Chapter 20: Snakes and Ladders

Chloe
I'm Chloe. I'm a consultant psychiatrist. I live and work in East London. That's where I am at the moment. I'm in my front room confined to the house, because I'm waiting for the results of a COVID test, sort of half working from home. So I've got my laptop, and I'm working on various bits and pieces of work stuff, sort of writing things and reading things, sitting at my dining table. The house is a bit of a mess. My ginger cat is asleep on the sofa. And I don't know where my other cat is, off somewhere. So yeah, that's where I am at the moment.

Eve
Can I ask you why you wanted to be involved in this project?

Chloe
Yeah, well, I was invited, which was very flattering. So my interest in psychiatry, I have a few interests in psychiatry, but probably my two kind of key interests which really intersect quite well, is that I'm very interested in law, medical law, and particularly law around mental capacity and mental health. And I'm also very interested in suicide and suicide prevention, and the way we talk about suicide. And I'm also interested in aspects of psychiatry and mental health, like stigma and discrimination and injustice.

I'm quite nerdy about, I guess, mental capacity law in particular, and the way it's misunderstood and misused. And I'm really interested in language as well. So this discussion about insight, I think, is really fascinating. So I'm really interested in the way we use words, in general, but obviously, in psychiatry in particular, and the different meanings that they hold and the underlying meanings. And that's something that I talk about quite a lot. And I write about quite a lot. And I spill my guts on Twitter about quite a lot, which is how I find myself getting invited to do interesting things like this.

Because I don't want to be in an ivory tower. And I have learned so much online, from activists and people with experience of mental ill health and of the help and the harm of the psychiatric system. I obviously have my own observations from working in it for a long time, and to a lesser extent being a patient in it. But that's not where most of my thoughts and interests arise from.

And obviously, I've learnt a lot from my own patients over the years. But I think that there's a really interesting rich world, which isn't making it into grant funded research projects, and the medical journals, and the things that we use as teaching aids.

I think that I've discovered this, not discovered - that sounds incredibly arrogant - of course I didn't discover it, I mean it's a discovery to me, of this world of people writing and talking and doing incredible things within the lived experience world or, you know, the activist world. All sorts of things just out there online. And yeah, it's a project that for a variety of reasons is really, really interesting to me. But that's because I'm quite geeky it really interests me. I hope that makes sense.

Eve
Yeah definitely. And I do want to say this is certainly a safe space for geekery you're in [both laugh]. You're with a fellow geek [both laugh] when it comes down to language and justice and injustice. And I suppose there was like a multiple angled motivation for creating this project and bringing people together to do this as a collective endeavor, both my experience in terms of lived experience, but also professional experience of managing mental health services and seeing the way that decision making around insight really played out for people. And played out in quite dangerous and damaging ways.

And I really want to bring that into the research around insight in particular, but also capacity more broadly. It doesn't feel that there's very much out there that *is* critical of the construct of insight. Because I've been researching this for about two and a half years now, and there was very little I could find that was actually critical of the construct itself.

But the really kind of broad, opener question that I have in my mind is when you spent time with the people that have been involved in the project so far, and read their transcripts, and explored what they were saying, what did you hear?

Chloe
Gosh, lots of things. And I think that it helped cement quite a few of the things that I've increasingly observed over time, and the frustrations that I have with the system that I work in.

I think we've developed a system of two polarised methods of harming people, essentially. And at the one end you've got excessive coercion, and at their other end you've got exclusion. And it feels like it depends on what sort of person you are, and by what sort of person I mean what sort of diagnosis someone's given you, but also what ethnic group you belong to, what gender you are, as to where people will place you, where people will decide you should belong in terms of that harmful spectrum.

What was interesting in all of these interviews, and everything that people were saying, that there was very different experiences but what was quite clear, in most of them, was this aspect of people crying out for help of

different kinds. And really, really needing help, but not being given it. Or being forced to accept something that they don't want.

So you've got people who might ask for help in one way and end up finding themselves, you know, handcuffed by police and in a cell, or detained, or otherwise coerced to do something, when actually they were asking for a different kind of help. And then you've also got other people asking for help and being told that the very fact that they recognise that they need help means that they don't deserve it. And all of these things are so rooted in our preconceptions and our prejudices and biases about how certain people behave, or how certain people should behave.

Yeah there was something that somebody said, there was a quote that one person said which I wrote down because I thought it was so powerful, which was neglect almost becomes coercive. Because it is. I think people can be forced into a position of such disempowerment that they feel forced to accept something that is unhelpful, because they don't have a choice.

I think we do an awful lot of talk in psychiatry, in mental health services, in the world generally, about autonomy and shared decision making and empowerment and people being empowered to make their own decisions, blah, blah, blah. But actually, lack of resources and centuries of compounded attitudes towards people with mental illness or people who belong to any kind of oppressed or minority group, means that actually that's just words. That doesn't really mean anything. We're not really that interested in empowering people to make their own decisions, or we're only interested in that if they agree with us. And that's what comes out of all of this discussion about insight.

And I think that that was something, that was a very sort of clear thread running through all of the interviews, which was that insight in itself, when you start to look at it and start to dig down into what that term really means, is that it doesn't mean anything, because it means something so different to different people.

I'm not surprised, but I find it very depressing really, when you say that you've tried to look, you know, into research and writing and academic stuff about this concept of insight and found it really lacking. And it really worries me how little questioning of convention there is in our profession, because I think some of the concepts that we're using are just *so* outdated.

Eve
Yeah, there's a lot there. There's so much I want to dig into [both laugh]. And I think the thing about what you just said about that frustration around the lack of critique, that's definitely what I was experiencing when I was searching around for really anything that was about, you know, tearing apart

this idea and looking at all the pieces of this very problematic, slippery construct that can mean very very different things in very different moments and exchanges.

Chloe
I get where the concept of insight comes from, as a psychiatrist, of course. Because we use it when we talk about things like if somebody seems that they might be psychotic. It's to see whether they truly believe some of the things that are going on, which, you know, even itself is not straightforward and has its problems. But the broad question is, does this patient really think that they're unwell or not?

And it's not completely without value in some ways. But I think that we don't think enough about what it means. And actually what I'd rather see is it replaced with something like, you know, what is the patient's view of the situation? Without deciding what they should have insight into or not, because that is *completely* laying our view as the clinician as the most important thing. That's the baseline, and then we measure the patient's insight based on how closely they agree with what we think.

And actually a much broader and more helpful thing to talk about, I think, would be what is their view? What do they think is going on? What do they think would help? Some people would say that it's just words. Well, I think words are important. And they say a lot about what's really going on underneath. And I think if you force people to confront their words, and really think about them, you start to change the behaviours as well.

Eve
You spoke about the very ingrained biases that exist in psychiatry, and how these can inform whether a clinician believes someone to have or to not have insight, or to have partial insight. Could you talk a little bit more about what those biases are?

Chloe
I think that lots of the interviews touched on them. I think what you see quite a lot of is that people with certain diagnoses, or who are seen to behave in a certain way, can be dismissed in some ways. So the typical thing would be somebody, very often a young woman, particularly a young woman who might self-harm, whose picked up a diagnosis of personality disorder, who will find themselves dismissed as manipulative or attention-seeking, or in some ways not worthy of help. Not deserving of help. Needs to be excluded for the sake of boundaries and forcing people to take responsibility. I think that that's quite a common thing.

One of the interviews touched on the stereotype of the Angry Black Woman, which I think is really, really important because we know that there is an over

representation of Black people within the Mental Health Act system, detained in psychiatric wards and the criminal justice system. We know that institutional racism exists. It's absolutely not a question of whether. It's a fact of life. I think that listening to that interview in particular, that experience of asking for help from the police and then suddenly being categorised as criminal or needing to be locked up.

I mean there are just so many [laughs]. I think there are so many biases, which all lead to harm in a multitude of different ways. And what's also important is that by focusing on just one aspect of exclusion, or coercion, or whatever, you then risk harming another group by overlooking them. So it's really difficult. But I think that what psychiatry has to do is really face up to its multiple biases and multiple ways that it harms people and not treat everybody in the same way. You know, we do have to have different approaches for different people with different backgrounds.

Eve
It's interesting when you bring in Ninette's conversation, and the way she talked about people being grouped and this trope, in her words, "The Angry Black Woman Who Has Lost It." I'm really intrigued when you talk about psychiatry confronting institutional racism and how, for me, as an outsider looking in, I can see that there is some of that reflection and that work taking place and people speaking out about it. But I'm curious that psychiatry hasn't confronted institutional misogyny. There's very little recognition that this is taking place in the mental health system.

Chloe
Yeah, I think that's a really interesting point. I think we risk diminishing one form of oppression if we use it as something to compare, but also of course they are linked. You know, I think that all of these things tie in together. But I think you're right, that we have not done nearly enough to address the problem of institutional racism. And I don't know, you know I can't speak for people, but I get the impression that the Mental Health Act review has not been felt to do enough to counter that, with that being its sort of stated aim. So yes, we're talking about it, but I also don't want to suggest that, you know, we're doing well with that and that's OK but what about this other thing. But that said, yes, institutional misogyny is *such* a big thing. And I think you're absolutely right that I think it's weirdly not talked about. It doesn't feel talked about to me.

I think it's really interesting that some of the aspects of psychiatry, in terms of training, in terms of service provision, which are really desperately in need, and seen as niche, and not given enough space in the training of psychiatrists, are often things that disproportionately affect women. So eating disorders. Perinatal psychiatry. Women and autism, again, is something that we know has been really traditionally overlooked and under picked up

because of the way that autism can present differently in women and men. And then this personality disorder diagnosis aspect and self-harm as well. If you look at these things over and over again, there is a pattern here. And I think the pattern is women and their specific needs not being taken seriously.

You know, I've been to talks about perinatal psychiatry and pregnancy counselling and that sort of thing, you know, when you're taking certain medications and want to become pregnant. And what's really fascinating is [laughs] that this is 50% of the population and doctors and clinicians talk about it like it's niche. Like they really don't understand about asking female specific questions and taking a female specific history. So I think in *so* many ways, yes, there is misogyny and it's not looked at. And yeah, this idea of attention seeking and taking up too much space, taking up too much time taking up too much attention, it does seem to repeatedly cloud women or people who are assigned female at birth.

Eve
Is this something that you see play out in your own clinical work?

Chloe
Oh absolutely! Yeah I mean the idea of the manipulative self-harming personality disorder patient is completely endemic in psychiatry. And it's a bit of a personal crusade to counter that. And I certainly do what I can. But those harms you see every day, even if you're working in a place where, perhaps it might be better than some places, and I'm not claiming one way or the other, you know, it's not my place to say whether I provide a good service or my colleagues provide a good service. You know, I'm not a consumer here.

But yeah, absolutely, and it’s not just psychiatry either, you know you see it in, I’m a liaison psychiatrist, so I work in a general hospital in an A&E, on medical wards, and you see it with things like expressions of pain, women are not taken so seriously a lot of the time, or it's written off as somehow psychological, often, where there is severe pain or certain physical symptoms. Lots of these things are not taken seriously. We know that lots of women have late diagnoses of ovarian cancer, for example, because the symptoms that they often present with are vague, yes, but also, women and their physical symptoms often aren't taken seriously by the medical profession. You know it’s absolutely everywhere. Everywhere.

And it’s a problem as a female doctor as well. You know I'm in a privileged position here, so I don’t want to enter too much into that, but, you know, believe me, it's a slog being a woman in medicine for various reasons as well.

Eve

I did want to ask you about the emotional impact of some of this, because whilst some of the drivers behind this project are philosophical, they're legal, I don't want to lose sight of the fact that we're all humans in this. And we're all affected. No matter where you sit, whether you are someone with lived experience, whether you're a clinician, whether you're a clinician with lived experience, no matter where you're at in this landscape, you're going to be feeling something. Is that OK to ask you about…

Chloe
Yeah absolutely. It's really draining. And definitely I ask myself quite often, and certainly more so since the pandemic has made everything harder for multitude of reasons, I ask myself how long I can realistically continue doing this. Because I do care so much about injustice, and it is such a driving force for me. But that also means that I spend a huge amount of my life feeling incredibly angry [laughs]. And that's not healthy. That's not good for anybody. And I keep doing it, because actually I love my job. And I really do care. I'm not saying I get it right all the time. But I care and I want to get it right. And I want to try.

And I also know that there's so many people out there in a less privileged position than me, you know the activists and the people who use or are excluded from services, the carers, the people who have been written off because of what people think about their diagnosis or their behaviour or whatever. And there's people out there with all of that and they're still fighting, knowing that it's going to get them further labelled as difficult or attention seeking or personality disordered or whatever else. There's people still doing the activism, writing stuff, sticking up for each other. And I don't want to be a clinician who says, "Oh it's too hard. I can't do it anymore." Because the impact on me. Because I have more privilege.

But on the other hand, as you say, I am a human being. And I have already, I think, paid a considerable price for being someone who works quite hard and gets quite drawn into things and [laughs] quite angry and quite upset. Yeah and I have been quite significantly unwell in recent years. And that's a risk that I run again.

Sometimes I envy people who don't give a shit [laughs]. Because I think that their lives are probably much easier. And I think they're probably in lots of ways a bit happier than I am. But you can't, well I don't think you can become one of those people. I mean, compassion fatigue is a thing, but I'm not sure, I don't know maybe burnout can lead you to not caring at all. It's a scary idea.

Eve
Yeah it takes me back to something, I think it was Helen, saying in her conversation with Hattie, that compassion fatigue is a thing and she's

acknowledging it's there but she's also saying but it's more than that. It's kind of a system-wide experience that kind of sucks people up into it. More of a kind of institutional apathy or an inability to feel too much. As you say, you're upset and you're angry and you're feeling unwell a lot of the time in this work and that must take an incredible toll. When you are asking yourself, you know, I don't know how much longer I can do this, how much longer I've got left, do you hear a response to that question? Is there…

Chloe
[laughs] Depends on the day, I think [laughs]. I mean, you know, I think realistically, I can't, I can't actually see myself, I've never been able to see myself doing anything else. And I do love it. I worry that it will become untenable or I worry that there won't be a health service anymore. Or the moral injury, by which I mean the sort of state of distress that comes from having to consistently act in a way that's opposed to your moral code, so for example by denying people help when you know that they need and deserve it, I wonder whether that's sort of untenable.

But I also think, well, I'm not qualified to do anything else. And, it's not something I sort of dwell on too much because it is quite scary. It's also my identity. You know, I've wanted to be a doctor since I was 10! I've wanted to be a psychiatrist since I was about in my third year of medical school. That idea of this identity that you've built your entire life around perhaps not being the right one is really frightening.

Eve
It feels frightening…

Chloe
I didn't quite expect to stray into this territory! [laughs]

Eve
…yeah it feels frightening to me as you talk about it, because it's an incredibly long road. And it's not something anyone chooses lightly. Obviously people have different motivations for coming to psychiatry, but you can't go in in a half-assed kind of a way [laughs] because just the sheer nature of the study and the enormous amount of information you have to take on board, and the amount of work, and the placements, and the learning, and over a huge number of years. What are some of your other frustrations? It might be things that came out of some of the other co-creators' interviews, or it might be from your own practice?

Chloe
Oh my God, we haven't got long enough to list my frustrations with psychiatry! [laughs] I think what comes through with a lot of this is, as I say the interviews are very different and the co-creators and the things that

they've said are quite different and obviously their lives and backgrounds are quite different but actually there are some real uniting factors. And I think that actually insight and this concept of insight is the thing of course that brings everything together and this idea of really having to conform and comply, which is really really worrying I think. Well, worrying suggests that it's a surprise and it's not.

But if we take this idea that insight basically means, "Does this patient agree with me as a clinician or not?" and then look at it, it means that it can so easily become weaponised, which is clear from the co-creators. If you don't have enough insight then you can be coerced or belittled, or told you don't understand, or have your autonomy taken away. But if you have too much insight, then somebody said you've compromised yourself as a patient. And that's what happens, then you're labelled as demanding.

People sort of walk this fine line, this invisible line, that we create. And they don't know at what point they're going to fall off it. Between, you know, being just compliant enough and not too compliant, or just insightful enough or not too insightful. So it's almost like people get punished for other people's coercion. So we coerce somebody into presenting themselves in a certain way because we expect that of them, and then we punish them by going, "Oh no you're too demanding, you're too insightful, you've got too much capacity." It's *so* bizarre.

And I think what was interesting for me, actually, it sort of made me reflect on my own experience as a patient, and I came to being a patient after having been a consultant psychiatrist for some years, and what I found was that my experience as a psychiatrist really, really impacted how I behaved as a patient. Because I had picked up all of the same fears that were described by the co-creators.

So I was exceptionally compliant, because I was terrified of being labelled difficult or manipulative. You know, I didn't complain about things because I didn't want to be labelled difficult, or manipulative, or demanding. I tried to be a perfect patient, because of the fear of that, because, frankly, of the fear of being told I had a personality disorder. And if that as a consultant psychiatrist is something that I'm terrified of being labelled, that tells you something about the attitude and stigma towards that diagnosis within the profession.

But yeah, I think that all the things that people were saying, the co-creators were saying, does reaffirm to me why the mental health system is a really frightening place to be. Because you are, it's like, you know, you're playing a game and your eyes are shut, and you don't know which pitfall you're going to fall into. And if you've been in the system for a long time, and you know the system, and you know the pitfalls, then you'll probably be labelled as

being demanding and manipulative, because you know the system, because you make it clear that you understand the system.

It's like, do you remember, I use this as an analogy for mental health services sometimes when I'm trying to explain how they work to people who don't work in them, there was this children's game show in the 1980s called Knightmare…

Eve
Yes! I bloody loved Knightmare!

Chloe
Yeah! It was like really really amazing sort of CGI [Eve laughs] that felt really kind of high tech…

Eve
It felt so epic at the time! [laughs]

Chloe
Yeah! [both laugh] So for anybody who doesn't know what we're talking about, it was this game where a group of kind of, yeah let's face it, quite nerdy children [Eve laughs] would be a team and one of them would wear this sort of big metal helmet that covered their head and they could only see their feet. And their team members would guide them through a series of rooms, which had like traps and quizzes, and obviously it was all on a computer. So they would guide them through, and the person with the helmet on obviously couldn't see anything, and their team were trying to guide them in a way that meant that they didn't get burned up in a fire or fall down a hole or something.

And I don't think that anybody ever got to the end. I'm not quite sure how you won. Eventually, the person with the helmet would fall down a hole and the team would be over. And that's basically I think how mental health services work. You put on a bloody great helmet on somebody so they can only see their feet. And a few well meaning people around them might try to guide them through these systems of traps and riddles and quizzes. But eventually they fall down a hole because they don't know where they're going. And they're expected to understand where they're going. Yeah [laughs] I don't know if that makes any sense as an analogy at all, but it does to me.

Eve
Yeah definitely. It's taken me right back to being a kid [Chloe laughs] and watching Knightmare. And I absolutely like, it was my ultimate fantasy to one day be on Knightmare…

Chloe
Yes! [laughs]

Eve
But now I've got that analogy in my mind, that it's likened to the mental health system, [both laugh] I'm not so sure. But I agree. And to go forward with that analogy I'm kind of wondering if you are somebody who is blinded, and who's in this CGI world, and you're trying to navigate it, and you have the privilege of your teammates who are trying to direct you even though you can't see. But I'm wondering, for instance, some people, some of the co-creators, don't have teammates guiding them, for instance Florence really comes to mind where her phrase that she used over and over again is, "It's just me, myself and I". And she is alone in it. And where does that leave somebody who is blinded, who is silenced, trying to navigate the system, this game, and not being able to? If psychiatry is a game, what are the rules?

Chloe
[laughs] Well, we've talked about Knightmare! God. That's a really [laughs], that's a really good question. And it's a really difficult question. I think the point of psychiatry as a game is that everybody's been given their own set of rules, and nobody knows what anybody else's rules say. And we're all guessing what somebody else's rules are. And there's all sorts of different things that you can do wrong. You know, I guess like snakes and ladders. Where if you inadvertently land on a snake, then you will go all the way back to square one. And that snake could be you've got the wrong diagnosis, or you are the wrong gender or the wrong race, or you once had an alcoholic drink in 1973 therefore you're too addicted for this, or it could be that you missed the letter therefore you don't have enough motivation.

Yeah I think that's the thing in psychiatry, and I think that the rules are something that we don't want to acknowledge, which is that we all have our own little set of rules that we're working to, and we're not sharing our rules with anybody else. And we're making, most importantly, we're making our patients guess what our rules are. And we make up rules based on folklore, based on things that aren't true. I'm going to be thinking about that for the next week actually. [both laugh]

Eve
Is psychiatry a game that can be won?

Chloe
God! No, because I don't think it should be. I think it should be a process. And I think there are probably games or battles within that, which can be won. So for example, I think it is very possible to have a mental illness, to be successfully treated for it and to recover from it.

But our problem is that so many of the services are predicated on that, which is why we have lots and lots of funding going into things like IAPT, which is great, but it's for the less complicated, well circumscribed problems that *can* be treated with a course of CBT or whatever. You know, we have things that may be successfully treated with one form of medication.

So there's little things within that which I think you can win the battle or the game, whatever you want to call it. By which I mean the person with the illness, the patient, the service user, whatever you want to call it, can win that game.

But like any other branch of medicine, a lot of the time it is a process. And it is something where people have to work alongside each other for a long time. And I think the problem is that psychiatry is a battleground. And it becomes a battle between clinicians and patients, for all sorts of reasons and in all sorts of ways. You know, it becomes something that we want to win. And something's gone really wrong if that's what psychiatry is.