**UNSW Disability Innovation Institute Podcast**

**Season 1, Episode 2: Inclusive Research**

JACKIE LEACH SCULLY:
Hello and welcome to the UNSW Disability Innovation Institute podcast. This is the second in our short series of podcasts about disability and inclusion. I’m Jackie Leach Scully. I’m Director of the Disability Innovation Institute, the DIIU, and the Institute has a particular focus on, a particular interest in, inclusive research and co-produced research or co-production. So, this podcast will be giving a basic introduction to some of the ideas behind inclusive research and particularly inclusive research that’s carried out with people with intellectual disability. I’m going to be talking to one of the most important members of the DIIU, Professor Iva Strnadová, who is our Academic Lead for Research and Professor of Special Education and Disability Studies in the School of Education, UNSW Sydney. Iva is a world expert on inclusive research, and her own research aims to better understand and improve the life experiences of people with disabilities, especially those most marginalised such as people with intellectual disability. So, first of all, I’m going to turn to you, Iva, and ask, can you explain what we mean by inclusive research?

IVA STRNADOVÁ:

First of all, thank you so much for having me, Jackie. It’s a great honour to be here at this podcast. In terms of the term inclusive research: in inclusive research, people with disability are taking part, not as participants who are objects of the study, but they are included as researchers.

JACKIE LEACH SCULLY:

Can you tell me what it is that makes research truly inclusive?

IVA STRNADOVÁ:

In my opinion, in my perspective, it is that all researchers are really included from the very beginning of the—even the research idea and then across all the phases of the research. It does not mean that everybody has to do the same thing, but really being included from the, very much the first, the initiate, initiated idea when the academic researcher and the researcher with disability work together on all under the idea of how much it is important from the research perspective, has there been research conducted before? Does the topic really matter to people with disability? Is it relevant to them, et cetera? And then, of course, it is, including every team member throughout the whole process until the writing, the reports and potentially considering another research application.

JACKIE LEACH SCULLY:

Oh, OK. OK. Now, in the introduction, I said that the DIIU had a particular commitment to inclusive research and to co-production. And I know that those terms are closely connected. But I wondered if you could tease out for us a little bit what what's the relationship between inclusive research and co-produced research or co-production?

IVA STRNADOVÁ:

These terms are describing the same philosophy or approach. So, I think the term co-production of research, co-design and co-production of research is wider, has been used across the different disciplines. In fact, it started even before the research field in consumer service. So, there's a long history, and it is basically about collaboration and collective decision making between the people who have been the consumers and the producers. So, in research, it is the collaboration and really collective making decisions between the academic researchers and researchers with disabilities and their organisations, if that makes sense.

Inclusive research is a very specific term, in a way, because it has been very often used in connection to doing research together with people with intellectual disability in the role of researchers, and inclusive research has been coined by scholars in that very field, Jan Walmsley and Kelley Johnson, in 2003. So, it does have a history, a long history that is evolving. I think the importantce of that togetherness is critical, it is not us and them doing research in the role of researchers, and I think that's also important to understand.

For me, I love working with my colleagues and friends who have intellectual disability, and while I don't have the lived experience of having intellectual disability, I do know what it is to have a disability: I myself have multiple sclerosis, and so some barriers are common to many of us who have that lived experience, so I think that also helps to facilitate just that camaraderie and teamwork and mutual understanding.

JACKIE LEACH SCULLY:

Mm-Hmm. And perhaps one thing I should say is that the DIIU is relatively unusual in having several of its members people who do have lived experience of disability, as well as being researchers into disability, and I think that's one of the things that marks us out if you like in the disability landscape in Australia and globally too. I know that people with intellectual disability face particular barriers, sometimes in being part of research, in being part of co-production and part of inclusive research. So, I wondered if you could help us, talk us through that a little, by giving some examples of research that you've done with people with intellectual disability.

IVA STRNADOVÁ:
Oh, very happily. So, if I start with an example of a research study that I've done with the wider team, but together with Julie Loblinzk that I mentioned, who is a woman with intellectual disability, self-advocate, long lasting self-advocate, so somebody who speaks up for the rights of people with intellectual disabilities and helps others to do the same, and also adjunct lecturer at the School of Education. And as we've been doing study looking at peer support for mothers with intellectual disabilities and there is a lot of prejudice. Again, we mentioned prejudice that people with intellectual disabilities can’t have relationships or can’t be parents, let alone good parents or successful parents and which is of course, not true. And so we were really looking particularly into what peer support exists. And we have interviewed, not just mothers, sorry, fathers as well and as the research progressed and we had to interview 26 parents, we kept on hearing the same stories and the same stories were around not having proper sex education in schools or any, and people of different age categories told us, including (INAUDIBLE). A good half of the people we talk to have experienced domestic violence and sexual abuse, and many of them had a child removed just purely based on the label of intellectual disability, not neglect or abuse of the child, anything like that. And so a lot of unnecessary...

JACKIE LEACH SCULLY:
Sorry, because the parents had an intellectual disability, they had the child removed?

IVA STRNADOVÁ:
Yes. So, for example, one mother had postnatal depression, which is not uncommon, right? But because she had intellectual disability, the social worker, so child welfare workers decided that the child needs to be taken away from her and it was, and it would never happen to somebody who doesn't have intellectual disabilities. In this case, later on, she had a second child, which they let her to keep, at the time we were talking to her, she was still fighting to get the first one back. So, there are so many inequities that people are not aware of. But why was this so distinctive? Julie and I kept on, you know, talking to parents and advocates as well, Susan Collins, for example, and we were analysing the data. We kept them coming through the sex education and preparation for the future life. It obviously was missing. And so we designed a study looking at how does sex education look like for high school students in New South Wales? And together we would do something to think the project interview questions.

We went back to students and surprise, surprise found out that the sex education is really very much a forgotten topic that only select topics are taught to students with intellectual disability. That a lot of the education is not accessible to them, so doesn't use, you know, Easy Read or visual so they don't understand what is being taught. And so that led, talking about the co-production and inclusive research, at the same time, we've met a team from Intellectual Disability Rights Service that support people with intellectual disabilities engaged in criminal justice system, either as victims or perpetrators, and they had developed a rights and relationship program and wanted to pilot it. And it was teaching the skills that people obviously didn't have and that's why they came to be engaged with the criminal justice system. And so we started to collaborate and think about what can be done, and we have done the pilot of this program with adults with intellectual disability, but also students in high school and on the feedback then adapted it so it can be rolled out to New South Wales schools.

So that is, you know, the beauty of this is that again, the program was co-produced by educators with and without intellectual disability. It's delivered to schools by educators with and without intellectual disability. It did a whole process is being the research evaluation and also by inclusive team and also the incorporation of data commendation. But you can see, I think on this long example, I'm sorry that it was long, you can see that it is something that takes time and grows and you really need to nurture such relationships and nurture the space for ideas. And in academia we are so often pressed with time, this funding is coming now and it needs to happen within half a year. And you need more time to do inclusive research properly and you might need higher budget because you need support for the people to be included properly and I don't think that is still well recognised by the funders.

JACKIE LEACH SCULLY:
No, I think you're right, either the external funders, sometimes the university structures as well are difficult, but the, you know, the idea of needing additional time before the research can even get underway to build up those relationships that you've spoken of. And you also mentioned the additional funding for people who might need support for those people who need it. But I know that you and I have also discussed as a practical problem the difficulty that some institutions have of comprehending the idea that a co-researcher might also get paid.

IVA STRNADOVÁ:

Absolutely. And then finding out within the structures because the co-researchers often don't fit the university box, it's not these box or the other. And so then finding kind people within the structures to help you to navigate the system and find a way that it can be done excessively is quite a puzzle. So I think this is something that needs to change. And I think it's again what you said before fantastically that it's the change of the culture. It's not just inviting and collaborating with researchers with disabilities, it’s having the structures that support that. That it's not your constant struggle and fight to get some basic rights for your colleague, just because they have disability.

JACKIE LEACH SCULLY:
And it’s against the, as you said, a lot of the university culture is one in terms of time pressures, time constraints to respond to funding calls very quickly, to turn research around very quickly. And it's sort of working against that and trying to maybe introduce the idea of slow research. Slow deep research. OK. OK. It's interesting what you were saying earlier, though, about that project with sex education, with younger people with disability, with intellectual disability, 'cause in a way, it's the same sort of exclusion as excluding from research. It's almost an inability to accept, in that example, that people with intellectual disability might have sexual relationships and need sex education.

IVA STRNADOVÁ:
And in fact, it tends to be much more like, again, I think you are absolutely right with the parallel because even the sex education is risk-averse. You know, how do I protect myself from getting pregnant rather than, you know, planning for family? And what does it take and what I need to think about? And I'm talking about some positive aspects of sexuality as well. One particularly striking thing for us was that some of the students we talked to said that, you know, sex education discourse is only heterosexual. That is never mention of people having other, you know, gender identities. And that was really striking, and the students struggled with that because they had to find answers elsewhere. And, you know, we had some of the students in our study, one of them was sexually fluid, but didn't know—sorry, not sexual, gender fluid—but didn't understand herself until she found answers, but they were not available in school. So, I think that's another example that we need to make changes.

JACKIE LEACH SCULLY:
Yeah. Which would be very different for a young person at school who did not have intellectual disability, we kind of take it for granted that they would have that discussion or at least some of that information. It's as if we're stuck still in a very sort of old-fashioned view of what people with disability and people with intellectual disability are like.

IVA STRNADOVÁ:
Absolutely. And I, you know, I love breaking those, you know, preconceptions. And it's funny, like when, example, Julie and me working together in inclusive research, I love the fact that when we go collecting data, so doing interviews and so on, I can’t drive, she is driving. You know what I mean? But there will be still many people in society who would think that just because you have intellectual disability, you can't drive. Here we are, she’s driving me, being Professor, I'm just very happily sitting next to her.

JACKIE LEACH SCULLY:
I know you're a skilled navigator, though.

IVA STRNADOVÁ:

Oh gosh, yes. You wouldn't to see that!

JACKIE LEACH SCULLY:
Both of us, Iva, are co-working on a project with some colleagues in UNSW and elsewhere on finding out how people with intellectual disability have experienced genetic testing or genomic testing for their condition. Do you want to say a little bit more about that?

IVA STRNADOVÁ:
I would absolutely love to. Thank you, Jackie. So in this project, we are trying to really achieve that genetic testing and genomic counselling would become accessible to people with intellectual disability and inclusive of them. And we already know from a literature review that we've done, that worldwide, only seven studies in some shape, not always deep ones, have tried to ask people themselves, people with intellectual disability themselves, about their experiences with genetic testing and counselling and what has to change. And so it's beautiful that now we are collaborating with New South Wales Department of Health on this project to make really big changes that are needed. The project is led by Dr Emma Palmer and on our team, of course, besides you and I Jackie, we have Jackie Boyle, who is a genomic counsellor and practitioner, and Julie Loblinzk, a lecturer and self-advocacy mentor. And I think that there are many things that we are already learning just from making this research inclusive and, you know, working across the team who has the academics and people with intellectual disability.

Also in our advisory committee, we have genetic associations and leaders in the field, but we also have the grassroots organisations and people with intellectual disability. So I think, Jackie, I think it would be fair to say that we are learning a lot in this process, aren't we?

JACKIE LEACH SCULLY:
Yeah, I would agree and even from the outset, I think it's again indicative of the kind of assumptions that people come with to the world of disability, and particularly intellectual disability that, you know, my background has been in genetics and genomics. I don't think I ever really thought about the accessibility in those terms of the materials or any of the guidance to people with intellectual disability. I don't think I thought about it at all, except perhaps to assume at some level that they would always be accompanied by somebody else. They would always have parents or something like that. It didn't need to be directed towards the person concerned. And of course, I'm pretty embarrassed about that now. But the realisation also that there is so much genetic counselling, genetic testing and just genetic health advice being given, but so little research done into it and no resources available for those people.

IVA STRNADOVÁ:
I think also what we're learning in this study is how much of the support is lacking once people learn their diagnosis or their syndrome or their condition. And so there are many, many gaps that we can see. But what is really exciting is that this is done in collaboration with New South Wales Department of Health, who are very keen to make changes and to acknowledge this is really a world -first initiative. So that's just something that is very precious. And we have many lessons, I think. For me, particularly was example of today, if I can, when our team met before the meeting of advisory committee, based on the suggestion of the New South Wales Council for Intellectual Disability, big thank you, and Self-Advocacy Sydney, also big thank you, we have actually developed now the list of difficult words in Easy Read that will be also provided. But it was such a, it wasn't easy to really come up with accessible explanations. So I think, and it was so great when Julie was guiding us through to create the easily, the most accessible. So I think, yeah, I feel I'm learning every day in any of these studies, really.

JACKIE LEACH SCULLY:
Yeah. And I found it quite challenging as well because I do tend to feel that unless you can explain something very, very clearly and simply, then you don't actually understand it yourself, because I think it's very common for academics to use jargon and we sort of forget what the jargon means. And then when somebody says, what does that mean? Or you have to really pin it down in very plain and simple terms, you find actually, you don't understand it nearly as well as you thought you did. So it's very salutary for us and a good learning experience to have to do that. Yeah, just coming back again to something you said earlier, you mentioned that coming to Australia was an opening for you revelation for you there. Is it that different countries have different traditions or cultures about inclusive research or not-inclusive research?

IVA STRNADOVÁ:
Oh, absolutely, absolutely. So, I'm originally from Czech Republic, from Prague, it is a beautiful country, beautiful city. But I particularly think that the impact of many, many years of communism, and, you know, though it finished in ‘89, 1989, it's still, the impact is visible now. I remember, like during the communism, people with intellectual disability would be either with families or very commonly in institutions which were purposefully built on the borders of the country so people couldn't see them. So, the whole mentality in Czech Republic, I'm not aware of anybody doing inclusive research yet, and it would be beautiful to see. There is still many, many fights just for people to get, you know, any sex education or supporting those who are there and think in their battles with the system. So while some of the battles are similar to us, but there is, I think, the heritage of the past will take longer to influence the change and the mindset.

JACKIE LEACH SCULLY:
You think in Australia, then we're fairly progressive in this respect?

IVA STRNADOVÁ:
Definitely, if I compare it between these two countries, I do think we are. You know, it depends. There is a lot that can be improved still, but, yeah.

JACKIE LEACH SCULLY:
It's not perfect by any means. Come back to that, to your vision for the future in a short while. But I wanted just to discuss with you a little bit. You've been working at the DIIU for a while and we've been putting together some resources for people who are interested in doing inclusive research. So can you say something about that?

IVA STRNADOVÁ:
Oh, definitely. So, we have developed guidelines for co-producing research with people with disabilities that are available on our website. Of course, it goes without saying they’re also in an Easy Read version and with Easy Read summary. Big thank you to New South Wales Council for Intellectual Disability for the fantastic job of helping them. And we have now the big pleasure to be just finalising the next set of guidelines, which are called ‘Co-production in Action’ and really give some very practical tips for academic researchers and others, of course, and for others researchers with disability, how to really think about and enact co-production in each and every phase of the research. So we believe these will be very useful, and they will be launched early next year. So stay tuned. We will have a lovely event to do that.

JACKIE LEACH SCULLY:
Excellent, we look forward to that. And I like the way you've emphasized there the Easy Read version, because again, I think it's symptomatic of the mindset that it is only people without intellectual disability, in quote marks, normal people, who do research because I've had conversations with people talking about those guidelines and they've been surprised that we would produce Easy Read versions, because why would any researchers need an Easy Read version.

IVA STRNADOVÁ:
And can I just talk to that? It's interesting because I've just lately talked with one colleague who has intellectual disability and we were talking about Easy Read, and she said, ‘It's my language. That's language I understand to.’ And I was thinking that that's so beautifully put, and we really need to respect that. They allow for better understanding in not using complicated words and providing short descriptions, explaining whatever we are trying to explain in Easy Read and using the pictures to explain it. I must say, though, that I'm part of a few teams, such as one team looking at HPV vaccination and how to make this vaccination, you know, accessible and inclusive of students with intellectual disability in schools with high support needs, which is led by Dr Alison Carter or another research project with Associate Professor Sue Wolfenden, in which we are again doing developing pathways through the accessible pathways for young people with cerebral palsy and their families through the health system, but really looking at social determinants of health and so much more broadly.

And after the fact that in these teams we've done training with New South Wale CID how to do the Easy Read, we only use for agendas and minutes Easy Read. And honestly, it's so much easier for all of us. You don't have a text, heavy pages, pages, pages of text. It's something that's so accessible for everybody, and we know we academics read all the time articles and books and students’ drafts and do marking. And so this is just such a beautiful, refreshing way of doing research. So I just hope it becomes much broader culture.

JACKIE LEACH SCULLY:
Yes. Yes. And I think that leads me very nicely to the final question or introduction I wanted to ask you, which is what is your vision for inclusive research? Maybe at UNSW and then maybe in the rest of the world?

IVA STRNADOVÁ:
I just would love inclusive research becoming legitimate and then supported, systematic and structurally supported option for research. I'm not saying that everything is just to use this approach, and you have research studies that it wouldn't make sense. So it is not saying now everybody has to do inclusive researches that would be unfair to do so, but it should be a legitimate option and well-supported option, which also means that we need to think how we build capacity of the researchers. And a typical problem we have in inclusive research that you will maybe get the funding and you can pay the researcher you are working with, whatever, because sure, of course, it's no question about it. But it's only limited for that time of the funding of research then. Now, then there is, of course, reflection of how the research went and planning next research. Now, me as academic, I'm paid for that. It's part of what I have to do, but my colleagues are not, and so they even do it in their free time, which is very unfair, or they have to constantly have to scramble for some funding to be able to build the research study to really from the grassroots.

So even having a system in which we can actually sustain and build capacity of research for disability who are not staff members, as per say, would be, to me, a question of social justice, which I don't see yet.

JACKIE LEACH SCULLY:
Now, you're envisaging there something with like a career path for co-researcher.

IVA STRNADOVÁ:
Absolutely. Absolutely. And support it. Really systematically support it.

JACKIE LEACH SCULLY:
OK, I don't think that's going to come tomorrow, but I would hope that I'm quite sure that with your work and the work of your colleagues, we're making progress in that direction.

IVA STRNADOVÁ:
Thank you, Jackie.

JACKIE LEACH SCULLY:
Thank you, Iva. Thank you for your time today.

IVA STRNADOVÁ:
Thank you for having me, Jackie.

ISABELLA BURTON-CLARK:
Thank you for listening to the UNSW Disability Innovation Institute podcast. The podcast is hosted by the Institute's director, Professor Jackie 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.