

Answers to Questions on Notice:

I'll start with a couple of questions about the consultation process. I think it was the AFDO that mentioned that. Obviously this is happening in the same context as proposed changes to the NDIS in terms of independent assessments, and you've raised the lack of consultation. Since you've raised those issues, publicly and with the department, has the department made any efforts to consult more closely on the bill and have direct engagement with you or your disability representative organisations about the changes? If they haven't done that, is this committee providing you with sufficient process to raise those concerns?

I met with Discourse Consulting in April of this year, by Zoom, to give my views about safeguarding for people with disability. I was not informed about the nature of the consultation, nor that the intent was to inform legislation. I was told that they were contracted by the NDIS Quality and Safeguarding Commission. My views have not changed since that date.

One of our Senior Advocates at PWDA, Stephen Kilkeary, was interviewed as well, on the 14th April, 2021. I was not aware of that consultation until this week.

Senator GREEN: Thank you. I've got some specific questions about the provisions of the bill which I want to get to but, again, if anyone wants to put any information about consultation or notice, please feel free to do that. Sam, you've raised quite a few questions around privacy in your submission. Can you explain for the committee—it's not something that we might understand intrinsically—why consultation with a person about sharing their information is so important, particularly a person with a disability. The bill provides for information to be shared between agencies, and I can understand the benefits of doing that. But you've raised issues about privacy, and I'm keen to understand what the difficulties will be with that and what problems tend to emerge when information is shared without a person's consent, particularly in the disability sector.

I have added a supplementary paper which includes some of the issues around privacy, but the issues arise here;

- *We are the most collected-about, overscrutinised and experimented upon persons in the Australian population*
- *The details of our lives, in every aspect, from employment to education to income to sexuality to health to relationships to*

continence and personal hygiene and behavioural aspects, as well as private financial affairs, are recorded and analysed. This does not happen to other Australians

- *The potential to misuse this information for social control is absolutely a concern. In addition is the lack of transparency around the algorithms that are being used to dictate what our funding will look like. The former NDIS head, Marie Johnson, has worked for some time highlighting that there is a dangerous lack of ethics and oversight in NDIS tech experimentation. There are articles [here](#) and [here](#) that explains the issue further.*

Senator GREEN: I imagine those particular privacy issues are acute when it comes to mental health or psychiatric conditions. One of the jobs of the committee may be to make some recommendations around amendments or something for the government to consider fixing in the bill. Is there a way to fix the bill to resolve some of these privacy concerns?

Yes. It needs to go back to the drawing board, this time with people with disability, their families and representative organisations. It needs to include ethics oversights and people who understand safeguarding, privacy and triaging systems around violence, as well as violence prevention in a traditional sense. It needs discrete consultation with experts who understand privacy issues and citizens' rights and the work that the Digital Transformation Agency, the National Disability Data Asset and other independent agencies are currently carrying out also need to be scrutinised.

Senator GREEN: I have a broader question about the Robertson review and the purpose of the bill. The Robertson review was confined to considerations of Ms Smith's circumstances; it wasn't a broad-reaching review into quality and safety in the disability sector. Despite that, this bill is implementing recommendations of the Robertson review. This is a very broad question about whether there are some shortfalls in the bill in terms of addressing safeguards and quality and safety—if there had been a broader review or an attempt to deal with some of the glaring issues in terms of NDIS safeguarding. Are we missing an opportunity to fix some of those issues in this bill?

No. The issues are that the Bill in its current format would not have prevented the death of either Ann Marie Smith or David Harris, in my view. These are complex issues which require scrutiny by people who

understand violence prevention, not bureaucrats developing a policy framework with often little understanding of either violence or the way it is manifested for people with disability. It needs to go back to the drawing board and then be considered after disabled people and their families have had a chance to examine the issues.

Senator POLLEY: Thank you very much. What is very frustrating for the people who have been on this committee over many years is that we have had inquiry after inquiry about disability and we finally had the NDIS legislated, but we still have these issues now, which is of grave concern. We have a number of submissions that highlight the fact that the government really has not implemented all of the Robertson recommendations. What I'd like to ask you is: are there any things that you see in this legislation that, if implemented, will make the lives of people living with disability better? If there aren't, can you highlight—very quickly, obviously, because I'm running out of time—the specific areas that are still missing and the overreach, and can you put on the record yet again the real impact that these changes are going to have on the individuals?

Attached in supplementary submission. Including the areas that are missing, namely developmental safeguards, allowing people enough funding – there is an austerity measures program in place right now and the agency is slashing peoples supports, which will kill us faster than anything else – and ensuring that we have access to the world.

This is about us not being regarded as human. If we were, people would be talking about risk in a different way. How to change the attitudes of non-disabled people and providers. How to make providers accountable when things go wrong and when we are murdered. We would be talking about providers as though they were men who hurt women, not asking them to develop solutions to prevent gendered, intimate partner violence.

That is what these measures do. But this should be a community conversation – it is about how we can be empowered to stay safe, not how a government agency can develop safeguards around this. Imagine if this was about non-disabled women who face an issue with gendered violence – the answer, we are told, is that a faceless government body will come up with a solution the violence by having some conversations with a few individuals who are probably (but not all) women, that they will develop something, not tell us about it and then develop laws about it,

again not telling us about it, to stop us being raped and bashed.

Some of these imaginary laws are going to involve us never being left alone with a man again. So they will ask another man, not one we have chosen, to drop in occasionally and ask if we're okay, to observe and collect details about our perceived safety on a risk framework he has developed without us.

And then that man is going to be in charge of the parts of our life where he considers that we are at risk – he's going to consider how we behave, what we are doing and other things that might put us 'at risk'. And by the way, he can ask others about us and share information with them, including our private information, and never ever tell us about it.

If we ran this scenario past the FDV sector, they would be rightly concerned. It would never happen.

There is one other thing I find remarkable. Despite the recognition that violence affects women disproportionately during lockdowns and COVID, there is no recognition anywhere that Ann Marie died during a pandemic. And for many of us, we are ALWAYS in lockdown. We are segregated and isolated due to ableism of others, due to physical access barriers, lack of support. Nobody is talking about even the bare bones basics of this scenario.

For many of us, providers are not safe. And government is even less safe. That is the case for most Aboriginal people, many disabled women and most people who live with disadvantage. It is ironic that disabled women like Shona Hookey and Peta Doig die on the daily and that nobody pays attention until the woman who is killed is wealthy, white and dies in a pandemic in extraordinary circumstances.

<https://www.nowem.org/blog-1/2020/8/6/domestic-violence-during-covid-19>

Please, let's do this properly. Thanks for the opportunity to give feedback to this process.