

Chapter 18: Catch 22

Anon

We get institutionalised. All of us. As much as we talk about the people who we support becoming institutionalised, it happens to us too. We get stuck in this way of speaking, and this way of seeing people, and sometimes it's really hard to break out of that. The more time you spend in that space, the harder it is to make the effort to break out of it.

And there are some days when I will write something and I'll read it back and I'll go, "Why did I just write it like that? That's not what I meant to say." But it becomes second nature, because you're hearing it all the time. And that came through in the stories, something about language, something about how we describe experiences and how diminishing that can be.

How the way we, as professionals again, describe somebody's experiences serves to devalue it and serves to diminish what they've been through, or diminish how they feel. That's not cool. Like that's not OK for people to feel diminished by, or demeaned sometimes. That came through as well, this sense of being *made less* by what's written about them, or what's spoken about them, by the conversations that they have to have. How someone's experience can be condensed into a couple of lines on a computer screen.

Eve

Yeah I think that was another thing that came through that really resonated with me. That's certainly my lived experience as well, is that gulf between what's going on for the person and the way that's being interpreted, analysed, and where that goes could end up in a situation of coercion, restraint.

Alex mentioned being restrained and that causing trauma. Ninette talked about the criminalisation, which we haven't even gotten into...

Anon

Yep. I have written down! You know, how human behaviour becomes a criminal act. And how a human response, without going into detail of what was said, how a reaction, how a human response, a response from someone who is suffering, became criminal. And that is a huge problem. We know that that is a huge problem.

There was the mention of 136 Suites, which I have some experience with professionally. You know, people being *processed*. This really hostile language of people being *processed* as if they've done the wrong thing and the way they've reacted is criminal, when actually this was a person in great distress who didn't know what else to do.

And again it's an everyday occurrence, the minute somebody shouts, or becomes irritable, that's a symptom of their mental health diagnosis. I tell you, if I went through a lot of the things that I've seen people go through, I'd probably punch you in the face. That would be my response. I would become angry. That would be my human response.

Because I don't have a diagnosis, nobody would tell me that that was because I was ill. They might take me more seriously. And that's an issue that came through as well, this idea of what one goes through being diminished by a diagnosis and not being taken seriously, particularly those aggressive experiences, those frightening experiences, are brushed over. People, you know, "Oh the necessary action was taken because somebody was a danger to themselves or to somebody else". Or whatever it might be. No. Maybe they were just responding as any human might, particularly a human in distress.

I mean it happens all the time, particularly again in inpatient settings, when there are restrictions in place and confinement is an issue. And people are stuck surrounded by people they wouldn't ordinarily be stuck with. If that makes them cross, we never look, as a team, as a system, we never look at why that's made them genuinely cross. We dismiss it. And we say, "You got angry and you shouldn't have. You shouted at me and you shouldn't have. That was wrong. You don't get to shout at me. I'm a member of staff. I don't come to work to be shouted at."

OK fine, I don't go to work to be shouted at, but if someone shouts at me it's probably because of something they've gone through, either something I have done that's made them annoyed, maybe they've misinterpreted something I've done, but we need to explore that. We need to work out why the person's cross. That doesn't happen. That conversation doesn't happen. They're just restricted even more. And it's that cut off. And it's that catch 22.

And it didn't come through in the stories in so many words, but it's my personal experience I can kind of bring, that I can make a comparison with this idea of being restricted. Someone gets angry about something, so then they're told, "Well because you're angry, you now can't go out." So now if I'm that person, I'm going to get even angrier. Where's the logic? It's taken me ages to get to this point, but there is such a lack of common sense in mental health services in general. We have no common sense. And we throw out normal rules of engagement. It just doesn't apply. None of that everyday logic and that common sense applies. Apparently.

You know if someone's cross, they've got something to be cross about. So probably telling them that they're cross and therefore there's a consequence of being cross is not a sensible thing. We take things terribly personally, as professionals. We feel affronted.

I had this conversation actually this week with a colleague, I can tell my patient, my service user, my whatever the word is today we want to use for people who are in need, that they have treated me badly. I didn't like how they were with me. If they try to do that, the other way around, if they try to say that something I have done has upset them, there's no space for it. It's not tolerated. There is no space for it. And in fact, it's punished. It might not be punished directly, but it affects how we as a team feel about a person.

And that came through, this idea of being challenging, being a problem. And again, it was this tipping point around insight and understanding, you need to prove as a patient that you understand where your care team are coming from. But if you understand enough to then challenge it, you're a problem. You're a problem that needs to be fixed. And that makes me feel incredibly sick. Even saying it makes me feel sick. That cannot be right.

To keep people stuck between this rock and a hard place in this impossible, walking this impossible balance, and this like tight rope, of proving that they, basically proving that they agree, is what it boils down to. It's not proving that they understand. It's proving that they understand and that they agree with you. If you've understood where I've come from, as your professional, and you've understood why I'm suggesting you have the treatment I'm suggesting or you do the thing, I'm suggesting you understand where I'm coming from, but you have now read about it and feel it's not appropriate for you, you're now a problem. You're now lacking insight into your own condition, into your own needs, because you disagreed with me.

In answer to your earlier question about if the Mental Health Act could have been reviewed and changed, what could it have changed? What could I have changed? Or what might I have changed about it? It would be something to do with that. Why is it that people who are not going through the experience that someone is going through get to decide how they are treated? Get to decide what treatment is right for them?

And I caveat that by saying there are of course, some circumstances, one of the examples was given where somebody cannot make that decision for themselves, there are circumstances where somebody is suffering so much, or they're affected so significantly by their illness that they cannot make the right decision for themselves. OK fine, we step in at that point. And we make the decision on their behalf. We have a best interests meeting, which is the policy.

And I didn't hear that mentioned. I didn't see that happening in the conversation earlier around that person lacking the insight and having decisions made on their behalf. I didn't see that process that should have taken place. They should have been able to recall that process and they

couldn't, for whatever reason, leads me to think that that process possibly wasn't even followed. But maybe it was and they just didn't remember. But unless you're in one of those, and I think those are relatively rare, cases where people genuinely have no understanding of what they're going through and so therefore cannot make a decision about what will help.

And again, insight, to me, there's another word. It's capacity. The two are interchangeable to me, in terms of the language we use. Aren't we always taught as professionals to believe someone has capacity until they're proved that they don't. We should always, and if I could change one thing it would be that, when somebody needs to receive help, needs to receive either inpatient treatment, community treatment, whatever it might be, ask them what they think they need first.

The best GPs I've ever met as a patient, are the GPs that sit in front of me and go, "What's your problem? What do you think is going to help? What do you think I can offer you?" And those were more physical health things, but we should be doing the same in mental health services. We should be saying to those people, unless it's absolutely unequivocally evident that somebody cannot make a judgement, cannot give a suggestion, ask them what they think they need. Nine times out of ten, they can tell you. And then honour that.

And it's about going to where they are. It's that thing again of meeting me where I am, instead of telling me where you think I am. Actually try to understand where I really am and ask me, because I might be able to tell you. Presume that I have insight, presume that I have capacity, to be part of this process. And then if you think I don't, you need to prove it to me.

Eve

I'm really curious about this construct of insight. And how there appears to me, going through this entire process of researching, of talking to people, of meeting people, it's been a long time going, a long time in the, what's the word? I was gonna say in the fire...

Anon

In the making? It has been a fire I think at times, I'm sure! [both laugh] It's been a heated...

Eve

It's been loaded...

Anon

It's been heated and it's been loaded. I mean this is a loaded conversation.

Eve

Mmm. I think one of the biggest things that stands out to me is the enormous gulf between the clinical construct of insight, i.e. awareness of illness, awareness of the presence of illness, versus what the individual person understands about themselves, and their own experiences and the way we articulate our experience of distress and the two being sometimes miles and miles apart. And there being very few instances where you can actually have a conversation about that.

I haven't met people, so far, who've actually been able to have a sit down conversation with their clinical team and say, "OK when you say I lack insight, what do you mean? When I say..."

Anon

I've seen them try to do that. Doesn't end well for the person. Yeah, I've got one particular person in mind who was very questioning, very inquiring. "Why do you say I don't understand?" And it floors healthcare professionals. We don't know how to answer that question. We don't know what to say, we just get a bit cross. Anyway, I interrupted you.

Eve

No no no...

Anon

It just struck me that I had a really clear memory of that happening. Somebody's actually saying, "You're telling me these things about myself, I need to understand why you think that." And by and large, their consultant said, "I don't need to explain it to you. It's just my opinion."

But I've also had the flip side where I've worked with a remarkable consultant who did always make the effort to say, "This is why I'm suggesting this. You can disagree with me. And if you disagree with me, I'll try to go with what you want. This is my perception. This is what I think and this is why I think it." And he was a very rare creature. You don't meet people like that, in those roles. Don't meet clinicians in that level of power, who take the time. And who give the respect to say to somebody, "I think this and I think it because." Anyway, carry on. I've probably thrown you off what you were trying to say!

Eve

No, it's really interesting. And I think it's important to acknowledge that even if these instances are rare, there are spaces where they have happened, and can happen. And we can build on that, that asking, and the willingness, and the openness, to challenge our own judgements, and ideas, and conceptualisations, as mental health professionals.

You know, I'm in quite a curious position in that I'm, in many ways I am a mental health professional and I'm also, in many ways, a person with lived experience and a person slightly outside of that, so I've got one foot in, one foot out, which is a curious place to be, never fully inside anywhere, but never fully an outsider in that sense. But I'm interested in...

Anon

Must be quite jarring...

Eve

Yeah [laughs] it's a strange, it's a difficult place to be. But I'm really curious, when you've described and when you've used the term insight, for you, what does insight mean?

Anon

I have honestly never, I've certainly never written that word down, ever, I can honestly say that I have never, ever, made a comment on somebody's insight. Because I don't think it's helpful. It's not helpful to my role. And maybe it's because I'm lucky that I don't, those aren't words I need to deal with. Those aren't words I need to put store behind, or have, kind of, in my vocabulary. I don't think I've ever written it down.

I've probably, you know, I might have said something like, "We share a different opinion." You know, if I'm writing a note, if I'm writing a written entry on an interaction with someone or a session with somebody, and their perception of something isn't the same as mine I'll have said exactly that. I won't say they lacked insight, because they don't. They have a *different* insight.

And this is why this particular topic was so important to me. And maybe I'm an odd fish. It would be really interesting to hear if any other clinicians have said the same thing. I'd be really interested to hear if anyone else has said this from the clinical side. I don't believe I have a right to tell someone whether they have insight or not. Your insight might be different from mine, and that's all I need to say. I'm not going to tell you that you lack it. It's just different.

Because one will have an insight. There's no *absence* of insight. There's *never* an absence of insight, even for somebody who is deemed, and rightfully so in rare cases, deemed not having capacity to make decisions, and everything they say is tangential, bizarre, psychotically driven, this is all the technical language again, and I can't grasp the reality, that still is their insight. That is their insight. It's right there.

There was talk around surveillance stuff. The interest in surveillance, and the fact that in the United Kingdom we have the biggest number of surveillance

cameras of anywhere. That's a genuine interest that can very easily tip into paranoia about being watched. So say I'm working with someone who is, quote, again, quote unquote, "paranoid" about being watched I might be able to provide them evidence to suggest the contrary to some degree, but I also have to be aware that I work on a hospital that's full of cameras. So I can't actually tell that person they're not being watched because they are.

So where's the line between, and I've kind of gone on to a bit of a tangent there about, where's the line between reality and fiction, fact and fiction? And that's why I don't believe insight is a helpful word. Everyone has an insight it's just not the same as somebody else's. And insight can change. You cannot ever, I believe, we can never without doubt say that somebody lacks insight. Their insight changes. Everyone's insight changes depending on what information they are being given.

And you may be, OK fine, you may be an individual whose information is being fed by bizarre, psychotic belief systems that no one else can grab hold off, because they are driven by illness. But in the time, and in the moment, that's what drives insight. So you can't say that person lacks insight. It's just not the same as mine. So I genuinely have never used the word. I probably have said it more in these conversations that I would ever have said it. But I'm also acutely aware that that's quite rare. Most people do use it a lot. It's a word that is an everyday occurrence in mental health teams of any nature that insight comes up. Insight and capacity. Insight and capacity.

I also hesitate whenever I have to use the word capacity, because capacity changes. And that's what it comes down to. Stop using those two words, because as I said earlier, for me they are used interchangeably, and that's kind of wrong. Stop using them as a weapon. Stop using them as a threat. We have to stop using those words as a threat because every single person says that insight is a negative, that when they hear that word that's a bad thing. When that word is said, when the word insight is used, it's used against them, without fail.

There was not one single person who said someone talked about my insight as a good thing. Even when there was an understanding, and an insight, into what they're going through. It was still used against them. It was still weaponised. And I simply cannot understand it. I cannot understand why, why that's the case. Why that word is so loaded.

Because isn't insight what makes us all individuals? Insight's just the way we see the world. Memories are insights. Again, that's another word, memory is another word for insight. To have insight into something is not to remember it but to have an attachment to it.

Insight is just, it's nonsense. It itself isn't nonsense, but the way we use it is just so arbitrary, and meaningless! Nobody ever lacks insight. Their insight is just different. And will and may change.

Bethlem
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South London
and Maudsley
NHS Foundation Trust

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