

Mental health crisis: Hearing from young people about their experiences. July 2017.

Introduction

This report presents a series of case studies and emerging themes based on direct interviews with young people in Leeds. The interviews were conducted by Common Room in relation to priority 7 of the [Future in Mind: Leeds Strategy and Local Transformation Plan](#) which is seeking to 'ensure there is a coherent city-wide response to children and young people in mental health crisis'.

Methodology

6 young people between 15 and 23 were interviewed individually during June and July 2017. The interviewees were asked to focus on one or two examples of a time in the past year when they were in a crisis or at 'breaking point'.

The semi-structured interview was based around the following questions;

- Can you describe the build-up to your crisis - when did it start 'bubbling'?
- At what point did you present to a support service or ask for help?
What time of the day was this?
- What happened?
- Were you receiving any ongoing support at the time? If so what?
- Can you think of anything which could have been a better response to your crisis?
- Do you think digital tools might help at point of crisis and if so what

might that look like?

- What might have helped prevent this crisis?

The information presented in these case studies has been reduced from the original data to increase anonymity.

Emerging themes

- The young people interviewed were often unable to articulate how their crisis built up or if there was something in particular which triggered the feeling of reaching breaking point.
- There was a preference for crisis support where assessments are kept to a minimum. People described wanting to make contact with someone to offload or to have someone around to help them feel safe, reassured or contained. *“When I’m full of rage I need to pour some of it out and calm down – get it off my chest.”*
- An informal setting over a clinical setting was often described as being helpful e.g. The Market Place drop in or Dial House. *“TMP drop-in has similar comfortable environment (to Dial House). Both are really supportive, non-judgemental, they actually listen. It doesn’t just feel like an assessment”*
- There were mixed feelings about whether an online response might be helpful in crisis. Some outlined the benefits of this, and most emphasised the need for choice and said that there was potential for online support to be helpful – in terms of accessibility and ease. *“Online feels more anonymous and I could be more open, more comfortable. Maybe feel less shame.”*
- A recurring theme was about getting a human, caring response which welcomed people – where the access criteria is set so that people might use it when something was bubbling rather than feeling like a full-blown crisis. *“Whether it’s online /text/ in person /phone, just having someone who sounds interested and is trying hard to engage would be good”. “Felt like I was fobbed off.”*
- Two participants who had tried to get help from adult Crisis Team gave negative feedback about their experience. They described a heavy assessment process, which didn’t feel welcoming or helpful, which had little capacity to respond helpfully. *“I tend to avoid using the crisis service and only ring them as a last resort because they can make me feel worse...You are told by your key worker to ring crisis if you feel bad. It’s basically the main option open to you but it’s not helpful”*
- Generally, those experiencing multiple crises with more complex issues were less satisfied with the crisis support they received.

Case studies.

As far as possible the interviews below present direct quotes.

Interview 1. Female, 22 years

Can you describe the build-up to your crisis - when did it start 'bubbling'?

My grandma had recently died. I was going through a really bad patch. I tried to call my Care Coordinator but they weren't available.

At what point did you present to services or ask for help? What time of the day was this?

At 7pm I was feeling suicidal and really struggling. ICS had recently discharged me but I didn't know what else to do so I rang them and was told, 'we can't work with you anymore'. I rang the crisis service and it was hard to get through to them. Then they didn't get back to me. *

What happened?

I ended up taking an overdose of tablets and went to A&E. I ended up not really feeling like a human. I know it's about safety but if someone wants to hurt themselves they will. The feelings of trust and humanity - there's something to be gained by that. I did find talking to other patients comforting.

Were you receiving any ongoing support at the time? If so what?

I have a Care Coordinator through CMHT and have been in different support services prior to that. Sometimes I go to Dial House or ring the Connect Helpline.

Can you think of anything which could have been a better response to your crisis?

More honesty. I'm not expecting them to fix it. But I want to talk to someone, be somewhere. Somewhere where they make you feel like you're welcome instead of a burden.

I don't want to be around my parents either.

When I've had a mini crisis before I've been to Dial House. The physical move away from where you are can be really good e.g a taxi to Dial House. You can't have the continuity of staff, I get that.

Do you think digital tools might help at point of crisis and if so what might that look like?

Whether it's online /text/ in person /phone, just having someone who sounds interested and is trying hard to engage would be good.

I'm the kind of person who would turn my phone off in a crisis. And I get board of typing. But I would try an online forum where you could actually contact a real human and communicate with them.

Phone calls can be difficult especially when you're in a state. Phone calls can be awkward - people can come across as shirty/ closed - and make it hard to open up. I can be really difficult to find words to explain - prompting would be helpful.

What might have helped prevent this crisis?

It depends when things start to get really bad. Sometimes I literally have no control - but I try hard not to get to that point. But if there was always a safe welcoming place to go that could divert crisis - e.g. the other week at Dial House felt more hopeful, more effective.

*Further feedback about the Crisis Service

I tend to avoid using the crisis service and only ring them as a last resort because they can make me feel worse - they can suggest really basic stuff that I've already tried e.g. 'have you had a hot drink' or 'have you tried listening to music'. Like one approach fits all - you know what they're going to say. It feels like they brush off the problem and have no understanding of how to help or that it's too much effort. They might promise stuff they can't offer, and I feel let down. I get used to the feeling of being let down and false promises. You are told by your key worker to ring crisis if you feel bad. It's basically the main option open to you but it's not helpful - a very robotic approach - you feel like they just want to get you off the phone and for me it doesn't achieve anything as I'm not taken seriously. As if you are standing next to a pond and they are telling you to jump in and you'll be fine. You jump in and it's deep and you drown because they don't save you.

Interview 2. Female, 15

Can you describe the build-up to your crisis - when did it start 'bubbling'?

It was 2 months ago. I didn't realise I was in crisis. My weight had dropped so much I became ill.

At what point did you present to services or ask for help? What time of the day was this?
Went to the GP with my mum who referred me straight away for specialist help. here.

What happened?

Within 2 or 3 days the school was involved, and talking directly to my parents. I went for a hospital check-up and they referred me immediately to CAMHS and then I was taken to the inpatient unit

Were you receiving any ongoing support at the time? If so what?

Nothing. I hadn't had any support before that, no-one knew I was struggling with eating.

Can you think of anything which could have been a better response to your crisis?

Not sure

Do you think digital tools might help at point of crisis and if so what might that look like?

Website/ live chat about ways of coping would be good. Would prefer text to a phone call.

What might have helped prevent this crisis?

More awareness generally. More acceptance so that when you do have a crisis might not be so overwhelming. Try to promote talking about mental health. Stuff on social media about how to manage, what a crisis might look like – so people are prepared. Stuff needs to be promoted more in schools

Interview 3. Female, 23

Can you describe the build-up to your crisis - when did it start 'bubbling'?

It was prolonged - built up over about a week.

At what point did you present to services or ask for help? What time of the day was this?
7:30 am Saturday reached breaking point

What happened?

Dial house or Connect helpline not open. The Market Place drop in was closed as well (before I would normally avoid Crisis centre in favour of these). I felt I my feelings weren't manageable. I felt suicidal. I rang the crisis team. They called me back after about 5 hours, and said they were unable to support me. I went to TP that afternoon and they could see I wasn't coping. They advised me to go to A&E (Jimmy's - because MH team are there). After 1 hour the ALPS came (6:30pm by now) and I underwent an assessment procedure. There was some confusion as to where this information would go - back to my GP? (they never received it)

They then gave me some information I already had. Nothing else happened that day. I'm now trying to access IAPT but unsure where it will be offered to me. I've now been waiting 6 months with no support in place at all.

Were you receiving any ongoing support at the time? If so what?

No just using TMP drop in.

Can you think of anything which could have been a better response to your crisis?

I can't fault Dial House when you get there but I find the distance a barrier. Even though they pay the taxi I feel bad about that.

TMP drop-in has similar comfortable environment. Both are really supportive, non-judgemental, actually listen/ doesn't just feel like an assessment

Do you think digital tools might help at point of crisis and if so what might that look like?

Maybe, depends on situation. It should definitely be one of the choices. I'd probably choose online instead of phone 'cause I prefer it - depends how long I have to wait or call back /sometimes if it's too late I'm too tired and want to talk in bed.

What might have helped prevent this crisis?

Longer opening hours for TMP and for DIAL house. TMP – out of hours/ evening provision. Dial house more capacity (I time my first phone call knowing their peak busy times e.g. 6-7pm is good time to call)

Less clinical response is more helpful to me. Otherwise it just feels like an assessment and often a waste of time – to have to tell your whole story/ history – when they are unsympathetic and the space doesn't feel comfortable. It's all about 'medical treatment' and nothing achieved. When I was in CMHT they don't encourage you to use the crisis service. There's an expectation you'll 'sit on l' till the next therapy session. They don't really like any other service being involved – even non-NHS. But they've never worked with me on a crisis plan.

The crisis team when I have used them have been patronising and unhelpful.

They actually said to me once "You know there's cuts to the NHS. You're a smart girl!" which made me avoid them for years. However, TMP encourage me to come back and say, "Use drop-in every day if you need to" and I have – it's been a lifeline. I have used it every single day for two weeks after work – where it was holding me and keeping me safe.

Interview 4. Female, 22

Can you describe the build-up to your crisis - when did it start 'bubbling'?

Not sure.

At what point did you present to services or ask for help? What time of the day was this?

It was a bank holiday 6pm

What happened?

Contacted Dial House as I was past the point of using Connect Helpline. I needed face to face support, not a helpline. I was really on edge, wanting to take tablets and I needed a place of safety.

I went to the crisis café and told them I was going to OD but wasn't taken seriously so I walked out. I was picked up by the police and was searched – they knew about the tablets – they took them off me – took me to A&E, stayed about 5 minutes then left me there. I sat there all night in the waiting area, no-one checked on me, I was feeling distressed – they told me they were waiting for the ALPS team. I went to the Becklin Centre and was told I was not 'at risk enough' to stay, sent back home. Felt like I was fobbed off, felt like they don't care, not interested.

Were you receiving any ongoing support at the time? If so what?

I have regular appointments with PD service but sometimes I choose not to engage with this. I have a crisis plan but don't value it – I've never really read it, it's not helpful. I regularly end up in A&E or with Police – sometimes they let me speak to the MH team, sometimes not. I've been sectioned before, and stayed 2 days, then discharged myself because I was irritated and confused by treatment – and I didn't want to have a blood transfusion.

Can you think of anything which could have been a better response to your crisis?

I wanted to be sectioned – so I had somebody there 24/7 for comfort and safety. Somewhere quiet, where I know there's people around – but not hassling me, and not just leaving me like in A&E – a place where I can talk to them if I'm feeling panicked. Dial House is nice when it's not busy – need to get away from lots of other people (other service users). A place where staff genuinely care, not making empty promises, not getting me to agree to making a deal with conditions. I might want to live there for a month before I'm OK again.

Do you think digital tools might help at point of crisis and if so what might that look like?

No

What might have helped prevent this crisis?

Nothing. I probably still would have self-harmed, hidden my tablets. Someone coming out to me would be good, but it just delays, prolongs it – if I'm gonna do it I'm gonna do it.

Interview 5. Male, 19.

Can you describe the build-up to your crisis - when did it start 'bubbling'?

Not sure.

At what point did you present to services or ask for help? What time of the day was this?
Daytime but The Market Place drop-in wasn't open.

What happened?

I went to TMP anyway. When I'm in a crisis I feel annoyed and full of rage. They saw I was in distress and didn't want to send me away if I'm a 'bad state'. They gave me a drink and tried to find someone who had 5 minutes to help me calm. Then sent me off. I know the staff there and feel safe and comfortable.

Were you receiving any ongoing support at the time? If so what?

Had finished TMP counselling – but had to take a three month break.

Can you think of anything which could have been a better response to your crisis?

No, it was good. I like TMP but it's not open all the time. Maybe extend the hours of drop in. But they are flexible for me which works for me.

Do you think digital tools might help at point of crisis and if so what might that look like?

Don't like the idea of online forum. What's good though is it could be open 24 hours. Bad – can't get the trust I need – so talking to someone face to face I can see what they're doing with my information. Wouldn't trust online / phone call / text.

Also, when I'm talking to my support worker I use a lot of sarcasm and body language to communicate – online I couldn't portray proper meaning of what I'm saying.

What might have helped prevent this crisis?

When I'm full of rage I need to pour some of it out and calm down – get it off my chest. It has helped me working on coping mechanisms to prevent things getting worse. Groups and learning coping mechanisms are good.

Interview 6. Female, 15.

Can you describe the build-up to your crisis - when did it start 'bubbling'?

Not sure

At what point did you present to services or ask for help? What time of the day was this?
5pm went to hospital

What happened?

Had seen CAMHS that day – and told to go to A&E if blood pressure got lower. Which is what happened. I was put on the children's ward, had a chest x-ray – which was fine. Then on observation children's ward overnight. CAMHS came next day and I was fed through a tube for 5 days. Then placed in Little Woodhouse Hall – have been here for 2 months.

Were you receiving any ongoing support at the time? If so what?

School nurse, had just started with CAMHS 3 weeks before.

Can you think of anything which could have been a better response to your crisis?

Would like a CAMHS worker out of house who you could contact directly on the phone or using computer. They need to be able to respond and work with YP, parent and rest of family.

Do you think digital tools might help at point of crisis and if so what might that look like?

You need a range of options. More practical advice online e.g. about eating disorders. I get nervous on the phone – would prefer live chat, texting. Online feels more anonymous and I could be more open, more comfortable. Maybe feel less shame. It's a lot less intense than a phone call – not actually having to speak out loud

What might have helped prevent this crisis?

Not sure.

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About Common Room

Common Room is a consultancy led by lived experience. We promote collaborative practice and connect the expertise of children, young people, researchers, practitioners and policymakers across disability, health and mental health to find the best ways of

- involving young people in decisions about their lives, services and support
- improving support services to ensure they can best address and respond to the issues CYP experience

We do this through

- offering training and service improvement support to professionals and services
- involving children and young people as partners in research, policy, and service improvement projects
- learning from lived experience through consultation and research with children, young people and families

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VAT Registration Number: 181051634