

DANA and DRC Workshops with NT Advocates – 10 November 2020

This document is a redacted and edited version (for privacy reasons) of live captioning transcripts from a workshop held over Zoom during late 2020.

Between October 2020 and March 2021, Disability Advocacy Network of Australia (DANA) collaborated with the Disability Royal Commission (DRC) Community Engagement team, to hold a series of virtual State/Territory focused workshops (one or two in every jurisdiction) on the topics of Restrictive Practices and Segregated Settings, with staff of the DRC in attendance. Identifying details have been removed from the edited transcript below. Participants were informed that sessions would be recorded to capture their insights and observations. The DRC organised for live captioning of this discussion by The Captioning Studio. Care has been taken but errors may exist in the transcription.

DANA would like to acknowledge the Traditional Owners of the various lands around Australia from which advocates participated in these virtual meetings and pay our respects to Aboriginal and Torres Strait Islander Elders, past, present, and emerging.

DANA would also like to acknowledge the time and generosity of participating advocates from a diverse range of advocacy organisations around Australia, and the funding of the Australian Government Department of Social Services for DANA to provide DRC systemic advocacy support. Visit www.dss.gov.au for more information.

An advocate from WA also joined this discussion with NT-based advocates.

Transcript of Zoom Workshop – 10 November 2020

MARY: Okay. All right. We've got the two Northern Territory representatives that were going to join and there may be somebody from WA joining as well, but we'll get started... I'll start with an acknowledgment of country. I'm in Hobart today, so I wish to acknowledge the traditional custodians of the various lands we're meeting on. I'm on the lands of the Palawa people. I wish to acknowledge their continuing culture and contribution they make to this city and region. I also acknowledge and welcome other Aboriginal and Torres Strait Islander people who may be attending today.

So we'll start with an introduction from DANA and we can keep today relatively informal because once you just get introduced to the Royal Commission people, we kind of all know each other.

DANA is doing this series of workshops. This is the fourth. We've done them already for Tasmania, ACT and South Australia and we'll do the other states between the end of this year and then into early next year. It's just one of multiple channels that you have to connect with the Royal Commission, but this particular series is so that we can talk with advocates about a couple of topics; restrictive practices and segregated settings are what we're going to talk about today and for the Royal Commission to sort of listen in really.

[Preamble, opening statements and introductions from attendees... *redacted for privacy*]

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MARY: So we might dive in to the first part of the discussion about restrictive practices. Now, I'm going to make an assumption, but I'm checking if it's true. For the people that you work with – P2 and P3, you can nod or put your hand up, and P4, you can dive in - do you see many people where they are under restrictive practices? Okay, P2 is saying no with the shake of her head and P3, what about you, do you and the advocates see restrictive practices being used much?

P3: We see... not restrictive practices in the traditional sense where a person is being restrained with medication or physical restraints. What we do see is a restrictive practice as in access to the client.

MARY: In access, you mean specifically where an advocate isn't allowed to access the client?

P3: Yes, or even the coordinator of supports where a SIL has such strict access to the premises that you have to request two weeks prior to the appointment and you're not necessarily guaranteed access.

MARY: I'll pursue this for a moment. When you say a SIL [Supported Independent Living], you mean a group home?

P3: Yes.

MARY: Under SIL funding now with the NDIS, where you have to give two weeks prior notice if you want to go and meet with the person?

P3: Yes, or you have to arrange to meet them external to the premises.

MARY: Right. Is that a new, just as a matter of interest, is that something new that's come in?

P3: It's something that occurred, that started about a year ago here in Alice basically around controlling... like attempting to control sort of the ins and outs of those group homes. At first we weren't... we thought it was like a safety thing for the clients, but then it can be used to restrict the client from communicating with their advocates or with their coordinators of support.

MARY: Mmm, yes.

P5: P3, can I ask, is this unique to one service provider or is it across a range of services or how would you describe that?

P3: So it was originally unique to one service provider, but since then two other service providers have gotten the idea and so they have also adopted quite limiting requesting access to client.

MARY: And is this... so would the client... so it might vary, but if the client has a phone, for instance, you could talk to them on their own phone?

P3: So most of the clients that this would apply to, they don't have capacity to use their hands or they have limited capacity to use their hands, so what we've relied on is just showing up to see them or they'll have a hospitalisation and the hospital will contact us and then we'll go down and visit them at the hospital. Or we make the application to go visit and then we're able to see them.

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MARY: Yes. Right. Yes, thanks, P3. P4, do you want to dive in in the first place about to what extent you or others at [WA Advocacy organisation] see restrictive practices being used in your everyday advocacy?

P4: Yes, I started off supporting clients with the Disability Royal Commission and then we had a shuffle around, so at the moment I'm standing in for the advocate because she's on study leave with exams. But when I started about 12 months ago with the Royal Commission and clients, we had a 15 year old girl with autism. She was in juvenile detention when she was 13, had been put into solitary confinement I understand for a number of months. We tried to get freedom of information but it wasn't successful, but part of that was because her father didn't follow up. He was fly in, fly out and we couldn't get him to sign all the documents. But that was one issue that we're trying to follow up on, basically teenagers in juvenile detention experiencing restrictive practices.

MARY: Thanks, P4. P2, can I come back to you about not seeing restrictive practices and just flesh that out for us. Tell me why.

P2: Because we mostly support people who live in remote communities. They're not living in any sort of supported accommodation. And so, yeah, it's rare for us to see restrictive practices because of that, because we're supporting people who live in their own communities who might get some very, very limited services in their own communities, but the way that things are done out in those communities there is - yeah, there's no restrictive practice whatsoever. Sometimes when people come in to an urban centre for respite then they are in a more restrictive environment, but in terms of, for instance, there might be a rule that you can't have your whole family there with you, you can go out and have a picnic with the family or whatever but they can't stay in the house with you. But other than that we rarely see anything that would be considered restrictive.

MARY: Do you know what's sort of bizarre about that of course is... what of course it shows is that restrictive practices come along with systems and services.

P2: That's exactly right.

MARY: Yes, so the cohort of people you're talking about haven't got services, they also therefore, by definition, sort of haven't got restrictive practices. It's really interesting, isn't it? It's predominantly systems and providers who put restrictive practices in place to help them manage people.

P2: Yes, yes, absolutely.

MARY: Yes, it's interesting. Some of the questions I think that we've got about restrictive practices may not be appropriate or applicable exactly.

P2: We deal with practices like you're not allowed to get drunk if you're going to go into respite. Those are the sort of practices that we see sometimes. We'll have clients ring us up because they're angry because they can't take beer into the respite centre that they're going into or you're not allowed to sniff petrol and use illegal substances while you're in there, I mean, those are the sorts of complaints we get from people going into respite.

MARY: Yes, it's about the rules, the rules of the place, and then people would prefer if those rules weren't in place.

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P2: Yes, absolutely.

MARY: Yes. So I think we will do this in more of a slightly free-flowing discussion rather than sort of the formal questions because some of the questions just, as I said, are not necessarily completely applicable.

P2, I'll ask the question for you first. So I'm presuming that some of the people that live on the remote and very remote communities at times end up in the justice system and are taken... they're removed, taken away from their communities and are in prison for a period of time or whatever and then I suppose come back again. So a particular question I want to ask is do you... when they are away from the communities, in prison or elsewhere, does [NT organisation] have any connection with them or is able to stay connected with them while they're away or is it just that you do stuff for people while they're in the communities and then when they're gone they're completely out of your sphere of action and they just come back again.

P2: It depends on where they're imprisoned, Mary. Because we cover such a big area, if they end up in prison in Alice Springs, well then we can continue to support them to some extent, but if they end up down in Port Augusta or across in Kalgoorlie or Perth, then it's very difficult for us to maintain contact and support of them while they're imprisoned.

I mean, interestingly, some families feel like their loved one is safer and better looked after when they're in prison. We've got some mothers who will say, "Oh, that's good he's in prison, he's having those three meals a day and the doctor is there and he's getting help when he needs help", because the situation for people out in remote communities can be so difficult at times, not enough food, not enough support for people who have behavioural issues. Some families feel a real sense of relief when their family member is in prison for a period of time because they're struggling to manage those behaviours when they're out in the community and there's very few services out there, so it's up to the family to try to manage what's going on.

MARY: Thanks. We'll come back to something about the behaviour support in a minute. P3, from your perspective of seeing people mainly around the Alice Springs area, do you have that same issue about people when they are away from their normal sort of place where they live or when they are in prison or whatever?

P3: I would say we have the same thing. Prison sometimes becomes a respite service. I mean, sometimes they get more care than they would get otherwise. It's hard for people to, say, get an NDIS plan if they don't have a fixed address or if their phone number continues to be changing, ever changing, yes.

MARY: Okay. P4, does this apply from where you sit in Perth or not?

P4: I have a couple of clients that have had adult children that do feel more supported if they do sometimes go into the justice system, they can't cope and they're quite happy to call the police out as well to get support. But then on the other side, you know, we've got teenagers who are going in with autism and intellectual disabilities - that is not supportive at all and they're not getting the support or help in the justice system and it's compounding the situation and they don't know where to go.

MARY: Yes. Thanks. I want to come back to that you mentioned about the behaviour support, P2, and so some of the families are really struggling because they haven't got behaviour support really

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for their family member. It's an issue around the country, lack of behaviour support practitioners, and it presumably is worse the more remote that you are. So one of the things that I'm wondering is... any of those people that you're talking about, are they likely to have an NDIS plan and in their NDIS plan are they likely to have proper funding for behaviour support plans to be written and is that stuff being put in place?

P2: Yes, lots of those people do have NDIS plans now, especially on the APY Lands, and yes, there's sometimes, not always, funding in those plans for positive behaviour support plans, but it becomes extremely complex because of it being cross-cultural. What is acceptable if someone is in a residential service in town in terms of managing behaviour may not be so out in community. People don't want to behave... families don't want to behave differently to other families. So it's very, very difficult for families to put in place behaviour management strategies if those strategies are not culturally appropriate and culturally acceptable.

So often there's a really good plan and it works well when the client is in town getting respite, but when they're home again, the family don't implement that plan because it's not culturally appropriate. It's not manageable for them, it's not the way that they would normally interact. So it kind of unless you've got consistency, those behaviour plans are very difficult to implement and to get that really good outcome of the participant understanding what the expectation is.

MARY: P3, from your perspective, do you see the same thing or different and do you see people having positive behaviour plans... positive behaviour support plans written?

P3: So we have assisted a number of people who were in prison that we were able to keep in one place, get an NDIS plan, transition them out. It's been difficult to keep them or to assist them to stay on a plan. No matter how much preplanning we do when a person is in prison or in juvenile detention, when they get out there's a lot of competing cultural stuff that goes on. Sometimes they'll have a family and so they don't manage their money very well - just a variety of things, just trying to locate them to meet their appointments or for their community engagement person that's being supported through the NDIS to even be able to find them sometimes is hard.

MARY: Does the NDIS ever fund phones for people and phone plans?

P3: Our experience is they haven't, although people are usually on some sort of pension and we've had a number of people that we've assisted to get phones and to do that. But when a person's priority is food, accommodation, family responsibilities, you know, that other stuff doesn't really work into their lives.

MARY: Yes, thanks, P3. P4 and in case the Royal Commission are wondering where I'm going with these questions about the behaviour support, really it's because that's what sits under or behind the restrictive practices, isn't it? It's why restrictive practices are used all the time, is ways of managing people's behaviour. So that's what I'm wanting to explore a bit more is if you're not seeing restrictive practices used so much, and in P2's case it's because the people you're advocating for are not receiving services who could be putting restrictive practices in place, then what is happening, what is the situation that happens around the same people who in other settings would have restrictive practices all over the place? So that's what I'm just pursuing about the behaviour issues. Was that you, P4?

P4: Yes, it was me, sorry. I'm finding... I used to be a planner but things have changed. We didn't have LACs when I was a planner, but I'm finding from an advocacy point of view I need more and

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more evidence to argue for a behavioural support plan initially and I suppose the whole idea is a behavioural support plan builds capacity and then theoretically they hope that the need for behavioural support funding will reduce and I think they still just pull it in initially for six months the amount of funding to build the capacity. But I'm finding I really have to provide a lot more evidence and reports to get that funding.

MARY: And the evidence and reports, whose cost is it? Who's paying for those reports?

P4: That's another issue. The NDIS like people to go through the mental health care plans and allied health care plans where they can get up to 10 sessions and then there's nothing. Obviously privately people can't afford it and also there's the waitlist. So it's like the chicken and the egg sometimes as well.

MARY: Yes.

P4: There's those gap, gaps there.

MARY: It's a separate topic, but I wonder whether those independent assessments that the NDIS wants to do... will they be of the type of assessment that would be of any value anyway for providing enough evidence about a behaviour support plan, but it's a separate topic.

P5: Mary, can I ask a question? If we can go back to the comments... I can't remember specifically who made the comment about the behaviour support plan and where it's not welcome in Aboriginal communities where it's not seen as culturally appropriate. Could one or all of you maybe expand on that a bit more and I'm interested to know, has there been ways to try to get around that or to try to understand more the cultural challenges or more about working out different ways? Is there anything you can comment on in terms of maybe some success stories or particular challenges?

P2: I think the challenges almost go back to child rearing practices, where people learn through doing. Traditional Aboriginal people - it's not about setting boundaries, it's about allowing people to do things and make mistakes and learn. So it's not seen as... putting loads and loads of boundaries in place to keep people safe is not the way people operate out in communities. It's about... you learn from watching how other people behave, you learn from doing things and making mistakes. You don't learn necessarily from your parents saying, "this is the rule".

And there are issues around gender relationships, so women, older women cannot necessarily tell their younger sons with disabilities what to do. That's not seen as appropriate. Often it's men who set the rules for men and because men die younger, a lot of those young men out there don't have a lot of fathers or uncles or people around to help them understand the expectations. If they have a significant cognitive disability, they don't go through men's business necessarily... and again, men's business is another way of men setting the example for men about how men are supposed to behave, but there is a lack of senior men around doing the right thing and showing young men how to behave.

And if you use substances or if you have an alcohol abuse problem and you might be as a result of that more likely to engage in behaviour which is exploitive of others so that you can get the resources you need to access whatever you're addicted to... yeah, there's a whole lot of reasons why it is very, very hard for those senior women to manage... particularly younger men who have cognitive impairment, maybe ongoing petrol sniffing or using ganja, marijuana, regularly.

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I hope that explained a little bit, P5. That might have sounded like a big baffled mess, but it's complex.

P5: Thank you, P2. That's very useful to know.

MARY: Yes. Thanks, P2. My set of formal questions about restrictive practices ... as I said, I'm just adapting as we go here because I don't feel it's going to give us particularly useful input. Whereas exactly what you're talking about, the practical reality of the advocacy that you do on the ground, is more valuable really for everyone to hear.

SIOBHAN: Mary, I just wonder... I think the common factor between those two scenarios of not having services is a form of neglect and then also restrictive practices are also sometimes used in a way that's neglecting to provide the proper support. So maybe some questions or some reflections on the effects of neglect on people's wellbeing.

MARY: Thanks, Siobhan, good prompt. Yes, if people would like to respond to that notion of what people experience... do you see it and would the people themselves see it in any way as neglect?

P3: I'll answer that. No. They themselves don't recognise... I mean, for the most part, certainly First Nations people do not see themselves as necessarily being neglected only because they don't always fully understand what their rights are. And in some respects, some of the NDIS stuff that's been provided is stuff that they never would have gotten otherwise.

I'll give an example of that. We had a gentleman who'd been in an aged care facility, he was a young man, but because of his complex disabilities he'd been held in an aged care facility for a while. He got out of that and was put into a group home and that difference for him was amazing and he was really, really happy. However, we ended up getting a notification from the hospital because they didn't feel he was being cared for properly. But if you were to ask him, he was better off. So sometimes it's a matter of measuring what we as a society think is appropriate care and what they themselves see as an improvement.

MARY: Mmm. P2, what do you think about this notion of neglect, and I suppose obviously the reason... one of the reasons for asking it is because the framing of the way the Royal Commission is looking at issues sits into that, you know, violence, abuse, neglect and exploitation. So would that neglect concept... is it a meaningful way in any way to think about the lives of people that you work with?

P2: Yes, I think it is, Mary. I mean, what we find is people from remote communities want to continue living in remote communities. People with disability out there... I've worked here for 16 years on 1 December and in 16 years I've had one person say to me that they would rather live in Alice Springs and that person was a lady with a cognitive disability who was being sexually assaulted by someone in her community on a regular basis. And she put up with that for... possibly the first four years that I worked here where she continually did not want any intervention or support if it meant that she would have to leave the community. She would rather put up with the fact that she was going to be sexually abused on a regular basis so that she could continue to live on country and continue having her family around her.

I agree with what P3 said that everything is relative and people will know the difference because especially our clients are coming into town regularly and having respite and being looked after properly when they're in town and then they will go back out to a very, very neglectful situation

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where sometimes they're not getting enough food regularly, where sometimes someone in their family is... because everybody is poor, everybody doesn't have enough resources. ...when every single person in the house doesn't have enough money for food, people with disabilities are often giving away their pension so that other members of the family can have food or there'll be someone who is exploitive in that situation who needs access to alcohol or who is using drugs and will take the money away from the person with the disability. Demand sharing is a normal thing that happens in remote Aboriginal families, so someone who's got resources has to share those with everybody else. But it gets all mucked up if there's substance abuse or a gambling problem or some other issue of that nature. I think everybody out there experiences neglect.

I mean, an interesting thing for us was that during the COVID period where the Centrelink pensions and benefits were increased by the Commonwealth Government because of COVID, we had a complete drop-off- of the phone calls that we normally get every day about people not having enough food. Because everybody is trying to live on nothing - yeah, everybody is experiencing neglect, but they're making the choice to live out there because connection to country is so important that people will put up with things that would be totally unacceptable to me so that they have that capacity to continue living on country, because the only other option is bring them in to Alice Springs or somewhere where they're hundreds if not thousands of miles away from everything that is important - family, someone who speaks your same language, access to cultural activities, being part of the community, that inclusiveness, yeah. Sorry, did I answer your question or go off on a tangent then, Mary?

MARY: It was a very useful tangent, so that's okay. I notice that P4 has dropped out, but she said she was going to, so we'll keep an eye out for when she comes back in again. S, feel free to say if you've got any other ideas for picking up threads from some of the other questions that we have been asking.

We might shift topic a little bit and go to talk about segregated settings. Again, does it apply the same? I don't know. You'll have to tell me. I have to say, and I'm embarrassed to admit this I don't know, for instance, in Alice Springs is there an ADE [Australian Disability Enterprise]? P3, can anybody tell me that? Is there an ADE in Alice Springs, is there any form of sheltered workshop type employment for people with disability in Alice? There is? Yes.

P3: So there are some what are now NDIS-funded services for work in Alice. [NT provider] is one of those.

MARY: It's now registered under the NDIS, yes. But do you think it's typical of the ADEs in the rest of the country, they employ predominantly people with disability and pay them, you know, \$3 or \$4 an hour? Is it that model or is it something better than that?

P3: It is that sort of model, but if you... you might have been a participant of that service prior to the NDIS, but if you for some reason didn't meet NDIS or you didn't have that in your plan, then you no longer could attend there.

MARY: Oh, okay. That's interesting. Alright.

P3: Just because I think funding became reliant --

MARY: On everybody having an NDIS plan, yes. Yes, okay.

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P3: So it's not like [another NT provider] up in Darwin...

MARY: Right. I need to remind myself, I'm just not very familiar with the ADEs in the Northern Territory I realise. I'm more familiar with them in other places. So in terms of segregation, obviously, P2, when you're talking about people living on country and in their communities, they're not segregated because they're living with family.

P2: That's right.

MARY: So that notion of segregation doesn't apply, does it?

P2: No, and it's totally alien to people. Everybody lives with their family. Your identity comes from your family, who you're related to out on community. It's like a big web of support in terms of everybody being related to everybody else and people know what's expected of them in community because of that web.

MARY: Yes. Thanks, P2. So P3, in Alice Springs then is that segregated idea where people with disability are kept separate... does that apply more in Alice Springs then in the same way that it does in other towns, cities, you know, elsewhere in the country?

P3: I don't think so. Certainly our clients definitely feel that they are part of their community. I mean, they're certainly First Nations clients who are integral parts of their families, so for the most part they don't actually even see their disability necessarily as a disability, yeah. The people that we seem to see are actually quite an integral part of our society.

MARY: Mmm. It's really... this is exactly why it's useful and good to do these sort of discussions with advocates from different areas because otherwise I think it's too easy to make an assumption that everything operates the same everywhere and how the Royal Commission will take all of this... the differences into account, though, is another issue. I think Siobhan grabbed some information about [NT provider] and put it up, thanks, to explain how they operate in Alice.

P3, the group homes in Alice Springs, though, were the ones you were describing earlier who are keeping where you have to make a two week... you know, book ahead of time to see anybody who lives there...

MARY: How segregated... to what degree of segregation do they operate in? Is it that they just contain all the people with disability who they care for and keep them quite separate?

P3: So it depends on their mobility. It depends on their connection to country. That same SIL had a gentleman with quite complex disabilities but very strong family connections locally. So no restrictions that they put on that person were going to keep their family from seeing them, which is the benefit of not worrying about the rules. So it just depends on how connected to the wider community they are.

So we have seen people who don't have any family connections here and those are the people who are isolated. Luckily, though, we have... when they do have doctor's appointments and when they do go, say, to the hospital, Congress, clinic and the hospital are really proactive in identifying issues and feel very comfortable in reporting those issues.

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MARY: And reporting them... when you say reporting them, P3, do you mean getting an advocate involved or reporting them to whom?

P3: Well, it kind of depends on what the level of the problem is. So they may report them to... if it's a person with a psychosocial disability who has been identified as being cared for by a particular group, so let's say the Purple House if they're a diabetic patient or let's say Congress if they use Congress's Social and Emotional [wellbeing service] or is being supported by Congress's family supports or Tangentyere [Aboriginal Community Controlled Organisation] (audio drops out) and will coordinate that for them. It's the people who aren't seen by say an OT or professional body and who also don't have any family... those are the people that we hold concerns for.

MARY: Yes. And so, yes, people who are more isolated generally then.

P3: Yes.

MARY: P4, you've popped back in again. We were asking about segregated settings. So in Perth and with the clients that you see, are they in segregated settings a lot of the time or are they commonly receiving services in segregated settings?

P4: What do you mean by the segregated settings? --

MARY: Segregated settings - I suppose we mean any of the settings, like group homes or ADEs, the places that are built and run specifically for people with disability where they tend to be separate from the rest of the community.

P4: No, I would say it's a real mix. I'm not supporting clients at the moment with the Commission, but I understand it's a mix. I would say, I don't think they are seeing many people at the moment in segregated settings.

MARY: Okay.

P4: Although, saying that, some of the past history... yes, they have, actually. Some of the cases, you know... things that have happened in the past and they have been in segregated settings.

MARY: In more institutionalised settings.

P4: Yes.

MARY: So they've moved on now to something better, but that's sort of framed what happened to them in the past.

P4: Yes.

MARY: Yes. Yes, thanks. Sorry, I'm going back to my cheat sheet, but my cheat sheet isn't much help to me because the questions are framed around something a little bit different.

In my original questions about segregated settings and restrictive practices we had some questions about how people with disability can make complaints about any of those settings. So leaving aside what they're making complaints about, I am interested in knowing whether the people... the clients that you deal with who in other circumstances, people would make a complaint about something,

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you know, if they receive the same type of service or lack of service or whatever.. is this a thing that the clients you work with would do? Would they think about making a complaint? Do they make complaints? Do they use complaint mechanisms and systems?

P3: Well, for us, they... it depends on the client. So we have had clients who have made their way with their wheelchairs to the NDIS office to make a quality and safeguards complaint, clients that we didn't have... until quality and safeguards got involved and then referred them to us. And then we have other clients who we see are being neglected and yet they do not want to make a complaint.

MARY: Yes, okay. P4?

P4: I would say with regard to the justice system and juvenile justice sometimes it's confidence, it's education of the parents and they're up against the justice system. They may put in complaints, but they don't get answers. They don't know how to follow it up. And it's having the confidence and education to take that on and the capacity and that's a major issue, I think.

MARY: And do they... so if an advocate is working with the young person who's in juvenile justice and with the parents, do you think the advocates are able to sort of impart that confidence to them? What does the intervention of an advocate do?

P4: Well, we would then support them, but previously they haven't been successful, so when they've tried it on their own, it hasn't worked. Then they come to us. Or with one of the cases it's quite complex, all this has come out two years' later, so then we help them apply for freedom of information and they're bringing a case now.

But previously, you know, there's complex family circumstances, maybe one parent families. They don't have the time, they don't have the capacity or the education or the confidence to keep challenging the system to follow up the complaints or they feel they're being fobbed off and they don't know where else to go. And then the other side is retribution. If you put a complaint in, will the client suffer?

MARY: And presumably people have experienced that retribution enough times that it makes them wary about making complaints?

P4: Yes.

MARY: Yes. P2, can I ask you about that issue? What do you see... do you see people making complaints, wanting to make complaints? How does that play out?

P2: Probably - look, we have some people who make complaints all the time about everything who are very comfortable with complaints processes, who know that they do have some rights and are very, very happy to exercise those rights. We have others who would never make a complaint and who need constant support who find the processes. I mean, complaints mechanisms are not necessarily friendly for people from non-English speaking backgrounds. So our clients are mainly people who don't have English as a first language. So having a sign up on the wall saying "you can make a complaint" is not really all that helpful, or saying that you have to get a complaint in writing is not all that helpful.

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It depends on,.. for us it's very much linked to families. Some families have high levels of English literacy and have had a lot of engagement with services over a long period of time and are pretty comfortable with using complaints processes. We've got other families who might have huge issues.

One family I'm thinking of, there's five adult children who all have brain injury from petrol sniffing. The mother of those adult children has a psychiatric disability, the father of those adult children was an alcoholic who has since passed away, and that family just don't have the capacity despite lots of support. And often they're really focused on the here and now, today, have we got enough food, have we got shelter, is there some domestic violence going on in some aspects of that family? They're not interested in a process that's going to be protracted. They want a fairly immediate response and a lot of complaints processes are quite protracted. So that's another disincentive to people to actually follow through with those processes.

But some families just don't have the capacity. They're in survival mode and they let a whole lot of really inappropriate things happen and they don't care because it's more important to worry about whether you've got food that day. So it's a big mixture, Mary. There's not a simple answer.

MARY: No. Thanks, P2. I want to ask about access to advocacy in a second, but I'm just going to pursue just if you think about using that family just as an example because for the Royal Commission to make a difference, they're going to have to have some really strong recommendations really in that final report that governments will have to pay attention to.

Of the problems that you see, are there potential solutions that the families know about or that advocates can see but that just don't happen? Are there any solutions you can put forward any, it doesn't have to be either big or small, things that would make changes for, make improvements for the lives of the people that you're working with?

P2: From our perspective, Mary, that family that I just talked to you about, what's made a difference - one of the people in that family has met the threshold for an NDIS plan and it looks like now she will end up in supported independent living. Her plan is being reviewed. That has made a huge difference to her life. She is getting yeah, we're kind of at the opposite end of the threshold. We're saying to people that services can actually help you and support you and you can have better life outcomes. So she's gone into a supported independent living situation which is extremely flexible and culturally appropriate, so not like normal SIL. She's really, really well supported and she is getting the care that she needs and that care - the kind of upshot of that will be that she will be able to better look after her own children and make sure they go to school and hopefully they will have kind of better life outcomes than her because she ended up at 16 having a stroke from petrol sniffing. She's had three children, one of them cared for by another family member, two others are still in her care, and the SIL is going to make the difference to her being able to provide adequate parenting.

I guess from Women's Council's perspective as an Aboriginal organisation, often people have the solutions themselves. Those solutions involve being able to stay in community. You shouldn't have to go away to get the support that you need. You shouldn't be told if you need services you've got to be in an urban centre. But listening to the innate wisdom that people have about what they need to resolve their situation and doing everything you can to act on that - yeah, trusting that individuals actually do have the capacity to identify what they need to have a good life.

MARY: Yes, thanks, P2. Can I ask the SIL arrangement, which is extremely flexible and culturally appropriate, what is that, who's running it, who's providing it?

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P2: [NT provider] in Alice Springs. They are a new player. Honestly, I've heard lots of negative things said about them by other SIL provides, but the reality is for this particular lady their flexibility has been life changing and they've got the police around there every second day because incidents happen.

But because they're not a traditional SIL provider, they don't have all the rules and regulations set up. They've gone into this going okay, we're learning as we go. And yes, there has been a few stuff-ups, there's no doubt about it, but all along the way they've maintained a commitment to trying to provide a culturally appropriate service and for this particular lady and for others of ours who have come from remote, coming from remote into a SIL environment is a huge shock because people are used to just doing whatever they want to when they're out in community. So to have a SIL that is much more open and flexible about supporting people in the way they want to be supported is a real benefit.

MARY: Mmm, thanks, P2. P3, are you seeing that [NT provider] or any other service in Alice Springs are you seeing them do stuff that's different from the traditional SIL providers?

P3: Well, we've - there have been a number of providers who've become quite flexible in the way they deal with people with psychosocial disabilities providing them a variety of different kinds of ways of having accommodation, that sort of thing, the community access people being quite receptive to changing wellness of a person and being flexible with that.

I would say that we as a service agree in that what you need to be is you need to be culturally appropriate and aware and provide those quality services. I also think there needs to be some sort of quality and safeguards around some of that flexibility, only to monitor what actually takes place. We as a service have asked for the community visitor program to be brought back for people with disability as a way of monitoring some of those things. But other than that, you know, we are happy with the way people generally are being flexible around the way they do things.

MARY: Thanks, P3. The thing that I want to ask all of you is to tell us what difference does access to an advocate or an advocacy organisation make and how hard or easy is it for people in the areas you cover to get an advocate if they need one? P4, I might go to you first for your experience in Perth and then come back to the two in Alice.

P4: I think it builds capacity for people, especially parents, to help access the NDIS for internal reviews or to tell their story with the Disability Royal Commission. People are sometimes at their lowest ebb and they don't know where to go and it's helping them build their own capacity and showing them a way forward and helping them submit applications, whatever that application may be. And sometimes we're seeing mothers at their wit's end that also are suffering from anxiety and depression themselves. Our funding has just been cut in certain areas, so we have a waitlist now for different sections of where we can provide support.

MARY: Thanks, P4. That's a common story across the country, unfortunately. P3, tell me about access to advocacy in Alice Springs and around.

P3: Well, obviously we've seen a trend over the last say three years of doubling each year of access to advocates.

MARY: A doubling of demand?

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P3: Doubling of demand, which... well, so this year we will have a waitlist. We have always strived not to have that, but the demand has been really great. So we will start to have waitlists. We will also start to have sort of a checklist of whether or not there are other services who are more appropriate for the person to try to get assistance from. So if they have a psychosocial disability, we might refer them to [Mental health organisation] as their advocate as opposed to us, unless they've had a difficulty there and then we'll keep them. But yeah, there's been a huge demand.

One of the things that we've seen really change about the demand is other... a lot of our referrals, like maybe as much as 50%, come from other agencies, so we'll get a referral from Congress, from Alice Springs Hospital, from an OT, from Flynn Drive medical clinic. We get referrals not necessarily from the clients themselves, but from the services they access.

MARY: Yes, who recognise that this person needs an advocate?

P3: Yes. Then what we do is exactly what was said and that is we try to build their capacity, we try to offer them support and then try to find the best way to navigate the problem that they see they have, so making it very person centred. We often identify that there are lots of things we would like to help them with but they themselves don't identify that as the problem. So that's where we stop.

MARY: Yes. Thanks, P2. P2, on your very large patch, tell us about access to advocates and the need for them.

P2: Look, advocacy is critical. Because the Government keeps creating intensely complex systems that are supposed to support people, people cannot access those systems when they don't have English as a first language. Without advocacy, you know, many of our clients and families would never be able to access the support that they need.

It's just... I can't even... I find it so frustrating that the Australian Government keeps creating intensely complex systems. The NDIS is impossible. It is just impossible for people to understand. They don't understand it. They don't go on the bloody NDIS portal, they don't know what the NDIS is or what it means or what it could be for them because it's just the whole system is being made stupidly and ridiculously impossible for people who don't have English as a first language, people who don't have computer literacy or access to the internet. Yeah, why, why did we make it so hard?

And you know what? The Commonwealth keep us advocates in jobs because of the idiocy of the way that we set up systems, because of all the barriers that we put in place to prevent people getting access to the services and supports they need, because the burden of proof that is put on people if they need to access a Commonwealth service.

It's just ... as you can see, it's a subject that... I spent half an hour with someone from the NDIA yesterday saying the same thing. Why do we do it? Because we do do it, we need advocacy. We need to be out there supporting people to get access to what they have a right to access, to get those basic supports they need to have a good life in their community.

It makes me furious because I don't think... I think that sometimes it's just unnecessary. It's peripheral, it's keeping bureaucrats in jobs. But because we set up systems like that, because you've got to prove all the time how much you need a service, advocates are critical. People out in [this] region wouldn't have any of the supports they need without advocacy. And they wouldn't even

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know to ask. It's us going out there saying "You have human rights" - guess what, what a big surprise - "and we're going to help you access those human rights."

So, yeah, just, oh, it makes me so cranky. Advocates are critical, Mary.

MARY: You don't need to tell me, P2, but it is true. Yes, it's just interesting how resistant... the bureaucrats that design the systems are very resistant to hearing exactly that message. It's very hard to get it through to them.

We've only got quite a short time left before we finish, so I want to ask what I think is potentially a tricky topic. The Royal Commission wants to look at violence, abuse, neglect and exploitation for people with disability. Sometimes all of those things are done by families, not by systems and not by services.

How should the Royal Commission deal with that, how do advocates deal with it, how do the individuals - one of the examples you gave earlier on was somebody who was being abused either by family or connections in community, and how tricky is it for people to even raise it or what are any of the solutions, what are the things that need to be heard or done or talked about about this topic where it's not the services but it's the families that are the ones perpetrating violence and abuse?

P2: Look, from me or from 16 years of observation it's an educational process. It should start with school kids. We should be talking to school children about human rights. Aboriginal kids out in those schools should have that information. It's not going to happen overnight and again, everybody out there is poor. You don't have enough money. So what we're doing is creating a situation where people are scrambling over one another to try to put food in mouths. We actually create the abuse and neglect that happens in those communities by keeping people in poverty.

I think if we addressed the poverty that people are experiencing, some of the abuse and neglect we see would disappear, and some of it did disappear when people were getting additional money through COVID. I think that has to be a long-term strategy to get everybody up to a level where they don't have to be taking money off someone with a disability in the family who's getting a regular pension or the old person in the family who's getting their aged pension, where everybody is looked after, where people are not forced into a situation where to survive they have to exploit one another.

MARY: Thanks, P2. P3, do you want to say --

P3: We agree. We think that... yeah, there just isn't enough to live on. I mean, if a person has, say, an aged care pension and they're supporting other family members who, for whatever reason, have a Centrelink debt or just haven't had the ability to report to Centrelink, then they're all brought down to live in poverty.

An example, yesterday one of our clients, both the mother and daughter have complex disabilities. One of our advocates tried to support them to go to Centrelink. Now, because of COVID rules, you have to stand outside of the Centrelink here. It's 41 degrees. There's a line up. Both people have disabilities. There's no way to make an appointment to come in. It ends up that those people stood there for a period of time and then just gave up, you know? They just make it so hard that they can't... you know, they want to try to do it, but they just can't.

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MARY: Mmm, all right. Thanks, P3. P4, can I come to you about that issue about where families are themselves the source of the violence and abuse?

P4: The source or the issues of bringing it up... I wanted to ask a question as well and it's all related about confidentiality because with the Royal Commission I understand confidentiality is for as long as the Royal Commission runs and you can't guarantee it afterwards. Is that correct still?

MARY: I can give my quick response. There is new legislation – P5 might want to come in as well, but there is legislation coming in in Parliament next year which will hopefully extend that confidentiality longer, yes.

P4: But not permanently because I think this is an issue as well. There's a sense of shame if someone has been abused by their stepfather, the mother may know. But there was a sense of shame in one family of bringing this issue up and going to the Royal Commission and she didn't want it out in the public. She'd been through a process before. But it's being able to say to families that this is completely confidential and to be able to guarantee that and at the moment you can't guarantee that, can you?

MARY: Not in a forever context, no. P5, did you want to respond to that about the confidentiality?

P5: Thank you, Mary. Yes, P4, in response essentially the key things are, as you've pointed out, at the moment we can't guarantee confidentiality beyond the life of the Royal Commission. We've requested that the Government amend... provide legislation to amend that so anyone that provides submission and other information to the Royal Commission say as you were describing just then and the Government has committed to early next year, or rather autumn next year, to amending the legislation to that effect. However, we've not yet seen the detail and we've not yet been advised of what the law will precisely look like, but it is our hope that our overarching request that people can be guaranteed confidentiality beyond the life of the Royal Commission, that we will achieve that.

P4: Right, thank you. I think it's really important and it will help people come forward.

MARY: Thanks, P4, and thank you for pointing that issue out particularly about where the abuse has been in a family context that it may even be that it's even more important around confidentiality. We're... --

SIOBHAN: That's a concern shared by advocates all around the country.

MARY: We're done down to our last two minutes. I just wanted to check before we wind up is there anything else that any of the advocates would like to ask or say in general in this discussion or to the Royal Commission in particular, anything that you'd like them to hear? You've done your bit.

I just want to say thank you very much. This has been a slightly more... a different version of these sessions than the previous ones, but it's been very good and I want to really thank P2, P3 and P4 for sharing your work so that the Royal Commission can hear and we've ranged across some topics that were a bit different today, but it's been really useful and really good.

[Formal wrap up]

MARY: Thanks, everyone. Bye.