# Transcript – Reflections on Seventh report, A duty to care from the disability community

[Pauline ] So our first question: what were your key takeouts from this report?

[Rachel] The need to do more in the disability space, that was really the big thing. It reminded me of a conversation that I had with one of the people from the suicide prevention team here. One time, she came to talk to me, there had been a suicide within the disability community, and she was just sharing what her [—] were to work with that community.

But our conversation moved on and reflected the fact that I made the assumption that many suicides will have a disability connection somewhere in the picture, either the person themselves or someone close to them, or somewhere in the mix.

And so from that time she started recording, her personally, whether or not a person, a case that she was working with, whether or not there was a disability connection. And she came back to me afterwards and said she was overwhelmed at how much there was, how many cases did have a disability connection. So that was with suicide, so you can only imagine what it's like in the violence area. And the other thing about the suicide space is that we don't collect data. So that’s a huge gap.

We don't consider the wider environment for the person, but we rely on anecdotal knowledge in the community to know that it’s happening. And the other thing that came to me with this conversation and other conversations I’ve had with people in the past in the community is the lack of information that's actually distributed across our community about our own self-awareness of what violence is and what violence looks like and what's acceptable and what’s not acceptable.

And often people only know what they've always known. And if you don't have the access to the information or literature, I mean, everything’s put out in the English. How much is put out in sign language? How much is put out in easy read or another alternative format? How much of that information comes to the community and the way that connects with us?

Because at the moment we read, when you read or hear about violence, it's, it doesn't show the connection, the disability connection in the picture. Media will often leave that part out of the story, or it's handled differently by the system too, even when the perpetuator is a disabled person. Therefore, the right interventions don’t come in.

And the third thing that I took from reading it — sorry, a big answer to your question — but the third point was that the system as we have now is not connected enough. And so 80 per cent of all disabled people are not part of a disability support service. And yet, there is a wide perception across public that disabled people still live within an institutionalised framework. That really came home to me during the COVID times when people made the assumption that disabled people would be taken care of by their support service provider, and yes, for 20 per cent, but for the remaining 80 per cent, no. And I think, and it comes through in the report is that there’s a disconnect everywhere, so there’s health, and there’s disability services, and so on.

And from my experience when I’m working within a disability NGO, people would often come and say they're really worried about a particular person, but the system or the constraints or our long contracts at organisation made it difficult for us to take action in the way that we really wanted to. And no one was really in a position of actually taking responsibility. And so there were a lots of hard conversations.

There’s no, if we don't do something then who will? And, but we're not allowed to do it. So what are we supposed to do? And I think when you talk about care — what was it, care for... Often a community will look out for its own, but we don't see a lot of disability leadership in New Zealand full stop, therefore we don't have an environment where there are enough disabled people actually being part of creating the solution and creating the outcomes that need to happen in order to get the changes that we want to see.

So I think, we’re just too invisible. Our voice is too small, the system works against us. And — but with Health New Zealand and with the new Ministry for Disabled People, now change is possible, and can we make those changes work to reduce the incidents? But it's going to be to be hard to measure that, because we don't have enough data about what happens now.

[Huhana] What strikes me is that we've got appalling legal practises around disabled, that there's very little in the law that protect us at a level that's needed, that we're expected to function at the able bodied level of being able to, you know, be able to change our situations.

But there's no resourcing, there's no safety net, there's no process for doing that. And that's a big issue. I mean, you can put anything in place for non-disabled and it will work a lot easier. But when you ignore accessibility, ignore language barriers, ignore some of the things such as needing your service dog with you or all of that sort of stuff, then it becomes a problem. And also ignore the power plays between a disabled person and a provider, disabled people and whānau as well. It's something I had a big issue with, you know, with when I was on the expert advisory group Tariana set up for domestic violence and also when Tariana also did that residential care report, I had already reported several residential carers for abuse of their clients.

I reported a rest home for elder abuse, and they closed the rest home down, but no one's done anything around disabled when there's abuse. Respite care is one of the big ones. I had two cases. One was an intellectually disabled young girl who the doctor concerned had been sexually interfered with while in respite, but the police wouldn't take a case, because she was non-verbal and lacking capacity. So the family were very upset, and of course we couldn't do anything, because the state doesn't have a process in place to protect our most vulnerable. Safeguarding Adults is for me, the organisation that can change all of that culture, but it needs to be funded and resourced properly.

But mainstream services, they are incompetent in the area of disability. They are not capable of addressing our needs. We have — Worst, it's still — abuse for disabled, it's not always physical. A lot of it is coercion and duress. One case I remember, a few years ago, and it was a woman with MS, just diagnosed, and her second husband. And she did a video saying she wanted to end her life and wanted euthanasia, but it's not available. And so they talked about it. And I watched the husband, and I saw he was very eager to support her, you know, which is unusual. I mean, if I said that to my wife, she'd have me — she’d clip me around the ears and tell me not to be so damn stupid. But he was very keen to support her, and I wondered if it was duress, because she did kill herself. And that was not jail, because he didn't — I don't know if he ever really did, but they didn't think he interfered with her process.

But it's — There's a lot — And this is why I have a concern about the EoLC [End of Life Choice Act], because there's actually a number of people with neurological conditions who have applied for euthanasia. And I'm concerned at the messaging. I'm concerned at the lack of — I'm concerned because they have a disabled man on SCENZ [Support and Consultation for End of Life in NZ] who is very pro euthanasia and quite keen to have himself topped off when he chooses.

And there's a danger in our community, because society does not understand the dangers that we have. And so in a situation of violence, abuse, there's actually, there's a real danger to disabled.

I've had to sneak in with one client who was always on her bed. She was bed-bound. And it was because there were rumours that her husband was abusive. So they pretended I had her condition so I could go and see her and talk to her and see if she was safe. That type of thing.

There's no refuge for us. They're all inaccessible, or if they are, they won't allow children, male children. If you've got a disabled male over a certain age, they need to be with the mother. They won't allow service animals. They don't allow your carers in there. So there's nothing for us to keep us safe.

There's no hate crime laws. There's no protection in our current laws. They don't recognise employment-based abusers such as providers, and that's where the danger lies for us. We are not seen under the domestic violence act as being a domestic case, and I had those arguments with Professor Denise Wilson when I worked under her team years ago. And I said, well, then you have to do a definition that is inclusive of those who sit within this other area. Because I said it's not always our family. It’s our carers. They become our family in many ways, because — and I said to her, it's different to an employee-employer situation to a sense, because it's an intimate relationship.

Whereas non disabled, it's not intimate with carers, you know, with employers. But with disabled, there's a difference. Our carers are intimate. It's different.

[Pauline] What challenges do you think are presented with some of the report? Obviously, that's one of them, being ensuring that we've got sufficient disabled people around the table to be part of the solution, but what other challenges do you think are evident?

[Rachel] I think another challenge is the need for people in services to recognise what to look for when there’s a disabled person involved or there is a disability in the picture in some way.

You know, the additional truth that people experience, that comes through in the report, but I don't think — what doesn't come through is the need for the organisation, from the people working with the whānau and so on, to actually recognise enough about what the disability experience is or what violence looks like for our community.

So I think, for most people, or most disabled people, I think when you see or experience it, the experience is that we don't get heard, or if we are heard, we are not understood. And I think that it’s a workforce issue. It’s something that just needs to be highlighted. I can give one example of that.

In the maternity space, for example, was that we did some work around the experiences of mothers, of mothers having babies, so mothers with disabilities, or when the baby has an impairment and the language and the system and the way that people talk about or work with people with disabilities is quite deficit-focussed and quite — not so empowering. Therefore, unless we take some concrete steps to reflect on the unconscious bias, to reflect on the realities of people that experience it, we're not going to see it, and we're not going to act on it. So, my worry is that, have we built in enough mechanisms to be able to start to recognise some of those additional experiences that disabled people have?

[Pauline] Yeah, I think that's a massive challenge, actually, to be honest with you. It requires people to consciously reflect on how they're interacting with someone, and to be fully aware of the context within that, within which that person's living. So that — yeah, it — that's a massive challenge. It's a very big challenge.

[Huhana] To recognise the unique issue around disabled if they are facing violence, and to have them implementing a support process, a package, whatever, wherever they are, because you won’t — because accessible housing is impossible at the moment. It's really hard to get and there's nothing. And so unless we have the state providing accessible housing urgently, which won’t happen, they've got to find another way of urgently addressing a safety issue. This is for physical disability.

For people who have hearing, of course, being deaf, that's another form of violence against them as well as removing language from them so they can't protect themselves. We need mechanisms in place identifying and, I think, safeguarding adults again.

I have been involved in the development of that, but for me that's actually the tool that we need, because they can advocate for what's needed for each different scenario, and they can step in. And that’s where Safeguarding Adults can. They're the specialist team.

The biggest problem is getting the resources and the systems to be available so that if there is a disability component to a client that that is able to be met without a battle with providers.

[Pauline] So you're actually, you're talking about an advocacy system that's available and accessible.

[Huhana] Yeah. And it's already being developed. It's well developed. The only thing they lack is resourcing. But they don't lack the passion, and they work with non-verbal, they work with verbal. So it's a specialist agency, advocacy service that can work with disabled people at risk.

[Pauline] Yeah.

[Huhana] It is specific to the issue of violence and abuse. And that, I believe is really the answer, because we can't guarantee the state can protect us. We can't guarantee Women's Refuge or anti-violence groups can protect us, because many of them inadvertently abuse the clients that are disabled without realising it. And that's where the danger lies.

[Pauline] So does the report speak to you in terms of a future focus at all. What do you think? Does it make you think about, you know — trigger some things that you think should happen into the future?

[Rachel] I think in the very near future we need to do a report like this specifically on the disability community. I think we need to highlight it, illustrate it, and force the funding changes.

But I think too that we need to get disabled people and their key allies together to be part of creating the solution and creating the resources and tools so that those who are working more closely with the people have a good few more things from the toolbox to pull up.

Yeah, and I think that with the changes that are happening to the way disabled people are funded, we've really got to keep an eye on this space, closely, even more. We need to build in safeguards. I think COVID has shown us that while it’s all very well for things to be independent and you'll get your funding, and so on, if the system falls down like it did with people getting COVID, where's the backup? Where’s the —? Yeah, I think that’s a big thing.

[Huhana] We did a bunch of research internationally — and Debbie Hager did this as part of her PhD — and so Safeguarding Adults came out of all that research. I mean, I've been involved for 14 years and we're only just rolling it out now. And that's because we've finally come to a point where we have the people in place, Sue, oh, gosh, can’t think of her last name at the moment, but Sue and Erica Butters.

[Pauline] Yeah.

[Huhana] Yeah. So Erica and Sue have doing a lot of the work around getting the information out there, but also anyone that's contacted that they try and step it up, and they've got advocates throughout the country.

But there was a bit of — I had another client, and I wasn't impressed with that advocate, but I was really impressed with how they're dealing with this young man. Yeah.

So it's just upskilling people and getting the right people onto the job, really.

[Pauline] Yeah. And does that also require an understanding from agencies as to where Safeguarding can fit?

[Huhana] Yes. They need to have a partnership relationship. But also, it takes the stress off the others, because if they know that there's an organisation that can — and they don't just deal with disabled. They'll deal with anyone who's vulnerable and at risk.

So, I lived in South Auckland on Massy Road sometimes we see a lot of elders begging, and I've seen one. We were just driving by, and we parked on the side just to watch, and it was this elder woman. And she had a whole lot of bags of kai that was given to her, but one of the whānau came out of their car. They turned up to pick her up, came out of the car. We watched and heard the abuse she gave her and told her she's not coming home till she gets money. Then they took all the kai and they left.

That's prolific here. That would be a Safeguarding Adult call. They specialise. So, whereas a lot of women — you know, we think the stereotype being a woman or a woman with children, but the stereotype is far broader than that.

[Pauline] Yeah.

[Huhana] And in the case of disabled, it's not just women. You've got trans, you've got men, are just as vulnerable in many ways. You've got children, you've got seniors, you’ve got elders. So you know, it covers the whole shebang, but it's specialised in the area that it's able to adapt to the need of the client, which is if the client's deaf, we have interpreters. If the client's blind, we had someone. If they're intellectually disabled, we have advocates that can work with them.

So that's what's missing in the current services, is all of that.

[Pauline] A larger question. What change do you think is required from government in order to support what we've just been talking about?

[Rachel] I think the government needs to acknowledge that disabled people have rights and that the system has a responsibility to ensure that disabled people are safe. And, you know, I think that we are in a time of transition now and — which is good, and I think, I think one of the things government needs to do is when they're talking about this topic, include references to our community.

Because often, we talk about Māori and Pacific communities, but we don't mention the disability community. But we know that a large number of disabled people are Māori and Pacific — so the intersectionality needs to be talked about and we're not visible. So, I think the government has a responsibility to raise the visibility of that.

And also, we need to build in some accountability measures. We need to build in a data gathering exercise. We need to really prioritise our focus in this area. And like we said earlier, collecting the data of, you know, is there disability in the mix somewhere, either the victim or the offender or anybody else in that environment that’s causing stress.

So, I think disability's so important, but using the right disability rights-based framework. Alongside the Treaty framework is really important.

[Pauline] And it requires having a comprehensive understanding of disability as well, doesn't it?

[Rachel] Yeah, yeah. We’re here. So, we're part of humanity, and we’re part of the rich diversity of our environment and — but we get shunted aside or devalued. So, I think it's really important that this work demonstrates the value of our community, that we are the contributing people that we can be.

[Huhana] I did a symposium with Heather Henare when she was the CEO of Women's Refuge and highlighted that there are three refuges in the whole country that have access, and even then, it wasn't right. And a lot of them just wouldn't work with disabled.

It's like they've got this stereotype in their heads, and they utilise that stereotype. And this is where the problem is. If you genderise violence only, I mean, and even if you — if sexuality is not understood — so, for instance, my wife, not my wife, my partner in 1996, beat the crap out of me, knocked me unconscious, beat me up. And it was a woman. I couldn't get anybody to take it seriously, to take charges or anything, the police, the judge, nobody would, because they didn't believe that women were violent towards women.

So, if we de-gendered and looked at it from our world, which is the disability world, you would find that it's not gender that gets the abuse, it's actually the disability and the vulnerability of the person. So, they definitely do need to understand that. They need to be taught. They need to find out that part of the demographic that they're losing and missing is the demographic of disabled people. Yeah.

[Pauline] And the value of having that person walk alongside also means that they have a wider understanding of what's happening within whānau —

[Huhana] They've got an expert with them who can be the voice for the client, who's able to help, who knows what their rights are, what processes, resources, blah, blah. So they're able to advocate, whereas a non-disabled person that doesn't have a lot of exposure and assumes things can often get it very wrong.

And particularly when you've got disabled children, male children that need to be with mum. And where else are they going to go? But they just don't allow them, because they view them as being the wrong fit for the refuge.

But the problem is they're just as vulnerable and traumatised, if not more, then what the parent is sometimes, because kids and animals are often used as abuse tools.