wish list that presents a useful starting point. In coming months the AYPH study will combine these findings with those from young people and service stakeholders to suggest a programme of action.

"You're the one that she knows won't leave her. That's what it comes down to."

Parent

"...if they were to empower my mum...then I would feel more empowered too. Because I know that my mum's on it. I know she knows what she's doing. And I know that we're not alone because she doesn't feel alone."

Young person

With very many thanks to the parents and young people who have taken part in our project so far and shared their stories with us, to the Sir Halley Stewart Trust for funding the work, and to YoungMinds for facilitating access to the parent panel.

For more information about AYPH's parenting project, contact info@youngpeopleshealth.org.uk and visit www.youngpeopleshealth.org.uk/parenting

This briefing paper was written by Ann Hagell

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