[SOMBRE MUSIC FADES IN]

PRESENTER: If you had 30 minutes to evacuate your house would you know what to do? Do you know what you'd take? Where you'd go? How you'd get there?

As natural disasters become more frequent and more intense across our country, these questions are something many have recently had to face.

But for the more than 4 million Australians living with disability, the answers to these questions aren't so straightforward.

Australians with disabilities are up to four times more likely to be severely injured or die in a natural disaster event but their choices in preparing for and responding to disasters can be far more limited when compared to those of non-disabled people.

The 2019-2020 Black Summer bushfires devastated the east coast of Australia, destroying almost 2,500 homes and leaving 5.5 million hectares of New South Wales burnt, 6.2% percent of the state.

[SOUNDS OF FIRE/PLANES]

The Images of our iconic animals reaching dazed and desperate for the bottled water of firefighters flooded tv screens and the world watched as our pristine beaches transformed into red-hazed refuges for locals fleeing the encroaching flames.

And for close to eight months, Australians like Marieta Adrião and Sarah Neto were having to decide between two unthinkable choices: stay or go.

[SOUNDS OF FIRE/SIRENS]

MARIETA ADRIÃO: I had that app that I was looking at the fires were getting close. I mean one was three kilometers away. I mean I couldn't see the… I mean I could see the smoke because the smoke was everywhere but it was three kilometers away and it's not the scariness of getting burnt. It's just like what do I do? Like I mean with Sarah like I mean, that was my top priority. The most important is Sarah and all her equipment and knowing and being able to I suppose to do my getaway. I suppose that I suppose that was the main thing with me with the fires.

PRESENTER: Marieta's daughter Sarah lives a cerebral palsy a physical disability caused by an injury to the brain that affects her ability to control her movements. It primarily affects the movement in her legs.

Can you tell me a bit about your chair, Sarah? How does it work?

SARAH NETO: Well, my chair, um, my chair it goes fast and it can go slow. To move back and move forward. It lays back when you push the right button.

MARIETA ADRIÃO: They actually explain it to me when she was younger. So a lot of the things we do that even blinking all swallowing. We do it without even thinking about but like with her you gotta… you actually have… she actually has to tell herself to do it. It's like…

we… I mean we know if to stand up we have to lift our legs. She literally has to… She can do it because her legs bend so… But the message doesn't go there.

PRESENTER: In 2019, Marietta and Sarah moved to a fully accessible home in Worrigee a small town two hours south of Sydney on the south coast of New South Wales, but less than a year into living in their new home. The town was terrorised by the black summer bushfires.

Sarah, do you remember the fires?

SARAH NETO: Yes.

PRESENTER: And what do you remember about them? How did it make you feel?

SARAH NETO: You couldn't see anything. It was just smoke. Gray and smokey. It was scary. Dreadful.

PRESENTER: As the fire script closer to Worrigee the possibility of evacuating their home became very real for Marieta and Sarah. Only there was one problem: the local evacuation centre wasn't accessible for Sarah.

MARIETA ADRIÃO: They've got disabled toilets, but they're what they consider disabled is for someone that's in a wheelchair that can move themselves. But what they need is a room where I can wheel Sarah in there, it would have a hoist… It's not good. Just having a disabled toilet. You know, yes, you can go in there with your wheelchair. But Sarah can't move from her chair to the toilet. If I go there what if Sarah needs to get the toilet. What am I gonna do?

If you have to sleep there, obviously, they need to have somewhere where I can take it from the chair and obviously they have to have a bed… Well the beds there but I mean obviously you're not going to have enough for everyone but there's a lot of… I mean, I see what when Sarah goes to the centre and there's a lot of day programs down in Nowra. So obviously there's a lot of disabled people and where do they go like, I mean, I'm sure I'm not the only person that has a disabled daughter. There must be a lot of people. What do you do?

PRESENTER: Faced with the choice of sheltering in place or moving to an evacuation centre that couldn't accommodate Sarah's needs Marieta made the choice to stay in her home.

MARIETA ADRIÃO: Because I felt I was safer at home. Then having to evacuate somewhere and not and then like fretting over everything. I just thought yeah. Well I had everything… Well… I had all the equipment. We you know, and it's comfortable and I figured you know, like I said I felt safer.

I don't know if it's an unsaid thing maybe people… I mean, we don't get fires like this every day, so it's not as though… But yeah, like you would… it would be nice for them to say well if you have to evacuate and you got a disabled child that requires equipment instead of going to the bowling club either the bowling club has the facilities there or you go to the hospital where they already have a lot of lifters, you know the stuff and that's where you evacuate to but then what happens to the sick people? I don't know.

It's been one thing after the other, like it's been three things this year like these last two years COVID, fires, floods. I mean if this is gonna keep happening every two or three years, which

probably it’s going to… but yeah, I don't know they yeah, they need to put something in place. I mean either that or we move somewhere else safer.

But in saying that, I mean look at the floods now, they haven't even got anything in place for normal people. Never mind people disabled. I mean that brought a tear to my eye because I figured if my house got flooded like that. How do I get her out? How do they… like I'm sure there's disabled people there what happened to those people? But then if I mean when I saw the people, you know, had to get away and get on the roof. How am I going to get on the roof it Sarah? But I'm sure in all those there is there's disabled people and I figured wow, like what would you do like, I mean this is that when it something that happens really quickly…

I don't know evacuate… how do they evacuate? I mean that that's the sort of thing. They do need to have something in place, but then at the same time because if you're evacuating disabled people as well, you need to have the facilities that have that. Otherwise you don’t… well to me my opinion is I'm not gonna evacuate if I don't have to, to go into a place where it's more stressful for me. So my thing was to stay, let them know that I'm there, and go from there.

[SOMBRE MUSIC FADES IN]

PRESENTER: For many living in the Northern Rivers region of New South Wales evacuation was not a choice. It was a matter of life or death.

Heavy rains in excess of 400 millimeters in a 24-hour period bombarded northern New South Wales and southern Queensland causing widespread flooding.

In Lismore, the Wilson River peaked at 14.4 meters one of the highest peaks on record in New South Wales.

The State Emergency Services fielded over 31,000 calls for help as locals jumped into their own boats to bolster evacuation efforts, rescuing hundreds from the rooftops of their homes.

The flooding inundated more than 32,000 homes and businesses across New South Wales and Queensland displacing thousands and leaving an estimated $2.5 billion dollars in insurance claims.

At least 23 people were killed in the flooding around a dozen remain missing.

Rachel Rowe is the CEO of Autism Camp Australia, a national organisation supporting autistic young people and their families. Her home and the headquarters of her organisation sit on the banks of the Tweed River where she was forced to evacuate when it flooded in February.

[SOUNDS OF RAIN]

RACHEL ROWE: So I was flooded in here. So unable to get out from around nine o'clock in the morning on Monday the 28th. We were flooded in here and we were waiting for the time to go down and she didn't and so and then the water was climbing at ten centimeters an hour. So I helped to get a number of elderly and disabled people actually by boat.

And eventually I was evacuated by boat as one of the last coming out between nine and ten o'clock at night in the dark and we were that was all done by civilian boats. Services on the ground was so completely overwhelmed but there was no provision for people here at all. It was civilian boats taking us out and it was civilian cars picking us up and taking us to the evacuation centre.

PRESENTER: After helping her neighbors and leaving her property, Rachel made it to the evacuation centre where she was met with a number of accessibility barriers.

[SOUNDS OF AN INDOOR CROWD/RAIN/PHONES RINGING]

RACHEL ROWE: When we got to the evacuation centre completely exhausted. We then had to queue for nealy an hour and a half to register and then from there we were taken to a space and I literally found a corner and was given a mattress, laid down and went to sleep. Woke up at about half past four in the morning and that was the point at which I struggled the most because as an autistic person, having… I had nothing tangible to hang on to at all and as an autistic person, the most important things that you need in order to to navigate a neurotypical world are structure and routine and an understanding of what's happening and to have nothing tangible to hang on to… so I had a meltdown in the middle of a very public space. I had a meltdown because a meltdown's been caused by either a sensory or an anxiety overload.

PRESENTER: Rachel's experience is one shared by many individuals and families living with autism. An experience she says could be improved with the help of social stories, a social learning tool that assists with the exchange of information for people with autism.

RACHEL ROWE: We have a social story for kids coming to camp and basically what happens is it's just an intro as a PDF like it's about a 15 page PDF. And in there it goes… "Hi. My name is Helene. I'm the camp leader" 'photo' "I'm the one who's gonna meet you when you arrive and when I meet you, I'm gonna take you to your room and you can unpack your clothes and you can do this and you can do that." All visual and written.

"Here's the program for the whole time that you're going to be with us," written and visual. "Here's if anything, here's some rules that you need to think about while you're here. And if anything if you feel worried about anything, these are the four people that you can speak to." It's a way of reducing anxiety and unknown around it. So yeah be great to have some social stories written around what to do in an emergency situation that are ready to go. So social story for a bushfire, a social story for a flood, not just written, visual. This is what's happening. This is what you know, when you join that queue to sign in at an evacuation centre that you've not just got a list of this is what's going to happen. We had nothing. We were just standing there not knowing how long it's going to take, you know, like something on the wall with a "this is what's going to happen in the next, you know, these are the next 10 things that are gonna happen to you," written and visual. Yeah. So those are all basic things that we would you know, and low sensory low anxiety raising spaces and accommodations my so when Kingscliff Tafe gets a phone call saying "That's it. You're on, you're in an evac centre," that Kingscliff Tafe has a plan for what goes where? Then trying to explain it. Putting it down in a way that someone could actually just start to to contemplate and defrag it rather than… something tangible. It's having something tangible. Yeah, so social stories, written in advance would be a great idea.

PRESENTER: Earlier this year in response to the flooding in southeast Queensland and New South Wales, a Coalition of 40 disability rights and advocacy organisations signed an open letter to politicians across the country demanding support for disaster plans for people with disability.

Steve Coulter is the Manager of Communications Media and Marketing at the Queenslanders with Disability Network which co-wrote the open letter with People with Disability Australia. He says action on disability inclusive disaster preparedness is urgently needed before the nation faces further natural disasters.

STEVE COULTER: The reason why we did this was because we've had numerous conversations, emergency situations with our members just from QDN, contacting us, "I've been flooded," or been in situations where you know, they're not getting any support, where they don't know what to do an emergency and they felt that more needs to happen. They felt more needs to be done. And so that's as and advocate organisation, enough was enough. And we came out with the open letter which was called 'Leave no Australian Behind'. In emergencies, you know, there's research to say that people with disability do get left behind.

There's a higher risk of injury or potential death. And in Queensland where 60 percent of our natural and disasters actually happen, that's a massive risk, when one in five of the population live with disability. Just in Queensland in the last few months, we've had two and disasters of flooding in the Brisbane area. And so it's real, it's happening and it's something that we felt that we needed to get together across Australia with other organisations and speak out for people with disability.

PRESENTER: And what would you like to see our politicians act on? What are your demands?

STEVE COULTER: So our demands basically is for support. It's for whatever government that gets in or gets elected or chosen is that we ask them to actually pledge and to commit to funding of the development of a national plan and roadmap to deliver on disability inclusive disasters. We're asking for investment multi-second sector targeted approaches underpinned by collaborative and inclusive research for people with disability. And we're calling for that action to happen. We wanted to happen soon because we don't know when the next disasters are around the corner.

And we've called on all candidates and all parties ahead of the election to pledge to this and to make a commitment that if they were to be elected, and obviously we're currently forming in government at the moment, that one in six and disability in the event of a disaster would be protected and no Australian would be left behind.

[SOMBRE MUSIC]

PRESENTER: The University of Sydney's centre for disability research and policy is a world leader in research on disability inclusive disaster risk reduction and has been working closely with communities at risk of natural disasters across Australia to develop and implement inclusive disaster preparedness plans.

Helen Styles is a research assistant and project officer for the Centre's Queensland project. She says disability inclusive disaster risk reduction has a very real impact on the experiences of people with disabilities in disaster events.

HELEN STYLES: Several years ago, there had been some thinking around. What do we do for people with disability? Why don't we create a list?

So you'll find that there are communities around Australia that have these things called ‘vulnerability registers’ or ‘register of special needs’ or… because the thinking was if we create a list of all the people who we know who are in wheelchairs or a rely on electricity powered oxygen tanks in order to keep breathing or you know, whatever it is that might mean that it's more difficult for them to evacuate by themselves or if the power goes out they could die, then if we know where they live and what they need will come and help them in an emergency.

Some communities still have those lists, other communities like ours had enough events since then to know that those lists don't work. Because the first time the list had to be put into practice. It all went to shit. Because everyone… we had a big flood and it happened overnight. So people woke up to discover their homes flooded. Swing your legs over the side of the bed and into water. And we have a gentleman here who was one of those people on the list and he tells the story of the police just turning up at his house and saying we're here to evacuate you. He didn't know who called them. He didn't know that they were coming. He was in a wheelchair and they said we're going to send an ambulance to you and the ambulance arrived and they said well, we can't take your wheelchair. And he went “well, what do I do?” and they took him but he ended up spending the next week in and out of the hospital and an evac centre in a borrowed wheelchair that he didn't fit into properly and he could barely use.

So his dignity, his mobility, his independence, all of these things are really badly impacted. And he's someone who now tells that story to help explain why that didn't work for him and what we need to do differently. So I'm one of these people that says the lists don't work because we know they don't. I mean you don't want to centralize things too much either like if you're if you put government in charge of all of the planning for each person that's never going to work. When you try and centralize things too much you take a lot of capacity out of the community because you're telling, like I’ll use my own Mackay example again, you're telling 118,000 people not to do something because the 1,000 people that work in council are gonna do it. Well, no, that's never gonna work. They're never gonna be able to cover off everything. You're never gonna reach the demand. They're not going to be able to reach people because they're flooded into their own homes, you know, all of that. You give 118,000 people the tools and capabilities to plan for themselves and respond themselves. Then as a council or as a fire service or a police service, you're now dealing with the gaps, not the 118,000 people. But if you do that gap work before ahead of time through collaboration, through individuals creating their own plans, 118,000 people create their own plans, and then they come and say to council, “This is where I'm finding a gap.”

“Oh, I'm also finding that gap.”

“I'm finding that gap too.”

Okay, so 500 people have this gap. Let's bring the 500 people together and work on the gap instead of "Oh there's 118,000 people out there, I don't know what's gonna happen in an event, but we'll cross our fingers and hope we can meet it." [laughs] One way makes a lot of sense to me. The other way is how we've been doing it for years and it's too many unknown variables.

PRESENTER: So what are the steps you take when you're preparing for a disaster? So for example, I've spoken with a woman named Sarah and her mother who during the black summer bushfires decided to shelter in place because of accessibility issues at their local evacuation centre. What are the steps that they should be taking in the lead-up to an event like that, to prepare?

HELEN STYLES: So what am I gonna do to go? What am I going to do to stay? Because ultimately it's shelter in place or evacuate. Go or stay. So Sarah has already gone "Go is really hard. I'm gonna focus on a really good stay plan," which is awesome because not a lot of people think about the stay plan very well. So Sarah and her family have identified the gap: there's not an accessible place for her to go. They've worked out a really good stay plan. Now is that time where you reach out to other people to say "What can we do?" and that can be, you know, obviously a trickier a bit and it's usually not a fast solution like a fast fix but the peace of mind that you could work towards that family to know that they're there is there are options and the options are usually there but no one's thought about them and put them into place and made it easy to access them. So having your council involved in that level of planning so that I don't maybe that I don't have to retrofit the golf club. Maybe there's that… you know that that hotel down the road that has the three accessible rooms and they make sure that they're available in bushfire… you know, it's all worked out. You work it out in peacetime not in war time.

PRESENTER: So how does the wider community engage with this? What's the best way for non-disabled people to help out the disabled people in their lives?

HELEN STYLES: That's a really good question. All of the research says that in an emergency or neighbour is going to reach you before anyone else will and communities that have higher social capital where people know each other tend to respond better and recover better after disaster. So getting to know your neighbour is one of the best things you can do and reaching out to neighbours, you know, anything that you can do as a community whether it's about holding a barbecue or a street clean up before storm season or what have you that can help people get to know each other. The one of the tricks is where we're working with service providers and councils and emergency services and people with disability. So we're helping them come up with ways they can invite people into their lives. So it might be about you know, that neighbour that brings the wheelie bins in for you once a week. That's probably someone you can rely on an emergency, isn't it? "Oh, yeah. I rely on them every week to take my bins in and out." Great! Have you talked to them about sandbags? So if you can't manage a wheelie being you're not you can't manage sandbags, you know, so then it's about helping them see a way to open a conversation.

But I think that if I was able to make a message to everyone in Australia, it would be to know your neighbour and and look out for the people in your street. It doesn't have to be your next door neighbour. It could be someone two streets over and it's okay to offer help because what's the worst they're gonna happen? Someone says no? [laughs] It's okay to say "I'm on

my way to the sandbag, you know to go fill up some sandbags. Do you want me to feel some up for you?"

The very nature of a disaster is they're things that overwhelm us. Our society, our system. They overwhelm systems. You only have to look at Lismore to see that. There will never gonna be enough SES staff or flood boats to help people. It was about neighbours jumping in their boats and going to help people. So we have to be more prepared for that. I think Australians have very high expectations of our governments and what they'll do for us. There comes a point where we have to realise that there is more that we can do, you know jump in and help someone if you see that they need it or ask them ahead of time. If they think they might need it. It's always better to be prepared and be pleasantly disappointed that you didn't have to help someone than to be in an awful situation. We just want to avoid those photos that you see, you know of people in Texas or wherever it was Louisiana sitting in flood waters up to here in an aged care home. Let's just all avoid that, shall we?

PRESENTER: So if people want to find out more about how to better prepare themselves for natural disasters, where can they go to find that information?

HELEN STYLES: Definitely go to collaborating4inclusion to learn about person-centred emergency preparedness and use the workbook there to have your own planning conversation. It's a self-guided, you know takes these four steps to create your own plan and then within that it also says to make sure you look to your local services. So if you're a New South Wales, you look to the SES, you look to the New South Wales Rural Fire Services to find out about what your local hazards are what you're where your local emergency points are etc. So you can you can think about what I need to know locally and then what I need to know for me and that's the person centred emergency preparedness.

[CALM MUSIC]

PRESENTER: Prior to the federal election the Greens' Spokesperson for Disability Jordan Steele-John and Greens Senator for Queensland Larissa Waters announced their party's commitment to providing future funding for the Queenslanders with Disability Network. As well as a commitment to the development of a national plan to deliver disability inclusive disaster preparedness, and investment in information, services, resources and supports by and for people with disability.

As the results from the federal election continue to roll in, disability advocacy groups are optimistic about future commitments to disability inclusive disaster risk reduction.

If you'd like more information on person-centred emergency preparedness visit collaborating4inclusion.org

[MUSIC FADES OUT]