DIIU Podcast S4E1 Transcript
Preventive Healthcare for People with Intellectual Disability

Intro Music 00:00

Prof Jackie Leach Scully 00:06
Hello, I'm Professor Jackie Leach Scully, Director of the Disability Innovation Institute at UNSW, and thank you for joining us in our fourth series of this podcast. Today, we're going to be talking with Dr Maryann Barrington about preventive healthcare for people with intellectual disability, first, I want to pay my respects to Elders past and present, and to extend that acknowledgement to any and all Aboriginal and Torres Strait Islander people who are listening to our podcast as we share our knowledge and practices across our communities, we also recognise the knowledge and experience embedded within the Aboriginal custodianship of Country. A quick word about the institute itself. The UNSW Disability Innovation Institute is a world first initiative. It focuses on disability research, education and knowledge exchange. We at the Institute take pride in undertaking work that's radically inclusive and that crosses disciplinary boundaries. The Institute's approach to disability is to see it 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, and joining us on the podcast today is Dr Maryann Barrington. Maryann is a postdoctoral researcher at the National Centre of Excellence in Intellectual Disability Health at UNSW. The Centre was established as part of the national roadmap for improving the health of people with intellectual disability. Maryann works there with the Centre Director, Professor Julian Trollor, and a number of other academics and organisations working together on a project to explore and improve preventive health care for people with intellectual disability. Thank you for joining us Maryann.

Prof Jackie Leach Scully 02:00
I'd like to start, if I can, by asking you, first of all, just tell us, what is the problem here? What are the experiences for people with intellectual disability or their carer support networks and for healthcare professionals when trying to access preventive healthcare?

Dr Maryann Barrington 02:20
Yeah, thank you so much for having me. I'm very excited to be here. I guess, to answer that question around, what exactly is the problem that we're talking about? People with intellectual disability in Australia and internationally face really stark health inequities. So for example, work from some of the researchers at our centre have found that in Australia, people with intellectual disability have a median age of death at 54 years, whereas people without intellectual disability in that same study showed a median age of death of 81 years. So it's quite a large gap, and 38% of deaths in the cohort were preventable for people with intellectual disability, compared to 17% in that cohort for people without intellectual disability, in addition to those higher proportion of potentially avoidable deaths and premature deaths, they also experience higher rates of multi morbidity and early onset frailty. And we know that these inequities are amenable to change if we improve access to preventative health care.

That is the purpose of our project, is to try to see these inequities get smaller and actually try and address some of the really key barriers to accessing health care, and this has been acknowledged by the Australian Government, both through the disability Royal Commission, which heard evidence around stigma, discrimination in healthcare, inaccessible systems, it saw evidence for poor health information, not very accessible health information, all these things that really exacerbate the problem. And as mentioned before, we have the national roadmap for improving the health of people with intellectual disability too. Now, partners in our project include Council for Intellectual Disability, and in their most recent campaign of Our Health Still Matters, based that campaign on the argument that of the 72 actions identified in the roadmap, only nine have actually been undertaken in the last three years, so it's a massive problem.

Prof Jackie Leach Scully 04:25
Yeah, can I just go back a little bit and ask you a question about the that gap in lifespan? What would you say to people who look at that and think, well, many people with intellectual disability have an intellectual disability as part of some other more global problem. How much of this gap in lifespan and in general health is to do with the condition that they have and that might possibly not be something that can be changed?

Dr Maryann Barrington 04:56
So in that study, which compared people with intellectual disability with people without intellectual disability, they investigated the kind of common causes of mortality as well, and the common causes of mortality include things like respiratory illnesses or cancers or cardiovascular diseases. So it's not the intellectual disability, it's the same chronic health conditions that the people without intellectual disability experience. But we also know, for example, they're less likely to get cancer screening, so then cancer isn't found until an advanced stage. So it really comes back to that inaccessibility of the health system and not the disability that's causing the early deaths.

Prof Jackie Leach Scully 05:40
Okay, so it's not so much the biology, if you like, of the of the condition, but just maybe a number of different things that stop people being able to access care, or perhaps even know that the care is available.

Dr Maryann Barrington 05:55
Yes, definitely, yep. So even even the health information before you even go to a doctor or go to a hospital, just the information that you have in your day to day life is not accessible.

Prof Jackie Leach Scully 06:06
So what can you tell me about the project that you're involved in? What have you been doing? And then what have you found out?

Dr Maryann Barrington 06:13
Yeah, so our project is a five year NHMRC partnership project, so we're partnering with a lot of disability organisations, health sector organisations and a number of academics, and it's a five year project. We're in the fourth year at the moment, so we're getting to the tail end. Over the project we've

been doing linked data analysis work to investigate cardiovascular disease, immunisations among people with intellectual disability. We've done policy analysis to look at how well or whether people with intellectual disability are even represented in health policy, and that we've seen that they look very represented. We've done and we're doing qualitative work as well. So we've done interviews with people with intellectual disability, support networks and healthcare professionals around their experiences with healthcare access, whether that be seeking healthcare or trying to provide good healthcare as well. And we've also interviewed people with intellectual disability around health information in particular and ways that we might be able to improve that. So we've got, it's kind of like a multi component project, where there's a lot of different phases that we're doing, and we're hoping to bring it all together to implement a model of care in GP clinics that might be able to adjust some of the barriers that we found.

Prof Jackie Leach Scully 07:36
Okay, how much of that is education of people with intellectual disability and their families and support networks, and how much of it is educating the medical profession and the GPs and so on?

Dr Maryann Barrington 07:48
So I think definitely, from what we found with the interviews, GPs and medical professionals do not feel equipped in their roles. So and there can be for a lot of things, not necessarily just from a knowledge perspective, but it can even just be the resources of their organisation. They don't feel like they're provided with the right resources to be able to meet the needs of someone who might have complex care needs. And so part of it is definitely trying to help healthcare professionals to identify what exactly it is that makes them feel not equipped. And if that's something that can be addressed at the individual level through education, or if that's actually systemic change that's needed. But we also know with support workers, disability sector support workers, they also don't feel like they get the right training or knowledge to support someone with their health, and that can be a bit due to the historic, I guess, segregation of like the disability sector takes care of, you know, supporting someone with daily life, and the health sector, they're the ones that take care of health, and so it's a bit of trying to address that. Well, part of someone's everyday life is their preventative health. And so Disability Support Workers should get training around how to support someone with that.

Prof Jackie Leach Scully 07:48
Yeah, it is kind of interesting, because we're putting the responsibility for preventive care onto disability support workers, but also, very often, to be honest, it's families, family networks to have the knowledge, to know that they have to ask for something, or that they have to advocate, and they don't always have that.

Dr Maryann Barrington 08:58
Definitely. It's not just support workers, as you mentioned, it's also really supporting families. We know from some of the interviews, families, our family members who are supporting someone just didn't even know what was available to them in a health service. They weren't aware that there was actually support that they could access. No one was helping them know about that, or telling them how they could do that. And so you end up with families who feel really burnt out and really stressed and really exhausted because they don't even realise that there's a lot that they actually can access.

Prof Jackie Leach Scully 09:48
That's right, you probably know about the project that DIIU has been involved in for a number of years now. You know GeneEQUAL which we're immensely proud of, what that project has been able to find out and do, but I know that one of the key and very early insights that we had with that group around genetic testing, which could be thought of as being a form of preventive care, because it is often trying to diagnose the condition that a person with intellectual disability might have that might involve further physiological and medical issues that could be prevented or looked out for at least, and that very often, people actually didn't understand the information that they were being given about how they could action that knowledge in their future life with their GP, and part of that was because the clinicians didn't really know how to convey that information. They were often convinced that they were succeeding in that. But in practice, when we asked the people with intellectual disability, it had been presented in an inaccessible way, and they weren't able to make the use of it that they could do.

Dr Maryann Barrington 10:58
Yeah, definitely. The communication of health information is a massive issue, and both in clinics, but also outside of GP offices, we did a recent study where we audited cancer screening information that's held online, particularly from government, state and federal government, health websites for bowel, breast and cervical screening programs. And again, it was similar thing there, where we found that actually they're not written in an accessible way. Easy Read documents often didn't follow Easy Read guidelines. Information was written at reading levels that exceed the general population. And websites when it came to web accessibility, clicking links, knowing where to go, they were designed in a very confusing way, and it is really hard to do web accessibility well, but it's a really important thing to do well, when our society is increasingly becoming digital and healthcare services are expecting people to know about their services through their websites.

Prof Jackie Leach Scully 12:01
Yes, and be able to be reasonably independent and find out that kind of information, rather than it being offered to them more more proactively

Dr Maryann Barrington 12:10
With people seeking information independently from our audit, we found that even support networks would likely struggle, struggle with the online cancer screening information. So it's not even that you could use these websites with support, because the person supporting you is also likely to find them very difficult.

Speaker 1 12:27
Course, all of this is coming out of, I suppose, a history, you know, socio historical context of, I suppose, of people with intellectual disability, not really being seen as having agency, being in control of their lives. Very often, the expectation being that their parents or their families or, you know, someone will be taking care of all of this for them. And I think we're in a really interesting transition when, on the whole, people are accepting that there will be people with intellectual disability who are leading independent or semi independent lives, who will be wanting to take care of themselves as best they can and find out these things for themselves, but who need additional support that possibly the

majority of the population don't need, although you've just said that some of that information out there is pitched at a higher level than the average reading capability or age of population in general. And I can certainly, you know, attest to trying to find out information, health information online, and finding myself completely baffled about which links I should follow and where I should go so and I'm reasonably well equipped at finding my way around these things. Do you think that there's a barrier of prejudice in a way that goes beyond that ignorance about what intellectual disability really means and what people within the diversity of it, let's say, is there any sense of a sort of active well, I can't think of a better word than prejudice or discrimination, perhaps even hostility towards people with intellectual disability?

Dr Maryann Barrington 14:06
I think there's still a lot of stigma and discrimination within the healthcare system. We saw that in the Disability Royal Commission, but we've also recently published a scoping review where we used a model of healthcare access that basically looks at what's going on, at the demand side, so people seeking healthcare, and the supply side, so healthcare service providers. And we did the scoping review to understand from both perspectives, how is healthcare access happening? What are the barriers? What are the facilitators? One of the things we found with that model is when you're looking at the experiences of people with intellectual disability from the literature, it was clear that you also had to acknowledge that that interaction between healthcare seekers and healthcare providers is happening within a very specific socio historical context, and traditionally mainstream healthcare services have never been equipped to provide healthcare to people with intellectual disability because it was the job of institutions. People were placed in institutions, and it was seen that that institution would provide all services for that individual. And then, as we did, deinstitutionalization and people started accessing mainstream healthcare services. These services never revised their models of care. They never revised the way that they provide healthcare. And so those really complex or unique accessibility needs that someone with intellectual disability might need are just not being addressed or considered. And so you've got that kind of not like that indirect discrimination, where it's actually that it's not that someone's actively trying to discriminate, but it's just that the system isn't designed for someone. But then certainly in that review, we also saw examples of direct discrimination where people were not being spoken to their support work person was being spoken to instead, or people were being left alone in hospital rooms with no support, no one checking in no one to check how they are. It was expected that the support worker would do that, even though, for anyone else that would be a nurse doing that job, and people you know, reporting comments that have been made by doctors and things like that as well. And certainly in our interviews, we've sort of, we've seen the same thing, where even with our interviews with healthcare professionals, a number of the professionals that we interviewed said that they know that people with intellectual disability come to their services and feel a degree of stigma and discrimination because of the way that the service is set up, right?

Prof Jackie Leach Scully 16:32
Well, that's that's revealing, isn't it? And I suppose also there's almost a vicious circle, at least historically, that services for people with intellectual disability, in terms of their general health, and particularly as they came to adulthood and then got older, might not have been provided because they tended to get ill and die earlier anyway, because those services are not provided, and therefore the known there was no need for them perceived at least. So hopefully, we're moving into the state where

not just people with intellectual disability are living longer lives and healthier lives, but we have more of an expectation that that's going to be the case.

Dr Maryann Barrington 17:10
Yes, certainly. And I think something that's very promising from interviews with healthcare professionals was just how passionate you could see a number of the people we interviewed were about seeing change in these systems. So I think as much as there are still problems, there's also a lot of hope.

Prof Jackie Leach Scully 17:24
In your work with people with intellectual disability. What kind of inclusive research methods have you been using?

Dr Maryann Barrington 17:30
I find inclusive research a really exciting thing to talk about, because prior to doing co design work, when I was doing my PhD, I just used very traditional research methods where there's a trained researcher, and they're the only person that's allowed to do anything. And then, as I started getting involved in more co-design projects, you get to be very creative and open and really collaborative in how you understand and create knowledge. And so for this project, we work with co researchers with lived experience of intellectual disability on our project, and we also work with a lived experience reference group, something that we've been doing as a team with our with co-researchers, is trying to find ways to do accessible, thematic analysis of qualitative data.

Prof Jackie Leach Scully 18:13
Wow

Dr Maryann Barrington 18:14
It's been very fun. It's challenging, and it really makes you have to unpack some of your beliefs around knowledge structures and academia and what's right and what's wrong. Of course, you want to balance that inclusive research with maintaining the rigor of what you're doing, but we've been working together to basically design ways to co analyze our interviews and to write our papers on those interviews and do our thematic analysis, and that's included following the traditional six step of Brown and Clark, for example. But we've been finding ways to make that activity work for our co researchers. So that's meeting with our co researchers, explaining the six steps of that thematic analysis to them, and actually hearing their ideas about what we can do together to make those six steps work. And so one of the things we did when we did deductive coding was we created this big, Easy Read version of the model that we were using, and we printed it out our interviews in like chunks, and together with co researchers, we would like actually place those chunks underneath the parts of the model that we thought that they spoke to the most, and we would discuss together. You know, well, we've got all these ideas under this part of the model. Do we think there's groups of ideas here? Would we call those groups different themes, for example, and just really trying to find engaging ways to make sure that everyone gets to make a meaningful contribution to our results and to what we're going to tell people that we found.

Prof Jackie Leach Scully 19:46

I think that's a really key observation, not obviously, in your project, but also, I think more generally, in that people with intellectual disability are very often, not always, but very often capable of doing much more than we generally expect, and the main barrier is that we're very set in the ways that we do things, and have always done things. Therefore, if people with intellectual disability can't do it that way, we tend to assume it can't be done at all. And it takes a different perspective, and also, you know, time and patience and the willingness to work with people and engage with them, to try, as you have been doing, you know, to develop alternative ways that may not look like the traditional methods, but that are as good as creative and can be as vigorous as those traditional methods.

Dr Maryann Barrington 20:42
And it's, it's a fun process too, but you definitely need to, I guess, go into it with that self reflection too, to be able to identify, you know, there's times where I found myself being like, oh, but that's not, not the way that we do it, and then catching myself and going, but that doesn't have to be the way that we do it. We can do it a different way,

Prof Jackie Leach Scully 20:59
Yeah, but it does take extra time, and that means extra resourcing. And again, that's, I think, a key message that comes over again and again in co-production work, that somehow we have to get that message to the sponsors and the funders and so on, that it does take longer, and it does often cost more, but the end result is going to be better. It's going to be worth it because of that.

Dr Maryann Barrington 21:24
It's that tricky thing where a lot of funders want co design work, but aren't necessarily acknowledging what co-design work entails.

Prof Jackie Leach Scully 21:31
Yeah, put bluntly, they want co-design but they don't want to pay for it. So what do you see as being that the next steps for your research?

Dr Maryann Barrington 21:41
I guess there's two ways to answer this is next steps generally, in terms of what we can do to try to improve healthcare services, and the next steps for our actual project, in trying to design a model of care to implement, and in terms of the things that, broadly, we can do in society to try to make healthcare services better. I think something that's definitely come through from the interviews is that constant siloed work between the disability sector and the healthcare sector, and we really just need to create mechanisms for joint working to make it easier and even encouraged for organizations and professionals to coordinate care together, share information with each other and really support each other in their roles. Because certainly from the interviews that we've had, people just feel that they have no idea how they can get things coordinated. They feel like this person has that information, and they have that information, and I don't know what's going on, and there just needs to be a much more collaborative environment, and I think we can encourage that through policy. We can also encourage that through training and helping each sector understand their roles and their responsibilities. Because I think worryingly, some of the things happening in our interviews with people saying that they were denied health care because they were on an NDIS package. And there's an assumption that NDIS

takes care of certain things. And so it's really clear, it's really clear that there's a lack of understanding. That's a big one.

Prof Jackie Leach Scully 23:06
Yeah, yeah, I can see that there's a there's a practical gap, there's practical siloization, as you said. But also I just like to mention here for our listeners, the DIIU also has another project called Disability Matters, which is an international project with four or five different partners. One of the aims of that project is to try to cross over, or bridge that gap between coming at disability from the healthcare point of view and coming at disability from the disability providers or service point of view, and also related to that, I think they the way that sometimes a person with disability, whether it's intellectual or not, their health care and their health care needs, are seen as being solely to do with the disability. That's not as we know. That's not the case. People can have a disability and at the same time have an illness or condition which has nothing to do with that disability. And there's some real problems there with not addressing the fact that they can be separated in a way that doesn't increase that gulf between the two, the two perspectives that you were talking about. So maybe, maybe in the future, we'll be able to do a podcast about that project, and perhaps we will have you on to give some insight from your point of view as well. That would be great.

Dr Maryann Barrington 24:33
That sounds excellent, definitely. And that's a key issue that came through our project too. Is that diagnostic overshadowing that everything about this person I'm going to relate back to their disability. And that's you know, it's not the case. You know, this person can have a disability and have depression and have cardiovascular disease. It's more than just that.

Prof Jackie Leach Scully 24:54
The fact that I'm deaf had nothing to do with my broken wrist, for example, it did affect my experience in hospital, but that's a topic for another podcast, perhaps.

Dr Maryann Barrington 25:06
So yeah, so the end goal of this whole project is to bring together everything we've found and try to implement a model of care that might address some of these barriers and the key barriers that came through to us noting that preventive health care is a huge area, and that many of the barriers that we're looking at are systemic and long standing. The key ones that we're trying to address are the lack of coordination and the lack of communication, because those were the two that we saw the most in all of our interviews. And one way that we're trying to do this is to support people to create basically a collaborative and coordinated health action plan. So we know, for example, that the government is investing lots of money in health assessments for people with intellectual disability, and the last, I guess, step or stage of those assessments is supposed to be an action plan that everyone agrees on and decides on. But what we can see so far is people don't feel like that last bit is happening, and so what we want to try and do is co-design with our lived experience reference group, with our co researchers and our partner organisations, an action plan that people feel like it actually gives them the information they need, and they know whose responsibility each thing is, and they know where they can go, and they know what supports available, because we think that might be able to bridge some of those key gaps in co-ordination and communication.

Prof Jackie Leach Scully 26:24
So you're looking at providing some kind of process or template for making sure that the action plan is drawn up and that everybody agrees with it. Is that right?

Dr Maryann Barrington 26:34
Yes, yeah, and that it's accessible as well because I think another thing is, people with intellectual disability often get left out of that equation. Oh, the doctor's written the plan and put it in their system. What about the person who actually has to follow that plan? Why aren't they given the information they need?

Prof Jackie Leach Scully 26:50
Thank you. Well, that all sounds very promising, and we hope that in a year's time or so, we'll be able to hear more from you about how that's been progressing.

Dr Maryann Barrington 26:59
Fingers crossed.

Prof Jackie Leach Scully 27:00
Okay, thank you Maryann, and thank you everybody for listening to the DIIU podcast and look out for the next one in due course.