

MENTAL HEALTH AND MENTAL ILLNESS

INTRODUCTION

Mental health problems are widespread, at times disabling, yet often hidden. In the UK, nearly half (43.4 per cent) of adults think that they have had a diagnosable mental health condition at some point in their life. One in six (17 per cent) of people over the age of 16 had a common mental health problem in the week prior to being interviewed (Mental Health Foundation, 2016). One in eight (12.8 per cent) of 5- to 19-year-olds had at least one mental disorder when assessed in 2017, and the prevalence of mental disorder among 5- to 15-year-olds has shown a slight increase over time (NHS Digital, 2018).

Since the 1960s, what we would now see as punitive and stigmatising attitudes to “madness”, with great reliance on institutional care, have given way to a more community-based, human rights-informed approach. These changes were enabled by the development of new generations of anti-psychotic and mood-stabilising drugs, and spurred on by vocal communities of mental health activists. Societal attitudes to mental illness have also changed, aided by campaigns such as Time to Change (www.time-to-change.org.uk).

Nevertheless, mental health services have not been given the priority awarded to physical health when it comes to staffing, funding and national treatment standards. Access to high-quality, timely and appropriate treatment, whether for anxiety and depression or for more extreme ill health requiring hospitalisation, has been insufficient. There has been growing concern in particular about the widespread mental health problems of children and young people, with demand for services outstripping supply. Recent national policy, as reflected in the

Five Year Forward View for Mental Health (NHS England, 2016) and the NHS Mental Health Implementation Plan (2019), is aimed at boosting provision and reducing the gap between mental and physical health services.

As with other aspects of ill health and organised responses to it, the field of mental health is also marked by deep inequalities. For example, black and minority ethnic people are at higher risk of receiving a diagnosis of mental ill health, and disproportionately impacted by social detriments associated with mental ill health. They can have greater difficulty in accessing appropriate care and support, and have more adverse experiences of assessment and treatment. Black and minority ethnic people are 40 per cent more likely to access mental health services via the criminal justice system than white people. African-Caribbean men are more likely to be diagnosed and hospitalised with schizophrenia and to be detained in secure institutions. The causes of these inequalities are multi-factoral, but discrimination and prejudice play a significant part (Bignall et al., 2019).

THE STORIES

In Chapter 1 (Section 2, p. 4) we offer an understanding of patient-centred care in general as:

- Understanding and valuing what matters to patients
- Seeing the whole person
- Respecting people's rights and autonomy
- Being customer focussed

Against these criteria, the stories below can be seen as presenting very much a mixed picture.

This chapter contains five stories about mental ill health: three from patients, one from a family member, and one from a psychiatrist who is also a patient. We start with **Audrey**, who works as a healthcare scientist and knows how the NHS works. Hers is a fragment of a story, which describes the process of getting access to the right services for her family member. We then move on to **Stanley**, who arrived in the UK from Zimbabwe in 1995 and had his first breakdown and diagnosis of bipolar disorder in 1997. Next comes **Alan**, who has also been living with bipolar disorder for over twenty years and now works as a patient ambassador talking to groups across the country about his experiences. **Nathan** is a teenager with various mental health issues. Finally, **Lucy** provides the

longest story in this chapter. She is a retired hospital psychiatrist with lived experience of a severe and enduring mental illness. As with other chapters, we have posed questions at the end, arising from these stories, to simulate your thinking and reflection.

Story 16: Audrey

This is a story fragment about the difficulties encountered by one person in accessing mental health services because they were never quite ill enough or were too ill to fit a particular service. Eventually a family member (who tells this story), with inside knowledge of the NHS, comes to his aid.

Audrey: I have personal experience with a close relative who has suffered for many years with mental health problems and been bounced from one service to another without any kind of effective treatment, being told he was either too severe for one service or not severe enough for the next. After five years, unable to work due to his problems and feeling effectively written off, he did get to see someone, was given a diagnosis and was promised a referral for CBT [cognitive behavioural therapy] but then heard nothing for several months. He is not well enough to chase his own referral, so I did the calling round. When I did, I was told that he was on a waiting list but they could not give me any indication of timescales as to when he would be seen as they had a “huge backlog”. They did say they were expecting it to be at least six to eight months before he got to the top of the list and we would not hear anything until then.

It was then that I learned that, unlike in physical health, where patients have the right to be seen and started on treatment within eighteen weeks of referral (and hospitals suffer penalties for failing to meet this target, meaning that huge amounts of resource are diverted to ensuring we meet it), patients with mental health problems have no such right. Concerned about his ever-deteriorating situation, I fought his corner and had to threaten to complain to the CCG [Clinical Commissioning Group] before they suddenly managed to find him an appointment the following week and thankfully, after five years, he is finally starting to turn a corner. I feel very strongly that this is just not right. People suffering from mental health problems are often unable to fight for their rights due to the nature and symptoms of their illness. This does not mean policymakers and the NHS has the right to ignore them.

Story 17: Stanley

Stanley came to the UK from Africa as a young man in the 1990s, hoping but unable to continue working as a journalist. Instead he had to combine low-paid manual work, and journalism training at college, while caring for his young family. It was a stressful existence and he experienced a mental breakdown in 1997.

Stanley: And yeah. I was then diagnosed with bipolar disorder, and for the next four, five years, not even ... 1997, 1998, yeah, about seven, eight years, next eight years I went through the revolving door cycle of going in and out of mental health, I was never mentally stable throughout that period. If I wasn't manic I would be at home, very, very severely depressed. Wasn't doing much, my life was not going anywhere.

And were you still working?

S: No. I couldn't work anymore. Dropped out of college, wasn't entitled to benefits because of my immigration status at the time. So, because I had a family and a young child, you know, we were being supported by social services, which was really difficult. They didn't give us any money, they gave us food vouchers, they paid our rent and that was about it. So, it was a very tough time then with my mental health. But it was in 2004 I had an admission, towards the back end of 2004.

But before that, even before that, throughout the eight years, you know, I had a fractured relationship with mental health professionals. I didn't trust them, I felt they didn't understand me and there was one important factor that they never did take into consideration, which was how important work was to me. You know, I remember the first consultant after my admission in 1997, I'd been discharged and was having an outpatient appointment with the consultant. And we were talking about, well, where do we go from here? And I said to him, well, I'd like to get on with my life, get on with my career, get back to journalism, get back to work. And his response was, forget journalism, it's too stressful a career for someone with your condition, you know.

And then a social worker, around about the same time, a few days later, my social worker – care coordinators as they're called now – well, my social worker, we had a similar conversation. And he actually told me, forget about work, consider yourself retired, enjoy the benefits you'll get for ... the money, the free money you'll get for ...

Consider yourself retired?

S: Consider yourself retired.

What age were you?

S: Twenty-nine. You know, so that didn't help.

Stanley goes on to describe one of his consultants.

S: You know, things weren't great between me and mental health services. I didn't trust them, I didn't have a great experience with them and I didn't have a great experience of my consultant at the time. You know, he was very distant, he never called me by my first name. It was always very formal. He didn't know my wife's name, he didn't know my children's names, it was as if all that was unimportant. It was all about medication, medication, medication.

I would go in for review meetings and it was so impersonal, I always got asked the same set of questions, textbook, from a textbook, I thought, you know. Can't remember exactly the questions, but I remember one question in particular that I always got asked, you know, he never asked, how are you, what's going on for you? You know, it was set questions, .one of the questions was, do you think you're special, do you think you've got superpowers?

And I knew what the questions were and I knew how to answer them, you know, if I said, yes, I have special powers, yes I think I'm special, I'd automatically be sectioned. So, one time, just after having answered the same question repeatedly, he asked me, do you think you're special? And I said, yes, of course I'm special. And he sat up, leaned forward in his chair, picked up his pen and, why are you special? I said, because I'm the son of a king. He says, oh, you're the son of a king. Yes of course, aren't we all children of God. You know, and that was just my way of being sarcastic and trying to show that your questions are stupid, insignificant, they're not helpful to me, they don't ... it's not about me, it's not saying anything about me.

Later, Stanley used his knowledge of the system to get access to a different consultant.

S: But then, I managed ... I used a loophole in the system to actually change my consultant psychiatrist. Because at each locality ... because psychiatrists are allocated according to your catchment area, so each catchment was allocated two consultants. But they worked according ... based on whichever GP surgery you were registered with determined which consultant psychiatrist you worked with.

So, I utilised that loophole and I switched GP services so I could switch to the other psychiatrist. Who, I heard, had a very good reputation; she was very understanding, she was very compassionate. And I just thought, she's got to be better than him, you know. So, I used that loophole, changed my consultant and my life changed.

You know, I remember my first meeting with my new consultant, it was at a time when I was struggling with my mental health, you know, I was becoming quite manic at the time. And she said to me ... we had a long discussion; with my previous consultant it was strictly fifteen minutes, that's it, fifteen minutes and no longer, and that was it.

With my new consultant, she sat and spoke to me for over an hour, and not even spoke, she listened to me. For over an hour she listened to me, asked me about, you know, who I am, what was important to me, asked about my wife, my children. She just wanted to let me speak about me, what was important to me, what mattered to me, you know.

And at the end of that hour, you know, she said to me, I can't cure your illness because there's no cure for bipolar disorder, as things stand. But, what we can do, and the important thing is, she said what we can do, is together, we can learn to manage your illness. And once we've learned to manage it, there is no reason why you cannot get on with your life, including getting back to work. And that was like a breath of fresh air for me.

So, when I met this new consultant, she actually put me in hospital that day. She said, I'm going to admit you today because, you know, we need to get on top of your mental health. But that was my last admission for the next ten years. For the next ten years I didn't have a single admission. I was back in work, I remained in work and my mental health was relatively stable. I had ups and down, blips, but because we had learned to manage it, we learned coping strategies, we learned how to recognise the early warning signs. But, I think the main thing for me was that I felt in control of my own life, of my own mental health. That was the biggest thing for me. And, of course, getting back into work was a big thing for me that helped me maintain my mental health.

And if you could just tell me a little bit more about, what are the things that she did that worked for you?

S: The main thing, the main thing that worked for me, was that she listened to me, and she saw me, the person, the husband, the father, the son. You know, previously, they saw the mentally ill patient, I was just a mentally ill patient, I was not a person. So previously, they saw the diagnosis rather than the person behind the diagnosis. So, that was the

main thing for me, that she saw the person behind the diagnosis, she listened to me, she understood me and she gave me hope.

And that was the biggest difference. And I learned to trust, because in a patient–doctor relationship, if there is no trust then I’m not going to share with you when I’m not feeling great. In fear, because previously, if I just said, I don’t feel great, it was straight to hospital. That was straight to hospital or an increase in medication, or a change in medication. Those seemed to be the only answers they had previously: it was, well, if you’re feeling a bit depressed, we’ll up your antidepressants. If you’re feeling a bit manic, we’ll up your anti-psychotics.

And if you’re feeling a bit special, we’ll section you.

S: Exactly. Now, where, with my new consultant, where she asked me about me, she asked me about my family, my interests, you know. What do I like doing, what do I do, and I learned to trust her. So, when I learned to trust her, I could answer honestly about how I’m feeling, knowing that, for her, putting me in hospital and even adjusting my medication was the last resort. She looked at other ways of dealing, like, if at the time my marriage was on the rocks and I was, you know, constantly rowing with my wife. And she saw that, and she said, well, increasing your medication is not going to stop you rowing with your wife, you know. So, she would look at other ways of how ... managing that situation, the reality. She looked at the reality and that, okay, this is what’s causing you the stress, let’s look at how we can deal with that situation, you know.

Story 18: Alan

Alan is a middle-aged man who once worked as a professional photographer. He was diagnosed as bipolar in the mid-1990s. He moved to Canada in 2000, returning to England in 2013 after the death of his father. Mental ill health was a feature of his life through these years, and shortly after his return to England he was admitted to hospital. He is very positive about the psychologist who subsequently cared for him.

Alan: I saw a psychologist and I was really lucky, because I was with her for just shy of two years. One of the reasons for that, she put it to me once: she does her own schedule, and I know it’s six months or something, but two years? Absolutely amazing. We became really, really close,

it was a really good relationship. The only reason why that ended, was because she went to another job.

She was the psychologist on the ward. On a personal level – psychology, it's all on a personal level – there was a really good relationship between us, I felt I could relax and talk with her.

And I would say to her as well, the times when I don't want to come down here, they're the times I need to come down here. So, there was a really kind of good understanding there. Well, she was really good at her job, and she taught me some really good, I found, CBT techniques. And also, they were one of the places that tried this out, and it was CFT, compassionate-focussed therapy.

Ah, I've not heard that one before.

A: Yeah, it was again treating the self with compassion, and one has just sprung to my mind now, imagining there's like a fog, and it's warm, and what colours are there, and you're walking into it. Things like that. Visualisation techniques. So being open to that as well, especially being, well, with my condition, also being "arty", creative, that had a real impact on me. So, yeah, that was like six, seven weeks, eight weeks. I'm not sure what happened in the end with it, but that was kind of a trial of it to see. I suppose the nature of the relationship was, after a while, being able to let go and make myself vulnerable, for so long, and also with her, it's kind of this mask, and I got so, so used to it, I can slip into it really quickly, but she was really good at picking up on that.

"How are you doing?" Yeah, I'm doing great, yeah. "But how are you really doing?" She was really, really good at that. Based on her ... I can't think of the word ...

Insight, perceptiveness?

A: Yeah, insight, perceptiveness, and also us actually having a really good bond as well. And also – a little thing, but there's no way you can prescribe any of this – but I'd see her on a Thursday, when one of my sessions was, and on the Fridays, I used to live near the hospital. So we would bump into each other, sit outside having a coffee, have a quick little chat, a hug, and then she'd go off. So, I kind of had that as well. So, we kind of had this, with hindsight anyway, this slightly unusual therapeutic relationship.

She was sort of setting aside the normal professional distance, and just behaving in a human way, it sounds?

A: Yeah, and it still felt like it was, it didn't feel, not inhuman, it didn't feel unhuman, but there was that additional little bit of an element, just like, how are you doing? Yeah, I'm doing ... and you would anybody, any friend or whatever.

So, yeah, that definitely helped again for me. One of the biggest things she said for me, was me not appreciating what I can actually do. I haven't thought about this for a long while. One of the things was, if I can do something, because I can do it, anybody can. Well, I've realised that's not true. But that, for a long time, and she would really drill into that as well. She's really good at picking the points, she's very, very good at that, and that was some of the first ones, and I think, stop being humble, this is not a good thing, when it's put in with everything else. You're just downgrading, almost, yourself.

So, that was really, really good, to help me work with all that stuff. So now, when I'm now doing stuff, it has a lot more of an impact in the way people apparently talk about me, but I can actually be humble about that. It's, oh, that's great. 'Cause I know, oh I have those skills. It doesn't mean I ...

Yes, so she was helping you value yourself at the kind of correct level?

A: Yeah, exactly, and then with that, then doing other things, it's like, oh my God, I can do that. It doesn't make me the bee's knees, it just means, that's great, I can do that, people like it. Oh, that's great, I'm really humbled by that.

So, yeah, she was amazing. So I think it was a combination of absolutely being top of her game, and also, I suppose, knowing as well, for me, that kind of certain boundaries weren't actually being adhered to. I think that kind of helped me think, well, relax, it's a bit unusual, it's what we make of it, rather than this is the prescribed therapeutic relationship. Like seeing her the day after, and you know, hi, a quick hug, have a good day?

So, I think for me it helped. I wouldn't say it became less clinical, less formal, should we say, and so, yeah, I think that's one of the reasons. And I'm sure, for two years, I mean, she did say to me towards the end, that she got a lot out of the sessions as well. And when she had her sessions, the psychologist, she would often talk about our sessions, and why it was so difficult for her to end the sessions. I think in the end her psychologist said, don't worry about it, you do your own schedule, it's up to you.

So, there was a really interesting relationship going on there. So, at the end of it all I gave her one of my abstract nature photographs,

signed on the back, thank you. I gave her a hug, and she was crying. It was so sweet.

So, it's interesting, 'cause it sounds, I mean, the thing about a service user–health professional relationship, it often is kind of a one-way thing isn't it? Whereas, what you're describing is more of a two-way, it was more reciprocal?

A: Yeah, for sure.

And that in itself sounds like a therapeutic thing.

A: Yeah. She is, I'd say even better at her job, I'd say, rather than very good, she's very, very, very good, because she obviously realised that that's okay, and this would really, really help the work that we do. And there won't be any negative impact by pushing that boundary a bit. I hadn't thought about that before, actually. She knew, it didn't just happen. She would have thought about it, at least afterwards, when these things started to happen, and nip it in the bud, or no, that's okay, that actually ...

So, it's like she knew where the boundaries were, but she made a judgement about where she could push them a bit?

A: Yeah absolutely. But I don't know how you could formulate that into suggestions, and how to work. You don't always have to keep to the boundaries. Well, I suppose so. But, that was the impact that it had. I think the important thing is that sometimes you need to tailor the therapy to the person that you're with.

The trust where Alan was treated has a forward-looking approach to engaging patients. He describes the transformative effect that his involvement in its “people participation” activities had on his mental well-being.

A: Really, really nervous, and really shy, but just slow, and the support, I mean it's a great team, and slowly doing different things. And I did talks at academic conferences, and NHS conferences and stuff, and to students, whatever. But, I always say to them, kind of before I started getting involved in this, I'd find it really difficult to talk amongst three people, and now I'm standing in front of 200.

So, first it was client contribution in the world, to the academic literature. But, yeah, for me it really did change everything, and I've spoken at the House of Lords and stuff, which I would never have

imagined doing before. When I did my degree, four years as a student, somehow I managed to get away with only ever giving one seminar. But that was the nerves and the social anxiety, and that was why. Looking back with hindsight, it would be completely different now. But, that was kind of the – I can't think of the right word – not the baggage, but that's part of me, anyway.

So, yeah, loads of other different experiences along the way, but that's kind of my, I've now been involved for probably just shy of two years.

So, the way you're describing it, it seems as though becoming involved in the participation work is absolutely relevant to your recovery?

A: Oh, absolutely.

Very interesting. And tell me a bit about that, so you've said something about giving talks and things, tell me about the range of activities that you do.

A: For me, anyway, doing workshops with DLR [Docklands Light Railway] staff, London Transport, 'cause they encounter, obviously, people that might be in crisis, so it's sharing my own journey with them, and also being quite open about my condition. So, I'm happy to talk about it. I always say to them at the end, 'cause they're big, burly East End guys, most of them, asking for help isn't a weakness, it's a sign of strength. So I try and get that across to them.

Business students, business apprentices in Canary Wharf. Get the younger generation, and they pass it on to their friends. So, I do that. Training researchers now, or service users to become researchers. Been to Manchester, Birmingham and Belfast, to talk about people participation, what it is, the impact that it's had on me, the research project, and how beneficial it can be for a trust as well, because who knows the best about the services that are provided? The people that receive them. In saying that to trainee nurses, you can see them, oh yeah. It's like, seriously, that's never crossed your mind before? But, for whatever reason it hasn't, so it's like, okay, I can do this and I get really nervous, but I can actually talk in front, and hopefully inspire some people.

And it's actually providing many of the things that other people would get from paid employment, like validation and responsibility?

A: Yeah, and it's helped me, kind of – it sounds really strange when I say it out loud – find my place in the world. And it's reminded me sometimes of skills and talents, I forgot I had, as well as learning new

ones. 'Cause, yeah, everybody up here would not recognise me, if it was three years ago, and I walked in. They wouldn't. So, I can see the impact that's had. And it also, being able to make a contribution that's valued, into the services, as well. And it's like, I suppose, I'm not a service user union rep, I can't speak for all service users, but being able to have that voice and directly affect change, and having it valued, and it's not lip service.

It's very empowering then, so that you can make a difference, which is a difference worth having.

A: Yeah, absolutely, yeah, it's really, really empowering. It never crossed my mind until it was pointed out to me at the hospital, the lead nurse – I've gone over there and sat on interview panels with him – kind of said to me, so we've never said this before, this rarely happens. I goes, what rarely happens? Well, you were on the ward for a long, long time. Yeah. We rarely, if ever, get to see somebody the other side. They said, it doesn't happen. And they said, so it's so great to see you, and now doing all that stuff, and hearing about all the stuff you do. It's great, 'cause from there how you were back then, to how you are now.

A lot of the time they've no idea what happens to the people who pass through?

A: You only see them in crisis, you only see them on the ward, you've got no idea what happens to their life afterwards.

Story 19: Nathan

Nathan started having treatment for mental health problems at around the age of 11 after his school became concerned about his hyperactive behaviour. When he spoke to us he was 17. Nathan, who identifies as gay, has had problems with his family and with his schools. He contrasts the problems he encountered at school, with his positive experiences of the Child and Adult Mental Health Service (CAMHS), especially the relief of being believed and supported.

Nathan: Essentially, it was really difficult in high school because not only are you juggling sexuality, you're also juggling that I wasn't the best in maths and English because of bullying because of other stuff I was focusing on obviously, so I have changed schools. But because of that it was

so difficult, I remember the amount of times that I just didn't want to be here and I was so suicidal and CAMHS, luckily, they do believe you if you say that. So if you say, I'm not in a good place, they will work with your school to make sure that you're not doing anything bad.

I remember someone I was seeing because they knew that I had a massive fear of certain subjects because I just got bullied in them; they made a plan with the school that I would only do half days. But that in itself was a really big thing for a therapist to get involved with the school and basically move your whole schedule just so you don't get bullied. That wasn't until the end of year eight, so you can imagine how the first two years were, they weren't the best.

I remember the teachers would just assume that everything you were doing was attention seeking or it was because of a bad family member or it would be because, oh, it runs in the family or you're just dumb. They wouldn't ... I remember I tried telling one of my teachers that my dad wasn't the best person and they just wouldn't believe me, they spoke to him once and went, oh, no, he's fine, and didn't believe me and didn't report it to a social worker or anything like that.

So you can imagine how that worked, the first person you're meant to trust is a teacher, so you can imagine it wasn't the best two-year period, but the second you come to CAMHS it's completely different, they believed me instantly, they offered to speak to you on the phone.

So I just went in, within my first few sessions I said, look, this is what my home life is like, I'm not saying this because I want attention or anything, I'm just telling you because I told my school, they didn't believe me.

And within the next few days we were having a meeting and they were saying how the school wasn't being professional because I was saying that I was being abused by my dad, not only that I was being bullied in school, the teacher didn't believe me in that. They were also saying that I was struggling with certain subjects and they, again, didn't believe me on that and I was saying I didn't have many friends and they didn't believe me.

I was saying that I didn't feel safe leaving school and going home. I was really anxious and a bit scared because my dad would stalk me when I came outside school and threaten me and whatnot. And the school didn't believe me about that either but, luckily, CAMHS, they did believe me and trust me and take me seriously. Because what they used to do is some of the therapists would wait outside with me until the taxi arrives, until my mum arrived. And I just thought that's such a small thing but such a big thing at the same time and it can really go a long way to make someone feel comfortable and safe.

Nathan describes the importance of the therapist establishing a good rapport with him:

N: I remember when I first came here the only reason I was able to open up was because the therapist I was seeing was able to tone it down and be a bit more funny with me, a bit laid back, and so I trusted him more. And that was a great technique to do to a 13-year-old. But had it been someone very serious who couldn't do that, I wouldn't have opened up, I probably would have turned my back on CAMHS and thought, well, I've already seen someone, I'm not going to bother with any more. So I think that's a really important quality: to be able to adjust to your audience or client, depending on the situation.

He also explains the importance of continuity of care.

N: I was seeing this very nice lady for kind of a longish period of time; they offered me, I think, sixteen sessions or something. After the sixteen sessions obviously I was fine and I stopped seeing them for a couple of months but when I had a bit of an issue, so I came back and I said I would like to see someone again, the doctor referred me. And because I'd already seen this person they asked her if she'd be able to see me again so I didn't have to go through it again. And I think, again, she was able to see me which was really good.

So now I'm seeing the same person that I was seeing last time, so I didn't have to waste two or three weeks going through everything again.

Yes, as far as you're concerned, you'd much rather see somebody that you already know than start again from scratch?

N: Yeah, well, it's mainly because here they don't mean to but they have a problem where if you say something, when they put it on the file the next person who looks at it will somehow get it wrong. Whether it'll be they've read it wrong or they've misinterpreted it, and they don't mean it in a rude way but they say, oh, yeah, you did something. No, no, I didn't ... and then you have a week or two weeks correcting them and it's obviously annoying, especially when you've seen someone for five years there's a lot of stuff to correct.

Nathan's experiences of CAMHS services have varied. He describes one unfortunate incident.

N: I had one person who on my first session they tried to diagnose me with something without speaking to me; within the first three lines they went, oh, you're autistic. I'm not autistic, I've done the test multiple times, I'm not. And you could imagine how that would be after seeing someone for two years and they have to leave and then you see this new person you've been waiting months for, months longer than they said you would be waiting, and within the first session like, oh, yeah, you're autistic, we don't need to see each other anymore. Yeah, you can imagine how that was.

We have a broader discussion about labels and diagnoses.

N: So the problem CAMHS does have is it doesn't like labels that much, which is understandable because a lot of people react negatively to labels, but labels can be really good because if you're having an issue and you're suffering a symptom of something, you know what to Google, but you know not to Google issues with breathing if you're having a panic attack because you might think you're having a heart attack or something and you rush to the hospital and nothing's wrong with you, you're having a panic attack or something like that.

So I think it depends on the person. I'm not someone who'd believe the first thing I see on Google so I think it's quite helpful for me to look things up. But, that being said, I had a friend of mine who'd believe everything she reads online and so it would be horrible and terrible for her to Google something to try and understand it more because she'd be completely wrong.

Yeah, it's interesting, it's a delicate balancing act then, isn't it, between the labelling that gives you some understanding of the symptoms and what to do, versus the sense of being labelled by other people and, therefore, not being treated as a person, just a set of conditions?

N: So because I'm very open about it, I don't care about the stigma, so because of that I think I'm able to look at the labels as a different approach to some people. So I'm able to look at it and see, well, it's not that they're defining me but, in fact, they're just defining how I can get help.

So for me I always see a label as kind of like a describing word in a way, I can use it in the sense of if I'm having an issue I can say, oh, I'm just OCD, not, I'm suffering with OCD, I could just say, well, I'm having a bit of an OCD epidemic right now.

Yes, because for you, you can take an analytical approach and it just helps to make sense. So have you collected quite a lot of labels over the years?

N: Yeah.

And is that in itself problematic?

N: Oh, definitely, it can be really problematic for some people. So with me it's not but, as I said, that's just because I'm the type of person I am.

But other people – it can be a terrible thing to diagnose them with something because then they think there's something wrong with them, so I think it depends on the approach and the person and the relationship the client and the therapist has.

What you're saying is actually this is quite a difficult area where the therapists need to be quite skilled and where the opportunity for misunderstandings is probably quite big?

N: Yeah, so many people have an issue where they get diagnosed with something and they get really upset because they've misunderstood it. So I think the best approach probably would be to look at the relationship the therapist and the client has, if they've got a good connection, then they could diagnose them with something and label it and know there's not going to be a miscommunication there, which is positive.

But obviously, if you've been seeing someone for a short amount of time it's probably not the best idea to label them immediately because they're going to then feel like, well, what do you know, you've only seen me for four weeks or something? Even if it's really obvious.

So I think the approach would be to speak to the parents because obviously parents play a massive part in mental health. Because otherwise the problem is when you tell the child, I think you might have something, they hear, I have something. So they can't see that you're saying, "might", not, "have", so they will go, well, I've definitely got this one thing, so they go and tell everyone at school, they tell the teachers and they don't have it and then they're really embarrassed and they get bullied for it.

Yes, it's a minefield, isn't it, is what you're saying?

N: Yeah.

On another occasion an initial misdiagnosis was an opportunity for a therapist to listen and to admit that they were wrong.

N: So my issue was when I thought I had OCD, and I do, but they thought I didn't have it for so long, so when I finally told this newer person, they said, well, I don't think you have it but we'll do the test and if you get sixteen out of twenty we'll do the test or whatever – I can't remember exactly because it was so long ago. But I did get pretty high in that test and she was like, oh, I was wrong, okay, well, that's good.

So because she was able to put her own feelings aside it turned out I did get diagnosed with something that I do have and they thought I didn't.

Yes, I quite like the fact that she said, I was wrong, and she was able to admit that without it being a big deal.

N: Yeah, yeah, it's really good to be able to admit, okay, even with all my training I was wrong, it's really helpful. You can imagine how it would be if you're continuously asking them to give you the bit of paper so you could fill it in and they tell you for years you don't have it and you finally do, and it's so good to hear them say, okay, I was wrong.

It's so helpful when they're able to say, I was wrong, and ignore their training for a slight moment or so. Because you get some people where they go, well, I'm trained in this area so I understand it maybe a bit more than you might. And it's like, yeah, but everyone is different, so you might end up having something, they just might not be able to notice it.

Because obviously, as much as you should be open in therapy, you're never going to be yourself truly, there's always going to be some things that you don't bring. Whether that's because of the anxiety of it or you just don't ever think to mention it, but there are always some things that you don't mention and that's why it's really important to listen to the person and just do the test, if it is a test, whatever you want to get diagnosed for. But if there's a test it's really important to do it, because there are some cases where they find out stuff they didn't know about you because you never thought to mention it and it turns out that that small thing helps you so much in getting diagnosed and it can really affect you.

The interview with Nathan concludes with a story touching on the themes of trust, honesty and openness.

N: If the client doesn't think you're polite or nice, they're not going to bother with you or they're going to lie to you. Because a big issue I had when I started seeing my second therapist, I found myself lying to make myself sound better than I was so they would let me leave the trust because I just didn't like the person I was seeing. But, luckily, I ended up just having confidence and just going to reception and saying, look, I need to see someone else, I do not like this person at all.

And they were really nice to me about it and they put me on the waiting list to see someone else. But if I didn't have that, I could have then gone home and done something really stupid because I didn't like the person I was seeing.

It's a really interesting set of circumstances because in a way you were in quite a dangerous position because you were not telling the truth to your therapist, you didn't like the therapist, and you did quite a brave thing by saying, actually this is not working for me.

N: Yeah, especially because I know that I had a big fear that the reception would tell them that: he said he didn't like you. And I would be told, no, you can't see someone else because this is person you're assigned to. But, luckily, I got over that fear and asked; they don't do that, they, luckily, don't do that at all but obviously that can be such a big fear for some people.

So I think if the therapist thinks you're hiding something it's good when they say that, I think you're hiding something. Or at least in my case I like people being direct with me. So one thing my therapist did do which I found really helpful: on the first session they get you to write a list of triggers and a list of things that you like or they just ask you and they write it down. So because of that she will always know to be direct with me so I don't feel like I'm being ... I don't feel like I'm just being treated as an idiot.

So because of that in sessions she'll be very direct and very blunt, which works for me and that's how we have a very strong connection, I'm able to open up about things because she took the time to ask me what I like, what I think is good, what I think helps me.

And that, again, is such a small thing that not many people think of doing but that's such a good thing to do because it can really open up the client to actually want to talk about themselves a bit more, to talk about what bothers them and what doesn't, to talk about how you like speaking to them and things like that.

Oh, you describe it as a little thing but I would say it is actually fairly fundamental, understanding what matters to the client.

N: Yeah, I think the reason some people don't ask is because they think they can probably just assume. But I think it is so helpful when they do ask and it's something that I haven't seen much of and I really hope to see more of it because that small thing this one person did made me want to go back and see the same person again when I was feeling depressed. Otherwise I could have been self-harming and then done something stupid at the end.

So that one thing opening up so many opportunities where I was able to save myself from something really stupid. And I think that's why it's so important they do something like that and that's why I really hope that I see more of it.

Story 20: Lucy

Lucy is a retired consultant psychiatrist who has suffered from mental ill health all her life from teenagehood onwards. She describes how as a healthcare professional she knows her way around the system but even so it hasn't always been easy to find the right care. Lucy also tells of her experience when she was hospitalised with sepsis in Chapter 5 (Story 14).

To start with, can you tell me, what is mood disorder?

Lucy: Mood disorder is a type of mental illness. It's depression. Anxiety is sometimes put in with the mood disorders, but it's depression, mania, it's disorders of a change of mood, so where your mood can go from anything from high to low, to things in between, or a mixture of the two in some cases.

I'd like to mainly focus on one aspect, which is how, over the years, you've managed to find your way around the system to get the care that you need. But I guess before we do that, it would be helpful just to have a rehearsal or a summary of who you are, what your job has been, and when you first realised you were ill.

L: Sure. Yes, I'm a retired consultant psychiatrist and I first realised that I had problems with my mental health when I was a medical student, although, looking back, it's clear that I had quite severe anxiety as a

teenager as well. And I saw a psychiatrist for the first time when I was a medical student, and then I've had quite a lot of psychotherapy, and I've also been on medication pretty much ... well, I think continuously, but not on the same type, since 1995, or 1994, so a long time. And I've been under the care of psychiatrists, which probably would not have happened had I not been a psychiatrist, I have to say, although it might have done at times. But I've had pretty much continuous care, apart from a period in the late 1990s when I was reasonably well for a while, and then I was out of contact, but since the late 1990s to the present, I've been under the care of a psychiatrist. And I think I've been very fortunate in that, and I can't imagine how a GP would have managed my illness, but I know there are lots of people like me who would have only seen a GP, so I think I've been very lucky.

And tell me why it's because you're a psychiatrist that you got to see a psychiatrist, and what difference does seeing a psychiatrist make for the kind of illness that you have?

L: I really negotiated my treatment myself, which I think would be really hard now because everything is so intensely bureaucratic. I was working at a time when it was possible for, say ... without anybody saying, oh, sorry, we've not got a contract with them. And I know that doesn't happen now because I've met people who have said, I desperately need help but I've been told I have to come to the service, and I work in it and I'm not prepared to come here. And that's changed just recently for doctors, in that doctors can now be referred nationally to the service that Clare Gerada set up, the Mental Health Service for Doctors, but that's only the last month or so.

And I think, as a psychiatrist, I was aware that many of my colleagues were not people I would want to see... I hate to say this but ... When I've taught specialist registrars, and they've said, oh, GPs are dreadful. And I said, well, there's a lot of variety amongst GPs and some of them are very good, some of them are not that interested in psychiatry. I said, how many of your colleagues would you be willing to see as a patient? And then they all laugh, because everybody knows exactly what I mean. But there's this kind of stupid delusion that somehow everybody gets the same care, and they don't, and there's no choice. And I just knew that I wanted to see someone who could offer me more of a kind of psychodynamic perspective, as well as a psychological perspective, so I actually arranged to see one of my colleagues, and he/she was willing to see me, in the 1990s.

Prior to that, I'd seen a psychotherapist who was also arranged via a colleague. All that was done through kind of colleagues' networks ... It became more formalised because I was then seen by the specialist affective disorders people, and that was good because I think, at that time, things were a bit more complicated.

For you?

L: For me, in terms of my illness, but I think I probably could have been discharged from there now, but I'm still under their follow-up. And I know, had I been a patient, I would have been discharged years ago, an ordinary patient.

What, because you weren't ill enough?

L: They just don't provide long-term follow-up for people with severe ... with my kind of illness, who are not local to them. You know, there are very few specialist mood disorder centres. Depression that's not psychotic is assumed to be within the realms of outpatient and GP care. A lot of GPs are struggling with people that they shouldn't be struggling with. IAPT [Improving Access to Psychological Therapies] services very often won't see them, because when suicide is mentioned, people don't get seen. There are a large number of people who are kind of stuck between primary and secondary care, and they get seen and then they get discharged back to the GP, and often they're left on medication, which they shouldn't be left on. And I used to see them in XXX, because I was working in a primary care service, and I would see people that really should have been having longer-term follow-up. So, I mean, I was on lithium for quite some time, for depression. I've known people discharged back to the GP who were on lithium for depression, and with no kind of indication of how long they should stay on it, because no one knows. And until fairly recently, and in many places it's still the case, it's just GPs are very angry about it, you'd have to refer back through the system again, to get people seen again, or wait until they're in crisis. So I've still had follow-up from XXX, and that's been great, although the service came close to being cut about two years ago, but then they gave it a reprieve, and that would have meant there wouldn't have been a specialist service, and if I wanted to see a psychiatrist, I probably would have gone privately.

So can you just tell me a little bit more about the illness that you suffer from? You call it ... is it a specialist affective disorder?

L: Well, it's a specialist affective disorders unit that I go to, but that's a special unit for people who have mood disorders. In other words, it's not just ordinary general psychiatry, it's a disorder that specialises in people with mood disorders, so they have a lot of concentrated expertise, especially around medication, that the average general psychiatrist possibly wouldn't know all of the latest evidence, wouldn't know the research. They used to have a psychologist attached to them as well, and that's been cut, but it used to be a unit that you could go to if you weren't getting better otherwise. In the US, there are specialist depression centres pretty much around the country, because there's a recognition that mood disorders are complex and sometimes people are left on medication, or don't recover when they could be much better. And they also look after people with bipolar disorder as well, so it's the whole range of mood problems.

And are you saying that really you've only been able to access this treatment because you're on the inside and you're in the know?

L: I think so. And I see young people now in medicine and who can't do that because it's not so easy to get that route because everything is so bureaucratic. So I have somehow managed to be under the care of XXX trust, despite living here for a very long time ... Under the radar, exactly how it was when I was in training, when my consultant looked after a number of people, and when he went on holiday, when I was a senior registrar, he would say, I'm a bit worried about x, y and z. He's a consultant, she's a consultant, if anything goes wrong, you know, this is what to do. And there was a kind of recognition that we did take care of people who worked within the system.

So if you were a member of the public and not a doctor, what would your kind of journey have looked like? How different would your journey have been?

L: It would have largely stayed with the GP, with possible long-term outpatient clinic appointments where I'd see different junior doctors who would tinker with my medication.

That's what it would have been like?

L: Yeah, and now I would almost certainly have been discharged back to a GP.

And in terms of your state of health, what difference would that have made?

L: I think I would not have been able to stay at work and I may well have come off my medication ... I certainly reached a point at various times when it was no longer helpful and it had to be changed, until I found the right one. And my current consultant has said that he thinks that if I hadn't stayed on it, I would have ended up in hospital. He says it's the fact that I have been very persistent with my treatment that has kept me out of hospital. I think I would have been in hospital at some point in my life, but I've managed to avoid it.

Have you never been an inpatient?

L: No ... When I was a medical student, a doctor I saw wanted to admit me and I wouldn't have it, and I've resisted ever since, and I never needed it ... I've had long periods off work, but certainly my current doc says he thinks I would have been a lot worse if I'd have not stayed on the medication, and I think he's absolutely right, I think I would have ended up an inpatient. I've been very persistent with trying to ensure that I stayed with treatment, and with the best treatment.

And that's because you know about what the options are.

L: I know, yeah.

So why do you think it is that in mental health there is this lack of choice about where you go that is different from physical health? There are all these kind of boundaries, you know, you have to go and seek mental health from a certain area, whereas if you've got a physical problem, you've got patient choice and Choose and Book.

L: Well, in the 1980s, when I was a junior doctor, we saw a lot of people from outside of the area. There was quite a lot of choice. In fact, I remember someone saying something like a third of our admissions were outside area, because we had people like X, who was an expert in his field and would see people with complex grief problems, from all over the XXX of England. And then, when managerialism came in in a very strong way, and at the same time, there was a retrenching of the mental health service, to say we are looking after only the most severely mentally ill, and that is community orientated, and you have to be cared for by a team, and a team covers a patch, and so we went through fairly rigid sectorisation. And then it became impossible to see someone from outside your sector, never mind outside your area, so if you didn't get on with your sector doctor, well, then you'd had it, really.

And I remember in XXX, we were able and willing to see people from the other sectors, but some of the consultants were not, and they were very rigid about it. And the GPs loathed it because sometimes they had patients across different sectors, and they loathed the fact that sometimes half their patients got a better service to the other half, and I fought very much to try and get us to be attached to GPs, not to sectors, so that we could work with GPs. But again, that did mean that ... It kind of ignored the fact there was considerable variation in quality ...

It varied in quality among the general practice or ... ?

L: No, amongst the psychiatrists.

Tell me a bit more about that.

L: Well, it's always been a shortage speciality ... If you get a good reputation as a centre, then you can fill your consultant posts, but if you get a bad reputation, then you end up it just being a string of locums. And I've watched different trusts go up and down in that over the time I've been a consultant. I mean, there was a period when XXX had a really good reputation, so it had all of its posts filled, and then there was a period when it went downhill and they couldn't keep staff. YYY went terribly downhill for the same reason, because it was chaotic, and I had a couple of trainees ... who went off to work in ZZZ, lasted three months, and said, well, if I stay here, I'm going to turn into the sort of consultant I don't want to be, so they moved. And then that means that that area just goes completely downhill and you end up with a series of locums, and it's pretty awful, because some of the locums are people who are okay, but some of them are dreadful.

And to what extent do you think are the public in the dark about this?

L: I think the public know about it if they've got relatives who have got mental health problems, and they also imagine that if they go privately, it will be fine, whereas they don't realise that most of the people working in the system are the people who also do private work, so they're not actually necessarily getting better quality by going privately. You've still got to know who the consultants are if you go privately. You know, I will not go and see anybody; I would only go and see people who I know, from talking to others, are worth seeing ... I don't want anybody insisting on tinkering with my medication who doesn't know what they're doing, because it's been very finely balanced at times.

So in terms of finding your way, I guess one could say you are in a privileged position.

L: Yeah.

When it works and you find the right service for you, what does that feel like?

L: It feels safe. It feels like you've got someone who you know that you can phone up if you need to. You can go and see them earlier if you need to. You haven't got to go through ... You haven't got to go and argue with somebody in order to be seen. For me, it's always been very important that someone has been prepared to talk to me about other things going on in my life, other than the fact that I need to just take the tablets ... They might not be a psychotherapist but they've got knowledge of what therapy is about. And that I feel like they're up-to-date in what they are doing.

And I talk to service users on social media sometimes and they tell me things that are happening, and I know that they're not getting the most up-to-date treatment, necessarily ... and I say, look, I can't give you advice, but I just say, my doctor has tried x, y and z and he is a specialist.

I do know that people who are not specialists in mood disorders are often reluctant to try things that there might be some evidence for. I got very, very ill about two years ago ... and I had to go on a second antidepressant, so I was on two. And my doctor put me on something that's off-label, but it's used in the US, and he prescribed it. My GP didn't, but then my GP agreed to prescribe it. That would never have been tried by a general consultant, but it got me better.

That somebody who is up-to-date and reading the journals and all the rest of it.

L: Yeah, and doing the research

And when it's not been so good and you've struggled to find the right service for you, what does that feel like?

L: Well, I've been lucky. I would say that there's only been one doctor I've seen that I didn't feel able to talk to that easily, and that was the first person I saw after the consultant I saw for years retired, and I didn't find her quite so easy to talk to, but she was still there. It was just that we didn't feel that comfortable because we'd worked previously together, and she just wasn't really a person I felt that at ease with. And it's funny, because I've seen her at other occasions since I stopped seeing her,

and she's so different when she meets me now. She was uncomfortable. But I've not been in that position, other than with GPs ... I had the same GP for twenty years, and then when he retired, it was quite hard, because I felt like there was no one who really understood my story, whereas my old GP had seen me through quite a long period of time when I'd been ill.

One of the things that I've discovered so far is that, when I listen to people's stories, general practice comes in for really quite a bad press, and this is not to do with mental illness, this is just in general. Really quite a lot of bad press. So when the GP service is good, from your point of view, what is it like?

L: When a GP service is good, you feel like there's somebody who's on your side, who will actually help you to get to where you need to be seen, and won't argue with what the specialist is saying, which is really important, because I've certainly known situations, when I was a consultant, where I would be prescribing something and the GP would be refusing to do it, saying, oh, we've had a letter through that we're not supposed to do this. And you'd say, well, actually that's not supposed to interfere with individual patient care decisions. I think we're very fortunate living up here. I say that because the local practice out here has no difficulty filling its posts. It's because, as you can imagine, GPs want to come and work out here, because it's nice. So I've always had good GPs, but the practice has got much bigger: there are a lot more people working part-time in it now, and there's more of a sense of it being not as easy to get to know doctors. For a long time, I saw a doctor who was a bit kind of unconventional in many ways, but I could talk to him, and he wasn't the least bit afraid of asking me difficult questions either. I mean, he was the person who put me on antidepressants to start off with. He was really good, but I do find that they're kind of more detached and business-like almost, now. It is more of a job for them and less of a vocation, I know that. But I'm getting to know a couple of them now that I find it easier to talk to, but there are twelve of them now, and there used to be five, and it's just not the same. But at least we don't have a shortage of GPs here and we don't have locums.

So now, thinking about your professional work, you will have seen/observed/experienced people who have felt that they've found the service that's right for them. What difference does it make to them?

L: I think it helps people get better, I really do. I really feel strongly that what's happened within healthcare is that there has been – and I think this is particularly important for mental healthcare – is there's been a

complete doing away with the importance of the relationship. And I see it in community mental health services and I see it when I talk to people who experience community mental health services. We're treating people as objects ... If you're suicidal, what keeps you alive is the relationship you have with the mental health professional. Having a different person come and see you each day and just say, do you feel like killing like yourself today? does not keep people alive. And I kept people alive through the power of my relationship with them, and by the fact that they grew to trust me, and I grew to trust them, and we worked on that and I was able to give them hope. If you don't know somebody, you can't give them hope, and if you don't know somebody, they will not trust you when you say you're going to get better. And all of that has gone. It's all become commodified. It's all about just getting people through the system. I think it's really affected risk in services, because I think risk has just become something that everyone's scared of. But I worked with some very complex people in my career.

When you see people, when they've struggled to find the right service for them, what impact does that have on them?

L: Well, they start to get really hopeless about it and they start to feel that services have got nothing to offer them and feel very cut off. I've met people on social media, through time on there, who have basically been told that services have got nothing to offer them, and they're discharged. You know, I just can't believe that, but that's what they do.

And why do you think the psychiatrist profession have allowed this commodification that you describe?

L: I think they've allowed it because they thought it would make their work easier, because they felt overburdened, but it's actually resulted in their work being less satisfactory ... A lot of that, I think, resulted in making it harder to recruit to the profession.

**MENTAL HEALTH AND MENTAL ILLNESS:
REFLECTIONS AND RESPONSES TO
THESE STORIES**

Immediate questions

1. What was the significance of work for Stanley? How might the NHS have acted differently in the light of this?

2. Stanley “used a loophole” to get the consultant he wanted. How do you feel about him “working the system” to get the care he needed? What issues does it raise?
3. Lucy also “worked the system”, using her knowledge as a psychiatrist to get the care she needed. How do you feel about this? What issues does it raise?
4. Alan is very positive about his involvement in patient engagement activities. What are the benefits and risks of patients becoming involved in these ways? What is the role of the NHS in supporting such activities for service users?
5. How would you describe the pros and cons of labels and diagnoses, based on Nathan’s experiences?

Strategic questions

1. What does good-quality mental healthcare look and feel like according to these testimonies?
2. What part can agencies play in combatting the structural discrimination that is often experienced by mental health service users such as Stanley and Nathan?
3. What might be the barriers to being able to focus on the person as well as the illness?
4. Why is the relationship between therapist and patient so important in these stories? What are the features of a good relationship? What is needed to create the conditions for good relationships? What obstacles need to be overcome?
5. What can individual mental health professionals and managers do to join up care better between specialist mental health services, primary care and other agencies, such as schools?
6. Why is continuity of care important? How can it be promoted?

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