



Episode 15:

The UNCRPD General Comment 1 -

An end for involuntary psychiatric care?

Transcript

Introduction [00:00:02] Welcome to Our Sick Society, a podcast series where researchers from King's College London and people with lived experience explore together how social factors contribute to mental health problems. We'll also have some guest presenters inviting people who tell their stories to investigate the issues that they're interested in, as well as the ones that we think are important. We want to make you think and question society's role in mental health. What are the systems and the structures which mean some people are more likely to be mentally unwell than others? And crucially, what steps should society take from national government policies to local grassroots community organising? How can we cure our sick society?

Alex [00:00:57] Welcome, everybody. My name is Alex Freeman. I'm a counselling psychologist and Ph.D. student at Stellenbosch University in South Africa. I'm currently participating in a Fellowship at King's College London, through which we are presenting this podcast. The subject of the podcast itself surrounds a controversial issue, which is about involuntary care. What involuntary care actually means is contested, but broadly in the current conditions refers to a circumstance where a person, usually somebody with a mental condition, is sectioned or institutionalised against their will for the purposes of treatment and rehabilitation. But of particular focus in this podcast is around what the UN Convention on the Rights of Persons with Disabilities, often abbreviated to UNCRPD, has stipulated about involuntary care in adopting General Comment One in 2014. So, what General Comment One states is that all signatories, and I quote from the General Comment One here "all signatories review the laws allowing for guardianship and trusteeship and take action to develop laws and policies to replace regimes of substituted decision making by supported decision making, which respects the person's

autonomy will and preferences". Joining me to discuss the subject are two lovely and very well-respected experts, my first guest is Charlene Sunkel. She is the Chairperson of the Global Mental Health Peer Network and an expert by experience and an academic and writer, author, besides. My second guest is an Emeritus Professor at King's College and a psychiatrist with many years of experience and many important papers surrounding involuntary care. His name is Professor George Szmukler. These two guests come at and have experiences of involuntary care from quite different angles and directions with the idea and experience of involuntary care. And I think it's both intriguing and enriching to have them both here. So, Charlene, if you wouldn't mind kicking ass off with that introduction.

Charlene [00:02:57] Thanks so much, Alex. Yes, glad to be here. Looking forward to this discussion. So, I founded the Global Mental Health Peer Network back in 2018. So also, currently act as the CEO. So, we're an international lived experience organisation. So, we are 100% constituted by people with lived experience from across the world. So, one of our focus areas are indeed human rights issues. So, we work a lot in bringing the voices of people with lived experience out to discussion platforms.

Alex [00:03:38] Lovely. Thank you. And Prof.

George [00:03:43] Yes. I'm George Szmukler. I'm a psychiatrist now retired, and I'm an Emeritus Professor of Psychiatry and Society at King's College London. In the past, I have done involved in various areas for quite a long time in the eating disorders, actually, but then moved into community psychiatry and had a number of roles in the community, including being the consultant for the emergency clinic at the Maudsley hospital, and then working with a high support team in the community with a whole range of supportive accommodations that we were helping with. My main current interests are in coercion and in reducing the use of coercion in mental health care, decision making capacity and mental health law reform. And here particularly, I'm one of the proponents of the fusion law. I also have an interest in human rights, in mental health care, and have been in the past the chair of the Human Rights Committee of the Royal College of Psychiatrists.

Alex [00:04:54] Excellent. I feel lucky to have you both here and for your common and intersecting interests on human rights related concerns. To get the conversation going, I was wondering, Charlene, if you could give some sort of background into the UNCRPD and why you think this is so important and controversial?

Charlene [00:05:12] Yeah, that's a very complicated question. I think we don't really have or firstly, I don't have the solutions. But for me, the essence is about people with psychosocial disabilities having equal rights than anybody else. And I think the big issue here is around legal capacity, making decisions. And I feel that's been taken often for too granted in the past where there was just this automatic assumption that people with mental health conditions are unable

to make decisions or participate in community life, you know, work, education, all those basic human rights that everybody else has. And I think we have been exposed also a lot to human rights violations, particularly. So, the CRPD in its entirety is quite a welcome legal instrument or human rights instrument for, I think, for people with mental health conditions. But for me, my, my specific concern around the CRPD, the whole issue around involuntary admission is the questions asked around involuntary care. Yeah, I have a lot of experience working with people with lived experience who had been involuntary admitted and myself also had that experience. And from people who I've spoken to, it's often about, the experience was much more traumatic than the condition itself.

Alex [00:06:38] So that's interesting. I'm going to get back to the experience of it because I'd love to hear from that. But just to introduce the General Comment but further, and I'm going to bring George into this. George, in the General Comment, there's a separation made between mental capacity and legal capacity, and I wondered if you could just flesh that out a bit for us.

George [00:06:59] Yes. As Charlene said, the just to say how important this convention is, this this treaty, and that the essential principles of non-discrimination, autonomy and inclusion are very fundamental. And these aren't new rights that are introduced by the convention, but they are tailored and specified as relevant and how they are relevant to people with disabilities, including psychosocial disabilities and cognitive disabilities. The challenge for psychiatry here is, as Charlie mentioned, this issue of legal capacity. So, the Committee, which has been created by the United Nations to monitor the Convention and also to give authoritative interpretations on various parts of the Convention that the Committee thinks is not well understood or that have not been adopted by in practice in the various countries. And the one concerning legal capacity is technically very difficult, but essentially it is saying that legal capacity is quite different. Mental capacity, semantic capacity is about the ability of a person to make a decision and particularly a treatment or care decision where the requirement generally for mental capacity is that the person understands the relevant information about what the problem is, what the alternatives are in terms of treatment, what would be the outcome with or without treatment, whether the person actually can appreciate that this is relevant to their predicament and also that they can use this information to think through their decision in a way which is consistent with what is important for the person, how it fits with their beliefs, values, commitments and conception of the good life. Whereas legal capacity refers to two elements. The first one is that the person has legal standing. That is, that they have the rights that the law provides. But secondly, that they have legal agency, and that is that they're able to act on those rights and to be recognised as having one's decisions, being legally respected. And those decisions might be concerning health or social care or various other decisions. And what the committee is saying, what is so controversial, so difficult for psychiatry, is they're saying that legal capacity must be fully recognised no matter what the person's mental capacity might be, no matter how their decision-making ability may be affected. And here what they are going on to say is to claim that substitute decision making where somebody else makes a decision for a person who lacks

decision making capacity, that this is something that is a violation of the convention and therefore to be abolished, and that the emphasis must be on support of decision making. And here decision, supported decision making is an obligation that states must have under the Convention and that with support a person will be able to express their will and preferences, which must always be respected and recognised, and people will be required more or less support perhaps, people who are having a difficulty with making the decision that with support they will be able to express their will and preferences is what the Committee seems to be saying, and that if there is a problem, so that the person may be unconscious for example, the best interpretation, that is the words used in this, in the General Comment, the best interpretation of the person's wills and preferences would be the basis for making an intervention or not making an intervention. So, it's it's a very strict abolitionist position on substitute decision making, which means, of course, involuntary treatment is absolutely a substitute decision because the person is saying, no, I don't wish to have this treatment. Now, that has caused a tremendous amount of controversy, both with legal scholars and clinical scholars saying, well, you know, this is this is difficult, certainly in the current world, the current way in which services are organised, it's hard to see how one can really completely do away with non-consensual treatment, involuntary treatment. And that even within the United Nations, there are other bodies within the United Nations which don't adopt the abolitionist position. So, there is that inconsistency because these bodies are quite independent of each other, although they are all within the United Nations. But I think one thing that is supported throughout the United Nations bodies is that supported decision making is a critical factor that one must employ in, where somebody is having a difficulty making a decision and that respect for the person's will and preferences is is generally endorsed by all of the bodies.

Alex [00:12:31] Thank you. I think that gives sort of a good overview of the debate. I wondered if, Charlene, if you had any thoughts about what George was saying and what your impressions of the convention are, given that it's so controversial that it's like flies in the face of people's general knee jerk reactions that involuntary care, psychiatric care is always necessary. And you started touching on the sort of context and, and how it's done and the way that people are treated within involuntary care. And I wondered if if you could reflect on that.

Charlene [00:13:00] Yes thanks. I think where first I would raise the issue about supported decision making. I think that shouldn't be misunderstood, that you know anybody can be assigned to be a support for a person. As George explained, you know, they need to be able to interpret the will and preferences of the person. So, in other words, the best is that person kind of knows who they would like to as a person who could support them through decision making. I think that that for me is very important. I think there is sometimes a misconception about that. Secondly, in terms of [in]voluntary admission. I think it is difficult that when you think someone is, for example, psychotic, they may run in front of a car, you know, or something like that. And I think that comes with like almost like a paternalistic approach that immediately, often with good intentions to protect that person. And then people think, you know, see involuntary admission as

a necessity. But what I've found in my experience in both myself, but also in communicating with other people who had the experience of involuntary admission, is that all you know is you do know, you know, something's going on with you. And the next moment, you know, the police is by your door, the ambulance is here, and cart you off to the hospital. So, I first have a problem with that because again, there's been no communication. And from what I've been figuring out is that this often lacking, nobody ever sits the person down and say, listen, we noticed, you know, you're not 100% or you're not yourself. How can we support you? Is there anything how we can support you? What would you like? Always put the decisions on to the person, how they would like to be supported. That conversation never happens in most instances. And secondly, the other issue for me is the conditions within psychiatric hospitals where involuntary admissions take place. It looks like a prison. I mean, it's really not a place that you can associate with care and help. I think in most instances, involuntary admissions won't be necessary because no one, whether you have a mental health condition or not, no one will voluntarily go to a facility that you perceive is where human rights violations happen, or which is not really conducive for your recovery. If I ever have to relapse and need care, I may recognise that I do need care, but I will refuse because I know I'm not going to expose myself to conditions like that. So, in that instance, I will be perceived as, how can I say, noncompliant and will be forced to go to treatment. So for me, that is why the human rights issues come in so strongly, because if we find instances where someone needs care and you know, if people say they have to be involuntary admitted for whatever reason, then the conditions in which they receive that care needs to be provided within a human rights framework and it need to be provided that it can take care of the needs of that person. Yeah. So, for me and there's a lot of issues in involuntary admission as well, and in South Africa, there's an undetermined period in which you can be involuntary admitted. George can correct me if I'm wrong, but I think it's Italy where you can only involuntary admit someone for three days. In South Africa it's undetermined. So, I think there's a lot of hiccups. And for me personally, I think if certain issues been put in place, especially more community-based care, involuntary admission in most cases wouldn't be necessary.

Alex [00:16:53] Interesting. George, did you want to reflect on anything?

George [00:16:57] Yes. No, I completely agree with what Charlene has said. The conditions in many psychiatric units are really poor, even in highly developed economies. And a staggering fact that people very rarely mention is the extraordinary difference in the rate of involuntary detention, even across European countries. So, if we look at Italy, Italy has a rang, in 2015 or 16, it had 15 involuntary detentions per 100,000 population. In Austria, it was 280 involuntary detentions per 100,000. In England, it's around 114, 115. So, it's somewhere in between. Now, you know, a 20-fold difference between two countries, in European countries, it is it is extraordinary to find such differences and also changes over time. So, in in in England, there's been a huge increase, something like a 40% increase just in the last decade. So, it's not really about the schizophrenia or bipolar disorder has not changed in that decade. So legally, there are some countries that have systems that deal much better with the sorts of crises that lead to

involuntary detentions. And I must say in Trieste, for example, which has the lowest that I've ever come across, and that is 8 per 100,000, which is even by Italian standards, it's extremely low. And there is now increasing evidence that there are alternatives to involuntary treatment, as Charlene has said. You know that if you provide within the community better crisis services, if you provide better community services for people, which will nip in the bud a developing crisis because the person is well cared for in a community service, then there is going to be a reduction. One form of supporting legal capacity that I think is under utilised and for which there is a strong evidence base, I think Charlene will agree, are advanced statements or advanced choice documents where there is recently a meta-analysis which looked at the number of randomised controlled trials and, two of which I was involved with, which showed a 25% reduction in involuntary detentions for people who had made an advanced statement. So there is a lot that can be done to reduce involuntary detentions and involuntary treatment. And it's also striking the lamentable lack of research in that area. So, there was a review by Piers Gooding, which reviewed all of the literature on alternatives to involuntary detention and he only found 42 studies that directly looked at how we can reduce involuntary detentions. 42 studies. If you compare that to the number of publications on a new drug, you know, you'll get 42 in the course of the year just for one drug. So, it's just this lack, lack of research, interest and huge variation in the rates of detention is really quite problematic, very problematic.

Alex [00:20:27] You mentioned advance directives, which just for the listeners who don't know, refers to when a person with a mental condition signs a document which states what treatment they would prefer should they become unable to make decisions for themselves. I wonder if, Charlene, you could answer this. What do you think of advance directives as a partial solution to the problem of too many people being cared for against their will when it might not be necessary?

Charlene [00:20:52] I think it definitely will help because at least it gives some power to that person. You know that their wishes will be respected in kind of a legal framework, erm, should they ever find themselves in a situation where they need support in decision making. And I think what was very important, as I mentioned, with decision making that that person can appoint in this advance directive a person who they would like to make decisions on their behalf if it comes to that. So, I almost think it's in there that included advance directives in the Mental Health Care Act, if I'm not mistaken. So, I think that's a nice, one of the good ways. I think what also could help to kind of reduce involuntary admissions and I think it's a very underutilised service in the community is peer support work. I think there are studies that show kind of reduced or hospital need for hospitalisation just for peers helping peers and supporting them. And through a process like that and also like like George said, nipping it in the bud, so I think we all I mean you learn to know yourself so you know, when kind of if I can put it in a danger zone, if you kind of understand yourself or have a peer guide you through the process, you are able to to act before you kind of spiral out of control, before it gets worse. So, I think that is important. Community based interventions will be significant.

Alex [00:22:25] Maybe, maybe for George, do you sort of consider advanced directives or for both of you to be an example of supportive care, or would you put it separately? The UNCRPD's obviously saying that involuntary care should be replaced by supportive care. How do you think advance directives fit within that?

George [00:22:43] I think that the CRPD Committee did endorse the use of advance statements, but therein there is a problem to do with will and preferences, which we may come to later on. But you know, the point of an advance statement and advance directive is that that a person, usually somebody who's previously been admitted to hospital and especially being admitted on an involuntary treatment order, on reflection, having recovered from from that episode, can look at, well, you know, what happened, how did this come about, what can we do to avoid this happening again and deciding that, well, you know, maybe, you know, if that particular treatment hadn't been used, but if another treatment had, I would have appreciated that that would have been more helpful or if certain people were involved. Would it be more helpful, perhaps, if my mother wasn't involved at that particular time? So very one can get into quite a lot of individual detail about what is helpful, what is not helpful.

Alex [00:23:54] And do you think it's always possible to honour those advance directives? Say somebody says, don't treat me if I do these things and they potentially a risk to themselves or others in that example?

George [00:24:06] Well, it does throw up a number of issues. Firstly, in England, refusals are respected, but not requests. So, you can't, you know, if you refuse haloperidol, that would be respected. If one makes an advance directive, but not if you're then put on an involuntary treatment order. Right. So, yes, that's that's very important. And what what we developed were joint crisis plans. This was a plan which which involved the service user and an advocate, an independent advocate or the person could bring a relative along or anyone that they thought would be helpful in going through the advance statement that they were preparing. When I talk about independent advocates and I'm including their peer advocates, I think they should be before a decision is made for involuntary treatment. There has to be a detailed discussion with the the person who's presenting as having a mental disorder that is requires treatment to try and understand the person's beliefs, values and so on. It must involve people who know that person well so that the person may be expressing a preference that does seem bizarre and odd when they speak to people who know that person well about how coherent, how consistent that is with the person's belief and values. And then I think it's important to have an independent advocate present to just make sure that the voices are being heard of all the parties to the discussion. And I think that that is the minimum kind of triad that is necessary before a decision for involuntary treatment is taken. A facilitator is extremely important, and there's very good evidence from the United States where a facilitator in very, very large study resulted in an increase from 3% of people making an advanced directive to 60%. So, I think that, in our studies

we used a facilitator, the facilitator would go through the plan and the options that the person might want to include. And then during the meeting in which the discussion occurred between the patient and the clinical team, usually with the consultant present, that the facilitator would clarify for both parties what the other is saying and really making sure that both understand what it is that is being discussed. So that facilitator is extremely important and that could be an independent advocate. In our study we used a psychiatric social worker, or a nurse who was independent of the clinical team, that worked elsewhere, and were just were doing this as, they're only specific role, was to be a facilitator. The problem arises with will and preferences. And what the, if I can come, to the Committee's view is, because you see, I would see the advance directive or the advance statement in different terms for a joint crisis plan that the person is making, on reflection, a statement about what they would like to happen if they should unfortunately relapse. And this is done on the basis of the person's deeply held beliefs, values, commitments, conception of the good, what is important in their life. And I would call this, these are the manifestations of the person's will, the will as being manifest in these reasonably stable, deeply held beliefs and values...

Alex [00:27:59] In the advanced directive?

George [00:27:59] Yes.

Alex [00:27:59] That would be in the... Okay.

George [00:28:01] So that's that's what they're saying: this is what I would like to happen. What they're predicting is that they're going to make preference. Now, how can one respect both the will and preferences here. Which, which is it, the one, that I as the clinician should respect? Should I respect the the the will, as I would say it, which is expressed in the advanced directive or should I express the preference that is currently that is the preference that I am being faced with and the person is saying this is what I want, I don't want the treatment, just leave me alone. I don't need to be in hospital. And I think most, the whole point, most people would say of an advanced directive is that the person's will is something that should be respected. In fact, I would say that what is in the best interests of the person is giving effect to the person's will.

Charlene [00:29:00] It's quite an interesting debate this whole will and preference. And I like the idea. I know like in South Africa, advance directives aren't used and it would actually be a nice thing because I see it as it is a kind of a symbol of protection of my will and preferences. And I think for me, knowing myself if I should relapse, I know what I do previously, you know, and an advanced directive gives an opportunity to to state that like like you know if I because I would often I don't look people in the eyes, I don't talk much, you know I completely seclude myself. I don't go out. And those for me are warning signs. So if one could state like that, if that and I know when admitted to a hospital, I have a tendency of calling the taxi to come and fetch me. And they usually do. But you know, to state that, that I need care and that and for me, again,

what's most important is who I assign to make decisions. For me, I see trust issues, you know, that I need that. I need to trust that person. I need to trust that they will be carrying out my will, you know, at the best interest of myself and who I am as a person and what is important to me. Yeah. So for me, I think it should be. Personally, I would love to see it as a legal requirement within the Mental Health Care Act. Okay, it won't, you know, kind of be a solution for everything. There's a lot of things that need to be really changed in order to really make that change, in terms of this, but for me, that's one way of doing it.

Alex [00:30:42] So in a sense, for you, the will that you have before you lose mental capacity, I'm not sure if that's how you think about it, but that will, before you become ill, would be important, Important to you?

Charlene [00:30:58] Yeah, absolutely. I think advance directives should, of course, be revised. I'm not sure there's any suggestions, but let's say annually, to revise that that advance directive because I mean, you can't have it forever because my, my will and preferences of five years ago is not the same as it is today. Things change. So I think that's also important.

George [00:31:22] Yes, I agree with that. It's very important. We are currently, in England and Wales, we have the mental health bill which does include or recognise advance statements, but it doesn't give them the prominence that the independent panel which reviewed the current Mental Health Act, which made various recommendations, that that led to the Bill, that the Government somehow hasn't emphasised and placed it in kind of neon lights, the importance of the advanced choice documents. And so I think that a number of people have said to there's currently a scrutiny, a Joint Parliamentary Committee that's scrutinising the Bill and consulting on it. I think a number of people and I certainly have suggested or proposed that it is terribly important that there is an opt out for making an advanced choice document. That is, that every person who has been admitted on an order would at the point of discharge be asked would they like to make an advanced choice document and that the, you know, the support for that through an independent advocate, facilitator and so on is made available. So I think it is an extremely important development that will has been shown to reduce the rate of detention and that receives very positive feedback from those service users those who created the advance choice documents, and they feel empowered as as Charlene has said, they feel empowered, more in control that they're having some say and have more confidence, a better relationship with the clinical team, especially when they have had a discussion with the clinical team. So I've been party to these discussions and they are not the usual discussion that one has with the patient. You know the facilitator being there, the independent advocate. You know, it's it's becomes a very in-depth discussion. I mean. Dr.. Why are you proposing that? You know, I have this medication. You know, I don't like this medication, so I'm put on the spot about, you know, why I've chosen this medication rather than another medication. and you know, why I've suggested, you know, certain interventions and not others. And but at the end of that, one has a much better, I found, I had a much better relationship with the patient. There was much more

trust on both sides. You know, I trusted the patient much more than before and I think trusted me the the kind of thought one gets. So I think this is a very, very important and requirement that that services should implement this and it should be an opt out. And what might apply to any patient who's been admitted, whether as a as an informal patient or as a involuntary patient.

Alex [00:34:24] And it was interesting what you said sort of about a patient professional trust that builds between you and the sense that if there's more trust, it's easier to understand somebody's preferences for themselves. Um, and in that in that way, the relationship between the two can sort of enable or disable capacity. I wonder, what do you think about that idea? Maybe Charlene.

Charlene [00:34:51] Yeah, I agree with George. I think the trust in a relationship with a psychiatrist is so important, and I think maybe because you break down trust, if you all of a sudden involuntary admitted or has been made about for you without you and that does you lose trust in the system and in the medical profession. So for me, at the moment I have, you know, a psychiatrist who I really trust who listens to me, which is very important, who takes my decisions seriously. If I don't want to be, if I want to reduce my medication a bit. You know, they they it's not like being persistent against me and making decisions on behalf of me, just making clear what the consequences may or may not be. I think that gives me kind of the sense of taking ownership of my own mental health. And and I think that is why outcomes is more positive in when there's a trusting relationship.

Alex [00:35:57] But I had another question, and it's about the differences sort of in your backgrounds and your different approaches to issues surrounding involuntary care. Prof, your experiences more from a psychiatric background in combination with academia and Charlene, your experiences as a person with a mental condition who then became an author and public rights activist. So I wondered with that in mind, what you feel is lost in communication between your experiences from each angle that you would like each other to know?

Charlene [00:36:27] Well, I suppose, and I must say, since I've kind of been in the mental health care system dealing with psychiatrists, I must say it changed a lot. I mean, in the past I had experiences where I wasn't listened to at all, you know, it was almost like I was ignored, like a Stop street. If I can express it in such a way, where my concerns or anything wasn't taken on board, I just felt completely disempowered. That conversation, again, as I mentioned, there's was no regard, so but I must say it changed a lot. I've seen really psychiatrists have changed a lot, especially in my work, and I've seen the great recognition for the importance of having that equal partnership, not like patient-psychiatrist anymore. I think that is important. Psychiatrists must always let the person lead their treatment and recovery and always have that good relationship.

Alex [00:37:34] Mm hmm. George.

George [00:37:36] Oh, I completely agree with Charlotte. It's. I think there has been a change, although there's still quite a lot that needs to be done. Where there is some kind of appreciation of the CRPD. And a lot of my colleagues, I think most colleagues would say, yes, the CRPD is excellent. And that if states actually took note of the CRPD and legislated accordingly, that the standing of people with disabilities would be immensely enhanced, there'd be much less discrimination, more respect, and it would be tremendously helpful. But Article 12, the one on legal capacities is has been the spanner in the works for many of my colleagues. They just say and it somehow discredits, in their eyes, not in mine, discredits in their eyes, the whole Convention. You know that, how can anyone say that, you can have a total abolition of non-consensual treatment, but it has had an effect. The WHO, World Health Organisation has adopted very much a supportive attitude to service developments, which is consistent with the CRPD. That's been important. And the Parliament, the Assembly of the Council of Europe actually made a statement, I think, in 2019 saying that mental health services must work towards the elimination of coercion. So there is an international movement in the direction of reducing coercion and dealing with these the two. I think the two very, very deeply rooted stereotypes of people with mental health problems, firstly, that they're incapable of sound judgements. And secondly, that they're intrinsically dangerous. And that's why in conventional mental health law, one has always this pairing of that the person presents a risk to the health and safety of themselves in some way and a risk to the safety of others. And they embody for me that and the absence of any discussion or any requirement that the person's ability to make a decision should be discussed. You know that conventional mental health law has basically two fundamental criteria. Firstly, that the person has a diagnosis of a mental disorder, usually not defined in any detail. And secondly, that they present a risk themselves or others. Mm hmm. And that's totally different to what one finds in mental capacity law, where the only justification for an intervention against the will of the person, or against the preferences the person expresses, is that they have an impairment of decision making capacity. And secondly, that an intervention is only warranted in their best interests. Now, decision making capacity and best interests are contested terms. And if we have time later on, you know I'm happy to go into a more nuanced version of decision making capacity and best interest, which relies, I think, on will and preferences, although I've been a bit critical about the way in which the committee has interpreted will and preferences. Nonetheless, I think there's something valuable in thinking in those with those two concepts.

Alex [00:40:58] And I hear you, George, sort of about the different reasons that people are involuntarily treated or the conditions under which the autonomy is temporarily taken away for the purposes of their rehabilitation, etc.. So I thought I'd ask Charlene first if you could reflect on what role you think stigma and discrimination has on people being treated against their will.

Charlene [00:41:19] Yeah, I think it's definitely played a very large role and I think people, what do they call like the presumption of dangerousness, which is also an issue that's been discussed

around this topic that, just based on your diagnosis, it's automatically thought that you will act out or you will become aggressive or act violent. And that's not always the case. Just if we look at decision making around medication, I mean, I've known people with schizophrenia whose choice it is not to take medication. They prefer to live with the voices that they hear. So for me, I don't see a issue with that, it doesn't cause them you know, it doesn't cause anybody else harm. But ja with the whole stigma issue that I mean, I added a lot of people immediately when you tell them you live with schizophrenia, you can immediately see the reaction. It's almost like they avoid you and they immediately think that you're going to attack them or some something. You know, do they understand that that's not how it is? I've seen people who do become aggressive with psychosis that I know if you can imagine that the psychosis is reality, because it's reality for that person. So essentially they respond to that reality, of that threat, when they become aggressive. And I think you can also imagine or always have an issue with the police involvement as well when it comes to involuntary admissions, because they often arrive heavily armed or, you know, in uniform, which again, is a threat, a threat to anyone, anybody gets scared when the police is at your door, you think, what did you do wrong? So you act. So I think one should also consider those aspects.

Alex [00:42:59] Yeah, those are some very rich reflections on how people might feel in that situation and kind of the ways in which stigma can really worsen people's experience and make them feel quite afraid. And I hear how this can be a barrier to them expressing their will, their views clearly. George, you've written a lot about fusion law, which I believe is a response to accusations that people are treated against their will on the basis of the diagnosis that they have a mental condition rather than their ability to reason and make their own decisions. I just wondered if you could reflect a bit on discrimination, what role you think discrimination has in people being involuntarily detained, and what the role of fusion law would be in ensuring that there's no or less discrimination.

George [00:43:45] Well, if you consider the two prejudicial stereotypes that people with a mental illness are unable to make sound judgements, and secondly, that they are intrinsically dangerous. These stereotypes are perfectly expressed in conventional mental health law, aren't they? So if you have a diagnosis of mental disorder automatically, we we need to, you know, watch out for the fact that you don't know what's good for you because you're not able to make sound judgement, you're not able to think clearly. And secondly, that you represent a risk to yourself or others and you just don't appreciate it. So the fusion law is, like the CRPD, an attempt to eliminate the discrimination embodied in conventional mental health law. And what colleagues and I who've worked on this, what we propose is that we need only we don't need a separate mental hospital. We need only a single mental capacity law or you know, those terms may not be the ones that one would want to attach. We just need a single law which is based on a person's ability to make the decision that they need or don't need the treatment and something like best interest. But I would interpret it as giving effect to the person's will. That is giving effect that is what is in the best interest is giving effect to the will, to the person's deeply

held beliefs, values, commitments, life projects and what's important to the person, as Charlene said. And the reason that we've called it a fusion law is because mental capacity law, like the Mental Capacity Act we have in England is very, very weak on protection and very weak on involuntary detention. In fact, it's not addressed. Who can authorise involuntary detention, where, for how long, what kind of reviews are required, and what kind of appeal mechanisms there are. So Fusion is fusing the strengths of both kinds of laws. Yes, there is a strength in civil commitment law, and that is that it spells out the regulations around the use of force, detention and force, which is very important. But the the overwhelming strength of the mental capacity type law is respect, respect of the person's autonomy, that is, respect for their ability to make a decision for themselves and for what is important to them in determining whether an intervention should be made. Now, you know what? I can perhaps won't go into it now, but one can recast decision making capacity in terms of will and preferences, along the lines that I've mentioned, that if there is an incoherence between the person's will, what is important, reasonably stably over time, important to the person and a decision or a preference that they're expressing at the moment, which is just not coherent with those, then one thinks, well, you know, maybe this person decision making ability is being undermined and one would only intervene in the person's best interests if one but one could change the definition of best interest to being giving effect to the person's will, giving effect to what is important to that person from that, so it's that person's perspective. It's not my perspective. This condition. I think if I were you, I would have the treatment. No, I'm not you. And you're it's it's your beliefs and values that I have to respect, not mine. I mustn't undermine your beliefs and values because I think mine are more appropriate or I would act differently. So if we had that and I think things are developing in that way, certainly in mental capacity law in in England. So there is a movement in that direction. I don't think that the CRPD committee had really recognised that there is a link between decision making capacity and will and preferences.

Alex [00:47:47] Well, that that's quite complex but, but interesting and I yeah, hear there's a bit more of a narrative sort of approach rather than a value laden assumption about what's right or wrong.

George [00:47:59] Yes, it's the values of the person who's decision making ability is being assessed that are the overwhelmingly [important]. But the other interesting thing here is the issue of rights, because what the CRPD says is that one must respect the rights, will and preferences. Now you can't respect all three. You know, people have a right to life but their will may be and their preference may be totally consistent with the will to end their life, you know, So there is a conflict there, isn't there? Or a person who says, look, you know, I'm prepared to take the risk of living on my own, even though I know that I might be exploited and that might be the subject of some degree of violence, certainly psychological violence. But, you know, I value my independence and living on my own. And this, you know, to give the case here where, you know, clearly the person has a right in the CRPD to be free of exploitation of violence, but the person's will is to live on their own and they accept the fact that they have this risk. How does one resolve

that? Well, I would resolve it in favour of the person's will in this case. But in other cases, I might actually think that the right to life might be more important than the person's will.

Alex [00:49:17] Mm hmm. And I get the sense that it's also about what's between the lines. It's not so simple as just to say a rights based approach. This is the way to approach every scenario. There's a lot of complexity in every situation and and context dependent, which I feel is also what Charlene was was reflecting on right at the beginning.

George [00:49:34] Yes, absolutely.

Alex [00:49:36] I did have one more question for Charlene, actually, around the advocacy work that you're doing as part of the Global Mental Health Peer Network, I was wondering what kind of advocacy you do and what kind of challenges you have in getting some of these ideas across about the rights of people with mental conditions in these scenarios?

Charlene [00:49:54] I think we we quite got the same goals in terms of human rights. And I think what's important within the peer network is, you know, we don't prescribe to anybody kind of what they should believe or how they should, what their stance is on certain things. They have a right to have their own opinion and perspective. I think that is important because at the end of the day, we all strive towards the same goals, especially when it comes to human rights issues. And I think just this discussion highlighted again for me how it's always about the individual. It cannot be a blanket approach in anything. We are all so unique, you know, with our own ways and our own belief systems and what we want from life and what's important to us. And for me, it's always about dignity, the dignity of that person. Yeah. So, so for us, I think the differences that we also see is in terms of even the regions, the lower- and middle-income countries to the high-income countries, in some instances, it's so different on what they want to focus on in advocacy, while others are on different topics. We find that, like those from the high-income countries, want to focus more on alternatives to coercion. They feel very strongly about that. Also, like peer support is an intervention. And then you'll also see like in low- and middle-income countries, especially from Africa, wants to focus a lot on human rights and stigma and discrimination. So, I think when we address this issue, it's always important that you also consider the country context and the influence and what you can do to support and reduce coercion within that communities.

Alex [00:51:31] It must be incredibly challenging to have to work in such diverse contexts where different logics sometimes apply.

Charlene [00:51:39] Yeah, but I think what's important we learn from each other because, you know, peer to peer knowledge exchange is quite important to us.

Alex [00:51:47] And does the peer network work with professionals in in the work that they do to educate professionals or exchange ideas about what the experience is like?

Charlene [00:51:57] Yes, often I think this probably the core component is that we take our own lived experiences and start conversations around various issues. We do, you know, we are part of like lecturing at universities, sharing our experiences also like influence policies at local and global levels. We've been involved in WHO documents, so we really try to bring our voices and their experiences to important discussions.

George [00:52:28] Hmm.

Alex [00:52:28] Nice. Thank you. I'm glad I have you both here and at the same time to share those different experiences and get different approaches from both of you on the same kinds of issues. So wonderful, as I said to have you both. I'm learning from this. I'm doing my Ph.D. I'm obviously learning from both of you and developing a more rich and complex understanding of these issues. And hopefully whoever listens, whether they're laypeople or professionals or users or families or the community or whatever, survivors can all benefit and get something from it. So, yeah, really appreciate it.

Charlene [00:53:04] This is really been an interesting discussion and yeah, it's been really enjoying it.

Alex [00:53:10] Thank you.

Outro [00:53:15] Thank you for listening. This episode was hosted by Alex Freeman. Your producer was Verity Buckley. If you want to know more about our guests or any topics discussed in this episode, please visit the episode description for links and helpful resources. This podcast is funded by the King's College London ESRC Impact Acceleration Account. You can stay up to date with future episodes by subscribing via preferred platform. And please do leave us a review. It helps us to reach more listeners.