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The University of Sydney

Leave Nobody Behind (Webinar Series)

Actions that people with disability and their representatives can take on DIDRR

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Captioned by: Bernadette McGoldrick

MARGARET MORETON: Good afternoon, everyone. Thank you for joining the Australian Institute for Disaster Resilience, which we might call AIDR from here on in, and the Collaborating4Inclusion Research Team for coming to our second webinar in the Leave Nobody Behind Webinar Series: Actions that people with disability and their representatives can take on disability inclusive disaster risk reduction, or what we might now call DIDRR. So, my name is Margaret Moreton. I'm the executive director for the Australian Institute for Disaster Resilience and I'm delighted to be your host today. I would like to start by acknowledging that I'm hosting this event from the lands of the Wurundjeri people here in Melbourne. I acknowledge traditional custodians of the various lands on which you're all joining us from today, and the Aboriginal and Torres Strait Islander people participating in this event online. I pay my respects to Elders past, present, and emerging, and I celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and the waters across Australia.

Before we begin, I have some brief housekeeping notes. Today's event is supported by Auslan interpretation and live captioning. So, please check in the chat window for information about how to access these during today's webinar.

The event is being recorded and this recording will be made available after the event, including a written transcript. We will be using the Q&A feature on Zoom - that's how we will take your questions - so please post your questions in that Q&A box and not in the chat window. You will be able to up vote questions that you like the look of and I will choose later the most popular questions and ask them to our panellists, so you click the "thumbs up" button. I'll do my best to get to those questions at the end of the presentation. I encourage you to use the chat window to say hello to one another, to share any thoughts or reflections

during the presentations, but I would ask that everyone please remain respectful of one another and our presenters at all times when you're posting your questions and comments.

So, the Leave Nobody Behind Webinar Series, if you happened to miss the first one, was designed with the intention of showcasing research from the Leave Nobody Behind Project, which is being led by the University of Sydney, the Collaboration for Inclusion Research Team. For the past 18 months, the Research Team has been working with stakeholders from across NSW, and beyond, and they are co-developing DIDRR initiatives that enable people with disability equal opportunity before, during, and after disasters. The goal of the project is to develop a framework to support multi-sector DIDRR. This framework will formalise the research team's findings that meaningful DIDRR can only be achieved through the collaborative action of government, emergency services personnel, people with disabilities, their carers, their representatives, and the organisations that support them. Everyone has a role to play, but central to all of this is the inclusion of people with disability in conversations, decisions, and in activities from the beginning to the end.

During our last seminar, the first in the series, we showcased person-centred and capability-focused approaches that governments and emergency services can take. Today's webinar will focus on the roles that people with disabilities, and their carers, can play. And in our next webinar, the third of the series, we will discuss disability support services. Together, it is the aim of the series to demonstrate the benefits of collaborative, multi-sector action.

As we enter today's webinar, I would just remind everyone that not all disabilities are visible. We had some concern in our first seminar about whether anyone with disabilities was involved in the webinar, and they were, indeed. So, you know, behind the scenes, this webinar series has

been very collaboratively developed and presented by people with disability.

So, to talk more about the project and the topic of today's webinar, I would ask that you join me in welcoming Associate Professor Michelle Villeneuve. She's the deputy director of the Centre for Disability Research and Policy at the University of Sydney, and I'll hand over to you now, Michelle.

MICHELLE VILLENEUVE: Thanks very much, Margaret, and thanks to all of the people joining us today. I'm calling in from the land of the Gadigal people of the Eora nation. I would like to pay my respects to Elders past, present, and emerging, and extend that respect to anyone joining us here today from the Aboriginal and Torres Strait Islander communities. I'd also really like to welcome any participants here who have been not only participating actively in parts of our research but also following the progress of this project along the way, and learning together with us, and we're really excited for the opportunity to do more of that today.

People with disability manage additional support needs in the face of numerous obstacles and complications that have their roots in stigma, discrimination, and marginalisation. And these things are expressed in inaccessible social, economic, and physical environments every day. Understanding how people manage is the starting point for making effective emergency management plans that are tailored to each individual's risks, support needs, and situations. It's also required for effective contingency planning, because in a disaster, access to the everyday supports and the continuity of services that we rely on every day will be compromised. How people overcome the everyday barriers to access inclusion and support is an important starting point to enabling preparedness for disasters. On this slide is an image of the

Person-Centred Emergency Preparedness, or P-CEP, capability wheel. It has eight areas that prompt self-assessment of preparedness, capabilities, and support needs in emergencies. For example, let's think about transportation. A woman and her husband are both blind and they each have a service dog. They own a car but rely on their support worker to drive. The flood event that hit South-East Queensland also impacted their support worker. Who else will they rely on in this situation? And think about management of health for a moment. People who are on controlled medications will only have access to a limited supply. A prolonged disaster event may impact not only the individual at their home and in their neighbourhood, but also the chemist and the doctor's office. What contingencies do they have in place to ensure their continued access to their medication?

And let's think about communication. Disaster dashboards are increasingly being used by local councils as a tool to provide their community with real-time information of unfolding disaster events. All warnings, response and recovery information gets channelled through the dashboard, but that information is not provided in a format that everyone can understand and use. How will people with intellectual disability, cognitive impairments, low literacy, and sensory impairments know what steps they need to take for their personal safety? How will not knowing, or not understanding, impact their actions? And who do they rely on for accurate information and communication support?

If you're an emergency manager, the hazard risk is your starting point. On this slide, there are images of bushfire, flood, and an education session on cyclones. For emergency personnel, the goal is to help people know the risks and get prepared. Hazard-specific messages are accompanied by detailed information about disaster risks that can invoke fear and confusion. It's typically accompanied by maps, flood, and

apocalyptic images of fire. If you have a disability or provide care to

someone with a disability, chronic health conditions, or who have other support needs, this can be totally overwhelming and confronting. People with disability experience individual and social barriers that make it

harder for them to prepare. We really need a new starting point.

We need to work together. Both sets of knowledge - emergency management and the lived experience of disability - are critical to ensuring equal opportunity for people with different function-based support needs so that they can self-assess their preparedness capability and what they need for support, learn about their local disaster risks and tailor preparedness to their local risk situation. Make a plan for how they're gonna plan and act together with their support network, and communicate that plan with the people who will actually be there when disasters strike. When gaps in preparedness are not matched to the available supports, we need to work together with our trusted support networks to identify the barriers and in partnership with government and emergency services personnel to remove them. This requires cross-sector, person-centred and capability-focused approaches to disaster risk reduction so that nobody is left behind. Leadership is really all about co-production in action, and that's what disability-inclusive disaster risk reduction is all about. Person-Centred Emergency Preparedness helps us to achieve that.

As Margaret mentioned in the first webinar, we considered the actions that emergency personnel are taking, and we came to understand that they've not had the right tools and starting points to support meaningful inclusion, participating, and tailored planning so that emergency personnel know what they can do to support people with disability, and take disability out of the too-hard basket. In our next and upcoming webinar in May, we're gonna learn about the challenges and the

opportunities for community health and disability service providers to contribute to disability inclusive disaster risk reduction and how they're overcoming the obstacles to their actions. But today, we focus on collaboration with people with disability, advocates, disability researchers, and carer representatives, to learn about their contributions in the co-production of new ways and new ways of learning and working together, so that people with disability and their support needs are at the centre of our disaster risk reduction practices. Today, we'll continue to learn how determined we actually are to make sure nobody is left behind when disasters strike and that we are collaborating for disability inclusive disaster risk reduction.

Today, you're gonna see transformational leadership in action. Transformational leadership is how leaders actually inspire, encourage, and motivate others to innovate and create change that helps grow and shape future outcomes. We'll learn about how these leaders today act as role models, build high expectations, and inspire optimism, have an acute understanding of the needs of other people, and how they request and think in new ways about problems. And this is the kind of innovation we need in disaster risk reduction that is disability inclusive. Please join me in welcoming our panel of speakers today at this webinar and let's listen and learn together with them.

MARGARET MORETON: Thanks, Michelle. Now, you'll all notice that, as I introduce speakers, a bunch of information will go into the chat about who they are. It saves me reading you these very long bios about these wonderful people who are talking with us today. So, our next two speakers are from the Queenslanders with Disability Network. The Queenslanders with Disability Network is a statewide network of, and for, and by the people with disability. The network seeks to address social

policy issues and gaps in services and systems that impact on the lives of people with disability in Queensland. So, please join me in welcoming Chief Executive Officer Michelle Moss and board member Peter Tully. I'll

pass to the two of you.

MICHELLE MOSS: Thanks, Margaret. And good afternoon, everybody. I would like to pay my respects to the land on which I'm meeting in Brisbane today, on Turrbal and Yuggera land. And I'll introduce my colleague, Peter Tully, in just a minute.

So, QDN, as Margaret said, is a statewide information of, by, and for people with disability. And we have been working with Michelle and the team, and a whole range of people in Queensland, co-designing, leading, and partnering in DIDRR. Thanks, Charlotte.

QDN has a unique network of people with disability and diverse disability, so all of our members have differing disabilities and there's a little bit about the different range of work that we do. But we have 32 peer support groups across the state that are led by people with disability for people with disability. And all of the work that we do places people with disability in that leadership role, and our motto is "nothing about us without us".

So, I guess we wanted to talk to you today about some of the work that we've been doing around DIDRR in a variety of ways and a variety of projects. But really have been about people with disability leading and co-designing the work. Back in 2019, we started working with Michelle and the team to develop the framework for DIDRR in Queensland, and from that, in 2020, just before COVID hit, we were able to co-design the P-CEP workbook that I know many, many people use as part of their resources. From that, we've done a whole range of other projects that have been in partnership with councils, they've been in partnership with

emergency services, and, of course, University of Sydney, and they have been led by people with disability, including people with intellectual disability. And we've got a great team of peer leaders who have been doing that work, and Peter Tully - who's here with me today - as well as being a board director, has also been part of that team. And we wanted to talk to you particularly today about the P-CEP Peer Leadership Program, which really is about developing the capacity of people to develop their own plans and to put that transformational leadership into action by helping others and using the effectiveness of peer support and peer learning environments to help others plan, help others understand the four steps of the P-CEP and to be more prepared and ready for disasters. So, Peter, are you there?

PETER TULLY: I am, Michelle!

MICHELLE MOSS: You are? Welcome, Peter.

PETER TULLY: Thank you.

MICHELLE MOSS: So, Peter, I know that you have been part of the DIDRR journey over the last four years, back in Ipswich when one of the first workshops was held. And I'm really interested for you to talk about why it has been important for you to be part of this work and to do this work.

PETER TULLY: So, Michelle, first of all, I would just like to acknowledge the Traditional Owners as well and pay my respects to the Elders past and present. And thank you for the opportunity to everyone you mentioned to be part of this live event this afternoon.

Coming back to your question, why has it been important for me to

be involved, is when I first had the opportunity way back, as you mentioned, Michelle, at the start of 2020, to be involved in this project, when I first heard the word "emergency disaster" I thought, "Oh, my goodness, what am I getting myself into?!" So, I think that one of the things that the project has allowed me to personally do is, before I go out in the community, is feel comfortable talking about emergencies or disasters. I feel comfortable that I can do some basic things myself to prepare for an emergency. Because some of you will know Ipswich well - we have our fair share of disasters over the last couple of years. And, thirdly, I have been able to take what I've learnt from the program and take it out into the community across all levels of council, local government, and federal government.

MICHELLE MOSS: Thanks, Peter. And Michelle talked before about transformational leadership, and I think the work that QDN peer leaders have been doing in communities across Queensland has really been transformational leadership in action. And Michelle talked about those important elements of leadership in being a role model, in holding high expectations of others, inspiring optimism, of being able to, I guess, think outside the box and think differently together. And I think that's been a really important part of the work. So, wondering if you can tell me how you've done this in the work and what's been your leadership in action, Peter?

PETER TULLY: So, from the photo that you saw just before, that was a trip down memory lane, where I went to the local Ipswich Show. And we had no idea that they were going to be there at the local Ipswich Show, and we were able to just get involved with them on the day, unexpectedly, because we were able to engage with council members and

show them how myself, my wife Linda, and my son Nick could be part of getting the key messages out at the local Ipswich Show. So, that's just one example from a trip down memory lane from a photo that I saw a few minutes ago.

But Michelle and Michelle, you both know there's many other stories that I could tell. Probably the one that stands out is when I work one-on-one with people and I get to take them on their own journey, and then I watch them feel comfortable about sharing that with their family members or their support workers or their service providers, and then they start doing it and they duplicate what they learned. So, Michelle, there's many stories that I could expand on, other than to express how important the co-design is and having people with disability involved from the start to the end, but more importantly when they're working through the booklet, make it their journey by meeting them where they're at so that they can do the booklet based on their own personal experience.

MICHELLE MOSS: So, Peter, in the different work that you've been involved in, as you talked about, there's one-on-one work that you've done with people in your local community through the peer groups and the peer networks, there's also been workshops that you and our other peer leaders have facilitated. There have been face-to-face workshops when we have been able to do that, as well as online.

PETER TULLY: Online.

MICHELLE MOSS: Online workshops with people from all around Australia, people with disability in other states and territories, to build their leadership capability. Do you want to talk - let people know a little bit about what happens in the workshops, which were also co-designed by

the team? But what are some of the ways of, I guess, helping people work through their plan and the four steps? What are some of the things

that you do?

PETER TULLY: Yeah, sure. So, I will use a recent experience of a workshop that I did recently out in the rural and remote, and we arrived and it was only a small group. But two particular participants that had come along for the day, they didn't really understand why they were there. They thought they had nothing to offer, nothing to prepare for an emergency or disaster in their local community. And just by getting to know them prior to joining the workshop, and then taking them on the journey - like I said before - meeting them where they were at, over the two lots of workshops that we did, Michelle, to answer your question, by the end of it, they were working through the workbook by themselves with their family members and their support workers. So, one of the highlights is, quite often people will pick up the workbook, or pick up any sort of material around - it could be an online workshop or getting involved in an activity - and they've just got no idea what that is. So, one of the things that the co-designed program had done with our peer leaders is allowed us to learn skills and ways of leadership and engaging them.

MICHELLE MOSS: And I know that you have a number of different games and activities, Peter, to help the learning experience that yourself and the other peer leaders have co-designed, and I think there's a backpack involved.

PETER TULLY: There's a "go "backpack and a "stay" backpack. Go is the green one, and "stay" is the red one, yeah.

MICHELLE MOSS: And people work through, with a whole range of different resources, to look at what would be in their "go" bag or their "stay" bag that is relative to them and their own individual needs, knowing that everybody has got different things around the capability wheel of what's important in their life and what they need in time of an emergency or a disaster. So, that's a really practical, practical way that people do that. And I think there's lots of great stories, Peter, that I've heard after participants have been through the workshops and, you know, really actively gone and put that plan into action with all their preparedness and their planning to make it happen.

PETER TULLY: Michelle, just quickly, when we were up at another workshop recently, there was a participant who did the earlier workshop, and what we did in the second workshop, we got him to bring his "go" pack along, and he actually demonstrated his "go" pack. And just watching how excited he was to share that, and the fact that he was prepared, is priceless.

MICHELLE MOSS: And I think, Peter, your example there just shows that leadership and confidence and the increase in knowledge that people have to be able to then take on their own leadership and act as that role model for others. And we've seen that happening in a ripple effect, haven't we, around...

PETER TULLY: Absolutely.

MICHELLE MOSS: So, Peter, bringing all people into the room together has been key. So, people with disability, disability and community

services, and our emergency services and councils - what difference has this made to the work? And just wondering if you would share some examples of that and its impact?

PETER TULLY: Yes. So, what we did when we ran the second lot of workshops recently, at all the rural and remote areas, we actually had the emergency services, Michelle, come along and present that part with us. Rather than us telling them about it and then them saying a few words, the peer leaders and myself, we got the emergency services involved in presenting that particular part of the workshop with us. Whether it was online or face-to-face, as you mentioned earlier. And what I found is, by getting them involved with us, not only are we learning about how to engage with emergency services, but emergency services are learning how to engage with people with disability. Because especially in the Gatton and the Warwick workshops that we did, the emergency services were asked some very good and interesting questions by the participants who were attending the workshops, and I think it really rose their awareness and made them aware, "Oh, we've got some work to do in this area." So, it was a good learning process by both of us being together and involved together.

MICHELLE MOSS: I think that's a great point, Peter, because it is about a learning experience for everybody, and I think when everybody is in the room together, we know that that's when the magic happens and that's when the transfer of knowledge and experience and, you know, the co-design and co-production has its best impact. So, Peter, I know that we've got one more minute left, so for my last question, I'll just ask you about what's your one key message for people to take away from today of the important actions that they need to think about in doing this work?

PETER TULLY: So, depending where your level of work is, I really encourage you, if you do one thing, just involve people with disability

every way you can, whether that's at the beginning with your co-design within a group, or whether you're just setting it up for your family members or your community. Just involve people with disability, begin a conversation, and just allow it to become their journey, and you'll be amazed as to where it will go.

MICHELLE MOSS: Thank you. Thank you, Peter.

PETER TULLY: Thank you, Michelle.

MICHELLE MOSS: And, yeah, they're just some photos of the workshops. And, as Peter said there, they're DIDRR in action.

MARGARET MORETON: Thank you to both Michelle and Peter. And it's probably just as well our cameras come and go because otherwise I would have been very distracting as I was beaming at you both and nodding at everything you were saying! And I can see that people in the chat thoroughly enjoyed that as well.

I would like to remind people that if you've got questions emerging for any of the speakers, feel free to pop them in the Q&A, and then to vote for questions that you particularly like.

Our next speaker, though, is Ainslie Whitburn, project coordinator with the Australian Federation of Disability Organisations. The Australian Federation of Disability Organisations is partnering with Fire and Rescue New Zealand - ah, New Zealand! Not really. NSW. To deliver the Fire Proofing Vulnerable Communities. This statewide risk reduction education

and training initiative, funded by the NSW Disaster Risk Reduction Fund, aims to create greater connection between people with disability and local fire services, increasing their preparedness and their ability to act in emergencies. I'm sure there will be some themes that are developed from

what Peter was just talking about. But please join me in welcoming

Ainslie.

AINSLIE WHITBURN: Thank you, Margaret, for your introduction. So, I'm Ainslie, and I'm talking about the Fire Proofing Vulnerable Communities project, which is funded by the Australian and NSW governments. So, before I start, I'd like to acknowledge the Traditional Owners of the land that I'm on, the Darkinjung People, and the lands that you're all coming from today. I'd also like to acknowledge people with disability, their families, carers, and supporters, and those individuals that have experienced, or are experiencing, violence, abuse, neglect and exploitation, and everyone who has spoken up and shared their experience.

So, next slide, thanks. Who are we? So, I'm from Australian Federation of Disability Organisations. We're a disabled peoples organisation working for long-term social change for people with disabilities. So, we have 32 member organisations, which are other national and state advocacy organisations, run by and for people with disability. We provide policy advice and representation to government on matters that impact our lives. And we also like to work with various partners on projects and inform and educate the community. So, that's just an example of some of the logos of some of our members. And some of them will be involved in this project along the way.

So, next slide, thanks, Charlotte. So, how did we start Fire Proofing? So, it started with Fire and Rescue NSW, acknowledging that,

you know, maybe they have assumptions and biases about people with disabilities, but also that the same might be said for people with disabilities, that they have some biases and some misconceptions around what firefighters do. So, they came to AFDO and together we developed a series of videos to increase disability awareness in Fire and Rescue NSW. These videos would be shown to Fire and Rescue NSW management and other staff, just to start that conversation about disability awareness. So, now I'm just gonna play a snippet of one of those videos. Thanks, Charlotte.

- >> What adds to our vulnerability, per se, is information is it accessible or not to us? That's the reality. So, because we don't have access to information, we become vulnerable. It's not because we have a disability.
- >> Yeah, so I think some people with disabilities just need additional assistance. I don't necessarily consider myself vulnerable, but in an emergency I would need extra assistance. I'm actually quite able to communicate that to them, and I guess I'd just like to be heard with that. It's something that's really important. Instead of firefighters assuming that I'm vulnerable and that I need certain things.
- >> So, I understand that sometimes it can be scary to have a first experience with someone who is deaf, for example, and they've never had that experience to know what's the appropriate language to use, what's the appropriate way to have a conversation with that person.
- >> Something that they are not listening or sometimes they're not taking action as soon as possible, and sometimes they don't have the information that we need to be understand. It's not enough

communication, yes, because most of the time I don't understand what they say. Face-to-face is even better to be know what we're talking about, so we can see their shape their mouth, what they're saying. Good communication is with clearly writing, the print-out is clearly, and the language is easy to understand, plain English, not those hard writing, and have more picture and less words.

AINSLIE WHITBURN: OK. So, after doing this, it was clear that we needed to hear from people with disability about how they needed their information, what they needed to know, and what they wanted firefighters to know. So, we began this project after we received the funding. We've got four objectives. It's to build the capacity of people with disability to engage with disaster risk reduction strategies, to connect people with disabilities to their local firefighters, to develop and deliver disaster risk reduction information resources, and to reduce, of course, in the long term, the high number of people with disabilities sustaining harm in fire events. Next slide, please.

Thank you. So, what are we doing? We're going to start by reviewing the current resources that NSW Fire and Rescue have, and some external ones as well. So, looking at accessibility, readability, and understandability. We like our "abilities"! And we want to engage with at least a hundred people with disability in our 14 focus group areas. And you'll see them on the map with the little markers, or there's the list down the side. We'll create disaster risk reduction information in various formats that increase actionability. And we want to promote those resources across partner stakeholders and on all platforms. And, of course, implement these, providing input into training and resources for Fire and Rescue NSW.

So, we are looking at two pilot groups. One at Wollongong, one at

Tamworth. And then we have another 12 scattered throughout the state.

We're hoping to be face-to-face but we may end up doing some hybrid or some online ones as well. Next slide, thanks.

Our project partners. Some I've already mentioned - Fire and Rescue are our delivery partner, working with us all the way along. The Uni of Sydney and Michelle's team, helping us with research and evaluation. NSW Rural Fire Service and Fire and Rescue have agreed to be our resource delivery partner, so promoting the end resources in their communities. And, of course, local governments and government agencies, both with promoting what we're doing and our resources, but also looking at other projects that are already happening, or are going to happen, that could link in. And our local organisations and networks. So, we want to connect with local people through these networks and we'd like them to also help distribute and promote our resources.

But at the centre of it all is people with disabilities. And we're really adamant that they have to be involved at every level and at every stage. So, people with disabilities are the project staff, so there's a number of us with various disabilities working on this project, both for Fire and Rescue and AFDO. All our project steering group members, at least five of them with various disabilities representing various groups. We have focus group participants, of course, that will all have a disability, and hopefully we'll be able to get a range of people with disabilities and different experiences. We will also have co-facilitators with a disability working with firefighters to run these focus groups. And we'll have our local community members in every community to help promote our resources, as well as community organisations, services, and other agencies.

So, at the end now, I'm just going to show another video that just demonstrates why it's so important to have people with disabilities involved in this project.

>> I think one really important thing is that we often don't - do not realise is that people with disabilities are very valuable resources for all emergency services. They have the information, they have the lived experiences, and they know best, so we should give them a voice. Nothing about us without us.

- >> I'm just a person, like everybody else. There are things I can do, things I can't do, things I like to do, and things that I don't like to do. And at the end of the day, I'm just human, like we all are.
- >> I mean, yeah, look at me, not down on me. In my eyes when you talk to me.
- >> Understanding I'm a person with intellectual disability, I need more time, I need more accessibility, to respect me for me to be able to present myself, to be able to stand up, to be talk about myself.
- >> I'm a human, just like everyone else. I want to be perceived as equal.
- >> I'm just human and that's about it.

AINSLIE WHITBURN: And that is about it from me! So, thank you, and please contact AFDO if you'd like any more information about the project. Thanks, Margaret.

MARGARET MORETON: Thank you, Ainslie. And I hope that you can see all those clapping hands and hearts that are floating all over my screen, as everybody thoroughly enjoyed that. So much to respond to and discuss.

Again, please throw some questions in the Q&A, if you like. I'm sure our speakers today will be up for answering anything.

So, next, we're going to hear from Dr Tonia Crawford, director of pre-registration programs and senior lecturer at the Susan Wakil School of Nursing and Midwifery at the University of Sydney. Tonia is a co-investigator on the Leave Nobody Behind Program and a registered nurse with 20 years of experience, including in community health. Again, we'll be popping extra information in the chat about her. Please join me in welcoming Tonia.

TONIA CRAWFORD: Thank you, Margaret, for that introduction. And thank you for this invitation to present our findings of research we've been doing as part of the Leave Nobody Behind Project. Firstly, I'd like to acknowledge that I'm presenting this from the lands of the Dharug People and I pass my respects to the custodians and leaders of this land. So, I will be presenting an overview of findings from out of this project, where we explored what informal carers thought and felt about their experiences of various disasters within the Australian context. Just to define "informal carers", we define them as those who provide unpaid care to support family and friends with various conditions, chronic conditions. They may receive income support payments from the government and they may also receive assistance from formal paid services.

In this study, about 55% of our responders were parents, but we also extend this definition to include spouses or partners, adult offsprings, relatives, or friends who might be providing this informal care. About 10% of the general population are made up of informal carers, and nearly 72% of them are primary carers as women, with an average age of 50. And we're looking at informal carers because, generally, informal carers are overlooked when it comes to disaster preparedness strategies. So, the

aim of this project was to study the experiences of informal carers and their self-reported capabilities, their preparedness, as well as support needs, and what advice that they might provide to other carers and emergency services.

With this study, we used a mixed-method design and we used a survey to find out the demographics of our respondents, what they reported as their capabilities, what actions, preparedness actions, that they'd undertaken, as well as their support needs. And we provided two hypothetical scenarios - one was a shelter-in-place scenario and one was an evacuation scenario, and we had open text boxes for the respondents to provide their experiences and provide an opportunity to give advice.

After this, we did in-depth interviews of carers to further explore their disaster experiences. So, a total of 61 people responded to the survey. It was a national survey. And then seven respondents agreed to participate in in-depth interviews - this is where we explored with a bit more in-depth their capabilities and preparedness. So, of the 61 respondents, 84% were female, just under half were mothers of the care recipient, 87% lived in the same household, and a little bit over half lived in a city. The three most common conditions that were reported were physical disability at 41%, followed by chronic health condition at 34%, and then, thirdly, in intellectual disability. The most frequent tasks that were reported as being required related to transport at 89%, followed by household chores, and then property maintenance. In terms of the types of disasters that people felt most confident of dealing with, those that were most confident was heatwave, with least confident dealing with bushfires. So, I'll just break down the three sort of focus areas, so I'll talk firstly about preparedness. And the three main actions taken in the last 12 months to prepare for emergency was associated with particular hazard types. The most common was preparing a property to reduce

damage by the disaster. This involved clearing gutters and downpipes of litter, trimming trees and branches, particularly near the house, clearing

around the house, installing and maintaining smoke alarms. So, that

entailed sort of the preparing of the property.

The second most common actions were that of stockpiling emergency supplies, and this was sort of having several weeks' worth of food and water, having personal hygiene supplies, food for pets or assistance animals, having a first aid kit, flash light, battery-powered radio, extra batteries, all part of this sort of stockpiling. And as Peter referred to earlier, a "go" bag to evacuate but also stockpiling for staying in place.

The third most of taken actions in terms of preparing related to reviewing property, vehicle, or life insurance policies. So, in the next slide, you'll see what the respondents referred to in terms of maintaining capability, and their capabilities were really focused on maintaining their independence in the event of a disaster. And this was independence both for themselves but also for their care recipients. During a disaster, as well as... And this was in the case of the shelter-in-place scenario as well as the evacuation scenario. So, in relation to the shelter-in-place, the capabilities related to having sufficient stockpiling of food, medications, and consumables to last several days, and that included access to drinking water - that was the most commonly reported capability. Having a generation of power, having a generator, as well as backup batteries. Having sufficient medication and prescriptions. And then having support from family and friends in order to provide for some of these basic requirements as well.

In the evacuation scenario, the respondents talked about their capabilities in terms of knowing where to access assistance, and this is particularly from family and friends, as well as neighbours, to support

them to evacuate. So, that was often related to transport to an evacuation centre or to their home, as an alternative accommodation. This was followed by assistance with communication about what was going on. Less reported actions related to having a "go" bag, having an emergency plan and communicating that plan, as well as updating emergency contacts. On the next slide, the respondents talked about their support needs, what help they would need in the event of a disaster. So, the survey asked about the degree of help, and a great degree of help was reported by 30% of carers in the shelter-in-place scenario, but 52% would require a great deal of help to evacuate. Now, the support needs predominantly reported were relating to physical and practical assistance. In the shelter-in-place scenario, this related to assistance with food, water, utilities, having a generator, having lighting, access to medications, assistance with hygiene care, clothing, personal care tasks relating to, sort of, tasks lifting, eating, drinking and so forth.

In the evacuation scenario, the physical assistance relating to helping to evacuate, accessing information, help with communication and contact with families, accessing the internet, and so forth.

The second most-reported support needs related to transport out with the evacuation, transport provided by family, neighbours, friends, sometimes council-run transport, if that was available, assistance to walk away from a location of concern and move to a safe destination, specialised transport to help transport equipment, such as wheelchairs and other essential equipment. In the shelter-in-place scenario, the transport or the moving related specifically to care of the recipient and assisting with transfers and so forth.

And then the third most reported support need was that of psychosocial and emotional support. Reassurance, mental health support to manage anxiety, and help with connecting with others, so that's social

connectedness.

On the next slide, couple of slides, we've got some excerpts that came from some of the carers, these informal carers, and their lived experience of evacuation. So, the narratives reported several different actions, depending on the type of disaster. To evacuate family members, medications, equipment, documents, pets, were transported most often to family and friends, but sometimes to a hospital, if family and friends were not available. So, in this excerpt here, the evacuation point was at a local club, but the club was fairly inappropriate for a child in a wheelchair that had very specific personal and medical requirements. So, in this case, the carer, you know, had to consider moving to a hospital if the evacuation centre was not appropriate, or staying in their own home, or parents' home, if it was safe to do so. So, it demonstrates that often evacuation centres really aren't that accessible. So, the reality of some people with disability means that the decision to go to an evacuation centre is much more difficult due to them not being very accessible. And often the environment is not very appropriate.

On the next slide is another scenario, another excerpt, where the carer of a person with a developmental disability talked about their property not being as prepared as it could have been. And this carer was actually a daughter of a firefighter, so she knew how to prepare a property and what they needed to do, but because the person they cared for required 24-hour care, the time was taken up with doing that rather than preparation of their home. In this case, it was a bushfire and they couldn't go early to an evacuation centre because of the type of environment of that centre. They would have had to strap their son to a mobility chair and he would have been screaming the place down. And so the carer, the mother, talked about some environments just don't work for people with some types of disability.

And so the next slide shows some recommendations that came out of this research. The advice from informal carers to other carers was fairly general in nature. They tend to talk about, you know, what they needed to do to maintain independence as much as possible. That included having, and communicating, a plan. Often people had a plan in their head but hadn't actually communicated it or written down. Having a grab bag of essentials and medications, keeping their insurance current, having copies of their important documents, and they talked about having it on the cloud or having it on a USB stick with someone in a different area. Keeping supplies of basic items in the house, having emergency numbers. So, that's fairly typical of the type of recommendations. Also talked about accessibility of emergency shelters, requesting emergency services to listen and understand, as Ainslie had talked about before. And including carers in preparing plans and including them in training of other people, and particularly perspectives of women. So, just to conclude, this research has really brought to light the voices and the experiences of informal carers. And it's really important that we can include informal carers in this planning and training to bring their experiences to bear. So, they reported actions that they took, the types of support they would need, and the advice they consider useful for education and training - both of other carers and emergency services.

So, just a conclude, I acknowledge our partners. And we have submitted this paper to the International Journal of Disaster Risk Reduction, but feel free to contact myself or our team, with Michelle, if you want some more information about this particular part of the project. Thank you.

MARGARET MORETON: Thank you very much, Tonia. I'm sure that people will be developing questions. And as you can see, everybody is very

interested in the contributions we're all making. Our final speakers today are picking up that theme of carers. So, they are from Carers NSW. In 2022, Carers NSW received grant funding to undertake a 3-year project, Care2Prepare, in partnership with the Physical Disability Council of NSW and GoCo. The Care2Prepare project aims to improve household and community resilience and preparedness, reducing the impact of floods and bushfires on people with disability, older people, and family and friend carers. Please join me in welcoming Sarah Judd-Lam and Courtney Jones to talk more about the Care2Prepare project.

SARAH JUDD-LAM: Thank you, Margaret, for that introduction, and also for Tonia, for that great data, which does really foreground our presentation as well. And it's great to be able to be here. My name is Sarah Judd-Lam and I'm co-presenting today with my colleague, Courtney, as well. And thank you for popping that bio, those bios, in the chat.

So, I wanted to just add our acknowledgements as well to those provided already for traditional custodians of the lands that everyone is joining from today. For myself and Courtney, that is the peoples that we extend our respects to the Elders past and present as well. Next slide, please.

Tonia expertly handled the definition of carer, which is excellent. But Carers NSW, if you're not aware of us, is the peak non-government organisation for family and friend carers in NSW. And we're part of the National Carer Network, a member of Carers Australia. Next slide, please.

Touching again on Tonia's definition of "informal carers", that's who we're talking about when we mention carers in our presentation. And the important thing to mention there is we have a broad definition of carers, in that we speak about family members and friends caring for anyone that

relies on the support of a family member and friend. That might include due to a disability, a mental illness, a health condition, or ageing. And, importantly, I quess to emphasise in this context, is that often the word "carer" is used for paid workers, which we do not include in our definition. So, we're just talking about those informal carers that Tonia mentioned, and there's over 850,000 in NSW. And before we move on to the next slide, it's also important to point out we know that a lot of people don't identify with the term "carer", they might not use that term about themselves or about someone that's in their life. But we do know also from population statistics and from research that's been done by the team presenting today, that the majority of people living with disability rely on the support of family members and friends, just like those living without disability do, and particularly where additional assistance is required to either evacuate or respond in a crisis, or to plan and prepare for a crisis, those family members and friends are often really critical to those processes. And that's really where our interest as Carers NSW in this topic of inclusive disaster risk reduction comes from, is that we know that the family and friend carers that we work with are often really involved in supporting that kind of planning and emergency response. And so in terms of being able to reach people with disability and include people with disability in that planning and safe response, carers really need to be part of that conversation. They can help convey information, they can help act in a crisis, and it really just helps ensure broader safety and health of the community, and for people with disability. And so if we can move to the next slide, please.

So, Margaret mentioned Care2Prepare in the introduction, and I'll hand over shortly to my colleague, Courtney, to speak a bit more about that. But essentially this program looks more broadly than just carers. With our partners, on the slide, we are looking at carers as well as people

with disability and older people, and we're building - excuse me - we're building the household readiness and the community readiness of three locations to respond particularly to flood and bushfire. And so by community readiness, we're talking about just working with local community stakeholders to connect and to sort of help the light bulb go on for community stakeholders that might not have thought about disability inclusive disaster risk reduction before, and just to try and make those responses more inclusive and integrated at the local level. And in terms of household readiness, we're talking about providing additional people on the ground that can support evidence-based responses for households in trying to plan safely where there's additional needs so that those can be addressed in a disaster response.

And you can see our partners there, and we have also Michelle and Jade from the University of Sydney on our steering group for this project.

I guess a question that comes up is, "Why are we including carers along with people with disability and older people?" So, obviously, each of those groups, and within those groups, there is a diverse variety of needs and responses - that's been touched on today, that we need to look at an individualised and person-centred approach. But what we also know from the research, and also just working with these groups, is that there are some common challenges. And we, in partnership with our partner organisations, felt that it was useful to approach inclusive preparedness from a broad perspective because things listed on this slide, like there might be a reliance on essential goods and services in these groups beyond the general population, and a greater vulnerability, as was explained further, if those things are not accessible in a crisis. There may also be different challenges and barriers that might affect timely access to information and support. And also we know from research that really there's just poorer outcomes, higher risk of challenges - both during and

after these disaster events - for all three of these groups. And so looking at them together, we felt, was a way of bringing resources together and leveraging those responses. But there's not a siloed response of "this is our approach to disability, this is our approach to ageing," but looking at what those groups have in common and trying to build readiness both within the households where these people are living but also within the communities where they're living as well. And so that's my kind of little introduction. And I was going to hand over to Courtney to speak a little bit more about what our project has been doing, but specifically some of the key takeaway points so far from the project, and we'll be talking today mainly from the carer angle, given that we've heard a lot of other perspectives today and following on from Tonia's presentation. So, I'm gonna hand over to Courtney to speak to the next slides.

COURTNEY JONES: Thank you, Sarah. So, Sarah touched briefly on the aims of the project, and our outcomes are obviously aligned with a lot of the outcomes and goals that people here today have. We have an overall outcome of increasing the inclusion of the needs of people with disability, older people and carers, in local disaster planning and response frameworks. And we would broadly like to increase the community awareness of those local disaster planning and response frameworks because we know, when the community has an awareness of those processes, they can act for themselves and also act and advocate for other groups. We're also seeking to increase the number of people receiving and providing care with their individualised disaster plans. So, that is our household readiness component, where we will be directly supporting people in a one-on-one situation to create those plans that are specific to the needs of them as carers and the people that they are providing care to. And we're also seeking to create a greater confidence

among people receiving and providing care about their safety and the support options that they have in the event of disasters. Next slide, please.

We often hear from carers about the challenges and the time taken to navigate their caring roles, to coordinate care packages and support services, and to juggle work and their own healthcare and their own life needs. They say things to us like, "You have to be very organised and you have to be prepared for plans to change quickly." And as Tonia said, these carers are very capable and demonstrate a high level of understanding of the need to prepare for disasters, and the capacity to do so. What they do lack is access to appropriate tools and resources, things that are specific to those complex needs for themselves and for the people they're providing care to. We see these skills as being highly transferrable and that, by offering support to carers to create these plans, we're able to continue to build capacity within that household to increase their safety during times of disasters.

We know from the early findings of the consultation that we are undertaking with carers and people with disability, and older people, that carers are focusing on their priorities, their exigencies, and these are things like maintaining routines and familiarity of environments to avoid triggers, to also understand how to provide continuity of access to their life-sustaining medical equipment or the scheduling of medications, and managing their own needs alongside those of the care recipient's. So, by taking the carer-centric approach and helping the carers to understand how to plan for, and prioritise, those aspects, it then frees up that space for them to think about other things, such as preparing and maintaining properties to avoid or limit damage, and other secondary issues in their list of priorities. Next slide, please.

So, we've spoken about the definition of "carers" and we see that

carer recognition is really a key to increasing the awareness of the complex needs that carers and care recipients have. We do understand that not everybody considers themselves to be a carer, they may not identify with this word or this role, and we also know that many organisations don't understand how to spot or have a correct - sorry, have an appropriate way to ask questions to identify if people are taking on these often very complex roles. So, by identifying the opportunities to improve response protocols, such as diverting people from mass evacuation centres where that's inappropriate and advocating for better ways to support priority populations, we can start to embed those carer-centric approaches into planning and response protocols, and help people to understand the needs of carers. Next slide, please.

The project at the moment is currently in a consultation phase, so we are working through a 5-phase process and our consultation is due to wind up at the end of the month, at the end of April. We're speaking to carers, older people, and people with disability, with lived experience of disasters, and those who live in flood and bushfire-prone areas. We're also speaking with community stakeholders and mainstream disaster risk reduction practitioners to help get an understanding of where there may be some gaps in skills and knowledge, and identify opportunities for providing resources that are appropriate and raise awareness about carer needs. We're also commencing this month a co-design phase, and that is co-designing of household tools and resources that we've spoken about, where we have people working directly with individuals to develop a plan, and also develop some training modules and tools for local government and business and the community sector. We are piloting this project in three areas - Gunnedah, Shoalhaven, and the Central Coast. And when we are finishing with that pilot, we will be able to roll out our findings, share our findings in a symposium, and roll out a tested model across

NSW. So, if anybody is interested in contributing to our consultation phase, if there's anything you'd like to share or to ask from what we have found so far, please do feel free to get in touch with us. And we do look forward to sharing our findings later down the path, when we have launched our pilot and are ready to share and spread the good model NSW-wide. Thank you.

MARGARET MORETON: Thank you. Thank you, both, Sarah and Courtney. And thanks to all of the speakers, actually. It's been fascinating, brilliant. Just listening to you all, I had a couple of reflections, which I might just share with everybody to give people a last opportunity - well, an additional opportunity - to throw a question in the Q&A.

I'm really struck by - and it's not the first time I've heard it - but I'm really struck by that phrase "nothing about us without us". It's such a basic, fundamental principle of all of this work. And I think it's a really good thing to remind ourselves of. And I was reflecting on how Peter began earlier on in the session, saying - and forgive me, Peter, if I get your words incorrect - but something like "it all seemed a bit daunting at first" and yet it became clear as you talked about your part in all of this, that it began to feel enjoyable and even a bit of fun. And that had me thinking about the leadership component that everyone has shared, one way or another, and how leadership can feel like it's a big thing and involves courage, and it sometimes does, and the ability to be articulate and stand in front and participate. I really liked how a number of you talked about how it just involves humanity as well. We're human. We just want to be a part of it. And a good dose of humour and fun. So, I'm so impressed by all of the speakers this afternoon. I might just go to a couple of the questions - they're now starting to flow in. Look, Ainslie, if I could start with you, I think I do need to ask the most popular question

first. Which is, "How do people connect and get involved in the Fire Proofing workshops? How do they find local contacts? Where's a good place to start?"

AINSLIE WHITBURN: You can probably start by emailing me. So, I'm happy to put my email address in the chat. And we'll be, sort of, as we organise each focus group, we'll target people in those areas. As I said, particularly local networks, you know, service providers, anything, really. So, I'll put my email in the chat, and please just email me your details and which region you're in, and then we'll add you to our mailing list when we start organising.

MARGARET MORETON: Thanks, Ainslie.

AINSLIE WHITBURN: Someone's already put it in!

MARGARET MORETON: Sorry, Ainslie, say that again?

AINSLIE WHITBURN: Oh, my email has just been put in the chat.

MARGARET MORETON: OK, great. Now, I'm not 100% sure who might have the answer to the next one - you might know, Ainslie, or some of the others. Peter might know. Is there an organisation advocating for mandated P-CEP implementation? I'm sure Michelle will have a view in a minute. For NDIS participants? It's really interesting, this link between the NDIS and the work that you're all describing and the focus on disability-inclusive DRR. Is anyone aware of whether there is an organisation advocating for the mandating of this?

MICHELLE MOSS: I can jump in and answer that because I think part of the advocacy work that we have been doing in partnership with Michelle and others around the country is to, yeah, talk about the importance that it should be part of NDIS planning. And, you know, there's a range of things happening in that space and we've certainly taken every opportunity we have with the NDIA to be identifying the importance of how that does need to be part of the planning conversation as well as in people's plans, to be able to be supported to do that. We did - and there's a number of DPOs on here - for the last federal election, we did some work to collaborate and put together a joint letter that was sent to all standing candidates across the country about the importance of this work and the national approach. And so I'll hand over to Michelle to add to that.

MICHELLE VILLENEUVE: Thanks. I think what is really powerful about this is having aware, capable, and prepared disability organisations, disabled peoples organisations, that are run for, by, and with people with disability, and disability advocates really aware, capable, prepared, in the know, and able to advocate from the point at which they're at. And I think Peter made that point really well, like, where do you start, how do I begin? Well, just involve and invite someone with a disability as your starting point. So, if you're a service provider, start talking with the people you support about their emergency preparedness. If you receive services and supports, ask that question of the people who are engaged with you. But what I would add is not everybody receives services and supports through the NDIS. So, I think it's also important for us to remember that Person-Centred Emergency Preparedness is about all of us and it needs to come at all of us, from ourselves, and from everybody possible angle. The one exciting thing about that is that Australia's new

Disability Strategy includes disability-inclusive emergency planning, and I'm really proud to say that lots of local government areas are on board with how do we actually raise awareness about Person-Centred Emergency Preparedness in our communities as one of their key strategies to supporting and enabling that at the local community level. So, yeah, thanks for that. And thanks again to all the DPOs who have partnered along the way to make sure that advocacy and that voice is being heard.

MARGARET MORETON: Thanks, Michelle. There was a question further down about the recording - and, yes, you will all receive a recording of this seminar, so that's coming.

I have a question now for Carers NSW, so for Sarah and Courtney, perhaps. I'll just read the question as it's written, "It's important for Carers NSW to be involved in evacuation centre audits in NSW for better accessibility considerations. I would suggest in all jurisdictions, just different carers' organisations. Is this something that's in the planning?" And maybe a broader question of, "How can we make sure that the needs of carers and those living with disability are part of evacuation centres?" if anyone would like to, as I say, perhaps starting with Sarah or Courtney, and then we'll throw it open.

COURTNEY JONES: I'm happy to speak to that. I can say that in the conversations that we're having with the disaster welfare services who coordinate the emergency evacuation centres, that there is an understanding now that the mass evacuation centres are not appropriate for all people. And our officers who are working in those pilot areas are in touch with the local emergency management committees, who are undertaking emergency evacuation centre audits currently. They're doing

this with the support of the Reconstruction Authority NSW. So, we do have, at this stage in the project, an opportunity to highlight what are some of the reasons that carers would avoid going to an evacuation centre, and they have been spoken about by myself and others today, such as, you know, these environments being too noisy and causing triggers and those kinds of things, and just generally not being accessible, which is certainly an issue in smaller towns, where there are not a lot of buildings or venues to select from. And so we do know that this information is filtering up, and that we are hoping to also advocate for processes where priority populations would be diverted directly to alternative accommodation rather than going to an evacuation centre, to go through a triage process, and then to accommodation. So, this might look like a priority phone number or, as part of their plan, being something that they can trigger prior to the need to evacuate, like an early warning kind of process. So, that's it from our perspective, from

MARGARET MORETON: Would anyone else like to add to that? Michelle.

Care2Prepare. Happy to open up to anybody else.

MICHELLE VILLENEUVE: Yeah, I think this issue of evacuation is something that's really important to think about because, for some of us, some of the time, we'll find ourselves needing to evacuate to an evacuation centre or to another place of safety. So, we absolutely need to be pre-planning and thinking for how that goes into our plans. I think - I think for everyone on the line, but especially for those of us who tend to wear a recovery hat, we tend to focus on disaster risk reduction after the disaster has happened, we've got this wonderful recovery workforce that comes in and is so aware of what needs to happen and what the challenges are, and I think some of the things we need to be thinking

about and doing is shifting our thinking to the long before a disaster, in order to do that pre-planning, that psychological preparedness we need to do. And as Courtney says, thinking about what are going to be those triggers and how are we going to make sure that we're not wasting time in the event of a disaster itself. We've had numerous examples during Black Summer fires and also during the severe flooding events, and during those events, what we see are people wasting a lot of time, going to evacuation centres, not getting their needs met, getting supported moving somewhere else that's not quite right, and in some cases - very sad situations - where people are choosing that the safest place for them is to go beyond fire zones into their own home to stay there. And those are really not acceptable solutions for any of us. So, I guess it's really more about advocating and saying, "We need to pre-plan and think, we need to have those hard conversations." And I think this work, all these wonderful collaborators here today are great people to reach out to when you start to get stuck. Because we will get stuck. There will be hard things about our plans that will make it really tricky, and we're really amassing quite a number of people with the know-how to help get us unstuck in that process.

MARGARET MORETON: Is anyone else keen to add to that? No. OK. I'm going to go to another question. And this is a little bit of a long question, and I might make is... I was interested in one of the slides, it talked about parents and parents not being included in the definition of "carers". And I was fascinated by that. Because I know many parents caring for adult children with disability. But I'm going to read Karen's question here. "Sarah spoke of the importance of extended family and friends in helping people to evacuate and their carers. During the 4 December in 2010 earthquake, the town entrances were blocked by armed civil defence and

emergency services to prevent looters and rubber-neckers." So, there's

always an interesting question when there are unintended consequences of well-intended actions. That's my addition to the question. But it meant that friends who actually came to evacuate people living with disability had to lie about why they were there. They didn't meet the entry criteria of being a resident or immediate family because that's what you needed to be able to be in order to enter the area. So, I agree with the implication in what Karen's question is, which is, "Is this accessibility need included in the research in the Care2Prepare?" And, if not, the implication

is it should be. And I'd just be really interested in anyone's comments

about that. I've met plenty of community people who have not evacuated

anybody like to make any comment about that question? I guess there's a

when perhaps it would have been safer to do so, because they wouldn't

have been allowed back in afterwards, so there is this question of

evacuation and then on what basis are you allowed back in. Would

straightforward question of, "Is it included in the Care2Prepare?"

SARAH JUDD-LAM: I might jump in there, Margaret. Also if I can address the parent comment as well, in case there was confusion there. Our definition of carers, which was linked to the NSW Carers Recognition Act, as well as a federal Act, parents are included if they're caring for someone that has additional needs. Where we make the distinction is that sometimes any parent is grouped in with people that are parents, for example, of an adult and have lifetime parenting responsibilities, that might differ from, say, the parenting responsibilities for a child that does not have a disability. So, we would include parents in that definition if the person that they care for, the child, has health needs, mental health needs, disability. It's just a parent of a child without those needs would not fall under that definition. That's just to clarify that. But in terms of the

question - thank you for that question - and it's something that comes up a lot, actually, in our research. And the reason that we refer to family-and-friend carers, and we don't just say family carers, is that we do recognise that caring roles are diverse and that there's often more than one person that's kind of the go-to person. And so I think it's a really important point and it's something that has come up in terms of the use of the term "carer". So, that's one reason that the term "carer" can be helpful because it describes a function or a role that can be someone in various types of relationships. But I think it also raises the question, when we're talking to any service providers, whether that be in kind of the care and the health and social care space, or whether it's in the sort of mainstream setting or the disaster setting, we not only need to raise awareness, but there might be people that have additional needs that need assistance, and those people might have others around them that need to be included, but the next step is then, "Who are those other people? How do you find them? What do they look like? And how might their needs differ?" So, I think we're definitely supportive generally as an organisation of ensuring that neighbour, friend, parent, partner, whoever the person is that is providing that care, or it's likely to be more than one, is able to be recognised for the function and the role that they're having in relation to the person. And so it can take time to raise awareness of carers at all, and then I think that often is a next step. So, I think those examples are really important and I think focusing on what role that person has in the person's life, what support they provide, and why that's important, is really important to communicate. And in terms of whether that's included in the Care2Prepare project, so because we define as Carers NSW, "carers" broadly, it is really anyone that is providing that informal role. So, yes, and we would include "friend" in any of those definitions that we're using. And so, yes, is the short answer to that

question.

MARGARET MORETON: Thanks, Sarah. We could talk forever. I'm always amazed at how an hour and a half flies by. But we are out of time. So, I would like to thank you all. I thank Michelle, Michelle, Peter, Ainslie, Tonia, Sarah, Courtney, and also our Auslan interpreters, Alisa and Caroline. I thank you all for your time today. On behalf of AIDR and the Collaborating4Inclusion Research Team, thank you all for joining us in this second webinar. There is one more webinar to go on 15 May. Please feel free to register for that. The registration details will be put in the chat. Again, a recording will be available for everybody shortly and it will be live on the Knowledge Hub. And when you exit today's seminar, you will be asked, prompted to complete a short survey. We do ask you to do that for us. We do review your comments and feedback and we use it to inform future events. It's been a pleasure to host today's seminar and, until next time, stay safe, and farewell.

(End of transcript)