IN THEIR OWN WORDS

THE MENTAL HEALTH OF CHILDREN AND YOUNG PEOPLE IN SCOTLAND

November 2016

Introduction

SAMH is Scotland’s largest mental health charity operating over 60 services in communities across Scotland, providing a range of support including mental health support, homelessness, addictions and employment services. These services, together with our national programme work in See Me, respectme, suicide prevention, sport and physical activity; inform our policy and campaign work to influence positive social change.

In Autumn 2016 the Scottish Parliament’s Health and Sport Committee announced a short inquiry on CAMHS and adult mental health services. SAMH was keen to ensure that the voices of young people, and those of their parents and carers who support them, helped to shape our submission to the Committee. This report sets out our findings.

There have been several recent pieces of research on the mental health of young people in Scotland which highlight increasing rates of poor emotional wellbeing. Referrals to CAMHS have increased over time, and the recent Scottish Health Survey flagged up increased rates of self-harm, especially amongst young women. Young people often do not know where they can get help with their mental health.

This snapshot report captures the voices of young people and provides primary evidence, in their own words, about the challenges they faced when they were seeking help, and what they believe would have been better.

In developing our 2016 Ask Once, Get Help Fast manifesto, our service users and supporters told us that they wanted SAMH to campaign on children and young people’s mental health. The Ask Once, Get Help Fast approach is especially crucial when a young person is experiencing poor mental health. As half of all adults with mental health

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2 ISD Waiting Time Statistics, September 2016
3 Scottish Government Scottish Health Survey 2015
problems develop their conditions before the age of 15,\textsuperscript{6} clear pathways to excellent support are fundamental.

**Methodology**

We launched a short online survey, which was advertised on our social media platforms and shared by our contacts. This survey asked a series of qualitative and quantitative questions, and was available to the general public for response for 13 days, between 27 July and 8 August 2016. Eighty-five people responded to the survey, and we held a further focus group with 10 young people. Although our survey was aimed at children and young people, in practice many parents filled it in on behalf of their children.

We were keen to explore some of the underlying issues in seeking support, and to understand the experiences of young people and their loved ones in their own words.

**Context**

At any one time, around one in ten young people aged 5-16 years have a clinically diagnosed mental health problem.\textsuperscript{7}

NHS Scotland and Healthcare Improvement Scotland describe the delivery of CAMHS as a tiered model of service organisation, as shown in the diagram\textsuperscript{8} below:

Commitments 7-12 of the previous Mental Health Strategy\textsuperscript{9} were concerned with the mental health of children and young people. Arguably the commitment which has received the most focus is the HEAT target mentioned in Commitment 11, requiring Health Boards to ensure access to CAMHS support within 18 weeks. This target was due

\begin{itemize}
\item[7] ICP Toolkit
\end{itemize}
for completion in 2015; to date, only 8 out of 14 health boards are successfully achieving this target.

It should be noted that the target for access to CAMHS support is only for Tiers 3 and 4; there is no current measurement of waiting times, support or outcomes for young people seeking help from the universal services or primary care or community-based support at tiers 1 and 2. Furthermore, there is currently no measurement of treatment or outcomes for the young people being supported beyond the initial access point at Tier 3 and 4 CAMHS. With over 16,000 children rejected for Tiers 3 and 4 treatment over a three year period\(^\text{10}\), the needs of too many young people are not being met.

**Summary of Findings and Recommendations**

The responses to our short survey, which were reinforced in our focus group, demonstrated a variety of experiences of engaging with CAMHS. While some young people received good support, and most felt they were treated with respect and dignity, there are many reports of long waits, inconsistent treatment, poor responses from universal services and a lack of choice. Many of the children and young people, and their families, we heard from expressed anger and frustration at the system. While some responses demonstrated a compassionate system working effectively, the majority of those surveyed had had a difficult and often negative experience. This is simply not good enough.

Communication and awareness must improve. Services must be delivered more locally and in good time. There must be an increase in capacity within CAMHS to ensure that good support can be delivered in the community at the early stages of a young person’s illness.

A preventative approach is required, and schools must meet the needs of children and young people, and fulfil their commitments in the Curriculum for Excellence. Links with NHS and social services must be strengthened.

Many respondents to the survey spoke of the challenges of getting CAMHS support for young people with neurodevelopmental conditions such as ADHD or Autism. Joined up work with the third sector and other specialists might ensure that those young people get additional support; training for professionals is also required; and greater coordination with education.

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\(^{10}\) STV News, [Report: Over 16,000 mental health referrals for young rejected](https://www.stvnews.com/), 2015
The length of time people waiting for a CAMHS assessment was very varied, from immediate, (following suicide attempts) to, in a small number of cases, three years. Many noted that they were still waiting for therapy to start.

"Couldn't get my son in. He really needed the help but CAMHS turn him away. I am losing my son. I think CAMHS is a joke"

"4 weeks only to be told my daughter wasn't bad enough to be seen. Apparently prevention isn't worth it."

"[My daughter] attempted suicide so it was immediate however [neither] the school nor GP responded early enough to early signs of distress and behaviours.”

Overwhelmingly, most of the children and young people we spoke to reported that they had received no support while waiting for their assessments.

"None. GP Services too happy to wash their hands of childhood mental health issues."

"I was given a list of websites which could help me in case my mental health got too bad"

"I saw my GP twice, who was very understanding, and my school were excellent. However, I did feel a bit “stranded” – my problem was recognised but there was limited resources to address it. By the time of my assessment, I believe my problem had deteriorated."

"Yeah and my GP welcomed me back to talk whenever I needed it."

"I was given behavioural help, which didn't help. CAMHS idea of help is for my mum to hold me close when I'm knocking lumps out of her."
“No one will help my son. I am struggling to keep him from ending his own life and no one cares. This is a joke no help for young people with mental health problems.”

**Did you receive follow up support?**

![Pie chart showing 55% Yes and 45% No]

Of those who did receive follow-up support after their assessment, most waited over a month. Experiences varied from six days to one year.

About sixty per cent said the support they received did not help. The most recurring comment was that the support itself was useful but lack of continuity created difficulties. Many also spoke of a lack of variety in the support they received, and that they felt they did not get a say in what they were offered.
Did you feel consulted on treatment provided?

36% Yes
64% No

“Sort of...it was quite a distance for me to travel and I had to work it round my school timetable which was quite stressful.”

“I was 13 and handed booklets with childish animations to read and that was it.”

“Brilliant support once seen”

“More interaction between CAHMS and education would be helpful. Explaining why my son behaves the way he does may stop him being excluded from school.”

“[I would have liked] the chance to carry on with same service despite turning 18 and relocating for university”
The experience of seeking help

Were you treated with respect and compassion by staff?

- Yes: 68%
- No: 32%

Did you receive advocacy support?

- Yes: 17%
- No: 83%
Support from others

Many respondents stated that parents, schools, friends and GPs were supportive but a lack of knowledge limited the support they could give. Many told us that they got most support from people who had similar experiences. Others replied that they would have benefitted from support from people with expertise in their special circumstances, for example, one respondent felt they would have benefitted from someone who had knowledge of adoption.

“GP was the best help I received I think even more so than the CAMHS team. Very, very reassuring and sympathetic with me and made me feel like I was doing the right thing, unlike the CAMHS team who made me leave my sessions feeling like I didn’t want to go back because I felt pressured to take blood tests and make diaries that I didn’t want to do or share.”

“School and GP pre suicide attempt were not very understanding or supportive. Afterward, the GP was great but school was awful. Didn’t have a clue or support staff to support – in fact we were told they could not support me in the school at all.”

“School were supportive when I was younger, but then started to get fed-up. Family and friends were either unaware, or very very unsupportive.”

“Not very. GP dismissed hearing voices. Treated as "attention seeking" by many. Parents felt out of their depth.”

“No knowledge but supportive - parents and friends. School didn’t listen to what was needing to be done and we ended up having to move schools.”

“Great, school has helped and offered support at every turn, unable to put further support in place as no diagnosis or CAMHS input”

Mental health education in schools

The overwhelming majority responded that they had received no mental health education in school aside from minimal information about coping with exam stress. Most said that any form of mental health education would be helpful – even if it was very basic. There seems to be a lack of knowledge about mental health issues amongst teachers, including guidance teachers. Even where teachers have some knowledge, our respondents suggested students with mental health issues are treated as ‘problems.’

Most suggested general lessons explaining different mental health problems, advice on how to support friends with mental health problems, good sign posting for help and reassurance that people experiencing mental health problems are not alone.

“We received little if any information. In senior years we talk about "stress", relating to exams which is completely different to the type of anxiety I was feeling. Since I
have left, they have introduced a mental health group, which I think is fantastic, but I
would still like to see this in the curriculum. I feel mental health should be taught
from puberty, about what is healthy, what is not, and how to get help."

“I think it would be great if schools would signpost to support and also talk more
openly about mental health. Also it would be good if school guidance staff /all staff
had training in this particular area as lack of knowledge seems to play a large role in
children feeling isolated but again this is not the staff’s fault!”

“I only received one class ever in my time at school. It was all useful but I think it
should’ve gone into more depth as to what each mental health issue means and how
much it can effect someone’s life. I also think schools should teach how you should
deal with having a friend with a mental health issue and show how much this can help
them on their recovery.”

“None formally, but one teacher set up an emotions group which was great. Some
more information would be helpful.”

“Educate the teachers first. Mental health issues are not contagious. Some primary
schools put the 'external front' of the school before children's welfare”

“We receive zero education, we had one lesson that taught us about physical and
mental health and learning difficulties but they said at the start of the lesson that
mental health was not important so we did not discuss that one at all.”

“Better co-ordination between CAMHS and education would be beneficial”

- A wide-ranging review of CAMHS

Recommendations

This is a snapshot, but the findings are not good. A wider review of CAMHS, and
measurement of the experiences of children and young people at all tiers is required to
provide a full picture to inform future service provision and delivery.

SAMH calls for a review of Tiers 1-4 CAMHS, with a strategic refocus and investment in
early intervention and preventative support for children and young people. As 50% of
mental illness in adult life starts before the age of 15, we need to ensure children and
young people get the help they need, when they need it.

The forthcoming mental health strategy must consider children’s mental health and
wellbeing beyond the NHS; links and partnership working are required between health,
education, social services and advocacy. The GIRFEC approach should be adopted by all
sectors.
The transition from CAMHS to adult services was repeatedly highlighted as challenging, given the different approaches taken, and the lack of coordination at this point. The Scottish Youth Parliament has recommended increased focus on supporting the mental health of 16 to 26 year-olds, in recognition of this age group’s specific mental health needs separate from children and older adults.\textsuperscript{11} SAMH endorses this proposal, and recommends that extending CAMHS support to young people up to 25 should be considered as part of a wider review.

\textit{“GP supportive but not his area of expertise.”}

- Better training and support for Tier 1 CAMHS service providers

Previous research\textsuperscript{12} by SAMH demonstrated that too many GPs had not had recent training in mental health, and most wanted more awareness of community based support for mental health. We reiterate the need for this training and information to be provided to primary care staff, to ensure appropriate care and treatment for young people at their first appointment. The high rates of rejected referrals to Tiers 3 and 4 CAMHS should be explored, to determine if referrals were made inappropriately, because of a lack of service or staff resource at Tiers 1 and 2. A better understanding of the overall landscape may also reduce unnecessary referrals to specialist CAMHS.

A&E staff must receive training on how to appropriately support young people who are presenting in crisis, and a more empathetic and less stigmatising response to self-harm is urgently needed.

SAMH recommends that universities and GTCS amend their current work to reflect that mental health and wellbeing is a priority within the teacher training curriculum. Priorities must be reflected in courses for teachers, as well as in their assessments for accreditation. CPD must be provided.

Community services, such as counselling and youth workers, must be resourced to provide more early support for young people. SAMH suggests that there should be a commitment to join up thinking at integrated joint board level in terms of supporting children and young people in community planning, health and social care service provision.

SAMH recommends better communication and support provided to young people and parents and carers while they are waiting for assessment and treatment.

\textit{“I want to know how to stop being anxious and depressed.”}

- Mental health must become a whole-school priority

SAMH recommends that the Standard for Headship requirement for new headteachers will include a specific commitment to a whole school approach to improving health and

\textsuperscript{11} Scottish Youth Parliament, \textit{Our Generation’s Epidemic}, 2016

\textsuperscript{12} SAMH, \textit{Know Where to Go}, 2014
wellbeing. We would welcome information about when all existing headteachers must meet this qualification.

SAMH calls on Education Scotland to ensure that the mental health and wellbeing elements of the Curriculum for Excellence are inspected and annual improvements are recognised and included in inspection reports.

We also recommend that curriculum guidance and resources should be developed as part of the next Mental Health Strategy for Scotland.

Thank you to the young people and families who shared their stories.

This report was compiled by Rachel Stewart, Senior Public Affairs Officer, and Kirsty Lauder, Public Affairs Assistant, SAMH.
Appendix 1 – Survey and Focus Group Questions

- How long did you wait for a CAMHS assessment?

- Was there follow up support after the first assessment, and how long did you wait for this?

- Did the support you receive help you? What would have been better?

- Were you consulted on the type of treatment you received? Were you treated with respect and compassion by health and/or social care staff?

- Did you have any advocacy support to get treatment, either from the NHS or in the community? (How long did you have to wait?)

- While you were waiting for an assessment, what support did you receive for your mental health? Were you referred to a support service to keep you well or provided with information to help look after yourself?

- If you were prescribed medication, did this help, and (when) was it reviewed?

- How supportive / knowledgeable were your parents / schools / friends / GP?

- What mental health education do you receive in school, and what information do you feel would be helpful?