**TRANSCRIPT: EPISODE 5: Disability and Disasters**

SPEAKER:

Welcome to Thinking on Development, the podcast by the Institute for Global Development at UNSW. Each episode we are joined by new guests to explore some of development biggest questions. This episode is produced in partnership with the UNSW Disability Innovation Institute.

DAVID SANDERSON:

Hello. Disasters aren't fair, they effects those already vulnerable the worst. People with disability find themselves at particular risk, perhaps unable to escape a collapsing building or flee unaided from a fire or flood. A favorite mantra in development is to leave no one behind, but Community Development actors is well intended but not perfect (INAUDIBLE) often do. The UN has said common experience reveals that persons with disabilities are more likely to be left behind in disasters due to a lack of preparation and planning, as well as inaccessible facilities and services and transport.

Furthermore, the needs of persons with disabilities continue to be excluded over long term recovery and reconstruction efforts. How then can disability not be an impediment to better survival from disasters? And how can Community Development actors and others get better at taking disability more seriously? To discuss this, I'm joined by three experts. Rosemary Kayess is a human rights lawyer and the Faculty of Law at UNSW. Rosemary is chair of the United Nations Committee on the Rights of Persons with disabilities, and was awarded the Human Rights medal for her lifetime of work, advocating for disability rights. Jackie Leach Scully is an internationally recognized bioethicists specializing in disability and feminist bioethics.

She is currently professor of bioethics and director of the Disability Innovation Institute, also at UNSW. And Michelle Villeneuve leads the disability inclusive community development research work stream at the Center for Disability Research and Policy at the University of Sydney. Michelle is an activity lead at the World Health Organization collaborating center for strengthening rehabilitation capacity in health systems. Rosemary, Jackie and Michelle, thanks very much for joining us this afternoon. Michelle, perhaps I can start with you. You specialize in working with communities to develop programs and services for people with disability in the context of disastrous reduction. What have you seen as the biggest challenges and barriers to effective program?

MICHELLE VILLENEUVE:

I think the biggest challenges is really related to the work that we are doing together with people with disability. Biggest challenge is that people with disability have not been included in the conversation, not in policy, not in practice, not in the preparedness, resources and tools needed that we all need really to get ready for disaster events. So, I think that's the biggest barrier. When we don't include people with disability it means that we don't know what their capabilities are, we don't know what their support needs are, and it means that it's really hard for us to provide responsive emergency management planning, actions and activation when disasters strike. And it also means that people with disability are left out when accessing services. Because if you're not there registering in a disaster event, then all the triaging and supports that follow mean that people with disability will be missed out in the long term of recovery as well.

DAVID SANDERSON:

That sounds astonishing, that people with disabilities are actually not asked what they think. Rosemary, perhaps I can ask you what do you think about that as somebody living with a disability?

ROSEMARY KAYESS:

Well, I'm definitely not dead with the disability, David. But yes, I do have a disability. It is astonishing. I mean, if we're going to understand what needs to be done and how to best respond to the needs of people with disability, the best way we can do that is to recognize the expertise of that knowledge within people with disability and they're representative organizations. The Convention on the Rights of Persons with Disabilities establishes within its general obligations on states that they should actively involve organizations of persons with disabilities in their planning process or policy processes. So, it's fundamental to the principles and standards of the CRPD that people with disabilities have a voice within the planning and the policy implementation, and around disaster risk reduction.

DAVID SANDERSON:

But are you finding that that's the CRPD, the Convention of the Rights of Persons with Disabilities, are you finding that's being taken up in everyday practice? Perhaps I could ask you, Michelle. I know you're very busy doing work on people centered emergency preparedness. Do you find UN conventions work in that? And if so, how is that taken up?

MICHELLE VILLENEUVE:

Yeah. And I think when we talk about inclusion of people with disability and Person Centered Approaches, we need to think not only about the UN Convention, but the Sendai Framework for Disaster Risk Reduction, which is our international framework, about, you know, how our nation is going to protect the rights of everybody, including people with disability. And I suppose when we think about the CRPD and the Sendai Framework, we can think of them as, you know, principles and ways to move forward, but not necessarily providing a toolbox of actions on how to do that.

And so, I think the work that we've been doing is really trying to work with communities. And I must say, not just including people with disability, but including emergency personnel, emergency managers, councils, services that support people with disability every day, bringing them together to work out actually, how do we do this? So, the Sendai Framework has a call to action which says we need to actually develop more Person Centered Approaches to disaster risk management. But doesn't really lay out exactly how would that look like in practice. And so, I think that's actually challenging for emergency managers to involve everyone, all of us in our own preparedness plans and actions.

When you take it to the next level of people with disability, who might rely on other people other services and supports, who have an additional support need they might have to manage in an emergency, you know. How do you navigate that approach? So, the work that we've been doing developing Person Centered Resources are really a bit of a how to guide and a conversation guide that starts with the person themselves. So, it starts by asking people, what do you do? How do you do it? How do you spend your time and who do you spend it with? How do you manage, you know, how do you manage your support needs every day?

That conversation sets the scene where we begin with the person, we begin with their strengths and how they manage every day. And in a way, it helps us to start prioritizing what's going to be important to that person when preparing for disaster. Now, all of us know that the last thing we probably want to spend our time on is preparing for emergencies. It's the ostrich effect, all of us who will go, yep, let's leave that for another day, let's bury our head in the sand, you know. That Armageddon is never going to happen, I'll put that off and off and off. That's problematic for people who need to plan around other people to support them or around technologies or tools that they need to manage.

So, what's great about starting with your ever day support needs is that you can start to already prioritize the things that are important to you and the things that you can't live without when a disaster strikes. So, you start to set those priorities, and it makes the actual planning process a heck of a lot easier. So, we move from being overwhelmed and confronted, and really anxious about preparing to, Oh, actually, that's how I manage every day, here are some ways that I can begin to, you know, to tick those boxes for how I'm going to manage if I had to say shelter in place for a long period of time or if I had to evacuate my house, who I would rely on and how I would navigate and manage those supports.

DAVID SANDERSON:

Perhaps I can bring you into the conversation, Jackie. I'm tempted to ask you about the ostrich effect. It's a great phrase and very accurate. But perhaps you could talk that too, of course. But what would you see as the barriers to better inclusivity when it comes to disasters, risk reduction, community development and people with disabilities?

JACKIE LEACH SCULLY:

OK, thanks. Actually, I think the ostrich effect is a really interesting psychological mechanism that we've been seeing a lot of, certainly in the pandemic where at the start of the COVID pandemic, an awful lot of places were hunting around for, you know, pandemic response plans and discovering that they were, have been stuck in a drawer somewhere since 2016, the last time we had any kind of pandemic. And there they were, they hadn't been looked at since. And it can be interesting to see what happens after this one if we can take any of that education on board.

But turn it to the issue of (INAUDIBLE), I can only agree with what Rosemary and Michelle have already said. I think it's interesting to think about why that is the case. You know, why for people with disability. And I think for what you might call marginalized communities in general is part of an overall trend for official term those in power, however you want to look at it, to always assume that they know best. And that in those marginalized less vocal communities, they can come in from the outside and tell them what's good for them and what they need, and how they're going to need it.

I hope we learned a little bit from our past mistakes in that area. With disability in particular, I think that at back of it, I'm afraid is just a fundamental reservation about people with disability and disability itself. I mean, I think that's understandable. Most people who are not disabled feared disability. They don't want themselves to be disabled, they find it sometimes difficult or embarrassing or awkward or frankly, frightening to be around people with disability. And however much progress, I think we've made as a civilization as a society, with the various national and international instruments like the convention that's already been made, and various laws internal to countries about employment rights and housing rights, and so on.

But I think still behind all that is a huge level of ambivalence towards people with disability, and because of that lack of desire on the part of many people just to get engaged to expose themselves, perhaps, to those contracts. So, that means at the other end of that, is a lack of knowledge by fear of people with disability, and just a lack of knowledge about what day to day life is like. And then, that leads to this situation that Michelle has described, with inadequate supports or sometimes just the wrong support. And in general, both a lack of imagination but also an inability to realize the imagination, an imaginative sort of projection can only get you so far. And there'll be always many, many things that one contact dissipate. I mean, I'm a person with a disability, I'm profoundly deaf. When I first came into this area and started reading about it, and one of the first things I've read was an account by somebody whose guide dog had not been evacuated along with her in a disaster. It had never occurred to me that something like that might happen. So, one needs to engage with the, what we commonly call the lived experience, I think, to understand that.

DAVID SANDERSON:

Rosemary, can I ask you to respond. Do you recognize what Jackie is saying?

ROSEMARY KAYESS:

Look, I think Jackie has hit on a critical point. And that's the arbitrary nature of disability within our society. I mean, impairment is just one aspect of the human condition, yet we as a society draw a line from this illusionary able bodied norm. And the further we get away from that able bodied norm in terms of impairment, all of a sudden you get a point where it's uncomfortable with society, and that's when it becomes disability. When it gets to the point away from that norm, impairment, gets away from that idealized norm, we as a society can cope.

And so then, we have created mechanisms to capture it and protection that has excluded people with disability and isolated them from the mainstream community. And it's because of that inherent exclusion, isolation and discrimination and inequality that people with disability are vulnerable. People with disability aren't necessarily inherently vulnerable, but it is that inequality and discrimination that leaves them in vulnerable situations, especially in terms of Disaster Risk Reduction. All those things you mentioned, first up, about lack of accessibility and lack of access to, lack of knowledge within Disaster Risk Reduction mechanisms and planning, that is exclusion.

That is exclusion because, like it happened here in the pandemic, they just assumed that people with disability all lived in group homes, were all tied up in service settings, and we didn't have to worry about them. But that's not the case. We're not a homogeneous group. And until we address some of that broader general accessibility, the stuff that Michelle does, which is so incredibly important is incredibly extensive, and will not ever get to the level that we require to be able to make sure that everybody has access to Disaster Risk Reduction. It's very intensive. So, what you've got to do is you've got to take that general accessibility pressure off and deal with the very specific individualized support that then makes it actually manageable.

DAVID SANDERSON:

Michelle, do you find that in your work? Rosemary mentioned assumptions about disability rather crass assumptions. Did you find that people may be well intended and yet, just stereotyped or whatever or the wrong assumptions when it comes to this?

MICHELLE VILLENEUVE:

That resonates so much for me in the work that I do. What both Rosemary and Jackie are speaking about, about people's hesitance around other people with disability. I think we grow up in a society where we are the people who are different. And that definitely happens in the work that I see. So, I'll give you an example. I work very closely with emergency personnel, with government stakeholders who work in emergency management roles. And I can tell you that sector from police to ambulance to your state emergency service volunteers and your rural fire service community engagement officers, all the way down the line, and all the way up through policy have the biggest hearts.

They have the greatest intent to protect all of us. Their hearts are gigantic, and their efforts toward protecting everyone in society are huge. So, you cannot fault people for trying to do their jobs. The challenge is that they've grown up in a society where we've other people with disability. And, you know, Rosemary pointed out those words care, treat, protect, those really resonate for me when we think about what happens in our emergency management responses. When we think about vulnerability. Rosemary used the word vulnerability as well. When emergency managers put that vulnerability hat on, and they decide that they're going to protect all of these vulnerable people, they actually reduce the nature and type of responses they can provide through their emergency management role.

It basically reduces their response to a resource approach. So, let's throw resources at it, let's throw equipment at it, let's throw people at it. That's not necessarily the response we need. In fact, what we need is proactive planning. And as Rosemary talks about that individualized in depth self assessment approach, so our PCPT tool is all about, our Person Centered Tools and Resources are all about affording that opportunity for individuals to start the conversation, for them to self assess what they need and how that can be managed, and to negotiate that in partnership with other people.

So, to come full circle to your question, how do we break down those barriers, for example in the emergency management sector. Exposure to people with disability helps to break down all of that stigma and those perceptions that the emergency personnel have about their role in relation to people with disability and Disaster Risk Reduction. But that stigma in general, and how to actually just listen and learn from people with disability and respond on that level. And I would say that some of the most exciting transformational changes were beginning to see as a result of these Person Centered Approaches to Disaster Risk Reduction.

DAVID SANDERSON:

Jackie, I know as a bioethicist do you have particular interest in terminology such as vulnerability and other terms?

JACKIE LEACH SCULLY:

Yeah. I mean, the idea of vulnerability is such an interesting and contested and complicated one because on the one hand everybody or every human person is vulnerable. And I would argue throughout your entire life, but certainly a particular point in your life, like when you're first born or when you're a small child, there's no way that you can say that you're not vulnerable in those days. But we live in societies in which certain evolve universal vulnerability, they kind of shielded from us because societies are built around the way that, let's say the Standard Model human is. And those people who fall outside of that are identified as having special vulnerabilities.

And I think it tends to dichotomize so that, in quote marks, "Normal people will think of themselves as not vulnerable." Because they're not actually exposed to those dependencies on a daily basis because they're met. Those needs are met without question. However, the people who fall outside are seen as not just more vulnerable but per se vulnerable. And the example I would like to give is about electric light, it's something that we take as being sort of standard. You wouldn't expect to have to ask for it, and yet many of us, I think, if we went through the power cut on the dark night, we find ourselves incredibly vulnerable because we're not used to navigating in the dark.

But on a daily basis, we're not exposed to that because we just switch the light on, and there it is. Where as for somebody who may need electricity for power wheelchair or for a ventilator even, something like that, it's a very different form of vulnerability. There's an idea, which unfortunately comes tied with absolutely horrible word, which I actually find quite hard to say, which is (UNKNOWN). Yeah. And the idea is that things around in the environment and the society, sometimes also attitudes make you either vulnerable or more vulnerable than you might otherwise need to be. And that becomes very complex. And I think it entailed a lot of unpacking to work out exactly how that's affecting people with disability.

But an example might be that someone with a disability, we know that globally, those people tend to be poor, they'd be less often employed, be living in poverty to not have those resources, that will then mean that they tend to be disproportionately among the people who can't drive their way out of a disaster area, OK. So, often nothing directly to do with the impairment per se is to do with the knock on effects that have been going on for a long time in their environment around them. And then, the situation of disaster or emergency brings out acutely what has been going on for a long time, and exposes them in a way that people who have more resources, more money and so on, are not exposed. So, it's a very complex idea.

DAVID SANDERSON:

I've not come across (INAUDIBLE).

JACKIE LEACH SCULLY:

You are lucky.

DAVID SANDERSON:

I'm dying to ask about resilience but I got to hold that thought because Rosemary, you were nodding all the way through this. Can I draw you into this, please?

ROSEMARY KAYESS:

I'm not even going to attempt to get my mouth around that word. But yeah, look, there's 2x aspects to it. Just to use COVID. Look, I know everyone's sick of the disaster days, sure but it's here with us, let's use it as an example. And COVID is really, really exposed to the inequality and discrimination that people with disability experience, just like Jackie highlighted. I mean, it may have nothing to do with their actual impairment, but essentially, because of the inequality and discrimination they've experienced, they will be in situations where they are more vulnerable and that vulnerability is created.

But then, it's also reinforced through the rhetoric around COVID, that they are somehow expendable, you know, from the very beginning of COVID. So, talked about vulnerable people, everybody else is just going to get the flu, and it's only going to be the vulnerable people that will get really sick and die, which just sort of reinforces that we're a little bit expendable. And that rhetoric is still continuing today. I mean, we have announcements of the deaths overnight, and they qualify those deaths had, you know, such and such died, you know, 40 year old man died he had underlying health conditions.

Now, I'm not a medical doctor but I get about 90% of the population has got underlying medical conditions. But it creates this illusion that there are weaker people and feed into that whole Darwinian notion that there are people that are expendable in these situations. And I think people with disability and older persons have really borne the brunt of that. And it can be reinforced in other disasters in terms of the costs that can be involved in addressing the inequality and discrimination that has existed, and how to make responses that are far more accessible.

DDI have a question for all three of you, if I may. We are living in increasingly perilous times, not these COVID as you described Rosemary just now, but other issues around the world climate, of course, leading to fires and floods and temperature increases, not least conflict, violence, urbanization. I don't want to take the conversation into a sort of a counselor despair, of course not. But I want to have this idea that in 10 years in the future we look back and actually we have managed to achieve the idea of leaving nobody behind. I just wonder what your views would be on how we got there, how we got to a good place, where actually, we weren't leaving people behind.

MICHELLE VILLRNEUVE:

Oh, that is such a good question, David. Thank you for asking it. I suppose what it makes me reflect on as our aspirations, what we're working toward in our program of research is being able to identify who is responsible for what, and look at ways to not only define those responsibilities but how are we going to share those responsibilities. So, the way that I look at how all of us need to manage in the disaster, no one person is going to manage completely independently in a disaster. And it doesn't matter how able bodied you are, you're going to need to rely on other people for support, for information, for actions and for decisions you're going to take through that entire process.

That's abundantly clear when we look at the long term of recovery of much of our, you know, Australian Eastern Board who suffered so much of the 2019-2020 bushfires, and significantly undergoing long term recovery and managing those effects. But when we think about people with disability, and we think about what would be that future aspirational goal, I think it's about knowing who's going to take responsibility for what. And also, I think it's about starting with people and their support needs and keeping that at the center of planning who's going to take responsibility. And one of the things that I often think about is, you know, Australia.

And, you know, I come as a Canadian, I come with the opportunity to sort of look in at the country I've migrated to and call home. And I think, well, one of the big cultural factors in Australia is this idea of volunteering. Stepping up when things are hard, volunteering. It's just a part of Australian society. And I think about that a lot when I think about my colleagues in the emergency services sector. Many of them have come to the roles because they started as a little nipper and went on to serve life saving, and then went on into volunteer with their state emergency services or their rural fire brigades.

And that notion of volunteering is really fundamental to how we respond, you know, culturally in Australia. And when I think about, well, what opportunities can and should people, all people including people with disability have in disaster risk reduction, the opportunity to have that opportunity to step up and volunteer in Disaster Risk Reduction in lots of ways before, during and after a disaster. And we will always have disasters, there will be responses required, I would like to see people with disability at the front of house when people are arriving at the evacuation centers and people being treated with respect, and feeling comfortable and safe. And having those needs managed because we have wider representation of people providing those supports.

DAVID SANDERSON:

And you mentioned little nippers, it's a very Australian, to have young children learning to swim. And thinking of Australia, are you seeing examples of people with disabilities that are having positions of influence and actually visibility when it comes to this?

MICHELLE VILLENEUVE:

Yeah, and that's probably the biggest part of our partnering with. So, Rosemary at the very beginning talked about one of the fundamental principles of the CRPD the Convention on the Rights of Persons with Disability. And that is the right to lead this conversation and working with the disability representative organizations to do that. We've been working for three years now with Queenslanders with disability network and a cadre of peer support leaders. They have an incredible network of peer support, and a foundational way that they actually support communication outward to their community into the, you know, as Rosemary might say, some of the most isolated people with disability who are disconnected and don't receive service and supports but who are connected through their peer support networks to this member organization.

What they also have is a voice upward toward policy decision making because of the role that their representative organization plays in gathering that lived experience of the everyday life of people in their community, and, you know, moving those issues upward toward policy advocacy. We've been doing exactly that with Person Centered Emergency Preparedness, having that conversation work its way out into the depths of communities, helping people with disability lead the conversation about personal emergency preparedness planning and having that conversation filter up.

What are the ongoing and unmet needs of people with disability before, during and after disaster, and using that information to support policy advocacy more responsive local emergency management and state disaster recovery planning processes that are more responsive to the actual unmet needs. Jackie mentioned transportation as a really hot button item for many people when disasters strike, is just one example of the ways that that information is filtering back up into change practices.

JACKIE LEACH SCULLY:

For me, I think there are two major things. One is about an acknowledgement of the diversity and non homogeneity, as Rosemary pointed out of people with disability. When I have conversations with people about disability, and sometimes also about disaster response, of course, if they're not disabled themselves, if they're not active in that world, then they tend to go in the wheelchair. And then, a couple of weeks later it will be made and looking at me sometimes or the deaf person or maybe the blind person or something like that. And a lot of responses, I think are built around those very traditional still true, but traditional ideas of disability. And I think we need to go beyond that to also acknowledge the person with an intellectual disability, the neurodivergent person, for example, who might not to the first responder appear disabled at all, but who's behaving in a way that they're not anticipating.

And they're a bit at a loss of what what's going on here. So, that kind of level of granularity almost which comes back to the stuff about knowledge, and being interested enough to engage and get that kind of knowledge and not be overwhelmed I suppose, by that diversity but think that there are actually ways of dealing with it. That would be one thing. And the second one, I thin, would be really trying to join the dots between the policy changes at the top, which as Michelle pointed out are changing or becoming more inclusive or attempting to become more responsive to people with disability, and to include them in at all stages of disaster preparedness and management and response and mopping up afterwards, and so on.

But particularly in Australia, we've spoken of the volunteer culture as being an enormous strength, and it is. But it's also potential liability in that people will always bring in to that work their own particular background and biases and prejudices sometimes. And unless efforts brought in, I think, to really try to change that sort of culture, you can have as much policy as you'd like. But when push comes to shove, and the heat for the bushfire or however you want to phrase it, then people may well that's back into standard ways of working unless they're trained in other ways, and really have their eyes opened on that front.

DAVID SANDERSON:

Maybe I can ask you a bit further then. I mean, as Michelle pointed out some of the most big hearted human beings on the planet work in this space. And if you're taught response, then it's top down command and control response. Obviously, rightly so. When we think about people's agency and vulnerability, perhaps we're thinking more about supporting people where they are and who they are, and their determination. Did you do see a tension there, Jackie, when it comes to that?

JACKIE LEACH SCULLY:

I think when it comes down to it, there needs to be an acknowledgement of not just of the knowledge that people with disability have with their lives. But as Michelle previously pointed out about their vulnerabilities but also about their capacities and their particular strength, which might actually sometimes be very useful in certain cases of disaster. I mean, this is pushing it anecdotally a little bit but I will remember being in the situation with some friends in London where a fire alarm went off in the building, and it was so loud that they were almost incapacitated. It was quite counterproductive that the brains were shaking almost, they could not find their way around. And it didn't affect me nearly as much because I couldn't hear it nearly as much. And in fact, I wondered why they were responding in quite (INAUDIBLE) as they were. So, just in that particular situation, it was a major advantage to me and to them because I got them out of the building, which didn't happen to be on five anyway, but there you go. It's exploring those sorts of complexities and the strengths and capabilities as well as the particular needs that individuals will have that I think is key here.

ROSEMARY KAYESS:

I think there needs to be some very specific measures that happen within countries that promote and foster both the top down and the bottom up. So, I think there needs to be the establishment of a high level independent focal point within government for driving implementation, monitoring and reporting of convention obligations. So, across all portfolio areas and across levels of government. And that has the responsibility for reporting on the convention progress annually to Parliament. So, making disability part of the business of the day of the Parliament. The establishment of a standing advisory mechanism made up of people with disabilities through their representative organizations to ensure the active participation and close consultation of people with disabilities across all levels of government. And that's organizations of people with disability for people with disabilities.

So, it's organizations of people with disability that are managed by people with disability led by people with disability for people with disability. The development of strategies to ensure that people have appropriate and accessible information, and prioritize high risk groups and ensures adequate resources to make sure those elements of accessibility can be provided. And actually, development of a disability inclusive Disaster Risk Reduction Framework in the lines of the Sendai Framework to inform the development of (INAUDIBLE) emergency response plans, and including in the context of public health emergencies like food and pandemics like we're experiencing. And this should adhere to the convention and reflect the Sendai Framework, and should include the active participation of people with disability through their representative organizations. And the development of a functioning National Disability strategy that is focused on implementation of the convention, and its principles and standards to address that, you know, inequality and discrimination that's already there.

So, we're not starting from a position without Disaster Risk Reduction way, you've got to address years and years of inequality and discrimination. And it just makes the job when the disaster actually happens harder to do. So, I think there are fundamental structural things that can be put in place that can recognize disability or recognize impairment is just part of the government's job of the day across all portfolios. That it's not just about specialized services in areas like residential care, education and employment, that people with disabilities are not homogeneous groups that all require some specialized service for them to exist.

And so, I think a lot of that has come from the fact that we base a lot of the discussions in Australia and everywhere else in the world, around diagnostic groups. And so, it comes down very much to the issue of impairment from a diagnostic focus, whereas it should be the way that the society is structured to meet the diversity of impairment within the human condition. So, they're my thoughts about how (INAUDIBLE), I think you're a bit optimistic. But in some years time we could get to a situation where people won't want to stick their head in the sand if a disaster strikes.

DAVID SANDERSON:

Thank you, Rosemary, you ended that perfectly. That the key to leaving nobody behind is actually perhaps to recognize everybody and everybody's role in society. Thank you very much to our guests Rosemary Kayess, Jackie Leach Scully and Michelle Villeneuve, and thank you for listening.