Episode 3: Disability, Automated Decision Making and Policy

**SUMMARY KEYWORDS**

disability, systems, decision making, technology, people, adm, automated, data, research, organisations, decisions, ways, algorithmic, important, automated systems, unsw, ndis, justice, work, biases

**SPEAKERS**

Prof. Jackie Leach Scully, Dr. Georgia Van Toorn

**Jackie Leach Scully**

Hello, I'm Professor Jackie Leach Scully, director of the UNSW Disability Innovation Institute. So thank you for joining us as we continue with the third season of our podcast series, and we're kicking 2024 off with the discussion about technology and disability in the emerging field of automated decision making, or ADM. First off I'm going to acknowledge the Gadigal people of the Eora nation, who are the traditional custodians of the unceded land, on which the UNSW Kensington campus sits. I'd like to pay my respects to elder's past and present and to extend that acknowledgement to all Aboriginal and Torres Strait Islander people listening today as we share our knowledge and practices across our communities. We also recognize the knowledge and experience embedded within the Aboriginal custodianship of Country.

**Jackie Leach Scully**

Now a little bit about the Disability Innovation Institute itself. This is an initiative focusing on disability research, education, and knowledge exchange. Its team members take pride in undertaking work that is radically inclusive, and that crosses disciplinary boundaries. Our approach is to see disability not as a problem to be solved, but as an integral part of the human condition to be encountered and engaged with rather than feared. So in light of that, joining us to discuss some disability issues associated with automated decision making is Dr. Georgia Van Toorn who's a lecturer in the School of Social Sciences at UNSW and also an Associate Investigator at the ARC Centre of Excellence for Automated Decision Making and Society. In 2023, Georgia was awarded a research fellowship at the Data Justice Lab at Cardiff University in Wales, where she undertook participatory research into the ways that automated systems can be recognised, resisted and reoriented to promote disability justice. And Georgia and I have been working together for about the last two years within the Centre for Automated Decision Making and Society in a couple of projects relating to ADM, and people with disability. So thanks for joining us, Georgia.

**Dr. Georgia Van Toorn**

Thanks for having me, Jackie.

**Jackie Leach Scully**

To kick off with a very basic and obvious question. Can you briefly explain what exactly automated decision making is?

**Dr. Georgia Van Toorn**

Yes. So in simple terms, automated decision making is when computers make decisions for us either on their own or with the help of humans. And these computers, use a set of rules or a model to understand how to make these decisions. And they follow instructions, which we sometimes call algorithms, which are written in code. And these use data to essentially make decisions or recommendations or perform certain tasks or functions. And that sometimes they learn how to make better ones in the future as well. They have that autonomous function of learning built into them. In my research, I like to not just focus on the technical aspects of ADM, but also at the social and political dimensions around how they're used. So I think that's really important to remember here, that context is always really important when we're trying to think about what is ADM, in my work, I often draw on the work of Algorithm Watch, which is a civil society organisation based in Europe, which does research around what they call ADM systems, they say that instead of focusing on the technologies themselves, we also want to take a holistic approach here and acknowledge that these are actually socio technical systems that encompass not just the decision making model itself, the algorithm that translates that model into code, but also the the entire political and social environment that surrounds the use of that system. And this means that the decision itself to actually apply the the system and the way in which it's developed and the purposes to which it's put are all parts of the framework.

**Jackie Leach Scully**

Okay, thank you. That's really, really helpful as a starting point for thinking about this. Now, we hear a lot about ethical issues in artificial intelligence in AI, presumably also in ADM, as well as a sort of offshoot of one manifestation of artificial intelligence. So what kind of ethical problems do you think ADM presents?

**Dr. Georgia Van Toorn**

Yeah, so this is a real growing area of research and public debate at the moment, especially in the last few months with the release of chat GPT. And I think historically, the conversation has really revolved around the impact of automation on for example, Job the the labor market and job losses, people have been concerned that their jobs are going to be replaced by machines, and the sorts of economic benefits and risks that automation brings for the economy. But I think more recently, research in this area has directed attention to other other sorts of ethical issues. For example, the biases that are present in data that ADM systems are trained on, which can lead to unfair treatment of certain groups. So for example, if data is if historical data is biased against a particular demographic, for example, that system might then perpetuate those same biases in its decisions. There are also concerns about the sort of opacity of these systems, there's this metaphor that's often used in the literature of a black box. So okay, we often talk about how, you know, these systems operate as black boxes make, which may mean that it's really difficult to understand how these decisions are actually reached. And there's a there's a real lack of transparency there that can make it difficult to hold organisations or individuals to account for their decisions. There's also questions around privacy and the fact that automatic decision making relies on vast amounts of personal data. And there's a risk, obviously, that that data could be misused or mishandled in some way, leading to potential violations of privacy. And then at a more sort of systemic level, I think there's questions around human oversight and accountability, especially in in democracies like Australia. So, for example, if a if an automated decision making system is depending solely on sort of automated processes, and there's a complete removal of human involvement, what does that mean for you know, who is accountable in that scenario? Can we hold elected politicians, for example, or public government agencies to account for the decisions that are potentially harmful, and I think we can point to recent examples like robodebt, that illustrate that really nicely. And then finally, I might just say something also about inequalities, you know, there's a growing body of literature around how automated systems exacerbate existing social inequalities and that how people that tend to be disproportionately disadvantaged by ADM, if they fall along certain axes of social disadvantage. So they may be more likely to have their life chances dictated by an ADM system in the first place. And they also might be more likely to be negatively affected by the outcomes of those decisions as well.

**Dr. Georgia Van Toorn**

So this has really been the focus of our research, Jackie, at the Centre, we sit in a node of the ARC Centre for Excellence for Automated Decision Making in Society. That's the note is based here at UNSW. And we sit across, there are four research streams within the center, then those focus on news and media transport and mobilities, health and social services. Our work as you know, Jackie sits across the sort of health and social services domain. And that's really important, obviously, for people with disability as they're coming into contact with those systems that are fairly frequent rate. And so they're more likely to experience the effect of ADM in those areas. And so our work has really been around, I suppose we come to this area with an interest in questions of justice and fairness, and a commitment to research that really, I suppose attends to the lived experience of people with disability. And so we have a number of projects that centers those voices in various ways. I would just touch first of all on our our dialogue group project, which is something that you and I are still in the process of undertaking this project. And what we're really hoping to do there is explore how people with disability experience, understand and imagine automated decision making, and particularly the types of, I guess, moral judgments and sort of ethical judgments that people make about technology and how they come to those, how they come to make those judgments, what are the forms of reasoning they use to think about the ethics of technology. And I think this is really important, because there's a lot of research suggesting, particularly in disability studies, really focusing on the importance of technology in terms of assisting people to live their best lives. And this really tends to, or at least some of it tends to present technology as generally a force for good when we know that there are, you know, these various emerging ethical and social problems associated with ADM. And this area of more critical literature, I think, is only just beginning to emerge, and particularly in engaging with the voices and perspectives of people with disability, who I think, who I'd say, you know, up until quite recently have been, more or less, quite marginal to the sort of critical debate surrounding the social and ethical implications of ADM. Yeah. Really trying to sort of engage with that those voices.

**Jackie Leach Scully**

Okay, so that's a huge range, and you've talked about the bias, or of being perpetuated because it's independent in the material the system to learn from, and therefore they learn how to be biased, in a sense, you talked about the lack of transparency, or explainability, perhaps at the systems and use of personal data and the lack or sometimes the lack of, of having some kind of human involvement or accountability, and ultimately, of making those social inequalities even more pronounced. So each of those who can think of as having some relevance towards marginalised communities of different kinds, my next question to you is going to be a very obvious one, which is what is the relevance of all of this and to people with disability?

**Jackie Leach Scully**

Yeah, that's great. I just wanted to say there, you reminded me that, I think was very obvious to both of us when we were first looking at this in this project. But there's a lot of emphasis in various reports in the literature about how ADM and AI in general can be used for assistive technologies in particular to make the world more accessible for people with disability. And most of the critiques sort of stayed on that level and we were interested, I think, in going a little bit deeper than that, and also seeing how less obvious systems are interacting with people with disability.

**Dr. Georgia Van Toorn**

Yes, you're right. Yeah, I think a lot of critique is really centered around issues of exclusion and, issues of usability, particularly when it comes to assistive technologies. And in that sense, people with disability in that literature are often framed as sort of consumers of tech, when really I think there's a much more a broader range of sort of positionality is that we need to explore here, and also questions of other forms of technology that, that people may not even be aware of, they're impacting them in their daily lives, it may not be technologies that they're used that using, that they're using, or that they want to use it, maybe technologies that are being used on them in quite ways that are quite hard to understand, or even sort of, that they may not be even aware of, for example, so a lot of ADM systems are operating for all of us in the background of our daily lives, without us necessarily being aware of them. And I think that's where engaging with that critique of those sorts of systems is really important.

**Jackie Leach Scully**

Yeah. Sorry, I interrupted you. We were telling us about the project, what have the findings been?

**Dr. Georgia Van Toorn**

With our dialogue group project, we've held a number of conversations with people with disability exploring, as I say, their views on technology, and how they come to form the their opinions. And what we've found is that people are really, they hold very diverse views about the potential benefits and the harms of ADM. And sometimes that depends on their individual circumstances or their background. So they might some put a lot of faith in new technologies to support them in their everyday lives, accessing the communities, helping them around the house, that sort of thing. And many, many people are really tech savvy, and they have been early adopters of smart technologies around the home, for example, because they find that really helpful. But also there's, there's questions around, you know, how whether those technologies are accessible to people either in terms of how they're designed, but also particularly around how affordable they are. So not everyone is able to afford the latest smart tech. So there's a question there around the sort of uneven benefits and harms of ADM and how those are distributed. And then when we look at particular examples where, for example, government relies on automated systems to make decisions to things like public benefits and services, we find that most people have a lot of people that are of two minds about this, they're a little bit ambivalent. So while they might recognise that technology and automation can streamline decision making and make those processes more efficient, there's also some concerns around for example, equity. So people question the extent to which, you know, should everyone be treated exactly the same if they have the same disability for example, given the diversity within in how people experience particular impairments or should certain groups or people receive Should treatment? Should there be more human intervention? For people who may be considered particularly marginalized or vulnerable? Is that what Justice looks like for ADM? So there's some questions around fairness and justice, and how people understand those concepts.

**Jackie Leach Scully**

Yeah, that is very interesting, because it's the kind of fundamental question really, isn't it? What does equality or equity actually look like in practice? And is it sort of neutrality towards difference? Or is it particularity? Is it taking that particularity into account? And I know, philosophers of justice, spent entire careers working that one out so well, we may, we may not come to an answer to it in the in the course of this project. But it's an interesting observation. And I think that it's that question runs all the way through the very fundamental level. One question is whether people with disability like a lot of other people in marginalised communities have more than the average number of encounters or level of engagement with service providers of different kinds with state and regional bureaucracies of different kind, what that does to their acceptance or otherwise, of the involvement of technology in decision making, Did anything come out of your findings relating to that?

**Dr. Georgia Van Toorn**

Yes. So this has come up a lot, actually, in my conversations with people, the idea that the harms or the outcomes that are experienced from ADM have a sort of compounding effect, because of the way in which people with disability are in constant contact with many different government or service systems. So they might be receiving health care, but also services through the NDIS. They might also be in contact with Centrelink, for example, on the Disability Support, pension, and a range of other government agencies and systems. So a lot of people that I spoke to actually mention this as a real concern that the harms that come from being either discriminated against or sort of flagged in various ways by these different systems are actually compounding. So for example, if you're in contact with Centrelink, and the Department of Human Services and the NDIA, for example, across all of those agencies, you might have particular labels or flags related to your file. And those agencies will often share data to so that your personal information will get picked up across agencies through Linked Data arrangements. And people said that the cumulative effects of that was was potentially quite harmful, because people tend to accumulate these multiple identifiers and flags across their records in multiple different systems. And that compounding effects leads to increased scrutiny overall, and interference in people's lives and especially that's especially true for people with disability, but also other forms of, you know, social identifiers, you know, marked by racial, racial or economic disparities, that kind of thing.

**Jackie Leach Scully**

Right? Let's say you have a system where there's an increased level of surveillance, maybe scrutiny anyway. And if there is some kind of an error, or even if and often they're just something that draws attention, that gets ramified across all of these different are many of the different systems. And that's interesting, because I think a lot of people, whether disabled or not, have a almost a prejudice that a technological system is necessarily going to be fairer and more, you know, more objective, certainly less prejudiced. How does that play out in these conversations?

**Dr. Georgia Van Toorn**

Well, and yes, I think that comes up a lot with people for example in our dialogue groups expressed that sort of similar sentiment that they'd have in the past quite negative encounters with service systems. So and human decision making systems and that had led them to be perhaps more open or receptive to the idea of technology contributing to decision making. And that really stems from a belief that technology could potentially serve to sort of counteract the discrimination that they've experienced due to the human biases embedded in decision making systems in government decision making systems, for example. So we heard some people say, Well, you know, the technology driven process or an automated process couldn't be any worse than what I've experienced from a Centrelink officer for example, But then on the other hand, we also hear a lot of concern that, you know, the ability of ADM systems, there is the potential for those systems to really ignore important nuances and complexities in people's lives. And this comes back to this point about data, reductionism and the way that quantitative approaches to decision making and data often strips away important context in a way for example, people with disability live with and experience impairment. And those are really we find that people put a lot of emphasis on those contextual factors, and are really concerned about the ways that ADM may not pick up on those areas of life that are perhaps less amenable to quantification or in more nuanced in ways that is not easily captured by ADM systems.

**Jackie Leach Scully**

So things like the I suppose the way that an impairment might fluctuate over time, or depend on whether you're at home, or in a strange place or something like that?

**Dr. Georgia Van Toorn**

That's right, though, the way they fluctuate over time, the way they intersect with other identity experiences of being so for example, trans or being a woman, or from a particular racial or economic background, people also talked about how living with rare conditions is also problematic for these systems. There's no, there's just simply not enough data on on those conditions, to inform, you know, to be able to make any sort of informed decision about what people might need, for example, based on their impairment category.

**Jackie Leach Scully**

Okay. So, in some cases, it's just not I won't say just but there's a fundamental problem about sheer lack of data. But it may be something more subtle than that as well.

**Dr. Georgia Van Toorn**

Yes, I think it's both the lack of data, the fact that disability and data about people with disabilities often lacking in the large datasets that are used to train algorithmic or automated systems, but also a broader point about how we capture the very complex and nuanced experience of disablement through quantitative data, and whether something as personal as someone's support needs can be really properly captured by a model that tries to sort of quantify disability in numeric terms, people find that hard to wrap their head around.

**Jackie Leach Scully**

Yeah, I can understand that. Sure. You mentioned earlier on the robodebt. I think it has been carved into the collective memory of Australia, really, but algorithms like that get used and misused in lots and lots of different contexts. And obviously, one of the contexts that people with disability in Australia encounter most is the National Disability Insurance Scheme, or the NDIS. Has the NDIS been using this technology as well?

**Dr. Georgia Van Toorn**

Yes, so the NDIS uses a range of automated processes in different ways and for different purposes. The probably the most widely sort of known about and documented use is for the purpose of creating support plans. So the NDIA, as I'm sure many people listening, are very aware, very familiar with the NDIA will ask people when they apply for access to the NDIS, they'll ask them to submit a collection of reports and documents documenting their disability, and a range of other things about for example, their demographic, their age, where they live, that sort of thing. And those data points, particularly the data points around their in their impairment, their age, and the geographic locations or where they live, those data points are used to generate what's called a typical support package. And that's a kind of template that is generated for people, for everyone based on a statistical kind of averaging or estimation of what people in that category typically require. Then that template then ideally gets modified by NDIA staff in a manual process through conversations with people. That's the hope that's the idealised kind of process but what we find sometimes happens in reality is that NDIA planners, or LAC, local area coordinators often will fall back on automated or algorithmic inputs or recommendations because they lack the proper training, or they might lack the time and the resources to actually have those really personalised conversations with people about what they need and and how their supports might actually differ from what the recommendation is that they've been given. So people will tell us that they they're given plans that don't reflect their conversation with the planner at all, or they sometimes even have the wrong name on the plan. So we see this evidence of a sort of automatically generated support plan, based on particular, a sort of data crunching exercise with very little actual manual intervention. And that's not in all cases, that's only in some cases, some people report getting really great plans and great plan. But we do have these, unfortunately, examples of people's plans being algorithmically generated with very little human input,

**Jackie Leach Scully**

Okay. In a way, that's the worst of both worlds, both the automated world and the and the human involved world. But you have too, too crude a plan? And why because it's all automated, but same time you have you don't have the involvement, or there is a human involvement, but they're cutting corners, for whatever reason. Is there a sense at all around that some of this is being deployed for cost cutting reasons?

**Jackie Leach Scully**

We've been talking here really about the Australian setting, are there similar sorts of things happening for people with disability and others in other countries like the UK or the US?

**Dr. Georgia Van Toorn**

Yes. I mean, this is something that National Disability Insurance Agency will say, not quite in that language, but yes, they talk about the importance of efficiency and reducing, the time spent and the sort of labour spent on planning, and but they will often cloak it in yeah, in language of efficiency, you know, streamlined decision making, and the importance of treating people equally. But, you know, as we, as we talked about before, many people with disability that we've spoken to don't necessarily see equal treatment as just they actually want to be treated in ways that acknowledge their individuality. And they see it as fundamentally sort of unfair that these extrapolations are made based on their sort of diagnostic category that they might fall under. They often will say, you know, you might have 100 people with the same diagnostic sort of label attached to them, but they will all have 100 different sets of needs, and preferences for their support. Well, it's equal treatment, it's not just, necessarily.

**Dr. Georgia Van Toorn**

So, my research is focused on those two contexts, in particular, the United Kingdom and the United States, where I would say that Australia has really sort of followed in the wake of those those two countries and adopted a lot of the same technologies, if not exactly the same algorithms or software, then then the models. So in the UK, for example, the way the Department for Work and Pensions uses an algorithmic system to determine the risk of someone defrauding the system, they use a number of what they call risk indicators and one of those appears to be that the person has a disability or lives with a person with disability. So there you see, you know, the sorts of cultural biases and assumptions about what it means to have a disability creeping into the data that feeds and trains these algorithmic models. In other jurisdictions in the Netherlands, for example, they use other risk factors related to someone's racial or ethnic background. So in the past, if you come from a different country, for example, you're not a Dutch national, then that is, according to the risk calculation model, it's more likely that you might commit benefit fraud, according to that model. So yes, we do, I think we have definitely sort of followed in the footsteps of the both of US and the UK, in that sense, might also note that the NDIA, at the moment is looking at these sorts of fraud, algorithmic fraud detection methods to try and identify the risk of fraud within the NDIS itself. And it's also set up these similar sorts of data sharing arrangements with the Department of Home Affairs, for example, which for me, raises some red flags around the potential of data related to nationality and race and ethnicity for detecting potential fraud. I think that's an area that we probably really need to sort of keep an eye on.

**Jackie Leach Scully**

Yeah, it's a real tension, isn't it between acquiring data that are useful and will benefit people and unnecessary to understand how to allocate things fairly, and just acquiring data indiscriminately and sharing it perhaps with less control than then there might be ideal. I wanted to ask now about what the response has been to some of these issues, emerging issues from the disability community, itself, particularly disabled people's organisations, how are they reacting? Are they reacting?

**Dr. Georgia Van Toorn**

Yes, this is an area that I really more recently began to focus on is what is the response from people with disability, and particularly from Disabled People's Organisations themselves. And I've recently written a report - what I'm calling a primer, which is basically an overview of case studies and concepts that try to give a picture of the sort of essential concepts that are needed to really understand and intervene in the politics of algorithms from a disability justice standpoint, and also examples of organisations that are doing that right now. So for example, in the UK, the Greater Manchester Coalition of Disabled People are actually one of the leading groups that are challenging the Department of Work and Pensions automated fraud detection system that I just spoke about previously. They're actually they've joined forces with a legal aid, civil society like legal organisation Foxglove, to, to challenge that the use of that system in the courts. Then in the US, for example, it's another area where we've seen a lot of disability led responses, that the state of Arkansas, for example, people with disability have pursued lawsuits, both under federal and state laws. And that's actually resulted in a number of changes and wins. So there was one case, for example, where an automated decision making system was used to allocate home care hours, and that system was halted due to some provisions in the Administrative Procedures Act, which the court ruled said that basically, the state had followed to follow public notice and comments rules within that Act. In adopting that algorithm, it basically failed to meet the standards of due process, and so that ruling essentially invalidated the whole system and put put a pause on the cuts that it was making to people's homecare hours, eventually, in that particular case, that system was replaced by a different automated system, which has its own set of problems. But that's just an example of where people with disability have sort of paired up with various legal organisations, Legal Aid being really important, in many cases, to challenge these harmful impacts of ADM, particularly through the legal system.

**Jackie Leach Scully**

Right, it's good to know that there are some ways in which a reasonable kind of pushback is occurring, I think that the message you seem to be giving here is that we're a system might be halted, but it will be replaced by an automated or equally automated system. So in a sense, these things are, you know, are there and they are coming and the question is really how best to how to ensure that they operate in the best way possible for people with disability. I mean, do you do you think there's any mileage in people trying to reject such systems altogether?

**Dr. Georgia Van Toorn**

I mean, I think it really depends on the context and the use to which these systems are being put. I mean, there, there would be many who would argue that there are some areas of decision making that should just be considered, you know, so called no go areas for automation, they are such high stakes decisions that are being made that impact people's lives in such severe ways that it's just plainly sort of immoral to sort of, to delegate those high stakes decisions to automated systems, because they're essentially unaccountable, and also, you know, the sort of, it's undemocratic in a way to that there's no one can be held essentially accountable for the outcomes of these systems, their authority is being ceded to sort of unelected agents if you like. So I think for me, it depends on it depends on the context. I think when it comes to things like the allocation of funding for social support for healthcare for home care, these are areas where if you get your funding cut or your care hours reduced, you might end up in institutional forms of care, or in seriously compromised living conditions. I just, I just don't think that that the use of automated decision making in those areas can be justified.

**Jackie Leach Scully**

Thank you. The wrap up question really is about the excellent work that you've been doing in this area, what's next for your research?

**Dr. Georgia Van Toorn**

I think I've probably spent the last few years trying to develop a sort of an account of the problems or the critique, if you like.

**Jackie Leach Scully**

So, it is from problem to solution now?

**Dr. Georgia Van Toorn**

That's right. Well, yeah, if not solution, then at least the potential for intervention and change and challenge. And I think it's really important that we remind ourselves that these developments in technology are not inevitable. We're not completely powerless to resist them or reorient them in ways that are more consistent with justice and human flourishing. And much of this work is sort of already happening on the ground. And some of it's quite invisible or not picked up on by, you know, academics. But there is a lot of work that's really important that's taking place within NGOs, within disabled people's organisations, for example, within tech justice movements, and I think it's really important to sort of highlight what's happening now and also think about the ways that we, as academics can contribute to and support those kinds of initiatives through research through doing whatever we can to kind of amplify those those voices in those positions. So for me, I'm really interested in research that kind of engages productively and and actively with advocacy and activism around issues of tech, justice and disability. I'm making a short film actually about a group of people with disability in Australia, a group of disability activists who are seeking legal redress for the harms that that they feel have been created for them by the NDIA's adoption of algorithmic decision making systems. And our aim there is to really translate some of those what can be seen as fairly sort of abstract dry problems into into real human stories and really trying to translate do that translation work that's involved for people to really understand the issues that are at stake here. We do that by focusing on people's lived experiences and allowing them to tell their stories in their words, and also exploring their motivations for getting involved in political and legal mobilisations against what they would they call Robo NDIS. And then Jackie, you and I will also continue our work on the on the dialogue group project, which is looking at you know, what, everyday people with disability think about ADM and what's important to them when considering that the ethics of new technologies and how we shape those technologies towards more just futures.

**Jackie Leach Scully**

That's all fantastic and particularly this idea of using a film to it makes some of these issues, more real, more concrete, because I think many people can feel very engaged and can empathise with say the problems of an inaccessible building, but something like automated decision making is so, so intangible, pervasive, but also intangible that it can be very hard to to grasp what some of these issues are. So everything that can bring it to the forefront of people's attention, including those from the people who are suffering from the effects as well who may not entirely realise what's going on in a way in you know, behind the shiny surface and in the hidden wiring if you like. I think we're just about out of time Georgia, so just want to end by saying that if you want more information about the ARC Centre of Excellence for Automated Decision Making in Society, their website is www.admscentre.org.au.

**Jackie Leach Scully**

Final thanks to Georgia Van Toorn for joining us on the podcast and giving us the benefit of your knowledge and expertise and we at the DIIU will be looking forward to sharing our next podcast with you shortly.