14. The Boldness

**Raphael:** Welcome to this special broadcast of The Boldness on International Day of Disability, 3CR 855 AM. The Boldness is about standing up for your human rights instead of waiting for some well meaning person to give them to you. My name is Raphael Caleb. The Boldness is going to be talking with Micheline Lee about her quarterly essay called Lifeboat and the National Disability Insurance Scheme. Welcome to The Boldness. Micheline, how are you today?

**Micheline:** Hi Raphael. It's lovely to be here. I'm fine. I'd like to acknowledge I'm on Wurundjeri land. Thank you.

**Raphael:** Now we're going to get straight down to business about the [inaudible] of it. Now the National Disability Insurance Scheme, what actually is the National Disability Insurance Scheme, Micheline?

**Micheline:** Alright, the National Disability, well, I'll call it the NDIS. So the acronym NDIS, which I'm sure your listeners have heard because the NDIS is actually in the media a lot. So the NDIS is a scheme that was introduced about 10 years ago, in response to a very urgent need for people with disabilities who need individual supports to receive them in a consistent and adequate and sustainable way.

**Micheline:** So before the NDIS, we had state schemes that were responsible for providing individual support. Individual supports cover things like the personal care that you might need to get out of bed and be showered, have your food prepared, or it might mean the bit of domestic help or going out into the community.

**Micheline:** It would also include the disability support equipment that you might need, like wheelchairs, like hearing aids and apps for visual impairments, things like that. Prior to this national scheme, this was being provided by states, but on a very ad hoc and underfunded and inconsistent way. So we were finding that some people were not able to access the services that they needed, even to, for example, have a shower when they wanted to.

**Micheline:** A lot of people were isolated. A lot of people didn't have the choice and control about how they would use their services. And the NDIS was supposed to change all that, and it actually was an amazing reform of national scale, well funded with a lot of bipartisan support with human rights policies. Such as that the individual gets to choose and control how they use their supports in order to meet their goals in lives. Yeah. So that's the NDIS in a nutshell.

**Raphael:** So Micheline, the idea of having that NDIS, essentially, it was supposed to give funding or provide a source of funding for people with a disability in order for a more inclusive and better life. Do you believe that it's actually happened?

**Micheline:** The NDIS was to, as you said, provide individual funding packages. And it was through these individual funding packages that the NDIS was supposed to be able to provide the individual choice. Because they thought that if you can be a consumer, then you'll be able to attract the services you need. In fact, that hasn't worked out as the designers intended. It may have worked if they had put enough community structures in there. Such as, we do have the support coordinators and also the local area coordinators. But their roles, which was to assist people to use their individual funding and to access the services they need, those goals weren't properly met by the support coordinators and the local area coordinators. Because they were underfunded, badly trained and the local area coordinators particularly were used for other administrative purposes rather than what they were supposed to be doing.

**Raphael:** Well then Micheline, what it really sounds like then, is that this is all very well, that the intentions of the NDIS was good, but the practical aspects of it, appears to have made people who have got disabilities lives, much more difficult. In a lot of ways, like the implementation of how it's gone about.

**Micheline:** Yes. So there are some people who have benefited from the NDIS and they tend to be those who can advocate for themselves or have effective advocates who can make sure that their needs are met. There are several problems with the NDIS, which as you've said, doesn't necessarily create a more caring and inclusive society like the NDIS intended.

**Micheline:** So we have, first of all, the NDIS itself is not as accessible as it should be. It is very difficult to navigate. The processes and the bureaucracy are not even at your ordinary business standards that you would expect. Even people with a lot of experience of tax and bureaucracies, and the most complex bureaucracies, say that the NDIS is just too complex to use.

**Micheline:** The fact that over 50 percent of NDIS participants are actually people with cognitive impairments means that the NDIS actually needs to be more accessible and to accommodate for people's different capabilities. So we've got the actual accessibility of the scheme itself. And then we've got the accessibility of the market. The NDIS has been set up by the implementers despite the great goals of the people with disabilities, the activists who initiated the NDIS. What happened was once the NDIS was at the implementation phase, people with disabilities weren't being consulted.

**Micheline:** And the implementers then started doing business as usual. And business as usual for them is there's this trend to use market approaches in order to deliver services. Not just social services, but all kinds of services in our society. But problems arise where the market approach or the neoliberal approach tries to deliver social services through the market system. Because in those cases, especially just selling something like electricity, which works or doesn't work, you're actually looking at people's complex needs and you're dealing with people who may be vulnerable. And need to have people with special expertise.

**Micheline:** It's also much more difficult to measure whether a service is a personal care service is working compared to say whether your electricity works or not. So we've got this system of this market approach. That in theory, that just because you have participants who have the money, that was supposed to grow a strong market of service providers and the competition between these service providers was supposed to build the quality of the services, and also motivate more initiative and new ways of doing these things by the commercial providers.

**Micheline:** But in effect, what has happened is that it's not the individual who's had the choices. A lot of individuals are actually in worse situations because of not being able to attract services. Because they live in remote areas where there are very few services available. Or people who, business providers think are not good business. So people who are maybe seen as a business risk. For instance, people who the service provider might see as being difficult, having difficult behaviors. And also people with complex needs.

**Raphael:** Micheline, this is all incredible background, detailed information about the NDIS. And what we're going to do, we're going to play some community announcements now. Because there's a quarterly essay called Lifeboat, which you wrote about the NDIS. And it might be a good chance for us to discuss what's in Lifeboat, because this is all really important. Let's play some community announcements and continue the interview with Micheline Lee, a published author who's written a number of books, including Lifeboat. Let's play some community announcements.

**Speakers:** Disabled people are worth every bloody penny. I'm okay with spending money on the supports that we need.

**Speakers:** There's more than 400, 000 people who should be on the DSP, but are on JobSeeker instead.

**Speakers:** I've got a life to live. I've got commitment. Like everybody, I came to shine.

**Speakers:** The only way to provide meaningful support is stronger grassroots movements.

**Speakers:** These institutions are never going to be our saviour.

**Speakers:** If everyone was the same, it would be a boring old world we live in.

**Speakers:** We need to do a lot of work in this country around shifting community attitudes towards people that don't fit the white, able, straight, cisgendered person.

**Speakers:** 3CR. Stay tuned. Stay radical.

**Pauline:** Tune in to Health Sovereignty. 3CR's International Day of People with Disability Broadcast on 3rd of December, 7:00 AM to 7:00 PM .We're talking about what health, well being and body sovereignty mean for multiply marginalized disabled people, their kin and communities living on unceded Indigenous lands. With programming by disabled broadcasters from the 3CR and broader community.

**Raphael:** Let's remember the history of the National Disability Insurance Scheme before continuing the interview with Micheline Lee about her book Lifeboat. People with disability had a long standing campaign. A battle, about the National Disability Insurance Scheme, about making it easier, more accessible for people.

**Raphael:** The Boldness, back in around 2013 to 2015, did a number of interviews of what it may look like. And finally the National Disability Insurance landed. So it is very appropriate we play a song by Eddie Inc called Finally Landed and then we'll continue the interview with Micheline Lee about her book Lifeboat and the changes needed to the National Disability Insurance Scheme now in 2023.

**Raphael:** Welcome back to this special edition of The Boldness. The Boldness is talking with Micheline Lee about a quarter report that she wrote called Lifeboat: disability, humanity, and the NDIS. And this is actually really important to note that Micheline Lee wrote a novel, 'The Healing Party', that was shortlisted for several prizes, including the Victorian Premier's literary award. Micheline is also a human rights lawyer.

**Raphael:** Thank you very much Micheline for giving up your time to tackle this really important subject. What we've been doing, we've discussed the background of the National Disability Insurance Scheme. The difficulties to challenges. How it's been hard that the National Disability Insurance Scheme in itself is not really accessible for a lot of different reasons. How did Lifeboat come about putting it together, Micheline?

**Micheline:** So I started doing a PhD on creative writing and law. I wanted somehow to bring together the international human rights legal experience as well as the real stories of people and to be able to write it in an engaging way. Lifeboat is I guess a combination of that, where using some of my experience as a lawyer as well as a novelist, I feel that too often... People with disabilities, we understand the structural causes, for example, of discrimination. And we understand how important it is that people with disabilities have a voice and are listened to and about the inequalities there. I wanted to write something that would bring those issues to light. I thought it was particularly important with the NDIS, because we're having a review at the moment and there will be lots of good solutions come out of the review. And I think that the undermining every reform, we do have to understand the need that the NDIS has to be leading on cultural change.

**Raphael:** Micheline how's this? I've got a quote in front of me. It's a great quote from Micheline Lee. "How people understand disability transforms how they respond to it. When they saw us as cursed or contaminated, they banished us, euthanized us, or left us on the streets to perish.

**Raphael:** When they saw us requiring protection, they institutionalized us. When they saw us as defective and in need of a cure, we were hospitalized and medicalized. When they saw us as tragic, they treated us as objects of charity. Now the NDIS is giving us a new identity; consumer".

**Raphael:** I love the way that quote really sums up what has actually happened with disability over a long time. Cause traditionally people with disability were banished to institutions that were abandoned. And now that new identity of consumer. To me, people with a disability, they're not viewed as people, they are as a consumer. They're an object rather than people in their own right. Would you care to comment?

**Micheline:** Exactly what you said Raphael. If disability was just seen as part of the normal variation of life, if people with disabilities were seen as equal with the capacity to make significant contributions to society, just like everybody else, then society would be more likely to include us. And I do feel that how society views or how other people view disability or how they understand it, really does affect how they respond to it.

**Micheline:** And that there is something about society where there's a reluctance to accept that we're all dependent in some way and that we're all vulnerable in some way. That we were born dependent, we're going to die dependent. That we have mental health days, that we have injuries, that it's all just a part of life and therefore society needs to cater for it. Because it should be seen as normal and expected that society caters for the diversity of human experience.

**Raphael:** It certainly is. The National Disability Insurance Scheme, in the current format, The Boldness has done a number of interviews over at least the past 10 years about the National Disability Insurance Scheme. And quite bluntly, because as a person with a disability and knowing many people with disabilities, NDIS, no matter how we dress it up, it is not the scheme that people with a disability fought for in order to have actually basic human access for their lives.

**Raphael:** In fact, it has become a commercial decision where people with a disability are essentially exploited by a scheme. Whether it's seen as using that word consumer.

**Micheline:** Yes. So this new identity of consumer really takes away from the humanity of, and the complexity of who we are, just like any other person. And for all the goals about acknowledging the needs of every person and their context and their capacity. We suddenly have this idealized human notion. Which has, as it has played out over the 10 years, has really disadvantaged those who can't fit into that role. And it's actually made society more individualistic in a way.

**Micheline:** And I guess that's why Bruce Bonahedi has used the term the NDIS has become an "oasis in a desert". And Minister Shorten has used the term lifeboat, and I've used the term lifeboat as well. And, we don't want to have to, as individuals, scramble onto a lifeboat in order to have these individual services.

**Micheline:** What we wanted was a more inclusive and embracing environment in a world or in Australia. Where we start making the structural changes that we need in order for the buildings and transport to be accessible. For education, to be more neurodiverse. And for individual supports to be properly addressing people's needs and done in a structural way, a collective way.

**Raphael:** This has been an absolutely fascinating, insightful interview about the National Disability Insurance Scheme. Now, Micheline Lee's quarterly essay 'Lifeboat: disability, humanity, and the NDIS', it's going to be available to the public from 11th of September, 2023. The Australian recommended price is $27. Thank you very much Micheline, for your time and generously telling us more about the National Disability Insurance Scheme. Thank you, Micheline.

**Micheline:** Thank you, Raphael. I've enjoyed talking with you.

**Raphael:** Much appreciated. On this special edition of The Boldness, talking all things Disability, let's go out with a very appropriate song, Access Access by Johnny Criscendo, thank you.