



Climate Health WA Inquiry

Inquiry into the impacts of climate change on health in Western Australia

Inquiry Lead:
Dr Tarun Weeramanthri

Witnesses:

Ms Samantha Jenkinson
Executive Director, People with Disabilities WA

Thursday, 5 December 2019, 1.00 pm

[11:15:06]

HEARING COMMENCED

5 PROF WEERAMANTHRI: Ms Jenkinson, I would like to thank you
for your interest in the Inquiry and for your appearance at today's hearing. The
purpose of this hearing is to assist me in gathering evidence for the Climate
Health WA Inquiry into the impacts of climate change on health in Western
10 Australia. My name is Tarun Weeramanthri and I have been appointed by the
Chief Health Officer to undertake the Inquiry. Beside me is Dr Sarah Joyce,
the Inquiry's Project Director. If everyone could please be aware that the use
of mobile phones and other recording devices is not permitted in this room, so
please make sure that your phone is on silent or switched off.

15 This hearing is a formal procedure convened under section 231 of the *Public
Health Act 2016*. While you are not being asked to give your evidence under
oath or affirmation, it is important you understand that there are penalties under
the Act for knowingly providing a response or information that is false or
misleading. This is a public hearing and a transcript of your evidence will be
20 made for the public record. If you wish to make a confidential statement
during today's proceedings, you should request that that part of your evidence
be taken in private. You have previously been provided with the Inquiry's
terms of reference and information on giving evidence to the Inquiry. Before
we begin, do you have any questions about today's hearing?

25 MS JENKINSON: No, that's fine, thank you.

PROF WEERAMANTHRI: For the transcript, could I ask you to state
your name and the capacity in which you are here today?

30 MS JENKINSON: Yes, it's Ms Samantha Jenkinson, and I'm
the Executive Director at People with Disabilities WA.

PROF WEERAMANTHRI: Thank you. Would you like to make a
35 brief opening statement?

MS JENKINSON: Look, generally, our submission, sort of,
was... it was very rushed, so I didn't get time to a lot of detail into it.
However, wanting to just really highlight what the impacts are of what we see
40 as being the effects of climate change on people with disabilities. And that as a
population group, people with disabilities are generally poorer, have less access
to services, and are going to be more impacted, in terms of their general health,
by some of the things that are happening with climate change. And as I think I
pointed out in the submission, it's sometimes hard to... people don't always
45 necessarily see the direct link. So we know that people with disabilities are...
you know, they're at a higher risk of vulnerability when it comes to things like
bushfires, extreme heat events, but then actually knowing that that connection
back to the climate and what's happening with global warming isn't always
50 clear. So that's what we've tried to articulate in our submission and hopefully,
I'll be able to do a little bit more today.

[11:18:02]

5 PROF WEERAMANTHRI: And thank you for that submission and your time today. I understand that People with Disabilities WA is the peak disability consumer organisation in the state. Could you tell us about your history, your mission and values and the other groups or organisations you regularly interact with in the health and disability sectors?

10 MS JENKINSON: Absolutely. So we are a peak disability consumer representative organisation. We've been around since 1981, started as a group of people with disabilities that got together, wanting to ensure that that voice was heard. We represent across disabilities, so that includes physical, intellectual, neurological, psychosocial, sensory disability, and we have both a membership base as well as providing individual advocacy and systemic advocacy to people with disability. And so within our individual
15 advocacy, for example, we have about 20 per cent of the client group are people with mental health issues, or psychosocial disability. About another 20 per cent of people with intellectual disability, and then neurological physical disability, as well, very high.

20 But then our membership has actually got quite a good mix of people with physical, sensory – people who are blind, deaf – neurological. So we really cross, sort of, everything, and we work from a basis of people – people come to us because they identify as having a disability. So it's not necessarily about
25 needing to fit into a definition of disability from any sort of funding system, which is more in line with the *Disability Discrimination Act* definition of disability. Our mission is advocating for the rights and empowering people with disability in WA, and we very much come from a human rights perspective on that. So it's very nice for me because essentially, if I'm not sure
30 about what our stance is, or something, I go back to the *UN Convention on the Rights of People with Disabilities* and look up the relevant article. So that's, you know, very handy, but it gives us a clear basis of where we're coming from.

35 And we very much think that people with disabilities need to be actually included to hear their direct experiences, particularly in the health system. We often have had a lot of experiences of people who believe they're experts on our lives speaking for us, and not actually understanding what the real impact is at a personal level for us. So we're run by and for people with disabilities,
40 with our governance is 100 per cent people with disabilities of a diverse range. We've assisted over 700 people with information and advocacy last year on a range of topics, going from NDIS access and appeals, which is the current hot topic – a lot of work being done on that – but also, we've also had an increasing trend of people coming to us around disability support pension issues. So
45 people who are on Newstart with disabilities trying to access the disability support pension.

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5 We also do a lot of issues around housing issues, where people are not getting the right maintenance, the right type of housing or tenancy management support. A lot of issues around guardianship, where people are... guardianship orders are trying to be placed on someone, and so we assist the person who potentially, actually, just needs better support, not necessarily a guardian. Discrimination in employment and a lot of stuff about accessing services. In our individual advocacy, we'd liaise a lot with Health Consumers' Council, and we've also worked with them at a systemic level around health rights for people with disabilities. Community legal centres, welfare rights, tenant's advocates, service providers in health, disability community services. And we also have a consortium of how to provide individual advocacy with Sussex Street Community Law Service and Advocacy WA to ensure there's some regional coverage for people with disabilities to access advocacy services. So that's... 10 yes. I hope that's enough of an overview to give you a good idea of... yes.

20 PROF WEERAMANTHRI: Do you have any specific ongoing connection with the health service providers?

MS JENKINSON: Not specifically. Because of our advocacy role, probably Health Consumers' Council is the one we have the closest link to. And we're in a situation where, you know, I could... we don't recommend any particular health services. We do have a connection with the Wheatbelt Health Network, where they provide some office space for us to go up once a month to Northam to ensure that there's advocacy services available on the Wheatbelt. And that's been a really good relationship there, and we're trying to get similar things happening in other regional areas. But generally, you know, when it comes to disability services or allied health professionals and health services, we've sort of supported people to make complaints about so many of them, but that's not a bad thing, because we always try and frame that in terms of, you know, that's an ability for those services to continuously improve. 25 30

35 PROF WEERAMANTHRI: So we'll just stay there for a second. We have heard from a variety of medical practitioners in these hearings. We are also going to hear next week, specifically, from the Chief Nursing and Midwifery Officer, the Chief Allied Health Professions Officer. Are there any specific questions in terms of your interaction with those professional groups that you'd like us to ask? I mean, in terms of your experience. 40

MS JENKINSON: There's nothing in particular that I can think of related to this particular topic.

45 PROF WEERAMANTHRI: Yes.

MS JENKINSON: I think the biggest issue that we see that comes up from people is that, apart from the people that might have a specialist

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5 in their area, so in particular, we'd be looking at, say, disabilities that have a thermoregulatory impact. So the specialists in those areas understand that, but that's not necessarily understood more broadly than that. So that's often the issue, is that the person with a disability actually has a better understanding of how their body is reacting than their GP does, or other allied health professionals that aren't in that specialist area that they might have their specific disability or condition in.

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PROF WEERAMANTHRI: Okay, good. So in these hearings, we've discussed the impact of climate change on vulnerable groups in Western Australia, with various expert witnesses, and also heard different definitions of vulnerability. I'm happy for you to go to that question, to give us your - - -

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MS JENKINSON: Yes.

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PROF WEERAMANTHRI: - - - understanding of that. But also, can I ask you a slightly broader question? As a consumer organisation, are you comfortable with the overall concept of vulnerability, or are there other terms that you favour?

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MS JENKINSON: So it's a really difficult one in terms of finding the right language to use. From our experience, we see vulnerability as really more about context than... you know, so it's more about the environment around someone or the context someone is in. So we use a similar model, I guess, when we're looking at abuse and neglect, for example, where the vulnerability that someone has to abuse and neglect will depend on the context that they're in and how much support is around them. And we would see the same in this sort of a scenario, that how vulnerable somebody may be is actually not so much related... it's partially related to their disability, but as much related to the level of support they have and where they're situated. So it's that combination of other factors that are the context around a person that can make them more vulnerable or not. So we don't have a problem with the concept per se, but think that it's more about context than necessarily about the person.

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PROF WEERAMANTHRI: Okay, thank you. So we're gathering stories of how climate change is impacting people living in this state. And you mentioned in your submission extreme heat events and extreme weather events, and also mentioned the criticality of energy supply for people living with disability. Can you give us some simple examples of how the weather links to energy supply and affects people with specific categories of disability?

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MS JENKINSON: Absolutely. So I have actually done a little bit of researching. So I did grab from Energy Networks Australia, they have a fact sheet on heatwaves and electricity supply, which I can provide here.

[11:27:38]

5 This is just a fact sheet, January 2019, from their website, that does look at some of the issues around... the biggest issue for us is that the increase in heat – you know, increase in the number of days that we've got as hot days, and how that impacts electricity supply is essentially – it's different in different areas, but I've also got just a copy here, a news article just from yesterday, where, you know, one of the Victorian energy suppliers is basically saying, “Watch out, there will be blackouts because of heat this summer”.

10 And it often... I mean, it's not so much a health problem as an energy supply problem, where just the number of people using air-conditioning and, you know, that increase in electricity use and how the grid network actually works with that. I have another article which was from January this year, where 15 3,500 Perth households, 39 degrees days, and there were blackouts of 2,000 homes in the hills, 3,500 in Perth. So that was just in January. So we know that it is happening, and we know that those outages have an impact for people.

20 The other information that I also had was about bushfires leading to outages, and there is some information – I think it was even on the Western Power website – around how quickly they could actually get to restoring power when there's bushfire risk and power outages happen. So how that then relates to People with Disability, for us, is extended outages which go beyond battery 25 backup. So there was an example – it was a couple of years ago now – of two young gentlemen with muscular dystrophy that relied on ventilation support, and they couldn't hear the alarm that their battery backup had run out on their ventilator at night. The support worker didn't hear that.

30 But the other thing for us is actually about the cost of that. The impact on people with thermoregulatory issues. So that tends to be anyone with autonomic nervous system issues. So that could be acquired brain injury, multiple sclerosis, spinal cord injury, cerebral palsy, other neurological conditions like Parkinson's. There's actually quite a large group. And even 35 people with amputees. Depending on the level of the amputees, they can have issues with their thermoregulation as well. So there are subsidies available for people who need to use air-conditioning. The Department of Finance has a Thermoregulatory Dysfunction Energy Subsidy scheme. To access that, you have to be a person who's a pensioner or on a healthcare card. And the amount 40 that that gives is \$720 a year.

45 So I live in a house with solar panels. We built our own home. It's very energy efficient in terms of its insulation. But because of my thermoregulatory needs, we have ducted air conditioning. We tried to be as energy efficient as possible. \$720 would possibly cover a quarter of our energy bill for a year. So we know that people... so there's the double factors, I guess, of... there's the risk of power outage and what happens when power outages happen, if people are living in homes where there's not good insulation, good air-conditioning, or

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any sort of backup for that air-conditioning. The higher risk of longer days in summer – the bushfire season is now extended – what that means for being
5 able to restore power if it does go out. So all of those sorts of things are compounding, then, for people who are needing air-conditioning as something that's actually vital for their health, the impact of that.

10 So I do have the fact sheet here, as well, on that one, if you want to have a look at that. I mean, I guess for us, it's sometimes difficult to see the direct connection between... like, we know the direct connection between heat and people's health, but then it's direct connection between the changes that are happening, that's increasing the number of hot days and the number and length
15 of the hot periods and the heatwaves, aren't always directly... you know, there's not always an easy connection to see there. Personally, I don't have any problem with the science that's out there behind that. I know that not everybody does, but that's, for us, not an issue. For us, the issue is more about the actual impact that that has on people with disabilities.

20 So we do see people doing things like going and spending the whole day at the shopping centre because they need to be able to be somewhere cooler and they can't afford to run their conditioning all day. But then that has the impact of, you know, actually going from your house to the bus stop or the train station because people are likely not to drive and are likely to be more reliant on
25 public transport in a 40-degree day.

PROF WEERAMANTHRI: I might just - - -

30 MS JENKINSON: Sorry, there's a lot of stuff there.

PROF WEERAMANTHRI: No, no. We might just get onto that in a second.

35 MS JENKINSON: Yes.

PROF WEERAMANTHRI: But just to go back to the, kind of, simple examples of why people with disability are particularly vulnerable. Just so I've got it clear, there's some people with disability who, for example, rely on respirators, which are powered respirators. And so if the power fails and then
40 the battery runs out – or do some people have backup generators, or - - -

MS JENKINSON: Some people do, depending on the level of support that they have. So some people... you know, there's different levels of ventilation. So there's full ventilator dependency, and then there's people
45 with the BiPap. I don't know all the details of that. So I think there are some specific subsidies and things available for people who have life support type equipment at home. But then there's also people who it's more about the be BiPap machines and things like that.

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5 So they're unable to get... you know, so they won't necessarily have generator backup or battery backup, and the battery backup will only be for a certain number of hours.

10 So I think our concern is that we haven't seen it as much here in WA, but it has happened in other states, where power has been out for, like, three or four days before it's come back on. Most people, if they need that sort of ventilator assistance, are actually registered with Wester Power, so they're known. It's people who are then reliant on that air-conditioning on those hot days that are not necessarily known.

15 PROF WEERAMANTHRI: So thank you. So that's, kind of, a critical life and death type issue which, you know, is managed in some way at the moment.

MS JENKINSON: At the... yes.

20 PROF WEERAMANTHRI: But, you know, there's always, as you said, those, you know, two young men who died a couple of years ago. That was a tragic incident. But the other set of circumstances you described was this thermoregulatory issue. So if we could just be clear, that's about inability to control your - - -

25 MS JENKINSON: Body temperature.

30 PROF WEERAMANTHRI: - - - your own body temperature, and the fact that the external temperature might increase and your body temperature might go up without the means to correct that because of your disability. Is that correct?

35 MS JENKINSON: That's correct, yes. So I have a spinal cord injury of a C6-7 level – I'm assuming you guys are doctors so you'll know what that means – cervical C6-7 injury. So I don't sweat below the level of my break. There's no other... the autonomic nervous system is affected, so there's no other mechanisms which will actually assist in my body cooling down or warming up automatically. So yes, if the temperature gets hotter, I get hotter. If the temperature gets colder, I get colder. And so I have to very much monitor my environment and surroundings to ensure that my temperature is able to stay stable, because that could lead to, yes, quite severe consequences.

45 PROF WEERAMANTHRI: So thank you for describing that. Going back to where you were, you did talk about air-conditioning and people seeking out air-conditioning.

MS JENKINSON: Yes.
[11:37:53]

5 PROF WEERAMANTHRI: And we were particularly struck with your suggestion that air-conditioned public buildings, libraries, community centres and the like, be open in locations with high temperatures. Others have labelled these kinds of centres cooling centres, potentially. Is this happening now? What would it take to make it happen?

10 MS JENKINSON: Yes, so I don't believe it's happening now. I think what happens now is we tend to see people who will specifically go, "Well, it's going to be really stinking hot today, so I'm going to go and basically spend the day at the shopping centre". Our biggest issue is because people... you know, if people are living in public housing or living on a disability support pension or Newstart, that there's often a cost associated. You know, I'll take my family to the cinema, but that's a cost associated with that. 15 If you need to take a taxi because it's not going to be connected... you know, because it's too hot to get to the public transport, there's a cost associated with that. So what we have seen is that people tend to do those things themselves. There isn't necessarily anything that's done to get that to happen.

20 I think to get it to happen, we'd need to have the local governments on board, because I think that's... you know, it's the local places which are already set up, the libraries, community centres, those sorts of places, which could potentially be somewhere that people could go. Those facilities would need to make sure that they had accessible toilets or, you know, other bits and pieces in place. And also potentially people being able to access taxi vouchers or things 25 like that, if they needed to, because of just that ability to be able to get out and about.

30 The direct link for us is really that it's people in public housing that are more at risk than... generally, if people are in their own home, they are more likely to be able to afford to have the air-conditioning. But we know that 60 per cent of public housing tenants are people who are on the disability support pension or the aged pension, and public housing houses, a lot of stock is very, very old, so it's not necessarily well insulated. Any air-conditioning is retrofitted. People 35 that do have air-conditioning, they've had to get grants to get the air-conditioning in, usually. It's not just done by Department of Housing. And they're unlikely to have solar panels or anything like that to help contribute to the cost of the energy use. So I guess, for us, that's the group of people that are most at risk.

40 PROF WEERAMANTHRI: And we've heard that same story about the factors in public and rental housing as well, from other witnesses. And you're saying, as well, that people with disability are more likely - - -

45 MS JENKINSON: To be in those - - -

PROF WEERAMANTHRI: - - - to be in those situations.
[11:41:28]

MS JENKINSON: - - - situations. Absolutely, yes, Department of Housing. So yes, so when I say 60 per cent of people of the public housing is people with disabilities and seniors, that's specifically people who are on a disability support pension or on an aged care pension. There may also be a number of people who are low income earners with disability who are in public housing because they needed to have accessibly-built housing, and that was the only way they could get an accessibly-built house on a low income as well. So it could be more than that.

10 PROF WEERAMANTHRI: Some experts have suggested that we recommend a public information campaign to highlight the links between climate change and health, and also about supporting concrete actions for people to take. Have you any ideas how such a campaign could be tailored to meet the needs of people living with disability?

MS JENKINSON: So for us, it's really important that information is done in multiple formats, and so accessibility is taken into account. And a key part of that would be around that... almost that concrete understanding. So, you know, one of the things we found... and I did give some feedback to some of the information that was put as part of the Inquiry, that it was quite complex. Like, it wasn't... you know, I'm an educated person who knows, actually, quite a bit about this space, but for most people with disabilities, like, I wouldn't be comfortable sharing that out because it was difficult to understand and see that impact the connections. So I think any campaign would need to be able to make those connections in a very clear way. And then the next step being, yes, the actual concrete action that someone might be able to take.

30 So, you know, for example, I guess, that direct connection of, you know, there's hot days, there's heatwaves, this is what that means. You know, without trees helping with air pollution, the air quality isn't getting any better, this is what that means. Yes, our big thing would be... and to ensure that that is done well, we would always promote doing something that's a co-design approach, that involves people with disabilities actually testing those materials, helping to design what they look like. And, I think, you know, one of the other questions you had provided previously, we've had quite a bit of experience trying to work on co-design models. So we actually have a co-design model that's actually available on our website that we suggest is used. I think, really, the key part for us is that multiple formats, accessible formats, but it's that plain English and easy English is the key thing. And it has multiple benefits for people with English as a second language, as well as people with lower educational, socio-educational, backgrounds, as well as people with intellectual disabilities.

45 PROF WEERAMANTHRI: That's very helpful in terms of us understand the communication challenge and approaches.
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5 Could you shift slightly towards the advocacy side? So you're an advocacy organisation, you've obviously got heaps of experience working in that. And this whole climate change field is a, kind of, mix of actions you can take and advocacy for things you'd like others to do, or whatever. And it's a partnership between civil society, government, the public, et cetera. And are there any tips about effective advocacy in such a complex environment that you'd like to give us?

10 MS JENKINSON: Look, what we find works the best is actually that there's almost multiple forms of messaging. So one of the things that I thought was really interesting about talking about an information campaign is... I guess I wonder about who is it targeting, in that some of the adaptation strategies and what can you, as an individual, do, in some ways, that is limited to a degree, because it's actually the decision makers that have got a lot of the power about what's going to actually happen. So part of that, I guess, what we would like... we would really like to... you know, it's been really... sorry, it's been really good to see, for example, the Water Corporation has really, sort of, actually said, "This is an issue. We've got the evidence, here's what's happening. This has to drive the policy that we're doing in our next steps" – some of their campaigning that's happening at the moment. I think that campaign is quite well done, because it's not just saying that this is up to an individual to make change, and I think that's a key part of it.

25 So when we're trying to get change at a decision making level, what we find is there's an element of people who can... not being afraid to have the people who say the hard things talking to the decision makers. So having those people around the table is actually really important. Sorry, I'm trying to think about... you know, we find that we work really well when there are people who are able to... who are not afraid to talk to media and other people and raise up issues in a very confident... that can be an almost confrontational way, but that there's always other people who are in the background to actually have a deeper understanding, who can work at the policy level, to actually understand what it is that needs to happen to move things forward.

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35 Because having the general community understand what's happening, although that's important, unless there's that actual next shift of the policy reflecting that change, which means you've got to have those people at the table as well, that are going to ask the hard questions. And sometimes, it takes a little bit of time to get... it's almost a co-design approach in that sense as well, because it will take time to get everybody in the room feeling comfortable that it's okay to be having uncomfortable conversations. I don't know if that helps, but - - -

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45 PROF WEERAMANTHRI: It helps, thank you. You did mention the adaptation word.

MS JENKINSON: Yes.
[11:49:09]

5 PROF WEERAMANTHRI: And one of the Inquiry terms of reference is to recommend a way to develop a climate change adaptation plan for the health sector in WA. And I think you may have already answered this question, but how can the health sector co-design such a plan with people living with disabilities?

10 MS JENKINSON: Yes. So I do think that it's... what we think is really good is when co-design happens when it's got multiple players around the table. So we've just been doing some co-design with the Department of Communities, and there are times when we have to go, "No, you can't just go off and write it, that's not co-design. You actually have to come back and work with people through it to actually know what's going to be in there that's owned by both groups of people". So for us, it was really
15 important that in – because that plan is specifically about the inclusion of people with disability in the state – that was important that that had... the majority of people around the table were people with disability, with the Department of Communities.

20 Because, I think, a climate change adaptation plan for the health sector includes such a... you know, the health sector is such a diverse sector, that people with disabilities would either need to be one of the stakeholders around a broader table, or that you might have some different groups that are feeding in, depending on particular cohort's needs into a broader group, that also then
25 included some representation of all of those different groups. Because the best thing about co-design, what makes it really work well, is that you're actually hearing perspectives that you don't know yourself, from other people. And that would include people with disabilities that have no idea how the health systems work.

30 PROF WEERAMANTHRI: And your submission also refers to data and the importance of collecting some - - -

35 MS JENKINSON: Yes.

PROF WEERAMANTHRI: - - - some data around, you know, heat events, health and disability. Can you answer a general question first, which is how good is the general health data on people with disability and, you know, is it too much to ask to then collect good, specific data in this area?

40 MS JENKINSON: So yes, the general health... there is an issue in that what we find is that... and it's partly around we understand that the definition of disability is hard to pin down, which is why, as an organisation, we work from a, if you identify as a person with a disability, then we have just
45 some broad categories. But what we find in health is essentially, because it tends to be more about your diagnosis than how you identify... so the Health Department collects some great data about carers, but not actually about
[11:52:11]

5 disability. And I don't know why that is. If there's an expectation that if you've got a spinal cord injury, you're going to go to Fiona Stanley Spinal Cord Injury Unit, so we don't need to collect it anywhere else. But, actually, that's not how it actually works. So at the moment, yes, there isn't a lot of good data that is collected by health around actually, does a person that's coming into King Edward have a disability and what their needs might be. However, they might collect the data that someone has a carer with them, so we find that a bit of a disconnect.

10 And I think that that's where, you know, if people are coming into... we don't know what the data might be of the number of people that come into emergency who have a disability that's related to heat stress, or even if it is a mental health issue, but it's related to, actually, some of the changing environment or, you know, when there's three days of 40 degrees or things like that. That sort of data isn't really collected at the moment, and I think that would help a lot. I think Curtin University has done some studies around deaths and heat.

20 PROF WEERAMANTHRI: Are you aware of any data linkage studies that look at people who are identified in disability data sets who don't turn up in - - -

25 MS JENKINSON: Not particularly, no.

30 PROF WEERAMANTHRI: - - - in the health services, or... no. Look, I just want to, kind of, circle back around to your starting point, which is, when you're in doubt, you go to the *UN Convention on the Rights of People with Disabilities*. I think that's really important, because, you know, that gives a, kind of, human rights framework for this whole discussion. So do you want to talk us through people who may not be familiar with that convention and what it says, without going through, you know - - -

35 MS JENKINSON: Yes.

PROF WEERAMANTHRI: - - - every single bit of it. You know, what it means for you and how you use it.

40 MS JENKINSON: Absolutely. So essentially, the aim of the document is to express what's in the basic human rights convention, but how does that relate to people with disability. So it very much uses some of the very similar basic principles. And what's really great about the *UN Convention on the Rights of People with Disability* is that there was a massive worldwide consultation process that included disabled persons' organisations from all around the world. And, in fact, I was lucky enough to be in a project where I was gathering information from people with disability in Australia to feed into what was going to be in the UN Convention.

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And essentially, it covers off on all key areas of life. So it looks at people being equal before the law, which, you know, directly relates to some of those issues around guardianship and supporting people to make decisions around being able to live independently in the community, and have the support to live independently in the community with whoever they wish to live with, which directly goes to some of the discussions happening at the moment with the Disability Royal Commission and group homes and institutions. Talks about having the same rights in employment, in education, which goes to inclusive education; the same rights in terms of access to political processes; and also community services, sport and recreation, the arts.

So it essentially goes to all those areas and is very much from an inclusion agenda of, "how do people with disabilities be included?", and that state parties, being the Australian Government, in this case, as a signatory, need to be able to work towards implementing the supports needed to allow those things to happen. And it actually has a... in the implementation part, there is actually a section on needing to improve data, as well.

20 PROF WEERAMANTHRI: Having promised that was the last question, I'm going to give you one more.

MS JENKINSON: That's okay.

25 PROF WEERAMANTHRI: And you do cover it a bit in your written submission, but it's specifically around natural disasters - - -

MS JENKINSON: Yes.

30 PROF WEERAMANTHRI: - - - and some of the specific needs or requirements of people with disability that need to be considered during emergency management. And you did give an example about just being able to get out of a danger situation, for example. Do you want to just, kind of, outline that a bit for us?

35 MS JENKINSON: Yes, sure. So probably the best example I've got, which might help, is the fires that were up in the hills a couple of years ago. So there was a gentleman with a disability who is blind and uses a wheelchair, and him and his wife, they didn't necessarily know what the different levels of alert warnings were for. She took him to a shopping centre locally, just in case. She went back to the home and just got out alive because the fire had already got there and burnt down. And it was only because they sort of went, "Well, we'll just go to the shops just the case", that he didn't get caught in that situation, because the time taken just to get in and out the car is two to three times... I'm terrible, I never factor in the time it takes me to get in and out of my car, and I'm always 10 minutes late to everything.

[11:58:14]

5 But that time factor is just... yes, that's the time that is absolutely crucial in something like a bushfire emergency. But that particular person, essentially, because they didn't take any of their equipment with them such as their shower chair, you know, suppositories, gloves, catheters, all those sorts of things, had nothing, had had to go and borrow and try and find equipment from friends, family... you know, I had a spare shower commode chair that I was able to borrow and lend him – because those sorts of things aren't necessarily... you know, the emergency shelter type situations are set up to be exactly that, they're emergency shelters.

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15 So that's, for me, become just something to think about of... and I guess it does relate to the idea of cooling centres, or where locations might be that you would use as... whether it's a shelter in terms of a heat wave, or from a bushfire emergency... how well set up are they? Do they have, actually, a changing place, do they, you know... is there somewhere that you know you could get some spare equipment from if you needed it? Those sorts of things. But also, yes, just the time it takes. We also are very aware that for people who are deaf and hearing impaired, although there are some alert systems that are being tried, they're still not perfect yet. Yes, so there is a real concern that people with disabilities are more likely going to be the people that might get left behind.

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25 PROF WEERAMANTHRI: Ms Jenkinson, thank you very much for your attendance at today's hearing. A transcript of this hearing will be sent to you so that you can correct minor factual errors before it is placed on the public record. If you could please return the transcript within 10 working days of the date of the covering letter or email, otherwise it will be deemed to be correct. While you cannot amend your evidence, if you would like to explain particular points in more detail or present further information, you can provide this as an addition to your submission to the Inquiry when you return the transcript. Once again, thank you very much for your evidence.

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35 MS JENKINSON: Thank you. Would you like me to be able to provide these documents?¹

PROF WEERAMANTHRI: Yes, please.

40 MS JENKINSON: Yep.

PROF WEERAMANTHRI: Thank you.

HEARING CONCLUDED

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¹ Note: Documents are provided at the end of this transcript.
