**Isabella Burton-Clark:** Welcome to the UNSW Disability Innovation Institute podcast, where we discuss the work of the Institute and other issues related to disability inclusive research.

**Jackie Leach Scully:** Hello, I'm Jackie Leach Scully, the Director of the UNSW Disability Innovation Institute. This year, 30th Of March 2022, marks the 15th anniversary of the signing of the United Nations Convention on the Rights of Persons with Disabilities by Australia. The UN Convention, or CRPD, is intended to protect the rights and dignity of persons with disabilities, and to support work towards their full involvement in all aspects of society.

And today I'm speaking to Rosemary Kayess and Therese Sands about the development of the CRPD, what has been achieved by and for people with disability since its enactment, and its future directions.

I'm very pleased to welcome a returning guest of our podcast, Rosemary Kayess. Rosemary is the Institute’s Academic Lead Engagement, and also Chair of the UN Committee on the Rights of Persons with Disability and was heavily involved in the drafting of the CRPD. Rosemary is also the chair of the Australian Centre for Disability Law, and teaches in the UNSW Faculty of Law & Justice.

And we're joined today by a first-time guest to the podcast, Therese Sands. Therese is the Chair of the Institute's Advisory Council, and she's worked for over 25 years in education, policy development, capacity building and advocacy in human rights and disability. She is the former co-CEO and a life member of People With Disability Australia, and a member of Women with Disabilities Australia. Therese also currently provides research and policy coordination to Rosemary in her role as Chair of the UN Committee on the Rights of Persons with Disabilities.

So welcome, Rosemary, and welcome, Therese, we’re looking forward to today's discussion, and I wondered if you could start by casting your mind back to the days before the CRPD was even launched and let us know a bit about what was involved in in the drafting of the convention. If I can go to you first Rosemary.

**Rosemary Kayess:** What the drafting involved was a lot of education on both sides, the drafting involved a lot of education for member states that didn't really understand disability. People with disability as we know, don't hold positions within public administration, they don't hold positions in senior levels of power within governments. So, governments have been operating in this expert-led area of disability where doctors and professionals, decided how societies responded to disability. And, I mean we frame it as the medical model and we talk about it in terms of the power relationships. But fundamentally what it meant was that there was a whole bunch of governments, members of the UN who didn't really know much about the lived experience of disability.

For the DPOs, the organisations for people with disability that were there, and all the people with disability that were there at the convention negotiations, they didn't really understand international law, the role of international law, what international law could do what it didn't to, and basically how it how it operated how the negotiating process was going to proceed.

So, in lots of way it was a bit of education from both sides, that was needed.

What was important was that the convention negotiations for the first time had unprecedented civil society engagement, there were significant delegations of people with disability that came and participated in the negotiations and contributed their lived experience as expertise knowledge to the convention negotiations. Now, many states went going with the belief they could just sign up, and that what they’re doing, as it existed, would be okay, and they wouldn't have to change anything.

Many still believe that what they signed up to was basically what they've always been doing. But the convention actually goes a fair bit further than that. But fundamentally, that's what it was about. It was about educating governments about the lived experience of disability and trying to encapsulate that to demonstrate how we could address the human rights of people with disability.

So, we knew all the rights were there, they’re contained in the two covenants, the International Covenant on Civil and Political Rights and International Covenant on Economic, Social and Cultural Rights, but they didn't have, they weren’t expressed in a way that was meaningful for states to be able to address people with disability.

**Jackie Leach Scully:**  Okay, thank you. From your perspective, Therese, have you anything to add to that?

**Therese Sands:** I think probably what I can add to that, because it is looking really what was happening in Australia, among the community of people with disability. So, in the lead up to the drafting, and actually through, it because there were a number of, there was several sessions held over several years at the committee, that was the actual negotiation process with all the countries and civil society in the room negotiating it and Rosemary had a significant role in that, in those meetings and facilitating working groups in specific areas, but people probably may not know that in Australia, there were significant national consultations being held by the disability community and organizations of people with disability, partly funded through the government to get the views of people with disability in Australia around what they would like to see in in a convention. And again, that in itself was an educative process because for most people with disability, we were coming from a welfare oriented policy and law area where human rights that the, the language of human rights, and the issues around human rights and how they apply to people with disability were not evident at all, we weren't part of the human rights community so human rights organizations didn't take disability issues, probably, seriously or include them in human rights activities. So, the consultations provided an opportunity again to provide education to the community itself, about what would a convention do, what is it about, why is it important to strongly position ourselves in the Human Rights Framework, and what it potentially could mean. And it also provided the opportunity for people with disability to provide their experiences and talk about their lives so that that could be incorporated into drafting text that was drafted before the Australian delegations actually got to the UN, and in fact the Australian—that drafting of potential text that was taken to the UN, Australia was one of the few countries that actually did that. And so, the organizations of people with disability and the disability community had very strong representation through Australian civil society of potential text.

And the actual adopted text of the convention contains many of that drafting that was done for the delegations to take to the UN, so it was actually really critical and important for the drafting process.

**Jackie Leach Scully:** Right. Okay, so there's a lot of grassroots contribution there, and it also sounds like from what you're saying that there was some basic educational work going on about what's the point of a convention for people with disability, specifically, perhaps the sense of, ‘aren’t they just covered by the other human rights conventions.

**Therese Sands:** I think that's actually right, people wanted to know what would a convention do, and how they could use it how it would achieve things in their lives that they currently at that point were not able to achieve in terms of eliminating barriers to a whole range of areas in life, to the prejudice and stigma that existed.

So, you know, there was a lot of discussion around that and also a lot of discussion, not just through the negotiation process but afterwards, about how to frame issues for people with disability in human rights language, as opposed to the current welfare oriented language, and the language of service providers around what was provided to people with disability, as opposed to what people were entitled to and recognizing elements of violence and, you know, laws that would perpetuate violence etc that was seen as service system practices, as opposed to torture and ill treatment, for example. So that language can be quite powerful in in addressing issues for people with disability.

**Rosemary Kayess:** And I mean the other thing was the discussion, like, framing it. It was very much tying it to the social model of disability. I mean, that was the language of the time, I mean, I know the social model’s been around for a lot longer than that, but there was still many people even within disability organizations themselves that hadn't engaged with that framing of the concept of disability.

So, it was as much, yeah, it was as much about education amongst people with disability as it was education of the states and the representatives from justice departments from around the world on the subtle difference of the way you conceive disability has a huge impact on whether people can exercise their human rights or not.

And it’s still evident today that lots of states just still don't get the difference between what gets called the medical model and the social model of disability.

**Jackie Leach Scully:** Sure. Now, as somebody very much not in the human rights, and international law world, is there any significance to Australia having been one of the first signatories of the convention, or is it all just kind of a pile on, on the first day when it opens for the signature?

**Rosemary Kayess:** It does tend to be a bit of pomp and ceremony. So, the convention was actually adopted by the General Assembly on the 13th of December 2006. And then it was open for signatory at the end of March the following year. So, 2007 was when it was open for signatory, and yes, there is a big signing ceremony and lots of states, come along and sign it.

All the signatory does is indicates that a state is agreeing to consent to the obligations of the convention and not actually consenting to be bound by that convention. So, Australia didn’t actually ratify, which is the process that you have to go through. You have to put in documents of ratification to the depository in New York at the UN headquarters and say you are bound to be consented by the terms of the treaty or the convention. And so we didn't do that until 2008.

So 2007 it was open for signatory, 2008 we consented to be bound, in 2009 it entered into force. So, Australia was under obligations, not to prevent the object and purpose of the convention from 2007, but from 2008 it had consented to be bound, and 2009, the committee, because they also ratify the Optional Protocol, the committee could make determination on their progress in meeting their obligations.

**Therese Sands:** I think probably the only other, the significance probably was Australia demonstrating its commitment that it signed on the first day that the signatory was open because initially Australia was opposed to the convention and argued against its development. So that sort of changed, I guess, once it was clear that states, were going to negotiate a convention, Australia did eventually change its mind and participate in the negotiations quite you know heavily and strongly and supported civil society.

So, being one of the first to sign it was a demonstration of its commitment. The ratification, again, people with disability and organizations of people with disability had a very strong campaign for Australia to ratify. So there's a lot of campaigning and advocacy for Australia to take that next step in terms of ratification.

**Jackie Leach Scully:** Okay, that sounds a really interesting 180 degree turn there from being initially opposed.

**Rosemary Kayess:** Yeah, it's really interesting how that came about too. I mean, Australia was taking a minimalist approach. This wasn't the first time; in 2000 when the resolution came up before the General Assembly for the UN to consider having a Convention on the Rights of Persons with Disabilities, it was the fourth time a resolution had gone before the General Assembly to have a Convention on the Rights of Persons with Disabilities. The previous two times, three times, ’87, ‘89, and ‘92 were all by European countries, Italy and Sweden; Sweden twice and Italy once, and got resoundingly voted down.

What was different about the 2000 resolution was that it was brought forward by Mexico, and Mexico got a lot of developing countries to support a resolution. Now, in terms of poverty, and the area of development, international development, the interrelationship, the cyclical relationship between disability and poverty is well understood. Poverty creates disability and disability creates poverty. And so disability is a big thing for developing countries. You know, two thirds of the world's population of people with disability live in developing countries.

So it was a big issue, so Mexico framed it as a social development issue, whereas the Europeans had framed it as a very traditional non-discrimination approach, which was to just say, ‘this is discrimination on the basis of disability, and it applies to all human rights and fundamental freedoms,’ whereas the Mexicans were proposing something far more prescriptive and something much more like we ended up with.

But there was a tension between that right through the negotiations of whether how prescriptive it should be or how minimalist it should be. The Australian position for the first few years was that all we needed to do was attach the existing declaratory documents to the ICC PR and the IC, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, the two generalist instruments of the International Bill of Human Rights.

And the only problem with that was the two declarations, the Declaration on the Rights of Mentally Retarded Persons, and the Declaration on the Rights of Disabled People carried with it built in limitations that are very—going to go back and use the terminology now—very medical model approach to disability very, very much institutionalized based framework so what you would have been doing with embedding half the problems into the human rights framework that we were trying to deal with.

**Jackie Leach Scully:** That is interesting because, again, something from an outsider’s perspective, the language and so on of those conventions, it's very neutral apparently, it’s very objective, and that sense, that picture that you give there of the importance of how its framed and what the resonances are and what the associations are, the track record and so on is a very different viewpoint, I think.

The numbers apparently are, at the moment they're 164 signatories and 184 ratifications. Do people move from being a signatory to being a ratifier, how does it work?

**Rosemary Kayess:** Well, that just means that 164 of the 184 countries that have ratified signed the, signed up to the convention, and that there's 20 states that have acceded. So they haven't signed up to the convention. But after, there becomes a period where it closes off from signatory and you have to accede. So it's just a slightly different process, but the outcome’s still the same, ratification is still the outcome, and that's consenting to be bound.

**Jackie Leach Scully:** Okay, I'm going to show no, no scruples here about pointing the finger: what kind of countries, which countries, haven't done it yet, it's not ratified or signed or anything?

**Rosemary Kayess:** I can't even put the finger at the US they've, they did sign but they’re never going to ratify. Generally small states that are concerned about cost imposition. I don't know who hasn’t, I'm not aware of the list so I can’t, I'd be making generalizations.

**Therese Sands:** I mean, it is one of the most highly ratified conventions, aside from the Convention on the Rights of the Child. So, it's a, you know, most member states have ratified the CRPD.

**Jackie Leach Scully:** Is that a good thing, that it's one of the most highly ratified conventions?

**Rosemary Kayess:** Yes it is, if we can get state practice to shift a little bit. The reason that having nearly universal ratification is important is because state practice can be very important in terms of moving, progressing, the rights. But also because it means that there's greater uniformity in the standards and principles that are being applied to people with disability throughout the world.

**Jackie Leach Scully:** We’ve got the CRPD at least beginning to be introduced 15 years ago. Have you got examples of some of the achievements it's helped towards, the gains in in Australia since it was introduced?

**Therese Sands:** Even though the convention has been, you know, ratified 15 years, and the government has, you know, established the National Disability Strategy and now the Australian Disability Strategy, the second iteration of that, to implement the convention, in a way it's still relatively early in terms of seeing significant change in practice and policy and law reform, particularly in areas where there does requires significant more, a higher level of social transformation, I think.

So, one of the good things from the disability community point of view, is they now have a language to talk about their lives, which is clearly puts them within the context of human rights. And so they can talk about, you know, lawful violence and forms of violence, you know, such as forced sterilization, forced medical interventions, and they can talk about that within a framework of human rights such as torture, ill treatment, inhumane treatment. That's kind of, that's very critical. They actually participate much more heavily with a whole range of human rights, civil society organizations in terms of advocacy and in terms of campaigning and human rights organizations have really progressed their understanding and are taking on issues for people with disabilities, whereas before they didn't really see them as, as human rights issues, they were more sort of about welfare programs, etc. So people with disability have a real language and they can talk about segregation in education and segregation in employment and, you know, we now are using the term ‘ableism’ and that standard of what it means to be human and how people with disabilities don't meet that standard and therefore the devaluing that happens in a whole range of areas.

So it's progressed a range of much more sophisticated advocacy, I think, and demands around policy and law reform, and it has pushed governments to take that on to recognize that they have to address many of these issues, so even the fact that we have the Disability Royal Commission, that was fought for many, many years prior to the convention to have such a royal commission, but the convention provided greater impetus for advocates to demand that the government recognize all forms of violence and the specific types of violence that occur against people with disability which they weren't necessarily seeing as violence, they were seeing it as perhaps ‘Oh, this is about regulation of service practice or regulation of programs or having better standards for programs’ instead of identifying particular actions, behaviours and systems as inherently creating violence, or, you know exploitation, violence and abuse for people with disability, so that's a shift.

And that's very welcome in, in the sense of government's progressing but it is slow. It is quite slow, and probably just, you know, reflecting on what Rosemary said before about, you know, it's really important. The number of states or countries that have ratified means there's a lot more states engaging around what does this reform entail. And so you do have countries that are engaging in reform projects, which hopefully will influence other states like Australia to recognize that what people with disability are arguing for that they, they can actually see something that another country is doing that could assist them. So, an example of that is Ireland has just introduced an assisted decision making act, and they have developed associated with that supported decision making mechanisms and structures to enable supported decision making for people with disability as opposed to substitute decision making and then they have the law that kind of sets that up and establishes it.

That's only just happened so we have to wait for what unfolds there, but it does provide sort of value to then be saying to Australia, that they're continual continual holding on to substitute decision making frameworks, can, other states are actually shifting away from that that's what the Committee on the Rights of Persons with Disabilities is telling Australia to do. They are resolutely not doing that and holding on to a very firm position that their frameworks are in line with the convention, and yet you can point to state practice that shows that other states are trying to make that transformation, so that they can be in line with the convention. We’re at the beginning stages before we actually see key transformation.

**Rosemary Kayess:** We have seen some slight shifts, we've got to take it a little bit further, I mean, the language is being used a lot more now. The concept of human rights comes up within our policy frameworks that wasn't happening before. And the CRPD is a tangible thing that can be put, we saw it in the terms of reference for the Royal Commission, we see in the explanatory notes behind various pieces of legislation that it's about meeting our obligations under the CRPD.

We just need to shift the actual understanding of what that means a little bit further, because we can still get the difference in disability where, you know, we talk about people with disability reaching their potential, their full potential. Whereas in gender, they will talk quite openly about equality. In race, they will talk about human rights. But in disability we’re still stuck in this care-welfare dimension that we just need to shift from the superficial language around it, to actually understanding it.

**Jackie Leach Scully:** Yeah, there’s sort of it an infantilizing framework there, the welfare one, and I think it does make a real difference whether the platform you're standing on is a human rights one and you’re effectively saying this, ‘this is a right that I'm due as an equal and you're failing to provide that,’ rather than the welfare which is a complicated thing, I know, but there's always a sense of supplication, I think, with welfare, even in those, you know, Northern European countries that tend to have a much more positive attitude towards a welfare state or at least did historically. There's always a lingering sense of something that could be taken away if the benevolence level dropped.

**Rosemary Kayess:** Well that was the case with a lot of the austerity measures through the economic crisis through Europe.

**Jackie Leach Scully:** Yeah, ‘this is a bit of fluffiness that we can no longer afford, it's nice to have when we can afford it,’ rather than, ‘It's not something that we can choose to drop or not drop because it's an obligation.

**Therese Sands:** And I think that's, I mean we're seeing that a bit with the National Disability Insurance Scheme, and that act, the *NDIS Act*, is underpinned by, it's actually written into the act the Convention on the Rights of Persons with Disabilities along with several other conventions, in fact. And so what we're seeing at the moment is, instead of seeing that as strongly based in human rights and entitlement, we have an approach at the moment that is framing it as a welfare program or a service program to assist people, and we'll have to have certain reductions because it's costing too much, so we're getting into that cost argument, it's, it's no longer about people with disability entitled to live an equal life in the same way as other people in the community. It's about, ‘we're giving significant billions of dollars to people with disability and we can't really afford to do that. We'll have to cut back on packages and they’ll have to sort of, you know, except lesser, then perhaps what they are entitled to in terms of having a good life on an equal basis with others so you know that that rhetoric has crept into, and is driving a lot of the policy undermining of the of the National Disability Insurance Scheme at the moment.

**Rosemary Kayess:** The irony is, is they don't get that final connection of what a human rights model is all about, what a human rights approach requires is that you address the barriers, you address the berries in mainstream society, so people can participate. The more that you specialize things and segregate people, exclude them from the community, you've got to establish parallel systems. And those parallel systems cost. And so, if they put as much effort into the disability strategy that they've put into the NDIS, then it wouldn't have become so financially unviable. Because the more you make the community accessible, the less disability supports people will require, the less parallel systems you will have to maintain.

**Jackie Leach Scully:** I think the perspective that we've got there is, is interesting to me hearing you say it's early days yet and things are beginning to move in a particular way 15 years on, and I guess that's kind of time scale that with these sorts of transformations or revolutions almost, we have to get used to. So, in our last few minutes, what are you hoping for the CRPD to make possible in the future, in Australia and elsewhere?

**Therese Sands:** I mean that's a massive question. But I do think it comes back to, I really would like states to be able to see that the convention calls for a social transformation, it's not business as usual. It's not doing the things the way they've always been done, and to really change the approach and attitude and understanding to disability and recognize that it's not tinkering around the edges with systems and a bit of Law Reform here and a policy there. This is social transformation and to really engage in that with people with disability and their representative organizations and start to, you know, really plan through what that might mean. So it's just things like moving from segregated education and segregated employment, instead of reinforcing those systems, what's the plan to get us to genuine inclusive education, to employment that is not segregated with lower wages, etc. What about autonomy rights, how will we have supported decision making for people disability, so we don't have guardianship regimes and mental health laws that detain people or confine them involuntarily or treat them involuntarily, that we actually respect consent of people?

Those are really big items that require significant, law and policy reform, and they're not, the government, I don't think and the National Australian Disability Strategy’s not quite getting to that edge of what the convention, the potential of the convention in terms of transformation is, so we need to get to that point and I'm hoping in future that's what we will see, is more of that social transformation.

**Rosemary Kayess:** Yeah, I mean I'd like to see some leadership that recognizes that need for transformation. You know, that recognizes that school education as we understand it now is not what it could look like in the future. And that there’s steps that we can take now to make sure that it doesn't look like it does in the future like it does now. So, we train teachers differently. We design schools and classrooms differently. And we reflect on the diversity of the human condition and the variety of ways everybody learns, and we have a pedagogy that can respond to that. And can make sure that education is the cornerstone for everybody, not just those children that can operate in the standard, you know, one teacher one classroom, 30 kids model. You know, it just doesn't work. And I think if we can get to a point where there is that leadership and there is that understanding, then I think other areas are open to change as well.

**Jackie Leach Scully:** Well that’s an optimistic note on which to end our conversation. Thank you so much to our guests Rosemary Kayess and Therese Sands, and we may well have you back at some point in the future to talk about where the CRPD is going next in Australia and worldwide. Thank you again.

**Isabella Burton-Clark:** Thank you for listening to the UNSW Disability Innocation 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.