UNSW Disability Innovation Institute Podcast, season 1 episode 1

Jackie Leach Scully: Hello and welcome to this podcast, which is the first in a series on the meaning of disability, inclusion and inclusivity. This podcast is coming to you from the Disability Innovation Institute at the University of New South Wales. I'm Jackie Leach Scully and I'm the director of the Institute, the DIIU, and joining me in conversation today are two very well-known names in the Australian and international disability landscape: Graeme Innes AM is and has been a human rights practitioner for 30 years and was Australia's Disability Discrimination Commissioner between 2005 and 2014. He is a company director and lawyer and well-known public speaker, and he's also currently the chair of the Advisory Council of the Disability Innovation Institute. And we also have with us Rosemary Kayess, who's a human rights lawyer in the Faculty of Law at UNSW. Rosemary is chair of the United Nations Committee on the Rights of Persons with Disabilities, and she was awarded the Human Rights Medal for her lifetime of work advocating for disability rights. I'm very pleased to have both of you with me here today, and I'm sure we will have a really interesting conversation around this topic.

I thought I would start by asking first Graham and then Rosemary, just what is your understanding of disability inclusion, disability inclusivity? It's a phrase which is used an awful lot nowadays in the public sphere and academia and public life and so on, but how do you understand it?

Graeme Innes: Well, I'm happy to give you my sort of quite unacademic definition of disability inclusion and inclusivity, Jackie. Inclusion is something that we all have in the community unless we acquire or are born with a disability, in which case the community sort of takes it away. People with disability for hundreds of years have been segregated from the community, so we haven't been able to work, to go to school, to play with, to interact with the community. And lots of times we've been actually physically segregated or locked away. And so inclusivity is something that people with disability want, or at least we want the choice to be included. And we tend to have to fight or struggle to gain that from the community. Now this, of course, is changing, but it's still the case. We're still segregated in schools. We're still, some of us are still segregated in work, and many of us are prevented from a doing a whole lot of other things because of the barriers either physical or attitudinal or structural, which exist in society. So I suppose to get society back to where it should be, we need to remove those barriers and stop that segregation and then we'll just be included like the rest of the community. And that's my sort of unacademic take on disability and disability inclusion.

Jackie: Thank you. That's really helpful. And Rosemary, how would you feel about that?

Rosemary Kayess: And well, apart from the fact that Graeme’s dumped a whole lot of pressure on me to sound really academic and knowledgeable. Look, there's not much more that I can add to that, inclusion is really about making sure that the community is structured in such a way that it accommodates, you know, the full range of the human condition and that all people can engage in society and participate within the community in a meaningful way. So it's about being able to go to school with your peers and your siblings. It's about being able to work alongside your neighbours and to travel on public transport with other people within your local area. You know, travel overseas to other communities and be able to get around and be able to be part of that experience of not just your local community, but the world itself as a community and so inclusion is about recognising that there is not just this narrow dimension of what is the human condition, but that it's a very infinite, and varied, varied experience, and that we all take on many shapes, many personal characteristics and that society should be embracing of all of those aspects. So it's not just about the built environment, it's also about the way we communicate, it's about the way we share information, how we present information, so we should be able to make sure that all people have access to all dimensions of our society.

Jackie: Right. Okay, thank you. Graeme, what you said at the outset that have made me think because you said something like that, inclusion is something that all of us in the community have and then accept. But I'm thinking that most people in the community who are not in some way excluded don't tend to think about themselves as being specifically included, do they? It's just it's, they sort of take it for granted that this is how life is.

Graeme: Yeah, I think that's right. And that was the point. I was trying to make that for people in the community without disabilities, but they have the choice to be included and they can choose not to be included. They can choose to, you know, to work on their own or to go away from society or whatever. But for people with disabilities, that that choice is taken away. And so, yeah, for people who don't have disabilities, it's not something you think about. You just take it for granted. But for people with disabilities, it's a constant struggle, and there are constantly little microaggressions which tell you that the rest of society thinks that you shouldn't be here. And I was thinking when Rosemary was talking that it's those last few words that you said, Rosemary, are really important because inclusion has to involve the whole of society, welcoming and embracing people, not just removing those barriers that you outline, doesn't it? Because even if you don't get that, then you're still not fully included because you're perceived as different or less able to achieve what it is that you'd like to achieve.

Jackie: Rosemary, did you want to add to that?

Rosemary: Well, look, Graeme’s quite right, it's a two-way street. I mean, you can be a part of the community, it doesn't mean that your… you can be in the community, but it doesn't mean that you're a part of the community. So unless there is that ability to engage and to interact with the broader community, then inclusion is basically a fairly one dimensional thing and it's not really inclusion. I suppose what the important thing is too, it's not just about the physical location, it's about the meaningful nature of the engagement. And so you can… it becomes this argument with group homes ‘oh, but they're in the community.’ Well, they’re in the community, but they're not part of the community. They’re still essentially closed environment. And most of the people in them don't choose with where they live, with whom and where they live. And I'd say a lot of them have very few choices about what happens within even that small community of their home. And so… That's not true engagement, that's not true community living, that's not being part of the community, it's just be located within a community.

Graeme: Someone said, and I wish I could remember who the quote was from and exactly what the quote was, but it's the difference, isn't it, between being invited to the party and actually being asked to dance?

Rosemary: Yeah, who was that Graeme?

Graeme: I don't remember, but it's a really good quote.

Rosemary: It is a great quote.

Jackie: And I think a lot of the people with disability will know that, you know, you have friends who are not disabled and they don't actually realise just how little inclusion there is or perhaps how much exclusion there is until maybe you tend to do something as a group and the building isn't accessible for whatever reason or, you know, you don't, you're not going to the cinema because some person with you can't hear the soundtrack of this, you know, induction loop or captions and so on. And then they suddenly realize that the world is inclusive of them, but perhaps not of everybody else.

Graeme I was just wondering, you, and Rosemary too, have been active in this landscape for a long time. Have you seen a change? You mentioned that things are changing. What kind of change have you seen in Australia over those years?

Graeme: Well, you know, I have seen change over the time, the time that I've been involved. And, you know, I'm an advocate. So the change is never fast enough as I'd like, as fast as I'd like. But there has been change. I mean, we are better now at building buildings and transport systems than we were 40 or 50 years ago, which are accessible to everyone. We're not perfect, but we're much better at it. And that's been driven to a degree by laws, but also to a degree by changes in approach. I think what hasn't changed as much is the attitudinal barrier, which I always believe is the is the toughest barrier to crack and where people in society don't stop viewing, you know, me as my guide dog or white cane or, you know, someone else is there as a wheelchair or whatever the other disability might be and just start seeing us as a participating member of the community. And that's really, that's really hard to to get past. And I would say, even among my colleagues and friendship group and neighbours, it's hard to get past and there are very there are very few people even in the circle that I'm mixing who just take the fact that I can't see as part of what makes up me and not all of what makes up me or the only thing that makes up me and that's full inclusion when you get to that point.

Jackie: Yeah. I’d agree with that. Rosemary?

Rosemary: Yeah, I think it also highlights, those sorts of instances also highlight the arbitrary nature of disability. And when I say the arbitrary nature of disability, we've all got impairments. I mean, everybody has got some form of impairment. Anybody you like at some point in their lives, they will be impaired in some way and to some degree. And it's the arbitrary nature of how we get away from what we consider normal. You get this arbitrary point that becomes disability. And that's when it becomes for our society, it's either, you know, it's too costly for the developers to go past that point of accessibility or the low expectations of people with disability is that, well, we'll just, you know, we’ll protect them, and we'll make them, you know, special residential facilities because it's obviously too difficult for them to be at home and in the communities you know, in their own home in the community, we've got to protect them all. Well, it's but yeah, it's just that really arbitrary nature of disability that point where it becomes uncomfortable within the community. And so then comes the process of exclusion. In terms of what's improved, unfortunately, I think it's all very superficial. Graeme’s right, yes, we do do transport a lot better. I love the trams from the university into the city, you know, I absolutely love them. But when you get to some of the legal exclusion that people experience and the policy based exclusion that people experience, we haven't really shifted. And you see that with the strict adherence and the fight that lots of governments put up, not to reform laws that really do strip people of their rights.

Jackie: Why do you think that is, Rosemary? Do you think, is it is it a matter of the cost? Is it a matter of the effort? Is there something else going on?

Rosemary: Look, everybody thinks it's attitudes. And yes, I think attitudes has a little bit to do with it. But I think most of it is driven by, now, because there are significant vested interests. And the part that attitudes does play is around that low expectations of people with disability, we're inherently always thought of as being vulnerable, you know, we're always lumped in that pile and the vulnerable, and so. It's still that care, treatment and protection ideology that people have around disability, and I think a lot of that comes from the exclusion that Graeme was talking about how people don't really interact with people with disability, so they see it from afar. And so they make assumptions about, you know, what people's lives are like, and so, we always suffer from our disability or we, you know, we're inherently vulnerable. You know, getting up and, you know being in a hotel and having baked beans on toast is such a heroic task.

Graeme: Yeah. And there's sort of a question, isn't it, Rosemary of what's cause and what's effect? It's quite cyclical because we're not included, because we're viewed that way. And because we're not included, then we're viewed that way, you know, it's sort of, it's finding the things that will break that cycle. And a lot of us do it to ourselves. A lot of I mean, it's like sort of glass ceilings or limits everywhere. Those expectations are held by a lot of people with disabilities who accept those low community expectations. And until you can break those down, then then people just accede to being excluded because, you know, it's the only option that that people think they have.

Jackie: Yeah, and I think also that there's something quite complicated going on when… And again, this may be something that familiar to both of you when somebody will say to you, meaning to be flattering and pay a compliment, ‘Oh, I don't think of you as disabled. I never think of you as disabled.’ And partly, I want to respond--well I don't because I'm usually too polite--But you know I want to respond, ‘Well, that's because I'm doing quite a lot of work to ensure that you're not put out by the need that I have. In other words, I'm trying to move around you to make sure that I'm included, rather than asking you to make certain things happen.’ But it also says something underlying, I guess, about how people do view disability and people with disabilities that it is something that nobody would want to be like. And so you're being complimented by saying you're not disabled, you know?

Graeme: That's right. That's right. Yep, and that's exactly it. And that second point, well, I don't know. Both points are really important. Jackie, I'm not sure I was going to sort of weight one above the other, but they're both pretty important. But that just to build on that on that second point, you know, the it's the way that disability is viewed and that negative view of it ‘Well you'll be a lesser person if I think of you as a person with a disability. So I don't think of you in that way.’

Rosemary: But then the other side of it, Graeme, is that inspiration porn side. I mean, that is just so annoying. It’s the only way you could describe it. I remember being, you know, this is what I mean by the baked beans analogy earlier. I was in a hotel in London. I was staying there. I'd been… And I just got into London the night before, I got up to breakfast in the, you know, the buffet type area and I was just looking at the baked beans and sausages, and this woman came up to me and told me about how inspirational I was. And, I really wanted to turn around and go, ‘What for thinking about having the baked beans?’ You know, all I’d done was get out of bed and get, and I was late, I’m always late, I was late to the buffet? What she’s said, that's a low expectation. Now, if she’d known that I'd left Australia four weeks earlier done a two week meeting in New York, done a fortnight teaching in Galway and had it come to London to spend a week with some friends before going home, I mean OK, if she’d said, ‘Well, that's a big trip to be doing.’ That would have been okay. But the fact that I was just sitting there, looking at the baked beans, for god's sake.

Graeme: I know, I have a friend. He's a good friend, who said to me, once, you know, ‘I just think it's amazing that you travel all around Australia and around the world by yourself. I just think that's absolutely incredible. You know, I couldn't do it.’ And I just sort of looked at him and said, ‘Well, what's the alternative?’ You know, well, I could choose not to do it. I could choose to sit at home all the time, but I'm actually engaged and interested and want to be involved, and this is where my career and opportunities have taken me. So, yeah, it's just you're dealing with it all the time.

Jackie: Well, remind me Rosemary never to offer you baked beans.

Rosemary: I love baked beans!

Graeme: Yeah, I quite like a baked bean.

Jackie: It's quite a nice segue. Maybe not the baked beans, but the idea of the travel and what you've just described to ask you, Rosemary, specifically, obviously, you've done a lot of work around human rights, and you're now chair of the UN Committee on the Convention of the Rights of Persons with Disabilities. So how do you see inclusivity relating to human rights? What power, perhaps, do human rights instruments have to to improve inclusivity?

Rosemary: This instrument is really quite interesting, The Convetion on the Rights of Persons with Disabilities. It had a significant amount of civil society, so, you know, people with disability organizations involved and people with disability involved in the negotiations, which was unprecedented for a human rights instrument prior to this particular convention. And so this convention is really owned by people with disability. They yeah, they see it as theirs and they really do use it as an advocacy tool. And I would say that much more so than other intersectional groups such as women and race served on the International Convention on the Elimination of Racial Discrimination and the Convention Against All Forms of Discrimination Against Women of. But the extent to which the disability rights movement feel such ownership at this convention is really quite interesting. Whether what that's translating to is high level demand for change--I see a lot of change with states, parties, not commensurate with the call for change. But it's provided a basis of discourse with states that is seeing minute steps, but that is starting.

Jackie: So you're sounding quite optimistic there about the potential future, at least, and certainly under your chairship.

Rosemary: It's a long term game. I look at, I don't think my chairship will be anything special. I don't think anyone's going to turn around and look at the time that I spent as chair of the CRPD and go, ‘Wow, that was pretty special.’ It may not be up to the baked beans, even. But, look, certainly the most important thing while I'm chair of the committee is that we gain the respect that the law requires of us. So, what I want to say the committee do with international law is to make sure there's no fragmentation between other treaty bodies so that when states look at their human rights obligations, that other treaty bodies are also going to uphold, as the CRPD for people with disabilities is, that that's going to be upheld across the board. That's not the case today. There are still areas where there is jurisprudence from other treaty bodies that isn't quite to our standard and that a historical thing, and that's just the nature of the jurisprudence has to catch up. And for me, the most fundamental thing that I want to see as chair, my time as chair of the committee, is that we get states to realize that impairment should never be the basis for the denial of human rights. Whether we get any significant policy change, I doubt I'll see it. But if we can just get the recognition that impairment should never be the basis of a denial of human rights, then I would have thought we've achieved a significant amount.

Jackie: That would be. Right. I just want to wrap up in the time that we have by asking both of you how you feel about that DIIU, the Disability Innovation Institute, which, as this podcast series is showing, we have a focus on different kinds of inclusion, and within the academic setting in particular looking at inclusion in education and disability inclusive research as well. So, I just wanted to ask each of you in turn: Graeme, how does the, how do you think the DIIU contributes to inclusivity? And that's from your perspective as chair of our advisory council.

Graeme: Well, you know, different things drive inclusivity. And so, the way that research is done and the institute has worked towards ensuring that people with disabilities are far more included in that research, right from the initial designing of the research through to the end of that research. And of course, the way that that research is done, is carried out, helps to change the agenda around inclusion. And if academics see people with disabilities engaged in research, then inevitably in the same way that if we see more people on our television and smartphone screens with disabilities, we start to think that inclusion is more acceptable. Then academics, seeing other academics with disabilities being involved in research starts to change their view of the way research should be done. But the other point about it, the contribution that it makes, is that because we are involved in that research, our lived experience becomes part of that, the research and the thinking behind the research, and therefore the research itself is more inclusive and will recognize more parts of the human condition, particularly with regard to disability, than it has in the past. And anything that is done with us is going to be more beneficial to us than what's happened in the past, which is that it's done for us. And, you know, hence the, to synthesize it, that comment about nothing about us without us, because the result which involves us will always be better than the result which doesn't because our lived experience is part of the melting pot that that makes that research better.

Jackie: Thank you. Thank you for that. And, Rosemary, you've had a very long association with the DIIU. How do you see it contributing, assuming that you feel that it does, but I hope you do. How do you see it contributing to progress in the direction of disability inclusion?

Rosemary: Look, I think Graham hit the nail on the head. I mean, it's really about embedding impairment as part of the human condition, so we research that disability is something that's included within that framework. And so what you see then is an evidence base that informs change within community. And so what informed that change will reflect disability and impairment, so if you've got, if you think about, well, let's just take urban studies and stuff like that. So if you've got an evidence base that includes people with disability, then the urban spaces of tomorrow will factor in disability. If you don't include disability in that evidence base, then the policies that are developed from it will not include disability, and that's how we ended up with, you know, the urban structures that we've got now. So having a focus to be able to enhance and support academics with doing inclusive research can only benefit the evidence base of the things we build, the things, the way we inform policy and also the way we think and the way we discuss within academia itself, the way we educate the, you know, professionals of tomorrow. And so--when I was studying, it was all gender and race. No one, there was no other intersectional elements that were included. Now disability is appearing on curricula and so students, higher education students at tertiary, tertiary students are engaging with disability as academic process, and that can only be a good thing as well. And I mean, the good thing about it is I would really welcome to see it happening more within my own faculty of law, because I think the legal system, if ever there's a profession that needs, you know, focus on the broadness of the human condition, it's the legal fraternity.

Jackie: Thank you very much for that. And I really do hope that we'll be able to see the DIIU contributing to all of that improvement and inclusion and expansion of thinking about disability, to think of it, as you said, as part of the human condition and not as some anomaly, that society can park somewhere else and forget about. So thank you both. Thank you, Graham Innes, thank you, Rosemary Kayess, for taking part in this podcast discussion. And everybody, please do look and listen out for our next podcast in the series, later on we’ll be taking a more focused look at inclusive education and inclusive research and other forms of inclusion. Thank you and goodbye.

Producer: Thank you for listening to the UNSW Disability Innovation Institute podcast. The podcast is hosted by the Institute's director, Professor Jacqui Leach Scully, and produced by me, Isabella Burton Clark. We would like to thank our guests for their time and insight. You can find out more about the institute and subscribe to our newsletter at disabilityinnovation.unsw.edu.au. You can also find further information about the topics discussed in the podcast, on our website and in the show notes.