

Are we listening?

Review of children and young people's
mental health services

Phase Two supporting documentation
Engagement report

March 2018

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Introduction

This engagement report pulls together findings from bespoke engagement activities that have taken place as part of phase two of the children and young people's mental health thematic review. The report identifies common and emerging themes in line with the key line of enquiry on children and young people's experiences of care.

These engagement activities are additional to the extensive engagement work included in the fieldwork. This report is intended to inform the overall phase two report for the review and can be considered alongside the engagement report for phase one of the review.

How this report should be used

This report is to give an overview of what we have heard from our engagement activities as part of phase two of the thematic review. It should be used to understand headline findings from our bespoke engagement activity.

Who did we speak to?

We worked with three stakeholders (Young Minds, Healthwatch Hillingdon and The Children's Society) from our Expert Advisory Group to organise the bespoke engagement activity for phase two of the review over September and October 2017.

We spoke to young people aged 12 to 25 who had accessed a range of services including school counsellors, therapists, accident and emergency, tier 4 inpatient services and private care. We also spoke to young people from a range of population groups including: young people with autism, young carers, looked after children, asylum seekers, young people referred into local authority tier 2 wellbeing services, and parents and carers of young people with special education needs and disabilities.

What did we find out?

The referral process

The referral process was a key event for most of the young people and parents/carers we spoke to. This included both initial referrals and referrals between services.

Parents/carers and young people perceived the referral process into CAMHS as being difficult to understand and lengthy, which was a point of concern.

Some young people we spoke to were concerned about high thresholds being set to receive a service, with some reporting that their GP would advise them to "pretend things are worse than they are" to ensure they received a referral. Some felt that this was due to the service not having the capacity to provide care for all who need it.

Although young people mostly went through their GPs at one point in the referral process, there were a number of other referral routes young people had taken, including via school counsellors, self-referral, A&E and other support initiatives for young people such as sexual health support services.

One of the biggest concerns for young people and parents/carers was a lack of support while waiting for a referral:

“There needs to be support in the interim while waiting for referrals to and treatment from CAMHS.”

Parent/carer

Often it was felt that there wasn't enough communication explaining the referral process and what to expect next, which could lead to increased anxiety for both the children and young people and their families.

“After my diagnosis I didn't receive any communication.”

Young person

Once a young person had been referred into a service, they felt the waiting times to receive that service were far too long.

Waiting times

Overwhelmingly young people and parents/carers told us they often had to wait too long to receive a service, with some reporting waiting anywhere from two months to a year. Some young people reported receiving some care at A&E immediately, but then still having to wait for more sustained support. Young people appreciated that there were underlying systemic issues that led to these lengthy waiting times, but largely felt that this wasn't an additional concern they needed to worry about.

Young people's experiences led many of them to believe that it was more likely you would receive care quickly when you reached crisis point. Young people often felt that they had only received care when they had either self-harmed or made attempts to take their own life. Young people were concerned that there is no support available while they are waiting for a treatment and that a “lot can happen in this time” – referencing personal experience of self-harm and suicide. One young person we spoke to who was still waiting for a service had driven to A&E after a suicide attempt to seek support and was told to come back in the morning as they didn't have capacity to support him:

“I turned up at the hospital without an appointment after a suicide attempt but was turned away and told to come back in the morning.”

Young person

“You shouldn't have to be suicidal to get an appointment.”

Young person

“They will never really take full care unless you are self-harming or suicidal.”

Young person

This was a significant concern for young people, as they felt that this was the only way they could get support. Some young people we spoke to felt that this approach meant that other young people may have been neglected because their mental health didn't manifest itself in this way:

"You don't have to be covered in cuts to be struggling."

Young person

Some young people spoke about this being widely known among young people and professionals, and expressed concerns about young people inaccurately portraying their condition to seek support. Others reported GPs advising young people to "pretend things are worse than they are" in order to get support.

Another point of frustration around the waiting times was a lack of communication around the length of the wait and a perceived lack of transparency with this. Young people would have appreciated having realistic times communicated with them at the start so that they could manage their expectations.

"I was told three to five days for an assessment and I had to wait for four weeks."

Young person

"I didn't get an appointment at all in four years."

Young person

"I knew for certain back in September that the treatment they were offering was never going to happen. I was disappointed but not surprised. Each month I was contacted and told it (DBT) had been pushed back another month."

Young person

Some young people we spoke to also expressed concerns staff were reducing the number of sessions a young person receives in order to try and tackle the waiting list.

Another young person compared their mental health to a broken leg. They felt that if someone had a broken leg and you waited a long time to treat it, it would become more expensive and take longer to treat – it was felt that the same applied to mental health and that waiting times were not beneficial to the young person or the system as a whole.

Some young people we spoke to had received a service at a community-based drop-in service. They had received this service quickly and spoke of the positive impact this had on their treatment. The instant acknowledgement of the young person and their need for support had a huge impact:

"When I walked through the door it took 30 seconds for someone to ask if I wanted to speak to someone – this instant acknowledgement is nice."

Young person

"That instant acknowledgement and low level treatment helps keep you sane."

Young person

Staff involved in young people's care

The staff involved in young people's care are seen as crucial to either a positive or negative experience by young people.

Many of the young people we spoke to reported positive experiences with staff. When young people had a positive experience they often reported staff being friendly, warm and emotionally sensitive as well as professional. These attributes were seen as being very important to the young people we spoke to.

Young people felt their relationship with staff was important in enabling them to get the most out of their support and feel at ease in doing so. When young people felt a real connection with the staff they were working with, they felt their experience of care was much more positive. Young people appreciated staff remembering likes and interests, and sharing some of their own experiences or details about their own lives.

"Week in, week out she would really remember things I had said. Not just because she had written them down. She would say 'I saw this in the week and thought of you'."

Young person

"The lady I saw was very calm and friendly which helped. I didn't feel any pressure to talk about anything and as I came to trust her everything came easier to talk about."

Young person

Staff having the time and skills to listen to young people was particularly important with young people reporting feeling reassured. Young people were concerned that even when staff did have these skills, they didn't always have the time capacity to use them fully:

"She [therapist] was really good at her job, but like most things she was in high demand."

Young person

However, some young people had had more negative experiences with staff caring for them and felt that staff could at times be judgemental and not always treat them with dignity and respect. Young people felt when disclosing so much to someone, it made it much harder when they received a judgemental response or sometimes no response at all:

"She made me feel so uncomfortable; I had to pretend things were better than they were so I was then perceived as a lower risk."

Young person

"The person supporting me looks out of the window when I am talking and forgets the names of people I talk about."

Young person

"She was just sitting in a room for an hour and I was just drowning."

Young person

Young people felt that when staff did not listen to them, it posed a real threat to their safety as well as the quality of care:

“They could be patronising and didn’t listen to me very well. When they wrote their summary letters of our meeting, they were often written with blatantly inaccurate or paraphrased information that was dangerously misleading.”

Young person

“They were prescribing me medication, but not based on what I was telling them.”

Young person

Staff changes were also seen as a significant area of concern to young people. Inconsistencies and frequently changing staff meant that it was harder to establish the connection that young people see as being so valuable; this was especially seen with bank staff and the lack of familiarity this brings. Young people found it frustrating to have to tell their story many times and to attempt to re-establish relationships with staff:

“The more you say something that is important to you, the less it means and the emptier you feel.”

Young person

“I had three different people see me. [I] didn’t feel connected to anyone.”

Young person

“I had to restart everything every time I saw another person.”

Young person

However, some young people saw changing staff as a positive thing as it could help them get the ‘right-fit’:

“The new (second) person I am seeing is nice. I prefer creative methods and she offers this.”

Young person

Stereotypes and stigma

Generally young people felt that there was still a stigma surrounding mental health. This was perceived not only outside of the mental health system, but within it too. Young people expressed concern that they didn’t always feel that they could be fully open with support staff in case they were judgemental about their mental health needs:

“I couldn’t explain my stories because I was afraid of being judged.”

Young person

“Disclosing is harder when you receive a judgemental response.”

Young person

“They (support staff) had entitled and out-dated views of mental illness.”

Young person

“Don’t tiptoe around things like self-harming. We already have to tiptoe around it with other people and it shouldn’t be an uncomfortable subject in counselling.”

Young person

It was felt that mental health should be addressed at an early age in schools and people should be empowered to “say it like it is” and speak freely about their mental health, especially self-harm. Young people and parents and carers felt that raised awareness would mean that young people were not identified by their illness and were instead identified as a young person who also has mental health needs, like everyone else.

“When you identify someone by their illness it becomes ingrained in their identity.”

Young person

Young people also spoke of a ‘young person’ stereotype and how they felt their mental health needs were sometimes dismissed as “just being teenagers”. Some young people reported sensing a marked difference in the treatment they received in their own clothes to the treatment they received in their school uniforms.

“She [counsellor] stereotyped me as a teenager and never gave me any feedback.”

Young person

Young people also reported experiencing mental health stereotypes and feeling that their mental health needs were dismissed by support staff:

“You’re not depressed. People that are depressed can’t get out of bed.”

Young person

Other stereotypes we heard about included young people with autism not being included in decisions about their care because it was assumed they “didn’t need to know what’s going on” and a young man who was asked if he was misusing substances when he was in a period of crisis.

Communication

Young people identified communication as being something that could improve in a variety of ways, across services.

Many of the young people didn’t understand important things like their diagnosis or the type of service they were being offered, because their mental health literacy was low. Young people felt that this negatively impacted on them and their care:

“I only vaguely knew what I wanted, I didn’t understand the system or terminology. I could kind of describe it. I was given options and was pushed into things I didn’t really want.”

Young person

“During my first experience with CAMHS, the experiences I best remember were largely being summoned away to meetings which I did not understand.”

Young person

“I didn’t understand what mental health was, so when I was getting referred to services, I didn’t understand what it was about.”

Young person

“I didn’t know how to describe what was going on with me.”

Young person

When young people had better mental health literacy, they felt they were able to better influence their care:

“I was able to influence my care because I knew what I wanted; maybe not everyone could do this.”

Young person

Young people also spoke about how services could better communicate between each other, especially when a young person is moving between services:

“There was no check-up (from GP or CAMHS following discharge from CAMHS and before entering adult services). This could have prevented things from escalating. There should have been better communication between services because my life was at risk.”

Young person

Young people also felt that communication from services needed to be timely. Many young people spoke about not receiving the right communications at the right time:

“After my diagnosis I didn’t receive any communication.”

Young person

Young people wanted to receive more communications about what they could expect from a service and when. Managing young people’s expectations was seen as particularly important, with many receiving communications with vague details and a perceived lack of transparency, which led to increased anxiety for the young people:

“‘Some point in the new year’ is another way of cancelling something without letting the patient know, a convenient excuse for never actually following something up as it’ll all be forgotten about in the new year.”

Young person

Person-centred services

A further key finding from our conversations with young people was the importance of person-centred care. This encompassed young people feeling included in decisions about their care, services being flexible around their individual needs, as well as young people being involved in shaping service design.

Largely, the young people we spoke to felt that they weren't as involved as they could be in decisions around their care. Often young people reported being 'pushed into' a therapy that they didn't want, not feeling that they had been involved in a final decision:

"I was pushed into family therapy when I said I didn't want it, and the issue I came with wasn't originally dealt with."

Young person

"I think because I am a child, but it would have been good to try different types of therapy. I wasn't asked for input around different options."

Young person

Young people highlighted that it was important that the care they received was individualised and didn't feel like a 'tick-box exercise'. They wanted the suggestions given to them to reflect their individual needs. One young person gave an example of being given options to help when they wanted to self-harm that they knew wouldn't work, and more personalised options not being explored.

When young people were more involved with decisions around their care, they felt that it helped with their progress to recovery:

"Both LINK and my school counsellor always asked me if I was still finding counselling helpful and if I had any suggestions on areas I wanted to focus on. This was really helpful in making sure I progressed."

Young person

"At my hospital, patients made care plans with the nurses... even things that weren't specific to me like general healthy eating and exercise were organised so I had control and choices about what I did to keep myself healthy and feeling as good as possible... being involved in creating it gave me an investment in following the suggestions and cooperating with the plans."

Young person

Most young people we spoke to had been asked if they would like another person come to their appointments with them. Some young people were grateful of this opportunity, as there were times when they felt they needed someone to support them. However, it did not always seem like the young person had a choice in their parent attending appointments; some young people felt uneasy discussing some aspects of their mental health in front of their parents/carers, and some wanted to feel more in control of their care:

"During my first referral... my mother was with me and I was not given any information about the situation up front, including the ability to choose whether someone came with me."

Young person

"Autism team was parent geared – they mostly spoke to my mum and not me."

Young person

Young people were positive about their care being flexible to their individual needs. Young people reported how it was important that their appointment times could fit in with their schedule and didn't fall at times when they would struggle to get there. It was important that care providers consider where a young person is at school as well as where they live, as often they will be travelling from school not home, which impacts significantly on travel times and ease of access.

"It was only 15 or so minutes from my house, but about 45 minutes from my school."

Young person

"I had to miss two hours of school for every appointment."

Young person

Young people also felt that the environment in which they received services was particularly important. Largely, participants agreed that generally somewhere non-clinical and informal was a better environment.

We also spoke to young people about whether they were offered opportunities to feedback on the services they received, or invited to participate in conversations about service design. When young people had been involved in these conversations, they found it a positive experience and felt this should be a regular opportunity. However, not all young people we spoke to had been offered this opportunity.

When young people had been asked to feedback it had taken a variety of forms. Some had been given a questionnaire, and some offered to take part in a group meeting or one-to-one meetings. Young people reported that a questionnaire at the end of their treatment made it difficult to sum up your overall experience of care, and they would have appreciated a conversation about evaluation and feedback to be an ongoing process. One young person had a particularly good experience at an inpatient unit, where patients gave feedback in management meetings:

"Management meeting was a clear space where our views were asked for and acted on. Being invited into a room and asked for feedback on the unit made it obvious our thoughts were valued... These meetings allow more immediate discussion and exchanges of ideas than simple feedback forms. It's empowering to be able to influence decisions that much."

Young person

Transition to adult services

The young people we spoke to referenced their transition to adult services as a particularly stressful time and this needed acknowledging by services in their transition planning:

"Turning 18, leaving school, joining university, is one of the toughest, life-changing transitions you can go through – the CAMHS/NHS transitions need to address that."

Young person

There was a perception from the young people that discharge from children and young people's mental health services was determined by age (that is, turning 18) and not by the young people's individual needs. When young people were discharged from children's services, the absence of a transition process made the move to adult services much more difficult:

"I was then discharged from CAMHS at 18 without a referral to adult services."

Young person

"I was discharged after my 18th birthday and am currently on the DBT waiting list (since September 2016)."

Young person

Young people were also concerned about the lack of communication both between services and with the young people to check how they were coping at times of transition. This was perceived as a time when the young person was at risk.

"There was no check-up (from GP or CAMHS following discharge from CAMHS and before entering adult services). This could have prevented things from escalating. There should have been better communication between services because my life was at risk."

Young person

Safety

Young people also spoke to us about their perception of safety. Largely, when young people were receiving a service, they reported feeling safe. However, some young people did report feeling unsafe when they didn't have control of their surroundings, for example when having staff observing their room overnight in an inpatient service. One young person also referenced feeling unsafe after disclosing their sexuality.

The time when most young people we spoke with reported feeling the most unsafe was while they were waiting to receive a service.

"Generally felt safe when in contact with services, but it was the time between services when I felt unsafe."

Young person