**TRANSCRIPT** Episode #5 Part Two  **“No one size fits all”: Disability and the Law**

TESSA DE VRIES

Welcome to **One in Five,** the Melbourne Disability Institute Podcast, bringing you the latest in disability research from the University of Melbourne. I’m Tessa de Vries. In this series we'll be looking at how research can tackle some of the biggest issues facing people with disability and their families. Join us as we talk to a range of people about new research findings, possible solutions and policy ideas.

This is part two of an episode about disability and the law. In part one, we talked about the law, supported decision making and consumer activity. In this part we focus on compulsory medical treatment, an area in which supported decision making, legislation, and disability all collide.

First up, we talked to Cath Roper

CATH ROPER

I work at the Center for Psychiatric Nursing

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Hamish MCLACHLAN

HAMISH MCLACHLAN

I’m the manager of Victoria Legal Aid’s, Mental Health and Disability Law Program

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And Elissa Scott,

ELISSA SCOTT

I work for independent Mental health Advocacy

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about the importance of supported decision making in compulsory medical treatment processes.

ELISSA SCOTT

Compulsory treatment can entail a number of things that may be holding someone within an inpatients ward against their will, may be keeping them in seclusion area of the ward against their will, it could also be administering medication by injection, which may require that person to be restrained at the time. So it certainly takes a lot of that person's autonomy and choice away, and can be quite a traumatic experience for that individual.

HAMISH MCLACHLAN

So it's quite widespread compared to what people might think, it happens to about 10,000 people in Victoria each year. And so it's something that not a lot of people come across in their ordinary life, but it is affecting a lot of Victorians every day. What happens is if someone is suspected to be having a mental health episode, someone can get in contact with the CAT team (the crisis and assessment team) and they might come to assess someone in the community, or otherwise someone might come to the attention of the police. And in either of those cases, the person may have what's called an “assessment order” made over them, which means that they'll be then taken into hospital into a psychiatric ward in a hospital and assessed by a psychiatrist. And if the psychiatrist is of the view that a set of what are called treatment criteria apply to that person, then they can be placed under a temporary Compulsory Treatment Order, and they can be given mental health treatment against their will. And that order would last for up to 28 days. And then at the end of that 28 days, the Mental Health Tribunal will hold a hearing to assess whether the person should go on an ongoing treatment order, either In the community as a community patient receiving compulsory treatment, or as an inpatient in the hospital.

These orders can go on for a long time. So an inpatient treatment order can last for up to six months. And a community treatment order can last up for 12 months and they can then be re-made on expiry. So some people will be under mental health treatment orders for 20 years. So the thing that brings you into the system would be an urgent situation, but it need not be urgent to keep you in the system.

CATH ROPER

When Australia signed the Convention on the Rights of Persons with a Disability, the domestic laws had to then change so that they’re consistent with the Convention. And that meant that our mental health laws had to change to become more rights to health, so that idea that you know, your actual human rights to refuse treatment for example, they don't, you know, on balance don't matter quite as much as your right to be able to access help if you need it. Whereas I think there has been a real switch, sort of globally, now, around rights based mental health, so that autonomy is given much more weight. And so under the convention that's very consistent with this idea of people's self determination and their rights to make their own decisions and the social model of disability, which is basically saying, yes, you might have an impairment but really a disability is its interaction between what you're going through and the ways in which society might be discriminatory or close doors for you and provide barriers.

It's really the Mental Health Act that talks about supported decision making. So there's an expectation that all clinicians, all staff working in mental health services (I'm thinking of hospitals in particular), should be working under a supported decision making framework. There are some formal aspects to that. There's a scheme called Nominated Persons, which means that legally, someone can nominate whoever they would like to represent their views or speak to what they themselves would want. It isn't about that person saying what they think is in the person's best interest. It's actually about them representing what the person would want. It's like an autonomy tool. There’s a Nominated Person Scheme that is part of the Mental Health Act.

There's a scheme where you can get a second opinion. If you're not happy with the psychiatrist’s opinion, you can access that.

And there are advanced statements as well. These are ways to try and keep hold of or have a mechanism for a person's autonomous wishes. The advanced statement, may be developed when you're not in hospital, and then it might specify what treatments you would prefer. And it might even say things like, these are the kinds of things that make me feel worse or more frustrated or whatever I like to pace when I'm upset, don't freak out, that's just something I need to do to kind of soothe myself or whatever. And that's really helpful, I think, to clinicians, because, you know, it puts them in the picture and they don't freak out and, and also, it's a tool for discussion.

So the focus ought to be on what we need to do to assist this person's decision making. Not let's make the decisions for them because we're worried about them, but actually exploring with them.

HAMISH MCLACHLAN

In the Mental Health Act yes, there is a legal obligation to take supported decision making. So even if someone finds themselves and compulsory order, their psychiatrist when treating them has to first try and obtain their and informed consent to treatment. And as part of that informed consent is defined as including that the person has been given what's called a reasonable opportunity to make their decision. And then reasonable opportunity is also defined as including that the person has been given appropriate support to make the decision. It is a legal obligation under the Mental Health Act that people are given support, so that they can make a decision, as far as possible.

However, a lot of clinicians probably aren’t even aware of that, that is the legal obligation. And even if they were there might be a debate about what you would have to do to fulfill that obligation what the extent of it was, and then also at the end of the day, would there be any consequences for them legally if they don't follow it? Arguably not, which is a shortcoming, perhaps, in the law.

CATH ROPER

It is a huge deal to allow treatments that are not benign, that can create weight gain of kilos in a matter of months on people, you know, 20 years of life is lost to those of us who've, you know, been on these medications do not want electro-convulsive therapy and be given that against your will, that can actually happen under the law.

And so they're, they're not benign. And I think there's such a danger of dehumanisation, in the act of doing something against someone's will, that we haven't faced as a community. We let this happen. We actually let hospitals do this stuff. We let a Mental Health Act allow this stuff to happen, but we don't take the responsibility for the community.

HAMISH MCLACHLAN

A lot of people might not be aware. But in Victoria, you can still be given what's called electro-convulsive treatment, what’s sometimes called shock treatment, and you can also be given that compulsorily against your will. But for that to happen, there has to be a special order from the Mental Health Tribunal. And the Mental Health Tribunal can only make an order approving compulsory ECT if they're satisfied that the person lacks capacity to make the decision themselves. And we took a couple of those cases on appeal to the Supreme Court on what's called questions of law. In one of the cases it was all about when can you decide that someone doesn't have capacity to make their own decisions and in that judgement, the Supreme Court said that if you haven't given the person all the support that might help them, you can't come to a conclusion that they don't have capacity, which is a really important point and was a really sort of groundbreaking case because of that. The Supreme Court said that the VCAT had got the law wrong, because that required a really high standard of decision making of a client that doesn't apply to everyone in the community. Basically, they said that she didn't have capacity to make her own decision, because she hadn't carefully considered all the advantages and disadvantages, which is a really, really stringent standard to place on people. And I think if we think about it, and your listeners think about it, it's quite rare for us to actually apply that really rigorous pros and cons, weighing everything to decisions, even really important ones like medical decisions. Quite often people will really just go with their gut or listen out for an important piece of information that's important to them and that will steer their decision making. So to require or have someone with mental health issues to undergo this very careful weighing of pros and cons, where everyone else in the community doesn't have to do that. If you have cancer, you can decide whether you want to get chemo or not, and people won't interrogate whether you've really weighed up all the pros and cons. And so the judge ruled that requiring that if our client was discriminatory, and therefore an error of law.

The court said in black and white you have to give people support before you decide that they lack capacity, which was excellent. But in coming to that decision the judge wrote a really remarkable judgment with some really outstanding words. And one thing that he said was when he was describing why it's so important for people to be able to make their own decisions wherever possible, and why it's such a grave and serious thing when you take that right away. He described it in words that I thought were really quite wonderful. He said, that when people make medical decisions, it's really core to their identity. And he described it that he said that some people make those decisions, as if it's to be the next note that will sound in the song of their life, which I thought was a really nice phrase and described it really well that people when you're talking about these kinds of decisions, it really goes to the core of who you are. And someone might make a decision because that is what they feel will fit with them. And some other note, to continue the judges metaphor might be discordant. And having that forced on you, and having something forced on you that doesn't fit with your sense of self. It's really traumatic and really corrosive to your sense of identity.

CATH ROPER

We’re in, you know, we're in a period of time, I guess I see it as being in transition, sort of moving into a role of facilitating people's recovery, their strengths and their decision making. So this idea that in fact, capacity isn't pass or fail. It's not about a mental test. It is about this legal capacity. It's about citizenship, and it's saying it's relational, so we can actually work with people to increase decision making, through our relationships with them, through building on people's strengths, through giving them information that will help in ways that will help them understand or, you know, their preferred ways of receiving information and thinking and talking and decision making.

ELISSA SCOTT

I think it's important to have someone independent, especially because of the power dynamics that play out when the treatment order is in place.

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That’s Elissa Scott again.

ELISSA SCOTT

But that said, I think the Mental Health Act came in in 2014. The changeover from substituted decision making to supportive decision making is quite a cultural change and quite a practice change for a lot of the mental health professionals in the field. And then I think it's been a hard shift for some mental health professionals. There's a need for training there, it's such a large cultural change for so many people, that it's not just a case of making sure that you invoke those mechanisms. It's also how you practice and what kind of questions you ask them what kind of assumptions you make when you're meeting with someone.

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Independent Mental Health Advocacy (or IMHA), is a service supporting people undergoing compulsory treatment. Advocates work with people one on one to assist them through the treatment process, focusing on supported decision making.

ELISSA SCOTT

I think the IMHA model itself is a great example of supported decision making. Because we sit outside of the mental health system, we're independent and we don't advise people on what to do so we often sit with people provide them information about their rights and options, and then work through a decision-making process with them. We might explore what positives or negatives people have experienced to certain treatments in the past. They have preferences, if they'd like to try something different. And then once we've figured out what they’re view or preferences is, we enact that decision. So we might go an advocate or, or assist them to self advocate.

We've developed our own supported decision-making workshop package that we're rolling out, but we're not specifically funded to do that. So it's a gap that we've seen that we're attempting to cover. We've also delivered some sessions with the Mental Health and Disability Legal team at Victoria Legal Aid on rights-based care under the Mental Health Act.

I suppose a number of different ways that you'd need to tackle supported decision-making being implemented in entirety. But the funding is, is lacking in that space.

HAMISH MCLACHLAN

I think one of the biggest barriers that we see is that these changes were made in 2014. And as Elissa was saying, they are pretty wholesale change to how people should practice in this area. But it wasn't as far as we're aware, accompanied by an investment and the resources that would enable clinicians to really do this properly. And so they're expected to operate with the same resources, but have to do this much more intensive, much more time consuming and much better way of practicing. So there's the funding aspect, but there is also like a training awareness education aspect that I think is still, we're still kind of getting there.

HAMISH MCLACHLAN

According to the United Nations committee, there shouldn't be any substituted decision-making full stop. Australia has taken the view that the convention doesn't require removing substituted decision making. And that's a big controversy, because I think certainly in practice, if there was no ability to use substituted decision making, then you would see a rapid uptake of supported decision making.

But while there is that option on the table for clinicians of using substituted decision making, well they will take it. So if you remove that ability, then that would really enhance the use of supported decision making, and funding to services as well, so that they weren't so time pressured with their patients. But so investing more; doing more training, raising more awareness about it will all improve.

CATH ROPER

So I think there are systems failures that mean that support a decision making is harder to implement. There's so much that can be done in the community. I think in many ways, the system that we offer is, in fact very flawed. Our conceptualisation of what is wrong people's lives is actually flawed. I mean, there is no one size fits all, and yet we are acting as if there is.

ELISSA SCOTT

I think it's such an integral right of a person to be able to have autonomy over their own body and the right to make choices what happens to them in their life. So, anything you can do to support someone to make those decisions themselves, is just so important.

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Thanks for listening to **One in Five.** We have lots of information and links related to the research in this episode up on our website, visit **disability.unimelb.edu.au** And you can sign up to our mailing list there too.

We'd love to hear your thoughts and we hope you join us next time on **One in Five.**