

Chapter 12: The Man Behind the Curtain

Shan

The hoop-jumping really pisses me off. Because I think again, this is where notions of insight and intelligence and everything come into it. Because you know, it takes a lot of stamina and energy. But it also takes a lot of brain space to be able to be like, OK, how do I navigate this process? What kind of things do I have to read? How do I formulate it in a way these people will understand? What are the NICE guidelines? What is this NICE guideline thing? You know, how do I access it? Is it accessible to non-clinicians? You know, all these kind of things.

I was very lucky that my younger sister is a junior doctor. So she was like, "Right here are the NICE guidelines, just cite these and they'll have to do something". And I was like, "OK". So I didn't even have to go find it. But you know, for me trying to find information in like, the DSM or whatever that other British DSM is called...

Alex

Is it the ICD?

Shan

That's it, yeah, about like dissociation and DID and all the DDNOS and all the different types of dissociative disorders. It's really, really hard to navigate. It's really really hard to, and the language feels impenetrable to me.

Alex

It's impenetrable. I also have an additional layer to it as an autistic person where it's like, I find it really hard to connect descriptions of psychiatric symptoms to my experiences of them. I only recognise myself as dissociating every so often. And it's not very severe dissociation, but I dissociate in response to triggers sometimes.

Even though I think I've read the Wikipedia page probably about 50 odd times by now, I've tried to find other ways of understanding it. I actually even asked psychiatrists and they really haven't helped. I need to have it like explained in a useful, because I find feelings and stuff too, or like explanations of those states, too abstract to connect to. My brain just can't connect to them.

I've got quite a good reading level, so even though I don't have the education of like, I have no background in psychology, I can broadly get to terms with the language used. It's just that no one really explains, "OK so if you feel like this, that is a problem." Or like not a problem but, "That is something we probably could do with hearing about."

Instead, it's like "Do you dissociate?" Well, can you explain what do you mean by that? I zone out and come to like 10 minutes later sometimes. Does that count? Yeah, sometimes I'm not aware of what's going on around me cos I'm too stressed out, you know?

Eve

I remembered when we had our initial conversations that we started off thinking about insight and its challenges. And its many, many challenges. And I think there's something, as someone who's been listening to both of you explain and talk through different scenarios, a really big thing that stands out to me is just how slippery the construct is. And how you can be seen to have insight when all things are going well and you're in agreement, and then as soon as you challenge something, or express a view that runs counter to the care that you're receiving and the views and opinions of the clinical team, that's when suddenly you sort of magically lose insight. And I find that really, really interesting.

Alex

I don't, like, it's not an individual problem. It's a systemic one. Like I'm not saying this because I think clinicians are in most cases deliberately going, "This guy doesn't want to do what I want him to do, he doesn't have insight therefore I need to override this or it's a problem". I don't think that's actually what's happening.

I think it is something that needs to be constantly at the forefront. You need to be questioning your own decisions around whether patients, wherever service users, have insight. And I think it might help to be asked, "So why don't you like this?" Or, "Why don't you want this?" Or, "Why do you want this?" Rather than being like, "Well, if you want this there's something wrong and you don't have insight."

When I say "lacks insight", or like being described as lacks insight, I'm having a personal response to that because that's a big deal for me as an autistic person. I've had my autonomy denied to me so many times. I've been infantilized constantly. I have people taking what I say for granted. I have people assuming I'm parroting other people's ideas when I'm not. These are things I've come to on my own. Like, it's very hard being autistic and in these services.

So the issue of insight is a really sensitive one to me personally, and I think it's a sensitive one to a lot of autistic people and a lot of people with learning disabilities. I don't want to stigmatise it, but at the same time I do want more of a dialogue about the judgment itself. And I think it will take more than that to really rectify the problems with it. But it's quite hard again to do this at the moment, because being so conscious of austerity and the constant lack of

funding, I'm conscious of the enormous pressure the NHS is under. It feels like [sighs] it's very hard to ask for stuff. And I'm constantly feeling like I'm scaling back what I feel like I want to ask for as a result. Like, it's really hard.

Shan

No it definitely is really hard being conscious of those things. And I've had that problem a lot.

I actually about a year, less than a year ago, got denied more psychological help because I had too much insight. So we've talked quite a bit about ideas of lack of insight. But I was told that I'm "too normal" to warrant further psychological therapeutic input.

And actually the psychologist who made that call after like, less than a 60 minute meeting with me, then went to the head of the nurses and said, "Oh, this person shouldn't be on a Care Programme Approach". And luckily for me, my nurse was absolutely furious about this and was like, "How dare she tell me what to do when she's only met you once." She got really angry and stuck up for me. But if she hadn't, you know, I would have been fighting a very lonely battle there.

Alex

Obviously I haven't spoken much about my background or whatever, but like I just wanted to flag up that we're both very sort of like, I really don't want to use intelligent, I'm really cautious, but we're both considered very bright by society. Like, we're both people with that, I don't quite want to say privilege again, it isn't quite, but we're people with that status.

And therefore I am constantly conscious, and I imagine you are too, about what that afford us. Like what we get from that, what benefits us about it. We've talked about how we struggle because we're seen in certain ways that don't necessarily match up with the problems we're there to be seen for. But I really didn't want the conversation to go by without actually expressly acknowledging that.

Shan

Yeah, no I think that's really good to acknowledge, definitely. I guess just to bounce off what you were saying about, you know, wanting more dialogue and more consideration of what service users want and why they want those things. I definitely echo that.

It would be really nice for, and I'm not saying that psychiatrists suddenly have to rail against, you know, and go all critical psychiatry and be like "We don't want diagnoses, we don't want meds" or whatever. I'm not saying that. But it would be nice if there were more kind of acknowledgment that actually, "This

is a very nebulous field of medicine that we're doing. And we don't always know what we're doing”.

Because when I tried to talk to my psychiatrist about identifying as multiple, she kind of shut down the conversation very quickly. And it wasn't really clear to me why that was. And to this day, even though I got on with her really well and everything, I'm like, “Well did she not believe in DID, or did she believe in DID but that I don't have DID? Or does she think I'm making it up? Does she think I'm lying or attention seeking?” You know there were so many possibilities.

She just said, “I can't diagnose that.” And I was like, “Well, you're a psychiatrist that's your whole training and job to like, stick a label on me, that's your point, your purpose in this circle we're in, of like patient, clinician kind of thing. And it was really infuriating, because her solution was, so she said to me, “I can't diagnose that”, but she didn't give a reason why. And it would have really been helpful for me to have that reason. And she wouldn't have had to go into huge detail, but it would have just been nice to have the context.

And then especially because what she did was she was like, “I'm gonna put you on the psychology waiting list”. This was several years ago, before I got refused more psychology. And I'd just come out of psychology that year. And so I was like, “Well, I've literally just been a few months out”. And she's like, “I'm putting you back on the waiting list”. And I think because she was so powerful in the hospital she fast tracked me up the waiting list, because I got seen within four months for an assessment, which for my hospital was pretty damn good.

And then when I was coming towards the end of that schema therapy that I did for nine months, my psychiatrist was like, “Oh, so are you feeling more integrated now?” You know, it was just very confusing for me because I was like, “Well, if you're talking about me integrating, then clearly you are understanding that I have this fragmented, not identity but...”

Alex

They're clearly weird about it as like an identity. That's really interesting. I think what's always worked well for me, and it's quite a rare thing I actually come across someone who's willing to kind of do that with me, is I want to learn. I really want to learn. I know that psychiatry, it's a field with many different approaches and many different schools of thought. And I'm not saying I want every medical appointment I have to be a seminar or whatever, but I want you to tell me what approach you're using is. And I want you to empower me to think about what's happening. And I don't want to just be given this medication, this diagnosis. I want you to tell me what's going on. I

want you to trust me enough to know that for myself. And I want you to actually engage with me, and I want you to have respect for me.

What I need to feel respected is for you to use \$10 words or whatever [laughs]. I don't want you to simplify things for me just because you think I'm mad or whatever and I can't comprehend sentences. If I don't understand a word you're saying, I will ask you. I will always ask. I like knowing new words. I like knowing new things. I'm interested.

Like I've said that with my counsellor, like, you know, "Please explain things to me, please just tell me what you're doing with me". It's also like a personal thing. I'm quite sensitive to being manipulated. Sometimes I get a bit suspicious. The best way for a clinician to avoid doing that is to be like, "Have you heard of this? I'm trying to do that with you". Telling me won't, in most circumstances, mess my treatment up.

Shan

Exactly yeah!

Alex

There's nothing in the literature to say you want like a Wizard of Oz, man behind the curtain thing.

Shan

Yeah, yeah.

Alex

I think there are some instances where that is the case, but if that is the case then I think it's troublesome and I'm not very comfortable with it.

Shan

There's still ways of doing that, though, isn't it? Because I remember when I started this schema therapy. So for schema therapy you have to do a 232-statement questionnaire. And the therapist was like to me, "Here's your homework, do this questionnaire". And I was like, "Well, this is a very long piece of homework. And it's right at the start therapy".

So obviously me being me, I went away and Googled, there was a little barcode or something, and I Googled the word on the barcode. And I didn't read up, you know, I was careful because I didn't want to mess up the questionnaire for her, you know in terms of changing my answers because I know what's going on.

But she was really surprised that I'd Googled it. And I was like, "But you didn't tell me what this was or what this had to do with anything". You know, and it's a huge piece of work. And it's, you know, rating statements like "I

feel no one loves me” and things like that. So I'm like, “You need to tell me what’s going on”.

Alex

I have seen the autism quotient test so many times in my life. You don't get diagnosed at the age I was and then get to adulthood without having seen that a ridiculous number of times.

So I was involved in psychology a few years ago, probably four years ago, went into it and it wasn't to do with my autism. It was to do with anxiety and stuff. I turn up, get given the usual bumf, get given the autism quotient. And I know what that looks like. You can not give that to me and not bother to say it's an autism test, because I know it's an autism test.

My autism shouldn't have been in dispute at this point. I have been to loads of psychiatrists, I've been in loads of services. Some people have actually weirdly said, “You don't seem autistic to me”. And I've realised since the reason I didn't seem autistic in those appointments, because there's a particular reason for those appointments, and I knew that, and I knew I needed to focus on them so I didn't do anything particularly autistic. I think because I was just focused on the appointment. So they're like, “You don't seem autistic to me”. I've been diagnosed with this probably at least six more times since the original diagnosis.

But the thing is, when she passed me it, and when I recognised it, I immediately felt like, I'd only just come to terms with being autistic in my mid 20s and that was shortly after that. And I felt like I was being doubted. And she didn't tell me what it was. And I was like, “Oh yeah, this is the autism quotient isn't it?” And she was like, “Oh OK, so you've done it?” And I was like, “I have done it so many times, you do not even know.” Like I felt she didn't trust me.

And it's on all my NHS records, all my GP records, it's on everything that I'm autistic. Why would I be lying? And I sort of rationalised it at the time. I thought about it since and maybe she wanted to see what things I particularly ticked off on the test, because I know that there's a few different components in that school of thought in thinking about autism. It's not one I personally agree with, but I think I kind of understand the rationale.

However, at that time I was having a lot of distress, I was really suicidal, really struggling, so to have someone hand me that piece of paper it immediately made me scared and made me worry. Actually, at the time, I think I worried that she was trying to take me off of benefits, or she was trying to get me off of benefits forcibly, which was a big concern of mine at the time when I was, obviously it would have been when I was like surviving on benefits.

But that's what I'm trying to say. It doesn't take that much to start knowing and start learning and start being quite well informed about what you're going through and what the processes are. Please bear that in mind when engaging with us.

Shan

I think there's something to be said for giving service users credit where it's due and recognising that they've, especially if they've been in the system a long time, you don't need to patronise them. You don't need to hide things from them.

Alex

The majority of us will not have gone to medical school, being a service user is an education in and of itself.

Shan

Exactly.

Alex

I mean, it's not necessarily the same kind of education, but it's an education. We are capable of learning. Like I've complained about meds reducing my ability to engage in stuff, but I was still capable of learning stuff. I was still capable of retaining information. It's just patronising. It's deeply, yeah, it's upsetting.

These are very, very kind of small things. And honestly I do really wish I could ask like more ambitious things. More kind of like, "Well, this needs to go, and actually just burn this down, well not burn this down, let's tear this up." I feel like I have been so drained by the system, so much of my engagement with this has been stripped away and all that's left is just like [in a singsong voice] "Please can you not do this, I don't like it very much" [laughs].

Shan

It is really hard fighting these kind of systems. Slight tangent but I had to do, well I didn't have to do but I felt compelled to do, a major complaint against my current university based on disability grounds. And that took two years off my degree, off my life, off my health. And that's two years I can never get back. And I'm glad I did it. I got a settlement payment in the end. But yeah, it does take a lot. It's really draining. And sometimes all you can do is hold your hands up and say, "This isn't right, but I can't say more than that right now, I can't do anything about it right now" because at the end of the day our responsibility is to ourselves, and not to save the system.

Alex

I feel so drained by that all the time. Like I want a better world, I want a better society, and I want a lot of things to be made possible.

I'm sorry I haven't given this project kind of more of a solid conclusion. But I suppose a lot of this isn't about solid conclusions. So it's fine, I'm unnecessarily beating myself up.

Shan

No I think we've said good things about listening and taking on board people's autonomy and you know, respecting...

Alex

I think basically I just want to flag up I do believe that that isn't it. I do believe that there is a lot of things inherently wrong. We haven't touched on like criminalisation stuff, because that's, I was under Section 136 last year but it's too fresh. I don't want to talk about it, so I've deliberately not spoken about that.

I don't want to come across like all I'm asking for, that all I really want is kind of quite, I keep thinking of the word "floaty", wooly idea. They're not. They are important. But like, I do not think the current way the institutions that we have work is fit for purpose. But at the same time, again like I've said, so drained from them that I struggle to really say anything more than that.

And I find that really fundamentally the biggest tension in me around having been a long-term, like a survivor of mental health services. I find that the biggest tension, the more I've seen the more I want things to be radically, radically reimagined and reestablished and to be challenged. But at the same time, the longer I'm in them the less I feel capable of really thinking [laughs].

Shan

Yeah, no, I hear you on that. I hear you on that.

Eve

I wanted to share with you both just a bit of where I'm at as well. Because listening to the two of you have this conversation, I have a trillion questions [laughs] that I would love to ask you both, individually and together. But also, simultaneously, what's running through that need is the recognition that it is exhausting. And it is draining.

Alex

They keep telling us to get jobs right, but what's there left after dealing with this? Like, when you're in the thick of it. I think at the time they kept being like, "Oh get a job". I was like, I couldn't, there was no energy left for job applications anyway.

Eve

Yeah, I'm kind of I'm reluctant to ask you the things that are swimming around my mind because I don't want to contribute to that process. I don't want to replicate what you've already experienced in the system.

Alex

I'm happy to answer further questions Eve.

Shan

Same yeah.

Alex

Also we're getting paid for this! [laughs] We aren't getting paid being in mental health services in general.

Eve

I think one of the big things really jumping out at me is that we're talking about this word insight, and mentioning insight, kind of as if it's a thing that can be pinned down. You know, measured and understood. But the tension for me is like, we've talked about insight from a clinical perspective, as in awareness of illness, but there's been times when I've heard the two of you speak about insight and being insightful, and having insight into what's going on for you, that doesn't feel that it matches that definition, that clinical definition of insight. So I'm wondering, for the two of you, what insight means to you personally and subjectively, versus the awareness of illness definition in clinical textbooks.

Alex

Personally, like if I say I've got insight into this, like it means I understand what's going on. And I understand what's going on in kind of like multiple levels. For instance if I say I've got insight into this process, the process of the work you're doing Eve, I understand that you're being funded by a particular institution, that you're doing what you're doing, why you're doing it, how you're doing it. I understand all those things. I also understand the power dynamics in play. I understand things are happening off screen. I understand my own ability to consent. I understand your ability to consent. And I understand the broader context into these things.

And I'm not saying this is the same as everyone's level of insight. I like being in situations where I have insight. Sometimes it's like, obviously there's like a meta level to this, like understanding whether you don't have insight into a thing. And that's its own kind of insight, obviously. And sometimes I've been in situations where that has actually been weirdly the most powerful level of insight I could have. Like the ability to acknowledge I don't understand what's going on, and that's stressful, and I should probably get myself out of the situation because I'm likely to come to harm.

So I think that's quite a lengthy definition, I suppose. I don't think for me it's just about knowledge. It's about knowing enough to be assured that I'm safe.

