

# The Mental Health Journey: 9 stories from people in Sheffield

**healthwatch**  
Sheffield




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These stories are people's individual experiences with mental health, and mental health treatment, in their own words. We would thank to thank each of the people we spoke to for their openness and for sharing their journeys. We hope that services can use these experiences to help improve things for others.

**Important:** Please note that some of the stories describe events which may be upsetting, including suicide, self-harm, addiction, bereavement, sexual assault, harassment, and other abuse.

## Hannah's story

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 Age: 30

I became depressed in my early teens when I was looking after my mum who was suffering from mental health difficulties. She committed suicide when I was 21.

I was her carer and had to look after my younger brother too who my dad was away. I spent a lot of time (with my dad) fighting getting help for her. It was really difficult to get her a bed in hospital, for example, and the community health care workers struggled to come out to see her. I had no support.

I remember once she took an overdose and I rang the ambulance, when they arrived they asked my mum if she had an overdose and she said no. Of course she would say no! They were nearly convinced that my mum was ok. I insisted they should take my mum to hospital. They reluctantly accepted but didn't even help my mum to walk to the ambulance so I had to help her and when she fell back onto me they realised that she had taken the overdose. In the ambulance, one of the female staff told my mum what a selfish, horrible person she was. It was the worst thing to say to her in that situation.

After when my mum was transferred to a mental health ward, for weeks and weeks, she kept saying, 'Hannah I am such a selfish horrible person, I'm so sorry.' She was fixated on it. I put a formal complaint against the paramedic, I didn't want her to lose her job but they needed to educate them to how to talk to someone who has got mental health issues and how to deal with them, because it was absolutely inappropriate.

My mum wasn't selfish, she believed we were better off without her and she saw it as a selfless act. In her suicide note she wrote, 'I hope you have a better life without me.' We had been telling them [the services] my mum was really ill for a long time but they didn't listen. When my dad was away, I used to sleep in the same bed with her to keep an eye on her to make sure she didn't do anything when I was asleep. My dad slept with his back to the door on the floor so she wouldn't leave. After each suicide attempt they sent my mum home because she said she was fine and they just discharged her based on that but only my dad and I knew she was seriously ill. We were never listened to.

In my teens my anxiety got worse and I started having lots of panic attacks and ended up being in A&E a few times. But it was misinterpreted as 'behaviour issues'. I was always blamed for making life difficult for others which wasn't a helpful thing to hear as a teenager. It was my introduction to mental health as I was told it was my fault my mum was ill because I made life difficult for her by not behaving. But I wasn't supported, didn't really get any support from school or anywhere else, no one cared or helped me and it made me quite self-destructive.

I talked to my doctors, but it was very difficult to get the help I needed. I was so self-aware and tried to manage my mental health because I knew it takes a long time to get help.

When I was 17, I decided to live on my own and worked as a support worker at Northern General. I realised my reaction to environment was important in realising my mental

health because at that time I wasn't looking after my mum and I became more aware of my own growing anxiety and struggles.

At the age of 18 I became very sick with depression for a long period. I just lied down in bed and didn't really eat anything, didn't engage with anything. I saw my GP every time and they sent me off with antidepressants and left me to it. It didn't go much further than that at that time.

After a long period of sickness, between two jobs, I tried to get some disability support, but I was told I wasn't qualified. I thought I wasn't worthy of the support, that I wasn't poorly enough. They didn't help me or support me. I had to rely on my partner but it wasn't a healthy relationship. I struggled in silence for a long time because I didn't want to bother people.

My next job was at a jewellery where they treated me very badly, I had a breakdown when I was working there. At that time I was back with my mum and our kind of mental health rubbed off on each other negatively. I started developing quite uncontrollable bad OCD [Obsessive Compulsive Disorder] behaviour. For example, I was convinced I chucked things in the bin and I checked the bins all the time and started self-harming. It escalated and I ended up being completely house-bound. I just left the house for CBT [Cognitive Behavioural Therapy] or counselling and was on different medication. I didn't find CBT helpful to be honest. I think they didn't take me seriously and it was just the tick box exercise.

I had panic attacks while driving so chose to stop driving because it was quite dangerous. I had 2 suicide attempts and ended up at the A&E. I think one of the reasons I didn't get as much help as I needed was because my mum was being so ill and suicidal, having been sectioned many times, and had multiple intensive care stays, I was adamant that I won't be like her, I won't kill myself. I decided not to tick the suicide box so I wasn't taken seriously.

My mum killed herself just two weeks after my 21st birthday. All my life, my mind had been building up on how to deal with my mum's suicide, which explained my OCD centred on fear of losing things. Fear of losing things was in fact fear of losing my mum from being a young child. And now that worst thing had happened. After my mum's suicide, I didn't leave the house for 8 months and then escaped to America and lived there for a month because I wanted to be away from my mum's house.

When I returned I was in good mental health for a while, I stopped taking medication, I did an access course and got into university but the anxiety which is like a learned behaviour came back only this time in a new form. It wasn't the OCD side of things, fear of losing stuff, but more like PTSD type [Post-Traumatic Stress Disorder], memories and things triggered me. I couldn't control what was upsetting me.

I got support from university support services for my mental health which was better than the help I got from public services. I had a mentor and I could talk about my anxieties and get it out of my system. I was managing well for a while. No-one told me I was stupid or irrational.

I still saw my GP and kept getting more CBT and it kept not working. I had tried ALL the things they told me to do, doing exercise, trying everything, but what I needed to do was to address the memories rather than change a 'behaviour' to deal with anxiety. I needed help to deal with the trauma and memories which triggered those behaviours, not changing the behaviours.

I needed something more specialist. Most of my anxiety came from hating myself because it went back to when I was a kid and I was told it was all my fault. I felt responsible for the death of my mum, that I didn't manage to keep her alive. I used these memories to beat myself.

I recognised my mental health didn't respond to counselling and CBTs, I was self-aware. Just because I didn't tick suicide box they thought I was managing ok. I knew what the problem was but didn't get the help I needed.

It was like a cycle, you go to the doctor, they refer you to CBT, give you medication, and then after a while back again to the GP.

I don't have much trust or faith in the system because of how hard it was to get help for my mum. She committed suicide under NHS care, they had to be held responsible. They failed, their protocols failed, I mean my mum wanted to die, but it was their lack of care and communication that led to it happening.

Two times I attempted suicide and ended up in A&E and each time they sent me home and said someone from the crisis team would phone me and come to talk to me but I never heard from them. They absolutely did nothing. I could have been dead in a ditch. No-one followed it up. It makes you lose faith in the system.

When I scream for help in a corner of my bathroom, nobody knows. If I had the proper support I needed I would be a lot better than I am now. I had to fight to get the help that I needed. The reason I finally ticked the suicide box was when I realised they were not helping me. It made a difference to the support I got. Finally, a year ago, after years and years of fighting and trying to get help, I got referred on from CBT to special psychological services which are based at St George's. They are really good, a kind of next stage between CBT and psychologic hospitalisation.

Hazel in St George's was amazing but she was my only contact with the entire team. I have never been able to see a psychiatrist. She offered Compassion-Focused Therapy. She treated me for Complex PTSD, and looked at things I was struggling with. It really helped me. Hazel told me she wasn't going to do CBT because I had been CBTed to death!

She was great but she was over-stretched and finally left and I don't blame her. She told me she was leaving and gave a long notice and suggested she hand my case over to the new person and we have a meeting with 3 of us so I wouldn't have to tell everything all over again to the new person because it's so draining. But it didn't happen because of the covid.

Now there is no one to see me and I am left without anyone and they don't have any new person and the covid has made it more difficult. Now I am struggling and self-harming

again. I contacted my GP to see if she could chase it up and see if I am not forgotten about.

There is a lack of communication within the system. My GP didn't have any information about my therapy treatment at St George's, didn't know yet my CBT history, didn't know anything about my suicide hospital admissions. Nothing about the crisis team was reported.

There is little communications between professionals. I think this is why my mother and I hadn't got the support we needed over the years. For example, when CBT stops or is not going right, no one chases things up. Or when the last time my mother was discharged from hospital she told one of the nurses that she was going to kill herself but the psychologist still discharged her because he thought she was safe to go home but she wasn't. There is such a disconnect in the system.


I feel like I am lost in the system and no one is following up what is going on. The stupid charts they do to tick boxes on a piece of paper before each session and put you on a scale is ridiculous. My anxiety and depression was always off the scale, despite all of that, I knew until I tick that suicide box (which I didn't want to tick) I wouldn't get help. I explained to them why I didn't tick the box despite being suicidal, because my mum killed herself. I had been terrified as a kid and had very strong feelings about it and literally until 2 years ago I didn't tick that box. Even my mum didn't tick that box because she didn't want people to know she was going to kill herself. She wouldn't be honest on that form. I wasn't honest for a long time. They should had listened to her family (me and my dad) because we knew she was seriously ill.

I think they mess up with a lot of people with that because they look 'fine' and not suicidal. It's a big scary thing to tick the suicide box, to tell someone else about that feeling isn't easy. But I had to tick that box to get help and I think I shouldn't have to tick that box to get help, but it was actually useful with Hazel at St George's.

Sometimes after the storm is the hardest time. Now my anxiety is attacking everything in my life. Am I still on their list? What's going on? I need to call St George's but I sometimes find it quite stressful. I imagine talking to a receptionist and they tell me 'I'm not sure what you are talking about' and it puts me off. You have to chase it up yourself and a lot of people don't have that drive to do that. When you don't feel great you can't chase things up. I feel like I am in limbo again!

## M's story

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 Age: 31  
Male, White

I started having depression and anxiety when I was 13 or 14. I spent some time in youth rehabilitation services.

Because of family circumstances I picked up the drink from a young age and became addicted to alcohol. It affected my mental health badly.

A doctor diagnosed my mental health issues and gave me Amitriptyline. I was offered CBT [Cognitive Behavioural Therapy] but it didn't work for me. They jumped into my past and childhood which was traumatic like family death and stuff like that. It was too much for me to deal with. So instead, I used more alcohol as therapy.

Because of the alcohol damage on my brain, I have a kind of forgetfulness and dementia. I hardly remember the last 15 years, most of the time I was drunk. For the same reason, I don't use emails because I forget my passwords and usernames. I am also dyslexic and have difficulty with reading.

Drinking ruined my future career wise but I am happy I finally decided to stop. Now I am in a better place. I have been receiving help from Sheffield Alcohol Services for the past 10 months. It's been helpful to see other people and get support.

Medication for alcohol really helped me to stop drinking and also involving with Brunsmeer football team (supported by Sheffield Flourish) was really helpful for my mental health. They were there for me even during the pandemic when all other services stopped working. They regularly phoned me and asked how I was which was very helpful.

I am thinking about trying CBT again, but don't know if it's the only thing that can help me, maybe this time it will work if they could stop jumping into my past and childhood. I really want to move on.

## Kelly's story

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 Age: 25  
Black (came to Sheffield in 2006 from Zimbabwe)

I lost my brother when I was 8 and I became very depressed and it got worse when I lost my sister too. It was more like a trigger or something. I am afraid of losing people. I think it was after my sister's death that I really acknowledged that I had mental health difficulties. Before that I thought it was just grief and the past but this time I realised it was different. It was quite overwhelming. I was overthinking and over-analysing constantly. So I went to my GP and the first thing they gave me was antidepressants and I took them for a while but then I stopped as I didn't want to get addicted to it.



In 2015, I was offered counselling but it wasn't helpful at all. I found myself reliving my life's problems every time I had a session. I wanted to take my mind away from what I had been through, especially the grief, move on and think about the future but it only triggered me more and made me go back to my traumas and focus on them rather than helping clearing my mind. After each session I went home with heavier soul. I realised it's not for me.

I am a creative person so drawing became my kind of therapy. I like to put myself around people because I hate being in my head on my own. When I am around people I feel ok, when I am not I am overthinking about many things.

During the pandemic in April, I went to my doctor again and the first thing they did was prescribe antidepressants again but I didn't take it. I paid for them and thought Ok I take them but went home and looked at them thought no. They might give me a boost temporarily but they don't solve my problems.

My mum is very African minded I think, she doesn't share or express emotions, she never told me she loved me, she never spoke to me and talked to me. This is how she grew up because her parents never told her they loved her or hugged her. So it's kind of 'normal'. But my sister before she passed away messaged me and said she loved me forever. Since then I try to say that to people I feel about them because I understand life is short. Each time I leave the house I tell my mum I love her and try to hug her. I am trying to let her know every day that I love her but I am not going to be like my mum to my kids one day. It feels so refreshing when I tell my mum I love her because I never heard it myself.

I have experienced sexual assault and I have flashbacks and medication doesn't tackle that. In the past I couldn't even talk about it but now I am in a position that I can talk about it. I came across a video (Adira) a few months ago and I commented on it. It made me so sad and I cried because I resonated with Ursula's story and I messaged her and went and met her.

I remember one day I went to Ursula's house and she spoke to me like no one ever spoke to me, she genuinely understood me and listened to me like a mother figure, acting more than my mum. We were both crying. After our conversation I went home feeling very light and I loved to go back to her house and talk to her again but I couldn't because she wasn't my mum and I didn't want to burden her with my problems.

Before watching that video, I was going to do something stupid but watching her story gave me a boost and later Ursula involved me with the food bank project and it was very helpful, I enjoyed helping people, and it had a positive impact on my mental health because when I am isolated at home my mind constantly focuses on problems and negative things. It was good to be out helping other people. If someone gives me some good energy I try to be cheerful and work towards that. Before talking to Ursula it wasn't easy for me to talk to people.

I don't like to talk to people who are paid to talk to me and listen to me without understanding my culture and without empathy and interest. I don't feel like that's genuine. I want a genuine human connection and talking to Ursula was much easier than talking to my counsellor.

I wanted to be a counsellor myself because I know I care and have the heart for people but if I become one I talk about myself and try to be a genuine listener. I understand it's a profession but I would talk to people because of interest not just money.

As a black person every day when you walk around, or you work somewhere, you are aware that the decisions they make affect your life and you think that it's generally because of the colour of your skin. For example, in healthcare I had an operation at hospital and the attitude I got was not good. They quickly offered medication and operation but that's it, they never wanted to understand what's going on mentally. I felt the stigma and their judgmental behaviour.

I applied for a job at a cafe which was Chinese and Korean and I was aware the majority of people there are Asian but I thought I would try it. The interview went very well because I ticked all the boxes but they didn't give me the job and I thought why? I realised because I was black and there was no other black people there.

What I don't get is the discrimination. We are so similar. We people are all the same why colour should cause all of these unnecessary traumas, discrimination, racism, and death.

That's the world we're living in, I guess!

## Fatima's story



Age: 45  
Black Somali

As a child I was in foster care. At the age of 16 I got depressed and at my late 20th, I had my first psychotic episode. I was paranoid.

Problems with a racist and abusive neighbour made my life more difficult. Because of their racist harassment and damage to my car, I lost my job at an agency. My paranoia got worse and I thought I was being followed and TV broadcasted my thoughts. For example, one day I made a coach trip to London and went to the MI5 building and told them I was being followed. I thought I was the subject of the war on terror because I was from Somali background.

In 2007, I was admitted to Stanage and Maple acute wards. I was given short term medication, felt better, but they didn't diagnose my mental illness. I was sent home with some medication, and a few months home treatment. During that time I moved home. My social worker said I should be happy. I wasn't.

They never warned me that I needed to take medication for the rest of my life. The side effect of coming out of medication, the withdrawal, made me suicidal. Before treatment I was paranoid but never suicidal.

My mental health got worse and I burned the curtains of my council flat. I was arrested and was on remand for 3 weeks. During those 3 weeks I was paranoid about food and



thought there was poison in it. Finally, 2 psychiatrists came to see me and said I needed treatment so I was sent to a secure private hospital in York in 2011. It was there that I was diagnosed with Paranoid Schizophrenia for the first time.

I was far away from family and friends and it was shocking but the good news was I wasn't sent to prison.

After about a year I was sent to another private hospital in Sheffield. The medication worked for me and brought me around. I did a fire awareness course and psychology and understood my condition. There was halal food for Muslims and prayer rooms available. We could celebrate religious festivals and even had an Imam at the ward.

In 2010 there were respite beds available but now in Sheffield people in crisis can't get respite beds. There are fewer and fewer beds and people have to go to other cities which is devastating.

In 2015 I fell ill again, had to stay in Maple acute hospital and Forest Close rehabilitation wards.

Some issues with private hospitals are that patients are left to over-eat. They gain weight and become diabetic, smokers, and have poor physical health. I gained a lot of weight and lost my confidence. It affected my self-esteem and mental health. Private hospitals are happy to have calm, sleepy, patients, and they please them food-wise. There are cakes, donuts, and chocolates available all the time!

Another problem with private hospitals is they want to keep the patients for a long time because of money. They don't want patients to leave. There are some forgotten people in hospitals who are kept for years and years because of receiving money from the NHS.

Respite worked well for me - close to home and free. What didn't work for me was being given medication without warning that coming off them could be quite dangerous and would make me suicidal. Not having a social worker after my first episode wasn't helpful either.


Now I have a care coordinator and psychiatrist. Diagnosis and proper treatment can help. Only because of not having them, it made me relapse and set fire to my flat and burn my curtains.

Now to get respite you need a SDS package. 10 years ago you didn't. SDS - stands for self directed support - and that is rationed by the council. Limited budgets and more needy people means you don't get weeks of respite - you only get a weekend. And the 10 bed respite place has now only one bed for all of Sheffield because 9 beds are for people coming out of hospital and waiting for housing.

Since Sheffield Health and Social Care closed Rowan ward and Pinecroft ward in 2015, there are 18 plus fewer beds and more people in crisis than ever. There's not enough beds to go around. I think there's a new respite place in Rotherham - not close for me - and not sure if that's free. Travelling can be very difficult for some people. You want to be near home and family when you are very ill. Sheffield needs to have secure hospitals.

## Billy's story

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 Age: 15

It started a couple of years ago when I was 13 years old. When I went back to school I felt I wasn't really prepared for it, I was in year 9 and I didn't keep up with the pressure and preparation for GCSE.

I felt like I would throw up the whole day and felt really sick and told the school nurse. My mental health slowly deteriorated, one day I just couldn't go to school.

We went to doctors I was misdiagnosed with tonsillitis, I was put on penicillin for a few days and I felt really ill. It was awful. I went to another doctor and they said it's anxiety and if you go back to school let them know. I got a nurse and support worker and they told me I can sit down in a quiet place out of lessons and I thought ok I can try that. I spent a lot of time in a quiet room feeling sick all the time... I was in tears all the time.

I got panic attacks on top of that... I was on edge.

At that point we didn't know I had developed Emetophobia with anxiety. I had to go A&E and it was horrible there... It eventually got worse and worse and I lost a lot of weight in a short amount of time because I couldn't eat and because I didn't eat I felt more sick. I was 33kg. I was admitted to hospital with the early stages of starvation. I stayed there for a week just trying to put on weight. At hospital they thought I had eating disorder which really annoyed me because I knew I didn't have an eating disorder...

Finally I was referred to CAMHS [Child and Adolescent Mental Health Service] emergency list but it was a 7 months waiting list which we didn't know at the time. During this time I was really struggling and refused medications because they made me sick.

At CAMHS I got CBT [Cognitive Behavioural Therapy] for six sessions and it helped me. I slowly felt a bit better but then they said there was no more they could do. So I was discharged from CBT.

I kind of managed to go back to school but any minor thing could be a step back for me. Eventually I was kind of settled in the paragon (a room for kids with special needs). They set individual targets for me and my dad used to come and sit with me.

The next term they started to put pressure on me, telling me you can go to the lessons, do this and that, and do more targets. Some people there had no clue what was going on and just put pressure on me. One night I had a panic attack after a long time. I went to school the next day and it was very stressful. I felt sick and had more panic attacks as soon as I entered the paragon. It got worse and worse to the point I couldn't go back to school.

We rang CAMHS but they said they can't help me anymore and told me 'just keep trying what you have already done'. It was disappointing. I was still seeing my medical doctor though.

One day I had to go to a dentist. They were very helpful and told me about a therapist in Nottingham who used hypnotherapy. I went to see him and it went really well but my parents had to self-finance this treatment.

Because of lockdown it stopped but I was able to have sessions over WhatsApp which worked but not as well as in person. Once lockdown eased I went back in person. I have finished treatment but have an open door if I need to go back for a 'top up' session.

What didn't work for me was school environment and pressure they put on me. They wanted me to go to certain lessons. I think I wasn't taken seriously enough. CBT worked but CBT is temporary and isn't a long term fix. You can do a bit of CBT but the information your brain processes about being sick doesn't change or go away with CBT.

What could help was other resources that could help with my Emetophobia. CAMHS didn't have resources that I needed and that was the problem. If they had other resources that they could introduce to me it could really help.

After CAMHS, coping wise I didn't, I just kept on going with everything but it's really hard. That's what I am doing now, keep going!

## Sarah's account (Billy's mum)

The condition, Emetaphobia, manifested itself in a restaurant when after our meal Billy went to the toilet and began to have his first panic attack. It took Bill's dad and I 40 minutes to get him out and to the car. It was Sunday and the next day was the first day back after Oct half term.

Bill struggled with swallowing his tablets and this led to extra stress as we were pressuring him to take them because they were antibiotics. I went to another doctor and they said it's anxiety and if you go back to school let them know. We were told by this GP that they would refer Bill to CAMHS.

Bill would repeatedly phone my husband and I at work begging to go home.

We decided to take Bill to A&E to speed up the CAMHS referral but the doctor said there was nothing he could do except write to our GP. He discharged Bill and wrote the letter; we later found out that the original referral by our GP had never been made.

We decided to take Bill back to A&E because he had stopped drinking too. He was admitted to hospital with the early stages of starvation.

Meal times was a constant battle of reassuring Bill that he wouldn't be sick if he ate; he would overthink about everything. He also could not leave the house with having a panic attack. We had to encourage him to walk to the end of the drive which he would only do at night when no one would see him. This slowly progressed to the end of the street and then out with the dogs during the day.

At CAMHS he had CBT treatment which only worked when he was in a rational frame of mind. Although we were recommended to try hypnotherapy and have found this extremely

successful in treating him. We had to self-finance this and believe if it was available earlier he would have recovered.

The school, although they didn't say it, were trying to keep the local authority happy so that we didn't go to court for unauthorised absence; they are still trying to do this now. They have very prescriptive paperwork to complete.

Bill is a long way off being a confident young man in a public setting but when we look back on how bad things became we are extremely proud of him.

## Leigh's story

 Age: 29

I have had mental health issues probably since my early teens but it went undiagnosed for quite a while and then I was diagnosed with borderline personality disorder about 4 years ago. I am also in the middle of an official diagnosis for Autism. I moved to Sheffield about six years ago and I was doing fine about a year but had physical injuries that affected my joints and that's a big part of my journey in Sheffield.

I was put in a borderline personality support group and it was good but too short. Something as life changing as a borderline diagnosis can't be dealt with by attending only 4 or 5 weeks one hour session. So apart from the initial psychiatric diagnosis there wasn't that much peer support. There are online support groups but they are not Sheffield specific and when you finish with that group you are offered other groups which are not massive support for people with borderline disorder.

I think using the right mental health services at the right time can be a huge factor. For example, I've been through Short Term Educational Program group (STEP) twice but I was in a really bad place and it really didn't work for me and it didn't have an impact. I had all these techniques to calm me down but because I had underlying issues and I was in a constant cycle of having a lot of panics, STEP didn't help me. I say it in the nicest possible way that I did challenge them because it was more geared toward neurotypical people with very basic needs—don't want to say basic because people go through things differently—but maybe less complex needs. I understand it is a broad one size fits all but I wish there was more knowledge and options in those groups. For example, if you are not ok with this then try this and that. The adaptability is what I like to see, everyone is different obviously, but there are enough people who have complex needs and need more accessibility. I know everything they do is coming from a great place, but it's lack of knowledge and not knowing what to do. Their training systems need to improve.

During the past years I have been in A&E twice (you don't want to go to A&E) or more and I have spoken to out of hours services quite a lot. I have also done CBT [Cognitive Behavioural Therapy].

Some of the worst experiences I had was with community mental health team (out of hours team). I rang them several times and it wasn't a good experience. Every time you are given the same advice and the training they have been given is the only thing they can

offer. When you call them you have passed the point of having a cup of tea in the bath! I don't want to say it was dehumanizing, but infantilizing, because I was like if I'm calling you I have tried all my things that might have been helpful. So there is this number you can call out of hours but they are not really going to give you anything. I was told if I was a danger to myself I had to go to A&E and I was in a strange position—looking back it is a strange position that a lot of people experience that. I was not at that point yet to harm myself and I asked for help because I didn't want to get to that point, but I was told to do the same basic self-soothe stuff that I already knew.

If I was told 'you are in a really bad place and we set you an appointment to talk to someone tomorrow' that would have been good instead of saying 'call us back if you feel worse' and again giving me the same advice. So it's either doing the self-soothing box or going to A&E. In between there is a grey area and a lot of people with mental health issues are in that grey area for a long time. We need help at that stage— in that grey middle area— because we don't want to get to the point of harming ourselves. It's like you are ok and can manage, or you are in complete crisis and have to go to A&E. There is no acknowledgement for that pre-crisis area. Out of hour services need to be more proactive like 'ok we'll arrange for someone to ring you up and sign post you and provide help before we reach to the point of ending up in A&E'. It wasn't a great experience. I have decided to avoid them because of that experience.

It really matters that you feel there is any other thing, more than the things you already know, that could help. You don't want to be told to do things that you have already tried. When all my usual self-care things are not working it means I need additional support. Also if there is any additional support it's not personally tailored.

They make you feel it's not the system which has problems but it's the user and that's not helpful. Their training doesn't really help to deal with people in crisis. I tried to tell them that, I don't know if I got my point across very well or not; when you are in a crisis state you are not intelligently talking to people.

Surprisingly, the turning point for me was when I went through Pain Services for my chronic joint pain and they had a psychiatrist there who was very good. She introduced me to a model of therapy called Compassion-based Therapy and it really helped me. I really liked her and could fully open up to her, I could speak about stuff that happened in my childhood that affected me which made me insecure about a lot of things in my life. Instead of trying telling me you have to be positive and think positively and your problems go away, the Compassion-based Therapy helped me to treat myself with the same kind of compassion that I would do for anyone else. It's intrinsically linked to helping people who are having intrusive thoughts. When you get a thought that 'oh that's bad' you get to see how that is bad. I had a lot of self-negative thoughts and instead of telling me 'oh you are amazing, you are great', it was like you are trying your best and understand yourself from different perspectives as a whole picture. So this therapy came from the Pain Clinic, not mental health services. The psychiatrist there was working with a lot of people who blamed themselves because of their chronic pain. She understood where it's coming from and helped me to realise the whole picture and that was a great experience and as I said a turning point.

Also it was at that time that I was told Autism might be an underlying thing for my depression and anxiety because it flares up those symptoms. In some support groups, I

met a lot of women who also had similar conditions and had gone completely undiagnosed for years and years. There is a link with people who have chronic anxiety, borderline, and Autism especially with women. It is a long dark area where they have to go through so many stages of getting an official diagnosis. From my understanding, a lot of people present with borderline because of undiagnosed Autism and they have borderline because of it.

They now try to acknowledge that borderline is a trauma-based diagnosis but there isn't much support out there and it causes a lot of mental health problems. You have to wait for a year for an official Autism diagnosis. I am now under Sheffield Adult Autism and I was in the middle of official diagnosis but it's on hold because of coronavirus. I have no idea when I get my next appointment.

I have been living my life as if this [Autism] has been the factor and the diagnosis helps me to explain and answer all the whys behind my anxiety—why I get anxious because of everything. That's a huge thing for me and it has been a massive mental journey for me in the last year.

I have got a bit of my mobility back. I have gone from being pretty much wheelchair bound, and then on crutches, to walking and that's a huge factor and I am now volunteering with Disability Sheffield. Part of having Autism is getting bad anxiety attacks and I try to walk instead of bottling it up and be like, 'I am 29 and I should be doing this and doing that', just the acceptance of being different is helpful. People deal with things in different ways. I am very anti 'you lose weight and exercise and your mood changes'. It's a complete lie—however a healthy life style can be one of your self-help techniques. Helping people has also been a big part of my recovery. When you realise you can use your experience to help others, it can help you.

During the pandemic, the short term educational team has rang me twice and I proposed to them they could offer something online but it's only 6 months into the pandemic that something is being offered now, when it could have been much sooner (especially with how much lockdown has impacted people's mental health).

My feedback is:

1- why can we not offer an initial online appointment, or have online groups which are more peer-led with the same understanding? It is important to be part of a group and talk to people who have mental health issues—the best thing about being a part of such groups is you talk to people who have been through the same issues and talk about their experiences of how they manage and cope and how they deal with things. Whenever I feel bad about myself I remember all the groups I went to and spoke so much about my condition and I hope sometimes someone will remember me 'oh, yeah that girl was really helpful'.

2. One size fits all is not going to work—for example, I know mindfulness might work for some people but for me it's really triggering, absolutely bizarre, and very unhelpful. I am a very enthusiastic person who would try anything but at the same time I experienced a lot of negative things. I wish someone directed me to the help that I actually needed.

3. When you are in crisis and really upset, I wish there was a more of an approach that was like 'you have this problem, these are the things that worked for people in the past'.



I am a massive advocate for people being in control of their health care, especially mental health. Because when you are anxious and depressed and not able to speak for yourself, being told 'this is what we are doing, this is how long it's for', people could pick from more available options. For example I went to a group and it didn't work for me and I got terrified and didn't want to turn up, and there was nothing else offered to me and I slipped right through the crack again. There's got to be personal choice no matter how unwell you are. It shouldn't be like if a person in a vulnerable position doesn't turn up then that's it. Not turning up is itself a warning symptom and there should be a kind of intervention there in the system.

Good things about organisations like Disability Sheffield is to make things a bit bearable; there is a lot of acknowledgment, compassion, and a lot of validation. They show you that there is a bit of light in there, especially when you live with long term physical and mental health disabilities.

## Anonymous's story (We refer to him in our report as D)

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 Age: 20  
Black/male

I started having mental health difficulties about 3 years ago when I started uni and was exposed to adult life, pressure, and stress. At the beginning it was like manageable stress and general anxiety but gradually it became like being paranoid, it was like, what's the word, like a kind of 'underlied', a kind of background anxiety, and I realised it wasn't normal.

It was a couple of months ago that I decided to seek professional help and the service I was looking for was one to one therapy; I wanted to sit down with somebody and talk about my problems. But it wasn't free, I had to pay for it and I couldn't afford £50 per hour. So I did a self-referral through the NHS website but it has a long waiting time. They called me once (one month after my online self-referral) and told me to do an online program called Silver Cloud but that's not what I was looking for. I prefer a traditional kind of one to one therapy, to talk to someone that could help me realise what's going on and what is the root of my anxiety. When I realised it's not what I was expecting I left it [Silver Cloud].

I have tried to find out how long I should wait for counselling through NHS but have heard nothing. At the moment, I am not getting any help. I feel my issues are not prioritised. Unless it's extreme they don't do anything at all. That's my opinion.

The pandemic affected my mental health at the beginning because some people use social interaction and environment to manage their anxiety, and the force to be by yourself and be in a confined space for a long time will just amplify it. It makes you worse because there is no way to distract your mind from anxiety.

I try to help myself. I am a Christian and I try to pray and meditate and stuff like that to ease my mind, find some clarity and not get into some dark place. Sometimes it helps.



I know part of my anxiety is because, as a young black man, I am constantly worried and anxious about things most people are not worried about. I have to be very cautious about certain things, places I go, not to be in a wrong place, and what I do. For example, one time when I was walking from university and it was evening and a bit dark, I was walking normally and had my headphones on and someone was walking on the same pavement towards my direction and when saw me quickly crossed the road. They don't want to go near you, if you know what I mean. I was like I'm not going to do anything to you, I'm just going home and it added to my anxiety and worries.

Social-wise there are certain things which might be quite easy and normal for other people to do, but you can't do as a black man. You don't have that freedom. If you go to a club, for example, you have to be very careful otherwise the security starts picking on you and kick you out. They think you are violent or want to cause problems just because of the colour of your skin.

You get targeted by shop securities, night club securities, and everywhere you go. It's something that white people don't have to be worried about or even think about. It's something you can't even talk about and have to hold at the back of your head. It makes my anxiety worse and if I tell other non-black people they wouldn't understand and think I am weird.

I haven't seen a therapist yet but if I could access a black therapist, it would probably be more relatable as they could understand my problems. If you are female and, for example, have experienced sexual abuse you would want to see a female therapist that would understand you better, you would be more comfortable to share your experience. My anxiety around racism and discrimination would be more understandable for people of colour. You can be more open and express that specific sort of anxiety that you face on a daily basis.

I don't talk about my mental health to my family and community, it's something you don't talk about. My community don't talk about traumas and think if they do they will be told off or get into trouble or something bad would happen to them and that might be the roots of many issues including mental health. Also in some religious families mental health is seen like more demoniacal and something not from God.

There is no understanding unless you share your story but black people have their own reasons not to share, and a lot of people just keep it to themselves. Especially for men there is no sense of being vulnerable or show vulnerability and that's why I don't talk about it with people around me. I prefer to talk and expose myself to professionals who could understand and help me.

I am happy to share my experience and hope it helps my community but prefer to be anonymous.

## Ursula Myrie's story

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Age: 47  
Black

### Personal Journey

I am a survivor of historic rape, sexual, physical, mental, emotional, and psychological abuse. In my community it's common because parents, grandparents and great-grandparents have been abused themselves so it's something we don't talk about it or we hide it under the guise of culture or/and religion. As a child I was told I had to be raped because I had demons inside me and you can't argue against that otherwise you would be punished.

I saw my psychiatrist when I was 7 years old because I was self-harming from the age of 7 but I wasn't properly diagnosed until I was 33 when I found out I had Borderline Personality Disorder (BPD). I went home and googled it and I ticked all the boxes. It was like a whole world opened up to me because I realised what was wrong with me. The roots of BPD comes from childhood abuse and traumatic past. So I traced it back to my childhood when I was sexually abused and raped repeatedly between the age of 2 and 16. Until the age of 33 I was told I was a mad black woman and that I was possessed by demons but after the diagnosis, I realised that I was neither mad nor possessed by demons and I knew I needed help. But the problem was the solution offered to me by predominantly white mental health services with a one size fits all approach to mental health did not work for me. I had to go inside myself and fix it myself. I chose to free myself from family and religion.

I have been sectioned multiple times over the years and every time I was sectioned it was the same issue, I was seen as more angry and more violent than the other non black people on the ward. Where the white people's behaviour on the ward was passed off as passion and anxiety, I was labelled as angry, threatening, and aggressive. But I was anxious as they were anxious. My anxiety was presented different to them because they didn't understand my history, my culture, my faith, my beliefs, or my trauma. So they over-medicated me to keep me quiet and not ask for the help I needed.

Over the years this hasn't changed. I have realised that black people are over subscribed in the mental wards, the proportion of black children being excluded from school is increasing, the amount of black people in prison is increasing, especially children or prisoners with mental health issues.

I have recognised 2 things here:

1-We have a problem in the black community, in that we don't think mental health issues exists, which it clearly does;

2- the statutory services that are meant to support us are not fit for purpose. They are not culturally sensitive. Culturally appropriate or culturally competent.

That's why I decided to set up Adira and I think of it as a bridge organisation between people in the African-Caribbean community with mental health difficulties, and the predominately white mental health services.

## Stories from Aidra

Adira is a survivor-led mental health and wellbeing service that supports black people with mental health issues. The whole reason why Adira was set up was mainly because of the gaps in Mental health services. I can't talk about other communities that's why I don't like the term BAME because we are not one single community. I can only talk about the black community.

Adira had to be set up because we were falling between the gaps because part of the problem is many black people don't believe in mental health and behind closed doors we say that's white people's problem while we yet populate the mental health wards and prisons.

Black people with mental health difficulties come to us first and the reason they come to us first is because we understand what's going on. For example, if someone comes here and tells me 'someone has put juju on me', I am not gonna be like 'what is juju?' If they go to a white person as soon as they ask what's juju, the conversation is over because if you don't know what's juju how are you going to understand me. If I tell you my pastor has said I'm possessed by demons, unless you understand my faith, my religion, my culture, my beliefs, you can't understand and help my mental health. They come to us for a help which is culturally appropriate, culturally sensitive, and culturally competent for them.

At the same time we can be a tool for the white community who approach us in a genuine and right way. We say NO to some white people because their approach is wrong. They use us for our knowledge, lived experience, and trauma and only pay us lip service or use our skin colour to tick boxes. It's about building trust and friendship like the relationship we have with Sheffield Flourish, for example, we see them as an ally because they approached us in a right way, they genuinely wanted to get it right and change things, so we involve them in everything Adira does.

When we create safe spaces for black people, we don't want it run by white people because we can't say what we want, behave how we want, we don't want to be used for ticking boxes. Let's go back to 20 years ago when the government started to acknowledge we were overpopulating mental health hospitals. They sent white middle-class men with suits and briefcases into the black community to say ok you've got a problem and this is how we gonna fix it with the one size fits all approach. First we [the community] looked at them and said we don't believe in mental health, if you know us you would know that, and secondly who the hell are you? We haven't seen you before in our communities and thirdly your approach is wrong, coming here with a suit and looking very middle-class in the most deprived communities, open your briefcase and bring out some leaflets and tell us how you are going to fix our mental health.

We didn't trust them and didn't want to talk to them. They went away and that's where the terms 'hard to reach' and 'difficult to engage' came from. Never ever say to a person of colour they are 'hard to reach' because you gave us that label. The language is important. We are not difficult to reach or work with.

I remember one day watching TV and Theresa May went into the parliament and asked why there are so many black people on mental health wards? And I think that's when they

decided to think about diversity, not because they cared about the black community and how mental health was affecting us, but more because we were costing the government money, as it is very expensive to house people on the mental wards. Then all of the sudden, white organisations started coming to us saying we want to engage with you.

It's all about trust. Our mistrust goes back to slavery but it still exists mentally today in 2020 by stopping us having a voice, or getting promotions, being discriminated against, racially targeted, and murdered because of the colour of our skin everyday. Mentally we are still being slaved as you see everyday racism and bias controls how we live, eat, walk, talk, work, and raise our children.

Overtime something like George Floyd happens and there is a knee jerk reaction from the white community to do something and it's like 'Look everybody we are doing something', and then as soon as it dies down they take away all the things and resources until the next George Floyd happens. The trust has constantly and consistently been broken. That's where the mistrust comes from. They use us and discard us whenever it suits them.

The situation for black men is even worse. We teach our men from the womb to be strong and by strong we mean angry and not to be soft and be prepared for pain. They are not allowed to cry or show emotion. They are told they are useless or stupid or worthless because that's what they gonna hear from the white man outside so they need to be 'prepared' for the real world. So by the time that boy leaves home he is angry, hurting and there is nowhere for his pain to go. And it horrifically affects their mental health.

There is a saying that it takes a village to raise a child, but it doesn't end there, the second part says the child who is not embraced by the village will burn it down to feel its warmth. And that is what's happening now, if the village (society) doesn't care about the child's mental health and wellbeing and ignores him, the child does everything (stabbing, shooting, being part of a gang, etc) and says 'do you see me now'? Because that's when I get your attention, when I stab somebody, when I come home pregnant at 15. Can you see me now, I am burning down the village?' This is why we see the rise of mental health problems in young black people.

But this generation have started asking questions and are willing to get help but unfortunately the current systems we have in place isn't working for them, it's working against them at every turn.

I was mad at Sheffield Health and Social Care because, for example, they say IAPT [Improving Access to Psychological Therapies] do this, IAPT do that but there are so many young black males coming to me and say they contacted IAPT but they were sent back to their doctor and again sent back to IAPT. This is the problem, they don't make services culturally appropriate, or culturally competent.

The young people (there are around 50 of them) tell me they want to talk to a black mental health therapist. A few weeks after we did the Black Mental Health live, a mum contacted me and said her son was back home from Uni because of Covid and the first day he arrived he had a complete mental health breakdown because of a racist incident he had experienced at the uni. He locked himself in his room and threatened to kill himself and other members of the family because he thought they wanted to kill him. For a few weeks the mum had talked to the doctors and they had recommended antidepressants

and she had called the crisis team several times. The mother had called them but they had passed her back to the doctor, the doctor referred them to IAPT, and they passed them back to the doctor and again to the mental health team. So the mum was scared that her son would either kill himself or the family and asked me if there is anything I could do.

I rang the people at SHSC [Sheffield Health and Social Care NHS Foundation Trust] and talked to them, and 20 minutes later the mother called me and said 'I don't know what you did but thank you, they are helping my son'. The only thing that helped that mother was that I knew people at the top at SHSC and told them listen this is happening so fix it. But it isn't my job and responsibility to do this every time.

Adira isn't a crisis organisation. What would have happened if I didn't have that access to people at SHSC? This mother tried everything and this is the proof that the system doesn't work for the black community.

Four weeks ago a 19 years old black young man killed himself. Recently a 20 year old called me and asked me if I knew of any black male therapists because he was struggling but the private therapist, even the cheapest one, charges £45 per hour and he couldn't afford it. So I had to call SHSC again and told them if this one kills himself too I would publicly hold them and IAPT responsible. He wanted to get help before ending up at a mental health ward.

### **Ursula's Feedback on Mental Health Surveys**

For a survey to work you need to build relationship with people of colour. Not once or twice a year sending out some surveys to tick boxes. How do you expect people to trust you and talk about their lives in one or two hours, relive their mental health journey, their traumatic experiences, and share it with a stranger?

We are people with lived experience and want to know what do you do with our stories, what is the result of all these surveys? We never knew what would happen to them. That's again when trust and mistrust comes in.

You can't put a price on my lived experience, no PhD teaches you the expertise of a person with lived experience. So when you expect people with lived experience to spend time on your surveys you should treat them equally and pay for their time as you pay a person with a degree or PhD.

What is the purpose of all these surveys anyway? Why do they come back with exactly the same questions each year and we see no improvement in the system?

## Alex's story



Age: 28  
Male (from Eastern Europe)

I moved to the UK about 10 years ago. In my home country I am still part of an ethnic minority group which means that sometimes I am confronted with the idea that I don't belong there. Here, in the UK, I am a foreigner, so sometimes I feel like I don't belong here either. Now with Brexit, and all the political turmoil that has come with it, my sense of not belonging has been amplified even more. The only time I feel like I belong is when I play music and interact with other musicians. I feel like my personal background is meaningless during the act of performance. As a musician, I have been inspired by British rock music and have always felt a connection with the culture as a result. At one point after Brexit, I was living in a shared house where I experienced xenophobic hatred and I had to move out as result. Although one of my current flatmates is a 'Leaver', we have actually become close friends as we have a lot in common besides our contrasting political views.

With regards to my struggles with mental health, these have come in the forms of isolation and a crippling sense of not belonging; being too different and being rejected quite a lot. Isolation itself manifests through the feelings of frustration, depression, anger, and a strong sense of boredom. I internalise the anger and don't project it on people. I have never been violent or aggressive or hurt anyone, but inside I have my battle which makes it hard sometimes even to wake up in the morning. Currently, I am struggling with sleep a lot. I have lost track of my internal clock. Physically however, I am in good shape. I exercise and eat healthy.

Social media has had a negative effect on my mental health because it is incredibly pervasive. It feels like you are always confronted with the idea that your life has not turned out the way it was supposed to. Personally, I only use social media to share my music. If I wasn't a musician, I would never go on social media. It's terrible because it makes you feel like you have failed in life when you see other people doing better. You compare yourself to others all the time, and even though deep down inside you know you shouldn't, sometimes it feels like you are conditioned to do so.

It's difficult for me to talk about my mental health problems in coherent way. It has always been ups and downs for me. For the last four years, I have been studying part time and working full time and it has been really stressful. I have talked to my GP about my problems, and they have always said that a lot of other people are in the same shoes as me. This can certainly make someone feel a bit better about their situation, but it does not necessarily help with the process of moving on. I have never tried medication because I don't want to get addicted to antidepressants. Maybe it's just my ego or pride, but I think I can push through life without antidepressants. There is no medication for isolation.

I have sought counselling at the University of Sheffield. Since the pandemic, they have switched to an online format and it was certainly useful to talk to someone. I haven't been to one-to-one therapy sessions because they are too expensive for me.



Not belonging has affected my self-esteem. I think men are still expected to be confident and steadfast most of the time throughout their lives. This social stigma has generated a lot of suicidal thoughts in my mind.

A couple of years ago, I became suicidal and I had a plan on how I would do it. Luckily, instead of executing that plan, I phoned the Samaritans and talked to someone about my feelings. Sometimes, it is better to call the Samaritans instead of booking an appointment with the GP because you can contact them at any time and dump a lot of information about your miserable life onto another person. It can be a very cathartic experience as you unburden yourself of all of your plights. You can't always do that with a partner or a friend. Knowing that you will never speak to the person on the other end of the phone ever again can be very liberating at times.

Music and singing have helped me to cope with isolation much better than booking appointments with counsellors. Counselling sessions don't really help you to move on I think; instead, you are trapped in this vicious circle of narratives about your miserable life that you cannot escape. You desperately want to find solutions and move on and escape the repetitive stories that lead to self-pity. If you think about your mental health as a scale whereby on one end there is self-loathing, and on the other, there is arrogance and stoicism, you want to be somewhere in the middle I suppose. You don't want to feel sorry for yourself for the rest of your life because you will always be a victim, a noble but miserable person who has been hard done by life. This is not practical, and you are not actually moving on; instead, you are stuck forever in the depths of your plight.

I have tried talking to friends and family as well but that sometimes creates more problems. My parents are from a different generation and they hold completely different views of life. I had a lot of arguments with them about my problems because they're very conservative. I disagree with almost everything that they say. For example, if I talk about my struggles in life with my dad, he will simply tell me to man up and deal with it which is not particularly helpful of course.

We live in a very complicated society where ideologies about gender are changing regularly. I think this is a great thing, but this means that we (the younger generation) are in a transitional period right now and we have to constantly face a tide of contradictions. I have met a lot of women who complain about patriarchy, toxic masculinity, and aggressive men all the time, but when you look at their boyfriends or partners, they are perfect examples of the very same male stereotypes that they criticize. Basically, some women validate the things that they condemn. The concept of 'what is a man' is really complicated and diluted these days. If you are not assertive, then you are weak and not sexy, but if you are assertive, then you might come across as being aggressive and oppressive. You have to be vulnerable and sensitive but not too vulnerable and not too sensitive at the same time. It is an impossible game.

These days, I rely on music and sometimes casual sex to help me relieve stress and anxiety. I am not ashamed of that because I need some form of human intimacy in my life to function properly. Still, I am looking for something more serious. The pandemic has deprived me of all the wonderful opportunities to socialize with other fellow musicians. I have lost a lot of momentum and felt suicidal in March and April. I guess, at the end of the day, you just have to accept that life is unfair and work hard to improve yourself every day.