## DISABILITY IN CRISES

PROF JACKIE LEACH SCULLY:

Good afternoon, everybody. I have been told that we are good to go. Welcome to this event, which is part of the UNSW Diversity Festival 2024. I am going to begin as is customary, we are gathering on the unceded lands of Bedegal people, and also acknowledge the custodians of the various lands on which you normally would be resided, and various lands of the people online today. I want to say what I have commented to a couple of people already, although the audience in person is sparse, we have over 600 people online, which seems to be the way big proportions are happening these days.

We pay our respects to Elders past and present, and celebrating the diversity of Aboriginal and Torres Strait Islander people and their continuing connection to the lands and waters across Australia. We particularly acknowledge at the University, our joint commitment to gathering and sharing different kinds of knowledge, including knowledge that is crucial for our management and understanding of the natural environment and the associated events in Australia. I am Professor Jackie Leach Scully, I am a Professor of Bioethics at UNSW and the Disability Innovation Institute who is sponsoring this event. Just a couple of words about DIIU, for those of you who do not know, it is the unique initiative that focuses on disability research and education, and knowledge exchange.

All of us take pride in undertaking work that is inclusive, that is radically inclusive, across the traditional disciplinary boundaries. Our institute's approach is to see disability not has a problem to be solved, but as a part of the human condition, which is to be encountered and to be engaged with, rather than something to be feared.

We are proud to bring this event, jointly with the AHRI, the AHRI itself which is the research, strategic collaborations to foster accountability where human rights abuse is challenged and rectified. DIIU and AHRI, sorry we have a very acronym filled afternoon today we have collaborated on several initiatives already.

DIIU itself has a long-standing commitment to issues on health emergencies and natural disasters, something like virtually 13 to 14 years ago when I was working in the UK, when I first became interested in this area. When I was working with a team of people who were involved in the technologies to do with responding to disasters and natural emergencies. During that time, it became very clear to me, and it was mentioned to me by others, the disproportionate impact of disasters and natural emergencies on people with disability.

Here in Australia, I think we should all have an interest in these kinds of events, because in addition to war, unpredictable natural disasters such as earthquakes, things to do with climate-related changes, such as floods and fires are becoming more regular and even familiar occurrences in Australia. Australia itself is well-known for extreme weather events, unpredictable weather events, but as climate change accelerates, so does the frequent damages in Australia and also in the Asia-Pacific region. Also in a country and region that has a past and present full of stories about natural disasters, disability is often overlooked. And that is the case, even though we know from all of the evidence that people with disability are disproportionately affected. In the 2023 report by the United Nations Office for Disaster Risk Reduction, the survey undertaken showed that only about 8% of disabled people globally reported that their local disaster risk reduction plans had given any thought to disability or people with disability. Only 16% of people reported they had input or involvement in the local disaster management planning.

We found that when experts in the media talk about disaster preparedness and community resilience, and things like that, the role of people with disability is often absent, and that seems to reflect this assumption about disabled people being vulnerable and having deficits, rather than competence and skills that can contribute to those plans and management, and that is despite the commitment to disability inclusion for the Sendai framework on disaster risk reduction, which is now more than halfway through its 15 year plan implementation, and to be honest the changes and that 7.5 to 8 years do not look terribly good.

One thing I'm hoping to do this afternoon is change that. In this discussion, our panel will respond to questions. They will explore intersections in disability and natural disasters, focusing less on vulnerabilities, and instead on empowerment. It is not just Ariella and me, they will share their experiences and insight on this topic. Our aim is to increase further discussion and action within the wider community. We are hoping in this event to generate some questions from the audience, both in person and online, and foster some discussion.

It is my pleasure to introduce our panel members. Dr Ariella Meltzer here is a Senior Research Fellow at the Centre for Social Impact at UNSW. She recently led a research project that was looking at accessible information provided to organisations during a pandemic and bushfires and floods that Australia has experienced. And I think that was one that DIIU gave funding to in the first place.

Joining us online is Dr Antoni Tsaputra, who is an active advocate for disability inclusive policies and development programs in Indonesia. We have worked with Antoni before and he completed his PhD at School of social sciences at UNSW in 2020, and in that PhD, he was focusing on the rights of people with disability within the development context of Indonesia. He is currently a lecturer in the School of education at Padang State University in Indonesia. He has been a regular contributor to international disability discussions and a guest speaker at conferences, including with the United Nations.

He has an ongoing commitment that I can attest to personally, by treating linkages between Australia and Indonesia through advocacy work in disability policy. We will be hearing from Antoni in due course.

Cheryl Durrant has over 30 years experience in the natural security sector with the Australian Department of Defence and Australian Army. Since leaving Defence, she has been working at the intersection of climate resilience, and she was the author of the Australian Institute for Disaster Resilience's Managing Disaster Exercise Handbook. I will not tell you what the acronym for that is. She also works on generative development and climate resilience, and is an executive member of the Australian Security Leaders Climate Group.

Danielle Santos is a mixed Filipino Australian, disabled researcher and lawyer and disability advocate, with nine years experience in disability research and direct practice. She has undertaken a diploma study of the impact of chronic climate disasters for disabled Filipinos across seven provinces. In 2024 she returned to the Philippines to further explore how to improve evacuation protocols in the Philippines for disabled people. That was funded again through the DIIU and the AHRI's joint disabilities seed grant. We will be hearing from Danielle about centring the lived experience and her work and innovative methodologies that she uses to build into every stage of the research project.

And last but not least, we have Prof David Sanderson. He is the Judith Nielsen Chair in Architecture at UNSW and he has experience working across the world in disasters and development, in practice, and most recently in academia. David recently initiated a long-term independently funded initiative called HowWeSurvive, aimed at reshaping disaster recovery in communities and elsewhere.

OK, that was a very long introduction. I hope people will mean more to you when you have been able to see them online.

I think we now move to the panel discussion session. We have a range of predefined questions which I will start to ask our panel to respond to. But if you have a comment or question, feel free to jump in. This is an informal session. And if you are online, then post a question in the Q&A or possibly the chat. And Kate, who has disappeared behind the scenes but is here, will be checking for questions online and we will forward them to me.

The first question I want to proffer to, and I will probably go to Ariella first if that's OK since you are closest to me. I said earlier that people with disability are disproportionately affected by disasters. You can ask the question, why is that? What is it that is happening here? Is it just to do with the fact of disability? Or is it something else?

DR ARIELLA MELTZER:

Thanks so much, Jackie. As you said in your introduction to me, my focus has been on accessible crisis information. My answer to this question is from an information perspective.

People with disability I think are disproportionately affected by disasters because very often they are not getting the crisis information updates they need. There are really good efforts to start making sure that information is getting excessively out there, but there is a long way to go, and a starting point that is quite far back.

I think historically accessible information has sometimes been treated as an afterthought, and that is not just in a crisis, it's all the time. But in a crisis it really matters because people need information and they need it right now.

I think the other thing is also in Australia when we make accessible crisis information, that is often done in collaboration between emergency services and other authorities with expertise on the emergency side of things. But it is done in collaboration with specialist organisations who make accessible information more generally. And those organisations are not really supported as a subsector of the disability sector. They don't receive a lot of funding. And they don't have a lot of stability as organisations.

So when it comes to an overwhelming thing like a disaster event or the pandemic was also part of my research, the amount of information they have to pump out and pumped out quickly is really fast. But the resourcing and set up they have behind that isn't always there, and that makes it really hard to get people with disability the information they need. Which then means that disproportionate effects can come to them compared to people who have more information at their disposal.

PROF JACKIE LEACH SCULLY:

Thank you. Now I am going to see whether the magic of technology actually works, and if one of our speakers... Should we go to David? David, if you are online, would you like to respond to the question about why people with disability are more effective?

PROF DAVID SANDERSON:

Thank you. I just want to say it's a privilege to be on this panel. I'm hearing quite an echo. Shall I keep going or stop? Shall I keep going?

PROF JACKIE LEACH SCULLY:

It's not so much the echo. We have got your picture on one screen but not the other. Keep going. I think keep going.

PROF DAVID SANDERSON:

Recognising there are brilliant people in this panel, and no doubt in the audience. A quick response from me. The word inclusive is there and you mentioned just now. The problem with disaster management is it is anything but inclusive. It is exclusive. Agencies are not rewarded, particularly by engaging with others. I know that sounds rather harsh, but that is a summary of the global conversation of a systemic issue over the decades that while we believe community centred recovery including everybody, the evidence is that those with power and the systems don't actually respond to that. Not because people are evil, I have never met anybody who thinks it is not a good idea, but we have top-down control which doesn't like consultation because it gets in the way of what they think of as being effective.

I am being deliberately provocative, but I think that's the case. I will stop there and let other people add to that or contest it.

PROF JACKIE LEACH SCULLY:

Thanks, David. Was the sound OK for people? And is the captioning working for people? Good. It wouldn't do to not be as accessible as possible an event like this.

Cheryl, how would you like to respond to this?

You are very quiet.

CHERYL DURRANT:

Thanks, David for being provocative. Coming from initially a first responder sector, my comment was for many years people with a disability were completely invisible. Certainly my early army, never saw, never thought, never engaged.

I think that is partly because the sector that is dominant within the space is a sector of response. Where we know that the best value of responding to disasters comes in the planning, preparing, mitigation, recovery. And so partly it is just changing the narrative to be more inclusive in many ways, more inclusive for voices from sectors that are not just about response.

Tragically I think a lot of the media about this is in fact focused on response, not on the excellent work done prior and post disasters. It is not even there.

PROF JACKIE LEACH SCULLY:

Thank you. Antoni, if you are there, what is your perspective?

DR ANTONI TSAPUTRA:

Thank you, thank you very much, and good afternoon everyone. I will be speaking today mostly on the context and situation we face in Indonesia. I can't agree more with what...

PROF JACKIE LEACH SCULLY:

Antoni, could you could speak more loudly?

DR ANTONI TSAPUTRA:

OK. I have been speaking quite loudly, almost yelling! I can't agree more with what Cheryl and David mentioned. We are seeing especially in Indonesia's context where people with disabilities are the proportionately affected. It may be due to the combination of both the systemic barriers and biases.

For example, the first structure is often inaccessible. Disaster prone areas, evacuation routes and shelters are difficult for people with disabilities to reach. In some cases, (inaudible) located on high grounds where steep stairs are nearly impossible to navigate someone using a wheelchair or with limited mobility.

One significant issue we face in Indonesia is indeed the lack of aggregated data on people with disabilities. The authorities do not have adequate information on where people with disabilities are located, what kind of disabilities they have, or what specific assistance they might need during an emergency. Without this data it becomes incredibly difficult to plan for inclusive disaster preparedness. And this data gap leads to people with disabilities being overlooked in both the planning and execution phases of disaster management.

For instance, during the 2018 Lombok earthquake in Indonesia, many people with disabilities were left behind during evacuations. And accessible shelters that were already prepared by the government were not... turned out to be not adequately prepared. This was just not a failure of infrastructure but also I think a failure of perception. Disaster response teams do not see people with disabilities as active participants in the recovery process. So when they built the shelters, they did not consult with organisations of people with disabilities.

So I think this kind of (inaudible) persists, even though people with disabilities have repeatedly demonstrated their capacity to contribute to disaster recovery.

PROF JACKIE LEACH SCULLY:

OK, thanks. And now we go finally to... We turn to Danielle. Danielle, from your perspective, from your work in the Philippines, do you have something to add to that?

DANIELLE SANTOS:

Idea. I think what Antoni was describing is exactly the experience I have had in the Philippines and what I found my research around the data gaps, being a lack of consideration for people with disabilities and a lack of follow-through on allegedly accessible evacuation protocols.

I think the big issue that has only touched on is even when there isn't a disaster event, disabled people are excluded from society. What disasters do is exasperate whatever existing inequalities exist. For example the island I am doing a case study on at the moment is geographically isolated and regional in the Philippines. It was hit by super Typhoon Odette at the end of 2021. It was not just disabled people that had issues getting to evacuation centres. It was every single person living in a slum on the shoreline whose homes were slipped away by the winds and by the storm surges. It was for people who are unaccounted for in censuses because they don't speak the right dialect and don't have the literacy skills.

Disasters exacerbate existing inequalities and frankly we live in an ableist world. So you can't talk about disasters as isolated events with the start, middle and end. If we want to really change what disasters look like for people with disability we need to think about how we improve and remove ableist systemic structures that exist all the time for disabled people, in between all the moments of disaster that are happening. And they are happening frequently and becoming more severe. So what do we do? I think the real question is what do we do in all those in between moments?

PROF JACKIE LEACH SCULLY:

Thank you, everybody. Just on that point, does anybody here have a question they want to pick out for one of the speakers?

QUESTION FROM FLOOR:

Two questions. Let me introduce myself. My name is Leah and I'm from New South Wales Fire and Rescue. I am a woman with a disability. I have two questions. Firstly, I want to ask, I'm curious if any of you know of any emergency organisations or management groups who have consulted to develop resources for women with disability to ensure they have awareness for preparedness, because in how information is disseminated, is there anyone who has that work and is information evenly distributed in English? And do people with disability have access to that information?

DR ARIELLA MELTZER:

I can talk to that one. Thank you for the question. In our research, we spoke to accessible information provider organisations who have done work on behalf of different emergency services and local councils. There were a number of organisations who have produced resources, particularly about preparedness in advance of an emergency. A lot of those were related to bushfires. Some of those are related to floods, and happen particularly after the 2022 flooding in Queensland.

One of the really interesting things, in terms of the answer to your question, in some cases those resources have been produced a number of years ago and stayed in perpetuity without necessarily being updated. Now we know that systems for evacuation and safety and recovery are improving all the time. And we want to see that updated information flow into the accessible products as well.

The other thing that I think is very interesting is the types of organisations who do that kind of accessible information work. So some of those organisations are small businesses or social enterprises who might focus on one particular format have accessible information, and that could be anything from easy read, easy English, Auslan interpretation and various prints for people with low vision and blindness.

But a lot of that kind of work is also done by disability advocacy organisations who do accessible information work almost as a side gig to their advocacy work. And what that means is that those advocacy organisations are very connected into the communities of people with disability they serve. There are some of those organisations who are doing work to make sure that information got out to the people with disability who might be the most disadvantaged in information flow. For example, people living in group homes or residential and institutional settings.

QUESTION FROM FLOOR:

Thank you for that answer. Fire and Rescue, because I'm committed to a partner in national disability organisation, who work with local communities in New South Wales. And we consult with communities and there are 80 disability groups in New South Wales that we consult with, all different types of disabilities require prior information. It can be translated into easy English, as well as Auslan. We want to make sure we check first that if they understand, if we can get consultation right, and we don't want to do all of the hard work and spend all of the money all the time, and then they still go, "I still do not understand." We want to always involve them throughout the whole process, but throughout it, until the end. And after the end of it, people are confident they can follow the process, as well as understand the issues. My second question is very short for the other lady in the Philippines and Antoni.

Disability inclusion DRI organisation, strong advocates for inclusion within your countries or not. That is my question for Antoni and Danielle.

PROF JACKIE LEACH SCULLY:

That was a question for Antoni and Danielle. Shall we go to Danielle, you are on screen, and then Antoni, is that OK?

DANIELLE SANTOS:

It is quite hard to hear what is being said in the room or if it is the online panellists. No, it is not a me problem. If you could repeat the question please, Jackie.

The issue is the mic is echoing for the audience, so we can't actually… being louder is not helpful.

PROF JACKIE LEACH SCULLY:

Is this better?

DANIELLE SANTOS:

Yes.

PROF JACKIE LEACH SCULLY:

Can you hear that better, Danielle?

DANIELLE SANTOS:

Yes, I can hear you.

PROF JACKIE LEACH SCULLY:

I don't think so. Do you have captions there?

DANIELLE SANTOS:

No, we don't have captions.

PROF DAVID SANDERSON:

I think, does DRI exist in the Philippines?

DANIELLE SANTOS:

Technically, yes. But in effectively. Philippines have a decentralised government system with 4 levels of government that do not coordinate well with each other, and the lower you go the more involved, the more responsibility there is with inclusive management of disaster response, but the less resources.

In the Philippines at each level there is a disability affairs office, they have a disability person who is supposed to be responsible for ensuring all disability inclusive policy across every single department. But that role is not salaried. That office is not fully funded, and no other departments… but departments that are most responsible for disaster response don't have disabled people involved there because they say that the local person will do that work, which makes it very very difficult for successful disability consultation and any successful preparation for disabled people, and as has been said earlier by Antoni, any effective data collection of who actually is in the community and who will need assistance during, for example, an evacuation.

Technical yes. But there are big issues in the Philippines around implementation. They have a lot of laws and policies, but no resources to effectively implement it.

PROF JACKIE LEACH SCULLY:

Antoni and I think earlier you mentioned there is a big disparity in situations, that it might not be ideal in Australia, but it is better than a few other places around the world. I'm wondering if we can move on for now anyway, perhaps go to David for the first one, because I know you have a perspective, a long-term perspective over these issues. The next question on my list is what can be done to improve the situation?

But I think we have had some indication about what the scale of the problem is. From your perspective, what do you think needs to be done both individually and systemically to improve matters?

PROF DAVID SANDERSON:

Thanks, Jackie. In fact, thank you for that, because it ties into the first question from what I understood. Of course, there is a lot of work going on around the world. As you said, in other countries, people with disability are literally hidden when it comes to recovery response and the other things. But what can be done? I want to do a shout out to Michelle Villeneuve at University of Sydney. I can see you nodding, Danielle and Cheryl. Michelle has been on a 10 year project to kick-off, institutionalise is the wrong word, but built into the system the whole idea of person-centred emergency preparedness, and if you go on our website, collaborating4inclusion.org has useful tools, and Michelle's work has been rooted on this, with the New South Wales Reconstruction Authority, and it is one of the best shows in the region. Super powerful and very inclusive. Michelle is the first person to see peace for everybody, and that is including inclusion in my opinion anyway. I would say to take a look at that stuff. There is a lot that can be done. This was a discussion that was some years ago, so there is a good direction, and of course there is more to do and that goes without saying. But there are good examples, and Michelle's work is one of them.

PROF JACKIE LEACH SCULLY:

Thank you. While people were talking earlier, I was thinking it seems to me one of the issues has always been it is not just in the area of disaster response, but in a lot of disability-related areas that access and disability inclusion is seen as a good thing, a good peripheral thing, like a luxury, perhaps, something to be included when times are good. But under crisis and under stress, there are not a lot of resources and it drops off the side or the edges. But it is not yet embedded. I think David said about person-centred recovery measures and so on. It is seen as a special measure, rather than something that is embedded in operating procedures. On one hand, we need to think about special measures in order to be inclusive, but temporarily until they become special measures, but routine measures to include inclusivity. How do people feel we can change the narrative, and in a sense changing the way we talk about and think about inclusion in the context of disaster recovery and rescue? And perhaps, I will go to Cheryl for this one, trying to be fair here, but also not to put you on the spot.

CHERYL DURRANT:

One of the most important things is changing the framework of how we view disasters. Often there are two fundamental things in a disaster. One is protection and the other is care. We often focus on the protection, not the care. If we take a care focus or leave no one behind focus, and I also shout out to the work David mentioned, certainly I am seeing more of a care and disability focus come into federal planning. It has always been there in community, not so much in local government.

Focus on care as opposed to protection as a way to see how we approach disasters. Second, there has to be better resourcing because we shouldn't be extras, but they are now seen as extras. The Auslan, the captioning, the additional resources cost money, and my experience being in a small community group and a government is money is often not there and these are seen as add-ons rather than part of the standard budget. I think that is a critical thing, the proper resourcing for those who are working in the space. But also the mindset of this is just a normative thing, not an add-on or extra.

I think Danielle hit the number. Before it happens in disasters, it has to happen generally, how we think about our ableist world and change the ableist world as the first step.

PROF JACKIE LEACH SCULLY:

Thank you. Antoni, I know you have been doing work with communities in Indonesia, trying to shift perspectives and change narratives. Do you want to say anything about that?

DR ANTONI TSAPUTRA:

Right. One way to change this narrative is to highlight success stories where people with disabilities have taken active roles in disaster preparedness and recovery.

One example of progress in Indonesia I would say the Difagana program. It also answers the question from the audience before about the contribution of projects in Indonesia. This program is a disaster response initiative that gains people with disabilities to become first responders in times of crisis, particularly in natural disasters. This is one of the results of ASP projects.

It is a volunteer disaster management organisation composed of people with disabilities. So it was initiated by the social affairs office of Jakarta in the centre of Java, with the support of ASA, and in collaboration with handicap International. I think what they have been doing is quite amazing. It has attracted news in Indonesia and shows how people with disabilities can contribute to disaster preparedness, even in emergency situations.

The program has demonstrated the potential of people with disabilities to play active roles in disaster management. They have a kind of peer-to-peer support as well, and they also have quite strong digital presence. They also have designed a disability friendly app designed to assist people with disabilities in disaster situations. They have even assisted about 300 earthquake victims in Lombok earthquake. They are heavily involved in first responders. So they help collect data, they did assessment on the needs of people with disabilities affected, and they also helped them evacuate and helping them to access shelter.

So I think this is a very good example that deserves more highlight in media coverage. So they have been really doing great work. But unfortunately it has yet to be scaled up. It has yet to be supported with consistent funding. Currently many of their programs are not well integrated into mainstream disaster management at first. And are underfunded.

PROF JACKIE LEACH SCULLY:

Thanks, Antoni. One thing I am getting a sense of fear is also about not just the need to think outside the box or the standard model human, but there is that diversity of need as well, diversity of abilities.

Because we were talking earlier, before the meeting started, about the work you do, but when you have talked about disaster recovery and disability, you funnel down onto a very almost stereotyped image of people in wheelchairs being rescued by helicopter. Which is not at all what you do. People's minds don't automatically jump to the kind of thing you do. Is that right?

DR ARIELLA MELTZER:

I think there is no particular image of what disaster safety is. That is probably one of the things that will immediately jump someone. Accessible information is from my perspective something that maybe sits behind the scenes. But there is a lot of elements to disaster safety.

PROF JACKIE LEACH SCULLY:

Part of changing the public narrative is a greater sense of what actually is involved in disaster preparedness and response than maybe the stereotype.

Did you want to say something? A weekend or two ago I was with the community fire unit of the new area I have moved into, and they were discussing what would happen if there was a bushfire in the bushfire prone area I live in. And there would be an alarm. I said at night time I will not hear an alarm because I take my hearing aids out and I can't hear anything. Response from one of the volunteers, "In that case we will come and knock on your door." That lack of imagination almost, me having to explain if I can't hear the alarm I will not hear the knock on the door either. Then we had a long discussion about jumping up at my bedroom window or something and frightening the life out of me.

I would like to go back to you briefly if I can and ask about changing the narrative. And changing and expanding public perception of what is needed in disability recovery and response, but also the involvement of people with disability. Do you have any advice about how actively to go about doing that?

PROF DAVID SANDERSON:

Was that to anyone in particular?

PROF JACKIE LEACH SCULLY:

That was to you, David.

PROF DAVID SANDERSON:

Thank you. It is the systems, not the people. I have never met anybody in this area who does not think community centred recovery is the absolute gold standard. Yet the systems conspire unwittingly. We have a top-down command and control, police pulled me out of the car, but recovery preparedness mitigation, the organisations are not incentivised to include the discussion of frankly anybody. That is a problem.

You were kind enough to mention our very modest initiative, howwesurvive.com, it launched two weeks ago, long term independently funded. Anybody on this call please be in touch because our ambition is changing our narrative, to take community-centred recovery seriously, to include that in the metrics of success, to have a long-term view for all people. I will stop there.

PROF JACKIE LEACH SCULLY:

One of the barriers to participation of people with disability you are saying is the systemic barriers and the way the system rather than willingness of communities and people on the ground?

PROF DAVID SANDERSON:

I think so, but that is my personal view. I think there is some evidence but I wouldn't suggest... (inaudible) against people with disabilities.

CHERYL DURRANT:

Can I add to that, because my personal experience, and I think like David there is goodwill everywhere. But there is quite a difference from reading about the statistics and the analytics, is that there is another level of knowing that comes from actually talking and engaging to people with disabilities. That is all types of disabilities. Often there are invisible disabilities which are missed, and quite small but important things as well, particularly those of mental health issues which is fairly back in the regional and remote area where I currently stand.

There is a third level which is really an emergency and what it might feel like navigating through a disaster, preparation, recovery. There is a different level of knowing. For example if I take my glasses off, I am having a very different experience in a disaster than with the glasses on. Sometimes that felt experience, and it can only come from working with those, and multiple of those people with disability, and often compounding with other socio-economic vulnerabilities.

The challenges with planning, leading recovery at all levels is to move beyond talking and thinking, which now people are talking and thinking about this.

But when I was drafting some work for the Australian Institute of Disaster Resilience, it was still coming to me second hand. The panel of advisers were talking to people with disability but I didn't have anyone with a disability on the panel. Just have to go the one step further and at every level you should be asking yourself if you are planning or researching or leading as a community leader, have I got everybody I need to be in this room in the room? It has to become the gold standard practice that second-hand knowledge is not good enough. You need the first-hand knowledge in the room. And that is the key thing for me that has to change.

DANIELLE SANTOS:

I might just add to this. A lot of organisations are working on short-term timelines, and that will not be good enough for me, for engagement and consultation with disabled communities. It takes time and it takes an investment in relationship building. I have been working with the communities in the Philippines for over four years now. That was long before I started doing my research. Because those relationships were necessary, to be able to actually get people to tell us their honest thoughts and honest experiences. Because you are asking people to talk about one of some of the worst days of their lives. You need a relationship to be able to have that conversation in a meaningful and frank way, and for people to be honest about what they need, especially when there is stigma and especially when there is bias against people with a disability, and the discrimination they face when trying to share their experiences in the past.

I don't think that is exclusive to a Philippines context or the global South. I think that is true as well in Australia. We need to invest in meaningful long-term relationships with disabled communities. We can't just show up for a four hour workshop once, never come back, never do any follow-up. And have no one in that room running at who isn't part of that community. That has been essential to my work. I always have people with that experience running the workshops I do, and running the interviews. And I also have translators that are part of the communities I am working in. I think that is absolutely essential if we will have meaningful policy engagement and policy development.

I think a unique part of that in the Philippines, and Antoni I imagine it is similar in Indonesia, when we talk to bureaucrats here it is not like Australia where there is a second-hand knowledge. The disaster responders and the people making policy here also lived through the typhoons, through the floods. And I think that does make a difference to community intervention response. It also means a lot of the workers here and policymakers here are incredibly burnt out and under resourced. Not just in the departments but in their homes.

I have spoken to disaster responders who have to choose between going back to their family home which had been destroyed by a typhoon and staying in a relief centre for over 24 hours to make sure that food packs were distributed. The context is really different. In that way it is indistinguishable from the Australian context, but a long-term relationship building an investment in that is necessary, it is needed for the change in narrative.

DR ARIELLA MELTZER:

With the relationships that Danielle has mentioned is also critical for information flow. One part of our research was looking at what actually makes information accessible. There are a whole lot of things about how information is made, the technical qualities, the format it is produced in. That's one of the really fundamental qualities of accessible information is that it is trusted. And a key part of the information being trusted is that it comes from the community whom it is for.

DR ANTONI TSAPUTRA:

Yes, if I can jump in, as Danielle has mentioned, one of the very key issues would be the policy reforms. For example, in Indonesia the disaster management law number 24 of 2007 is outdated. It doesn't take into account of the rights of people with disabilities. I think there is a need to harmonise laws and other policies related to disaster preparedness, the UNCRPD, in Indonesia I have been working a lot with international organisations, including DFAT in Australia, so the focus of our work is on internalising the importance of compliance with the UNCRPD and harmonising the national and local laws with UNCRPD. This is really not an easy thing to do.

The government still both at national and particularly local governments they are still closely, what do you call that, stick to the old way of understanding disability as only a welfare issue.

I think making sure that the UNCRPD is fully harmonised with the local laws, particularly those related to disaster management is also very important, particularly for countries in Southeast Asia.

PROF JACKIE LEACH SCULLY:

Thank you. Unless somebody else from the panel wants to jump in, I want to throw a question out generally, perhaps someone in the panel, Cheryl might know about this, but also people in the audience, your experience in the Australian context, whether there is a discrepancy between the resources and issues that you mentioned with the difference between Australia and the Philippines, and Indonesia. Whether that plays out in an even more minor way, the difference between urban and regional Australia, and their similar issues to do with resourcing and burnout of responders in regional Australia, compared to the cities? I don't know if anybody here would be able to respond to that.

CHERYL DURRANT:

I think it would be really hard to respond to because every Australian city might have a different experience, certainly I have experienced the cyclones in Brisbane, the experience in Hobart and in Sydney might be different. Or even rural and remote Australia would be different to remote Tasmania and even in the Northern Territory. I think it is a broad continent with different experiences. It is hyper-local, as with other things that has been listed, information has to be hyper-local. Australia has very different climates for different environments. The important thing from all of the planning is it cannot necessarily be standardised. It has to be the knowledge at the hyper-local level.

PROF JACKIE LEACH SCULLY:

Thank you. I want to ask if there are any questions from the floor or any questions coming from online. Questions or comments. If not, we will head on. One of the questions I wanted to ask is, what are the benefits of communities, considering people with disabilities as a community, what are the benefits of those communities being more involved, particularly in the recovery and resilience stage, in the rebuilding, if you'd like, between the drama of the immediate crises?

I think we often think about the response that happens to a disaster under time pressure. Perhaps, there is a kind of a psychological desire to move on from that and move back to normality, and perhaps forgetting a little bit about the lessons learned from the last disaster. How can we draw on the experiences of the community who have gone through that experience in the between times, so that it does not become forgotten? Anybody want to have a think about that?

COMMENT FROM FLOOR:

I have dealt with a couple of communities through disasters, and certainly the responses (inaudible) obviously (inaudible) and having to deal with people (inaudible) they struggle with and the knowledge from that. Simple things like one lady I spoke to (inaudible) so very simple and small, but going forward and resilience and recovery (inaudible) making sure (inaudible) I can run emergency, but you have to ask those questions. (Inaudible) experience from previous disasters…

PROF JACKIE LEACH SCULLY:

Thank you. How do we actually do that? How do we build that into the process? Any ideas there?

DR ARIELLA MELTZER:

There were some really good examples in our research about accessible information provider organisations and disability advocacy organisations collaborating with emergency services in the way you have described now. And I think that is where the sweet spot lies, merging everybody's expertise. I spoke to one woman whose accessible information business, they ran training for… I'm not sure what type of emergency service, but an emergency service on how to do plain English, often people use caps lock to indicate emergency, but that is not a great accessibility move for accessibility.

But the people who know about the specific information that needs to go out in different crises and that is where it is. I have a colleague who does a lot of work on collaboration, not from a disaster or disability perspective, but just in general. He would say that collaboration is really hard, it is really hard to get it right.

I think this is an example where the different expertise makes it really important.

PROF JACKIE LEACH SCULLY:

Anyone else on the panel want to comment?

DR ANTONI TSAPUTRA:

Yes, Jackie. Jackie, if I can provide another example in Indonesia. We have some decent action through the work of the Lombok Disability Creative Centre, or LDCC, I have some photos of this disability-led group. LDCC took a leadership role through the COVID pandemic, the mobilised resources and provided help to households, including those with disabilities. Even at the local government was assisted with updated data of people with disabilities during and even in the smallest neighbourhood. They have been of great assistance to the government.

They also organised community-driven initiatives to provide essential supplies, including food, medicine and household products to vulnerable households. They also raise awareness about how to prevent the spread of the virus. By taking on the leadership role, it really showed people that they have unique problem-solving skills and a deep understanding of the needs of their communities. By leading the efforts, LDCC ensured the recovery process was not only inclusive but also tailored to fit the specific needs of the community. This type of leadership is critical because it empowers whole communities to take ownership of their recovery. It also ensures that recovery efforts are sustainable as they are built on local knowledge and resources.

As what I have seen, community-led recovery also fosters resilience. So when people with disabilities are involved in leading recovery efforts, they help make sure the entire community is better prepared for future disasters. This creates a kind of more resilient society where everyone has a stake in the recovery process and has the ability to contribute to future disaster preparedness efforts.

DANIELLE SANTOS:

I think I might just add, whilst I agree that disabled communities leading recovery effort for their communities can be powerful and I've seen that in the Philippines. I also heard from participants a lot of critique of how mainstream disaster response teams assumes disability organisations as leaders within the disabled community would take on the entire responsibility of rescuing other disabled people and ensuring their safety with no integration into the kind of mainstream services, and that caused significant issues, because these groups of are disabled people were largely mutual aid organisations.

They had no institutional support or resources to ensure they could save everyone. But because they existed, institutionalised disaster responses entirely ignored the disabled population. So there were still people left behind because these organisations couldn't know everything and couldn't do everything. I think what Ariella was saying about the importance of collaboration and integration and not segregation of disabled led responses to disaster recovery and resilience are absolutely necessary for a sustainable and long-term solution to the challenges faced by disabled people during disasters.

PROF JACKIE LEACH SCULLY:

Thank you. I am aware we are moving towards the close. I particularly want to throw out one provocative question that is not one of the ones that any of the panellists have prepared for, so I'm really throwing this at them and the audience.

We have mentioned ableism and I think for me at least one of the issues underlying many of these problems is a hidden and sometimes not so very hidden ableism. And the sense put bluntly that people with disability are often not worth quite as much as people without disability. I am seeing some nods in the audience. They are in a sense less worth devoting resources to. Part of that segregation is the sense that these groups can look after themselves, if it works, great, if it doesn't, sad but...

I think many people particularly in Australia and similar countries would quite vehemently deny that element of it. I was recently in Vanuatu on a project and talking to some groups of disabled people about resources there, and they were very blunt. I asked the question, "Why do you think there aren't resources put towards your communities?" And they said, "Because our communities don't think we are worth anything." I suspect we don't get past that kind of attitude in one generation or two. That there is still a liking sense even in places like Australia that is inhibiting some of their activities.

But that is what I think, and I am ready to be shot down in flames if people on the panel think I am getting it wrong. What do you think? Maybe we will start, go through the panel, David, what do you think about that?

PROF DAVID SANDERSON:

A horrendous thing. I was reflecting on being involved in northern Pakistan where people with disabilities are literally hidden away. It was an earthquake recovery program. You could literally put someone away in a corner. I wanted to acknowledge that reality for swathes of humanity. I will stop there.

PROF JACKIE LEACH SCULLY:

Thank you. Ariella, what do you think?

DR ARIELLA MELTZER:

You have posed a very tricky question, Jackie. I think there is degrees of what you're saying, and I think the degree I see in the accessible information setting is, "We can cater to these accessibility needs because these ones are easy. We can set the setting that will put the captions on. We can hire an Auslan interpreter. We can do the things that are straightforward to do."

But when it comes to communicating with people with disability where it is more complicated than just an easy fix, maybe that is the place where it is maybe not quite as overt as what you have said, Jackie, but it's about people are feeling they can abdicate responsibility of the information requirements are in the too hard basket.

But we then have the organisations who are specialists in accessible communication, and they have the skills to do that. This is where the collaboration piece comes back in of if we do have people who know how to communicate even in the cases that other people might put in the too hard basket, then we need to give them the resources to do that, because they can.

PROF JACKIE LEACH SCULLY:

That might be well-meaning, but sometimes going into the too hard basket. Danielle, what do you think from your perspective? There is still a lot of ableism in the responses in the Philippines I think you said.

DANIELLE SANTOS:

I think it's more of it than what you have been talking about, Jackie, not just in the Philippines but also Australia. We have seen that in the report that was released from the Disability Royal Commission. In Australia I worked on the Royal Commission for the entire four years collecting stories of Australians. And they talked about being left behind during disaster responses. But they also talked about being left behind in the COVID pandemic, and the ongoing COVID pandemic. Because wearing masks or asking people to socially distance is not considered an accessibility feature by any organisation that I have worked with at the very least.

There are mass disabling events like COVID, like the conflict happening in Gaza currently. And they are not seen as disability issues because we underthings disabled people's lives matter as much, friendly. And yes it might be more explicit in a context like the Philippines but we are still killing so many disabled Australians every day across our country as well.

I have not been exempt from disability discrimination in a context like the Philippines, I have lost jobs, I have been denied healthcare. These issues of ableism are invisibilised in Australia by respectability politics. It's not just as I said in disaster contexts. Disabled people live there lives every day in all contexts, and we don't do enough to save ourselves. We don't do enough to care for the disabled communities and disabled communities are forced to save themselves.

PROF JACKIE LEACH SCULLY:

Thank you. I think... I am not going to say a great final word. A great wrapping up. I don't want to be the final word somehow, just emotionally. Are there any questions from the floor or online that we might go to before the end?

QUESTION FROM FLOOR:

To finish on a positive. (inaudible) was telling me (inaudible), very encouraging, very (inaudible). We talk about (inaudible).

PROF JACKIE LEACH SCULLY:

Thank you. I'm going to wrap up there. I'm going to thank everyone for their efforts because I know technology hasn't always worked in our favour. It's complicated trying to get the sound balance right between speakers and the floor, and the people online. And I know the panel haven't always been able to say what they wanted to say, and also when you're online it's much harder for me as MC to know that you want to say something rather than when you're here and I can get your eye.

Thank you for your efforts. This has been recorded and the recording will be available on the DIIU's website. There will be a transcript cleaned up so the people who have missed anything and want to catch it again, it will be available there. We hope we might see you again at another DIIU event, particularly to do with disaster preparedness or response, which is one of our emerging focuses or foci of research interest within the Institute.

For those of you from UNSW, the Diversity Festival goes on through the rest of the week and there are things like pop-up Auslan workshops and so on for those who are interested in experiencing some of those.

Thank you once again, all of our panellists present and online. A particular thanks to the people behind the scenes who are Kate over there who has done wonders, Kate from the DIIU, Lucy from the DIIU, Kylie and Drew from the AHRI who put a lot of effort into this event. So thank you.

(Applause)

END OF TRANSCRIPT