**TRANSCRIPT Episode #4
“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.

ANNA ARSTEIN-KERSLAKE

I think there's so many different areas of the law that are still oppressive and marginalising people with disabilities. And people don't know about it, they don't think about it.

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That's Anna Arstein-Kerslake at the Melbourne Law School. In this two-part episode, we'll be looking at ways in which the law interacts with disability. In part one, we'll look at recent research on disability and the justice system.

ANNA ARSTEIN-KERSLAKE

There are some particularly bad laws here in Australia. When someone's charged with a crime, they can be found unfit to plead. Probably not surprising it's people with cognitive disabilities that are being disproportionately found unfit to plead. And then in some States, they can then be held indefinitely, or held for longer than they would have been held if they’d actually gotten a trial.

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The shift from substituted to support a decision making

ILAN WIESEL

the idea that what matters is our own choice and control. So that person with intellectual disability they should be supported to reach the decisions that reflect their own will and preferences,

TESSA DEVRIES

and how these concepts apply to consumer law.

YVETTE MAKER

Most consumer and contract law is about helping people to get out of a contract, if there's been some undue influence if there's been a decision that they didn't have capacity to enter the contract, and so on, which can get people out of a difficult situation or a situation that they shouldn't have lawfully been placed in. But it doesn't do anything to enhance people's access to those services. So it fixes a problem rather than facilitating the exercise of rights.

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Stay with us on One in Dive as we explore what research tells us about disability and the law.

First up, we're going to talk to Anna Arstein-Kerslake

ANNA ARSTEIN-KERSLAKE

I am an academic here at Melbourne Law School. I am the Director of the Disability Human Rights clinic.

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And Piers Gooding.

PIERS GOODING

I'm a research fellow at the Melbourne Social Equity Institute,

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who were part of a team working on a research project about the unintended consequences of a law designed to protect

PIERS GOODING

The *Unfitness to Plead* project was fascinating two year project whereby we looked at unfitness to stand trial laws across Australia and internationally, unfitness to stand trial laws, where courts are able to determine that an individual lacks the decision making ability and understanding to participate in the criminal justice process. It's based on a sort of humanistic protectionist idea that it would be unfair to subject someone to a trial that they don't understand, which could then end in their punishment. And you can understand that the problem is When people put through these alternative processes after being deemed unfit to stand trial, they can end up in situations that are far worse than if they had gone through a typical trial.

ANNA ARSTEIN-KERSLAKE

So one of the key stories and key individuals that made us be particularly motivated to take this on was Marlon Noble. He was held in the general prison population in Western Australia for over 10 years after being found unfit to plead. His case was, unfortunately wonderful example of how bad laws are.

So Marlin’s case it was a situation where when he was quite young, I believe he was around 18 so old enough to be charged as an adult. He was arrested for the sexual assaults of two girls, I believe it was, in the community he was that that he grew up in and was living in in Western Australia and he was taken to prison and it actually took a very long time I believe it was two years before he got a full hearing for finding whether he was fit to plead or not. Ultimately, they decided he wasn't fit to plead. And he did not then get a trial and instead was placed directly in the prison population and essentially forgotten about. Around 10 years later, a family friend Ida, got back in touch with the family. I think she got back in touch with the family because Marlin’s mother actually passed away. And Ida realised that Marlon was still in prison. And so Ida basically took it upon herself to be an advocate for Marlon, and to get lawyers involved and find out what was going on. Ultimately, what has happened is that after significant work on Ida’s part, she did get the court to look at Marlon’s case again. And when they did that they couldn't actually find the police officer that had initially arrested Marlon. They did go interview the two women who Marlon was initially charged with sexually assaulting. And they also spoke to the mother of those two women. And none of those three people had any recollection of Marlon ever assaulting them in any way.

ANNA ARSTEIN-KERSLAKE

So it's unclear exactly what happened there. Why Marlon was actually arrested in the first place, we don't know. But in light of that the case was taken to the UN Committee on the Rights of Persons with Disabilities. They heard the case and decided the case, basically finding what you would suspect that his right to legal decision making has been violated that his right to liberty and a number of other human rights have been violated and that Australia needs to as quickly as possible, to change the laws in this space to make sure other people's rights aren't violated in this way, which which we know they are being as well. There are other similar stories of people's rights being violated and being found unfit to plead not getting a trial, then being put in facilities and forgotten about and not having legal mechanism really to challenge that.

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Today, Marlon is living back in his community. But because of complicated legal reasons, his release from prison was not straightforward. And despite never having been convicted of a crime, he's still subjected to community orders. We asked which groups of people are most affected by these laws.

PIERS GOODING

So people with intellectual cognitive and psychosocial disabilities, are likely to be the ones subjected to unfitness to stand trial laws. That's the group that the law is designed to capture. Indigenous people are more likely to have disabilities than non Indigenous Australians. And that's for a complex array of factors related to entrenched poverty, and disadvantage and colonialism and the lingering impacts of that. And they are often the individuals in jurisdictions like the Northern Territory in Western Australia, who are found unfit to stand trial.

ANNA ARSTEIN-KERSLAKE

We have also seen some people that have hearing impairment and don't have appropriate translation. It's often the case actually, that an ASL translator isn't even provided. So that's another one that we have seen some examples of people being found unfit. When it's simply a hearing impairment that's impeding communication with various people in the criminal justice system.

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WE asked how the project was addressing some of these issues.

ANNA ARSTEIN-KERSLAKE

So what we wanted to do is not only do a project where we were telling Australian State and Federal government what they're doing wrong, but we also wanted to have a concrete solution embedded in the project. What we decided to do because no one had ever done it in the context of criminal justice before, is ask for money to implement supported decision making for people with cognitive disabilities charged with a crime. The goal was both to try to avoid findings of unfitness and also to provide evidence that support for decision making in the criminal justice system, and at the point of being charged with a crime is both feasible and possible and will improve outcomes improve efficiency in the court system, and also will allow us to protect the rights of people with cognitive disabilities charged with crimes.

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The project involves training people who had a background in disability support to become Disability Justice support persons. Once trained, they worked alongside lawyers to provide a range of support to people going through court proceedings, who are at risk of being found unfit to plead or not being able to participate fully

PIERS GOODING

Support entailed all kinds of things because they were faced with accused persons with a range of disabilities and a range of circumstances. So I think as diverse as human beings are, is as diverse as the kind of support that was provided, it included communication support, it included picking people up and getting them to their meetings included talking to Centerlink officials to try to work out whether the person was going to be given a breach of their bail conditions by not complying with some kind of welfare obligation. It included pictorial support so that people could place the order of events in the case that they were involved with. It involves contacting family to get them involved to assist the person in court. It involves explaining what judges were doing. It involves providing information to supports on the disability assistance need to that individual. It was vast, I could keep going. The point was that people with disabilities who come before the courts have all of these additional needs. And often duty lawyers don't have the capacity or necessarily the knowledge to deal with a support needs. And so having that extra support person, there was a way to give a leg up to that individual. And in a way to even the playing field, as we described it, it wasn't about providing special assistance, it was about just evening out the playing field so that they had ramps if you will, onto an equal plain with others in accessing justice.

ANNA ARSTEIN-KERSLAKE

What we did find is that everyone involved in the project individuals using the support the supporters and the lawyers that were involved in the cases. We found almost unanimous positive feedback from this extra support being provided when it was a person with cognitive disability charged with the crime. Of course, the laws need to change as well. But providing the support is a way to ensure that practice is changing on the ground.

PIERS GOODING

Several lawyers explained that it was what they saw as the future of community lawyering. That the high rights of people with disabilities in the criminal justice system was essentially for them a civil rights issue, because there were so many incarcerated individuals with disabilities. By having a Disability Justice support person there embedded in the community legal center it provided knowledge for the lawyers as well as that individual assistance to the person. But it also provided knowledge to the courts. Courts were often hungry for ideas for how best to respond to individuals with disabilities because they didn't want to see them coming before the courts, prosecution wanted to reduce offending or reduce the likelihood of re offending. So they were hungry for ideas, but often the only solutions they had were legal ones, whereas the Disability Justice support person was able to bring some of that disability accessibility knowledge and come up with solutions that involve Disability Services, that involved housing services and sort of allowed them to better communicate and understand this person so that they could respond in a tailored way to their circumstances.

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The project showed very clearly the benefits of providing this extra support. Interestingly, the results are also showing a likely and significant cost savings.

PIERS GOODING

So we did an economic cost benefit analysis to look at what it would have cost to not have the support person there. Now, we looked at what it would cost for the Disability Justice support person to provide the assistance they did. We costed their time we costed the time of those involved in a particular outcome in a case study. And we compared that to what would have happened had they not been there. The cost I think for this one individual case, which was a Victorian case ended up being something like $5,000 all told. The cost had it gone to unfitness to stand trial proceedings, which is in a higher court so would have involved impaneling a jury and it would involve senior judges, would have cost somewhere in the vicinity of $300,000. And that’s just for the court proceedings alone. So immediately there you can see a $295,000 savings, admittedly it's a hypothetical, but it was costed using government data on the cost of these court proceedings. And I think that can be expanded around the country, because it’s well acknowledged that it's extremely expensive to have people detained in prisons. So I think there's enormous potential for that economic argument alongside the rights based arguments.

ILAN WIESEL

I think in academia, most of the work on supported decision making is within sort of legal studies, law studies. So the convention was a key driver of the shift from substituted decision making to supported decision making. And then there's sort of other fronts where the shift needs to happen and one is in what I would call an institutional front

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That’s Ilan Weisel from the School of Geography at the University of Melbourne.

ILAN WIESEL

People with intellectual disability, many have lived until not very long ago in institutions where they just did not have opportunities to make decisions, because decisions were made on their behalf by staff in institution. And even though we've had deinstitutionalization, many have moved into to group homes and other settings, where still opportunities for making decisions and making choices are denied. Part of it is actually changing the structures of the support services and housing. So it's not just about legislation, but about developing models of support and housing that are that actually give people decision making opportunities.

And then a social cultural front where you think about the people who provide support for decision making they, they don't necessarily follow the law. They don't read the legislation to think how are we going to support our or daughter or brother or sister? I guess they follow practices, they follow other people that they observe. And those practices are mediated by their own cultural biases.

So I guess the question that we've looked at in this project is how do you change behavior and actual behavior and practice. And we thought that maybe if we can provide people with a resource that is based on practice and experiences of other people and can show them what we know from research that actually works that people can do, and follow some principles in providing support for decision making. That that’s another way to reach the same goal.

So this is a project that's led by Latrobe university that I'm also part of. It's led by Christina Bigby from La Trobe University. It's looking at the practice of support for decision making.

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They talked to adults with intellectual disability or acquired brain injury and their main supporters about the decision-making process

ILAN WIESEL

Then they through a kind of workshop where we offer them some training, using the framework for best practice in support for decision making. And then we do a follow up interviews, to understand whether practice has really changed, and experiences change in any way. So it's trying to understand, I guess, to learn, what are the practices out there, what's actually happening, and then also whether through intervention through some kind of providing resources to supporters or we can improve practice across the board, I guess not just among paid support workers but also for families.

And then hopefully, once we've established what types of training are actually effective, then we can make this resource really available online so families can use it. And I guess, disability support services.

YVETTE MAKER

Traditionally, people particularly with cognitive disability, especially people with diagnosis of intellectual disability or acquired brain injury or severe mental health conditions, have not been expected to have legal capacity to make their own decisions to enter contracts, which then can affect the exercise of a whole range of rights not only in terms of simply being recognised as a legal actor with legal agency and choosing the goods and services that you acquire, but also in terms of living independently and being included in the community, in terms of access to flow on rights in terms of you need heating to ensure that you have good health. You need electricity, access to the Internet, and so on to access a range of other services including your social protection services, which might include Centerlink the NDIS itself and so on.

TESSA DEVRIES

That's Yvette Maker.

YVETTE MAKER

I'm a Senior Research Associate in the Melbourne Social Equity Institute and Melbourne Law School

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Yvette and her colleagues work on research projects focusing on consumer activities, how service providers function and how to improve access for people with disability.

YVETTE MAKER

So the NDIS is designed to make it more possible for more people to live independently in the community, and a big part of that is being able to set up all of these accounts and manage them and also deal with problems when they arise. There was really a lack of research around the needs of consumers, particularly with cognitive disability, and certainly a sense from consumers, from advocacy groups and from industry, that there was a gap here. And we've spent the last couple of years starting to explore that, with a particular focus on supported decision making, but also looking quite broadly at what retailers and providers are doing at the moment and what they could be doing better, which includes maximizing support, but also things like providing accessible information for people and really straightforward things like doing disability awareness training, so we've ended up looking quite broadly at the issue.

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To identify the biggest challenges and work through potential solutions event and her colleagues went through a process of consultation. They talked with a range of people, consumers with disability, disability advocates, retailers, for services like the internet, gas, electricity, water, and so on.

YVETTE MAKER

We came up with a set of scenarios based on what people had told us of possible issues that we heard that people were having. So things like getting two bills, one for electricity and one for gas and mixing them up paying the electricity bill twice, and then the gas gets cut off. Those kinds of things that we heard all the time, or people having difficulty paying, but when they called the provider, they felt that they weren't listened to, they didn't get assistance, it escalated their distress and didn't help them to solve their problem.

So we went with a set of those scenarios to some focus groups of people with cognitive disability, and with our ideas for what might be done about those things. So in the example of bills someone had suggested something really straightforward, two different colored bills. So the electricity bill is one color, the gas bill is the other. And then we took all of the information that they gave us, essentially came up with a set of guidelines for retailers to improve their processes on these two prongs of accessibility and supported decision making.

So we have the long more technical report, which sets out the Human Rights arguments and the Australian legal arguments and so on. And then we have what we've called a top five tips sheet, which is the short version of what we think are the really the most important things for making services more accessible.

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These resources are available on our website.

YVETTE MAKER

And one thing that might helpful, I suppose, is to talk a little bit about what supported decision making looks like in this space. We've really thought about it as being something that has multiple levels. And we focused on the role of retailers in facilitating supported decision making. Traditionally, we've really thought about supported decision making in terms of the relationship of the decision maker, and then the personal people who are supporting them. And here we've been looking at that role of third parties, and really view them as having a number of roles.

So one is to facilitate supported decision making, which means, firstly, as I said, presenting accessible information. So for example, if you've got the 30 page version of the contract, if you can also have a shorter, easy English or easy to read format of that, then they can be read side by side with the support person to catch the crucial pieces of information and to work through that process and make decisions together.

But then there's the other element of that is recognising support people, so making space for them to be involved in phone conversations. We heard examples where people were told that their supporter couldn't come on the phone and explain something because they weren't legally authorized and there are privacy concerns which are can be legitimate concerns, but again needing to think through how can we work those through so that supported decision making can be possible.

And so they're really big two elements. And as I said, the third is recognising that role of the supporter while having enough awareness and understanding in an organisation that supported decision making has to be led by the person themselves by the consumer. And so we're not sliding into substituted decision making situations and leaving that space for people to make bad decisions as well. And if people don't want support, they don't want to choose a support person and so on, that being an acceptable choice for people to which really requires organization- wide awareness of these principles and how they apply.

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And what are the key messages for retailers? How can they implement these findings?

YVETTE MAKER

Again, we've really prioritised support and access to support and really encouraging retailers to put that up front, so to ask all consumers at the outset or as early as possible, if they would like to use support in some way. So normalising that as something that all people can do use at certain points, and particularly when you're contracting for services that can be quite expensive and can be a significant financial obligation. Retailers were very concerned about not being discriminatory in that questioning, very aware that they didn't want to be asking questions about do you have a disability and those kinds of things which would not be appropriate for a range of reasons. But again, coming up with some standard language around would you like to take some time to think about this before you sign? Is there someone that you usually talk to about these things, all those sorts of more general questions that can become a standard for frontline staff, but really assist people in that way, and then a follow on from that of asking people as a matter of course, if they would like to list a support person on their account, which can make it a lot easier for someone else to be involved at whatever level the consumer one. And then that really needs to be backed up with accessible information.

ANNA ARSTEIN-KERSLAKE

The challenge really is erasing those preconceived ideas about cognitive disability, and about what that means and about what that means for participating in decision making in general. But decision making and the denial of decision making on the basis of membership in a certain group is a problem all throughout the law and all throughout how the law is implemented. And it is people with disabilities that are disproportionately affected by that.

PIERS GOODING

Well, I think even if you look at the major policy of the NDIS it's really an attempt at redistributive justice. I think that's the beauty of an idea as simple as supported decision making. It makes sense, redistributing resources to those who require a little leg up in order to enjoy things on an equal basis with others makes sense to most people when you describe it that way.

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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 on our website, visit disability.unimelb.edu.au to check it out, and you can sign up to our mailing list there too. In part two of this episode, you'll hear about compulsory medical treatment orders, the practice of supportive decision making and the real-world impact of legislation.

CATH ROPER

You've got this mental health legislation that's telling you that you can act on behalf of someone else, you can make decisions on behalf of someone else, because they don't have capacity. But on the other hand, you meant to be providing a recovery focused service where you're paying respect to people's self-determination, but yet their own wishes for treatment can be ignored so you can not want treatment and be treated against your will.

HAMISH MCLAUGHLIN

There's a whole lot of provisions in the mental health act that where people have rights and their obligations to do things, but there aren't necessarily legal consequences if those rights aren’t upheld, or those obligations aren't fulfilled. And the supported decision-making example is probably a really good example of that.

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Join us next time on One in Five.