

DANA and DRC Workshops with TAS Advocates – 4 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.

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Transcript of Zoom Workshop - 4 November 2020

MARY: We'll get started and I'll get each of you to introduce yourselves in a second. But I will just start. In the first place, I'd like to acknowledge that we're meeting on the lands of Aboriginal people all around I was going to say "all around the country", but actually it is, because most of us now are in Tassie today but we have Royal Commission people who are with us from other places. I'm on the lands of the Palawa people and we acknowledge their elders past, present and emerging and any Aboriginal people who are with us today.

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

MARY: Okay, thanks. So what we're going to do is we're going to talk through these topics to try to go through in a bit more detail about restrictive practices, which we'll do first, and then segregated settings we'll do afterwards. We've allocated about half an hour for each topic.

I've got a few prompt questions, but there are other ways that you can also provide some information. In the email that you would have got that P3 sent out in the invitation there's a link to two surveys, so one is about restrictive practices and one is about segregated settings. So in your spare time feel free to put in some answers to the surveys as well.

P2: MARY, can I ask how long are they going to be open for?

MARY: P3, can you answer that?

P3: At the moment we're just keeping them open. We haven't set a deadline, so at this stage I'm sure we can keep them open if that will help people respond.

MARY: They'll probably be open for ages, P2, to be honest, because we'll just harvest the information every now and again and pass them on to the Commission. We don't do the New South Wales and Victoria versions of these workshops until the beginning of next year. We might remember to prompt people every now and again to put in some information in there.

So starting with restrictive practices, and some of these questions sound like advocacy 101, so I apologise in advance. They're just prompts for us all to think about them. So the first question is, what are the effects of restrictive practices on people with disability and the follow-on from that, the sort of part B to that first question, is how do restrictive practices lead to further violence, abuse, neglect and exploitation of people with disability?

P2: All right, I'll start.

MARY: Thanks, P2.

P2: They have the effect of isolating people, of making them even further disadvantaged because either the restrictions are so restrictive, obviously, that it makes people's lives miserable. You know, anyone who's on a restrictive practice appears to have very little opportunity for supported decision making, to really participate in decisions that affect their lives because they tend to

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encroach on other areas of their life as well I think. And I've forgotten the question you asked, MARY.

MARY: I probably should have started with something else, actually, which is, (since I can see all of you, except P7) put your hand up if in your everyday work you see people who have restrictive practices in place.

P2: Approved and not approved.

MARY: Okay, so basically every advocate has their hand up to that question, and P2's made a point about whether they are either approved or authorised restrictive practices or nonapproved or authorised and I expect that you see both. I don't know whether P3 is going to do one of those instant polls this time like we tried last time, but we might contemplate doing a little bit more of this in future, this might be hard because it's a guesstimate probably, but of the clients that you work with, any idea what percentage would have restrictive practices in place; 10%, 20%, 50%? Does anybody want to give me a guesstimate about what their gut feeling is, and I know you probably don't have that in front of you in the form of a statistic.

P2: Authorised or not authorised?

MARY: Okay, well you tell me, P2, what percentage authorised and what percentage non authorised?

P2: I would say for people living in group homes and those sorts of settings there would be an extremely high proportion of people who have unauthorised restrictive practices, you know, probably 80% I would -say--

MARY: 80% of people in group homes?

P2: Yes, and they don't even realise that they are subjected to restrictive practices.

MARY: Yes.

P2: I'd be interested to see other people's opinions.

MARY: Anybody else want to have a go?--

P4: I tend to agree with P2 on that. For example, in group homes people are under restrictive practices and don't realise they are actually. Sometimes the support people, the staff in the organisation, don't even know what they're doing is restrictive practices. I haven't had anything from the senior practitioner recently, but I know that 18 months ago I asked for the state of Tasmania how many authorised restrictive practices and for all of the state 18 months ago it was eight.

MARY: Eight authorised?

P4: I'm talking 18 months ago; I don't know now. I was stunned, I was absolutely stunned that there were only eight. It was 18 months ago.

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P5: We've got a real problem in Tasmania with reports that go to the Senior Practitioner for assessment of restrictive practice. That's been a longstanding issue and in the last - well, since the transfer to the NDIS you couldn't report to the Senior Practitioner whether there was a child that had restrictive practices, but that's been changed recently - sorry, before the transition to the NDIS, you couldn't report. It was only adults that you would report to the Senior Practitioner for assessment about restrictive practice.

Now children can be reported, but they have really low numbers of reports. So even in the education system we would see exclusion, so any child that's been excluded in education, suspended, attending part time where there's behaviours of concern involved, there's nearly always restrictive practice involved. So I can't give you an exact percentage but, you know, a lot of the advocacy cases that we deal with in education involve some kind of exclusion.

MARY: P5, do you think that the people in the education system, the teachers and others, do they.... are they familiar with, do they use the term restrictive practices, do they know what it means, and do they think about it in that way or not?

P5: I'm hoping S will come, our southern advocate, to the meeting but she had another meeting that clashed with this one. There's a new program that the Department of Education have got for State Government, but I'm not sure what it's called. She'll know. And my understanding is that it's about acknowledging that teachers and people working with children with challenging behaviour require additional assistance and understanding beyond the behaviour assessments that have been done and any recommendations that fall under those assessments and that it's more to do with if a child needs some kind of restrictive practice or movement or something. I mean, a lot of the practices may happen because they're keeping children safe, for example, so they might be even physically steering someone away and then there's a whole range of I don't know, because it's new, how many schools are taking up that option to get that to improve their understanding of how to work with those children.

So it's something that we can talk to the Education Department about more. But I do know in Tasmania in the private school settings that where children exhibit challenging behaviour they are just excluded, but that's the usual response and usually told that they're better off going to the state system who have been practising inclusion or they've had policy for a long time around inclusion and probably they've got more supports in place for children who have challenging behaviour.

MARY: Yes. Thanks, P5. For the other advocates predominantly not dealing with the education system, do you think that the average support worker has an understanding, a proper sophisticated understanding, of restrictive practices? Everyone is shaking their head. Okay.

P6: I would say probably the majority of the clients, the participants I have worked with have had a restriction in some way or another. I actually flagged yesterday something about chemical restraints. Someone had said something about oh, we need a behaviour support plan for this participant because of their chemical restraints. This person is nonverbal, confined to a wheelchair and it's like why would they be on a chemical restraint..... no behavioural issues and the support organisation is asking for a behaviour plan for chemical restraints and I'm like, so are they actually on this medication because of chemical restraint or is it because of seizures or is it

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because of behaviours. I just said, "Well, I want to know why and what they're on, why you're warranting that."

I think chemical restraint is a big thing that organisations and service providers don't understand, especially in Tasmania, because they haven't had chemical restraints I guess under the restrictive practices. Even locking fridges and saying to people, "No, you can't have that food" or locking away items, special items, I find that a lot of support workers still, even with the change with the quality and safeguarding coming in place, still don't understand what a restrictive practice is.

P2: MARY, there's a really insidious nature to restrictive practices and that's the language aspect of it. So what they say..... if I had a dollar for every client that said to me, "Oh, that's the consequences, isn't it, P2? The consequences is that I'm not allowed to do this or I'm not allowed to do that or I'm made to go to my bedroom", you know. So it's the insidious nature that really painting it as something else when it's actually a restrictive practice.

For example, a client who drank the coffee, you know, and is not supposed to drink coffee, so they drank coffee and they said, "Okay, the consequences of that now is that you're not going to [Self Advocacy organisation] anymore." Well, that's not a consequence of drinking coffee. The consequence is that you might be sick from drinking it or there might be no coffee left, but they're using it as a punishment. So clients don't understand the difference between what is punishment or what's restrictive practice and, you know, what's a consequence. But certainly there are a lot of providers who use the intricacies of language to paint it as something else.

MARY: Mmm. Somebody mentioned there about the Quality and Safeguards Commission, the transition to the Quality and Safeguards Commission. Did you see that there was good information, good, effective information, provided and shared widely and sort of training of support workers as the Quality and Safeguards Commission came in? Did that have any impact, do you think, on restrictive practices and the use of them?

P6: I think training is available. The senior practitioners have always said we'll go out to group homes and do the training, and stuff like that, with the staff, but it's just the organisations I guess under the NDIS getting all the staff together and how do you pay the staff? We're in a business model now. Everyone thinks about the money. So the NDIS don't pay for training for staff and stuff like that for staff meetings and stuff.

So I just think it all comes down to, you know, it's out there and I think it's always been out there. It's just it doesn't get fed back to the support workers. It goes to management, but the training doesn't actually go down to the people that are actually doing the on-the-ground work.

MARY: Mmm. --

P5: MARY, can I just say in relation to that it might be interesting to see what plays out with people reregistering.... all providers have to reregister that are registered initially to be a provider for the NDIS, so therefore as part of that reregistration there are certainly questions about restrictive practice and then to reregister you would have to show that you had an understanding of it and that your staff did. So we might see over the next year or two an improved understanding across the sector on the ground.

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MARY: Yes. Thanks, P5. Are advocates ever involved or brought in as providers are doing their quality audits? Would any of you ever... like would you know if any one of the organisations was having their quality audit, would any of you be likely to know that? Would you be involved or brought in in any way to support people? Does that happen now at all.

P7: On our behalf, no. But we probably could be involved if, say, a client who was participating in the audit requested us to be involved.

MARY: Yes. We'll come to trying to think of some of the solutions or changes that need to happen, but I've come off a Webex meeting that goes for most of the day today with the NDIS Quality and Safeguards Commission and they are relooking at the indicators that are part of those quality audits, they're looking at the indicators right now to add in some more around COVID and other disease management stuff. But it's an area that needs attention really because, like you said, that's how the service providers prove to the Commission that they're doing their work properly.

P2: Mary, I'm involved in the audit for [TAS provider], so an ADE, so we go along and support clients who've been selected to be interviewed, yes.

MARY: Yes, yes. I've got a specific question about --

P6: Mary, sorry, I've probably noticed, like P2, a couple of services that don't usually refer to us after they've had their audit have started to refer to advocacy, so I don't know if that's from a quality and safeguarding picking up on stuff through the audit to say you probably should have referred to that...--

P5: Yes, there's actually a specific section about advocacy.

MARY: It's slightly off topic from what we're talking about today, but it is related. What barriers do people face in making complaints about the use of restrictive practices? P8?

P8: Yes, I think that the nature of restrictive practices is that either there's an ignorance of rights, so the staff are not aware of what they're doing, or maybe they're ignoring someone's rights, and so that person is isolated, as P2 was saying. And so if there's not really a great knowledge about people's rights, they're not really going to know about advocacy either or about when to refer to advocacy. So it's sort of like a double isolation chamber.

MARY: Yes.

P8: Just an observation, yes.

P9: Sorry, you go, MARY.

MARY: No, go.

P9: I was going to say it's the same for people with disability. Many don't recognise what's happening is restrictive and taking their rights away. So having the power to speak up about

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something when you don't recognise what's happening is impossible, you know, without someone independent there letting people know.

MARY: Yes. Thanks. So do you think, well, basically what you're saying is people are not making complaints about restrictive practices because neither they nor the staff that are putting the restrictive practices in place are properly aware that these are restrictive practices, yes?

P8: Yes, that's right, or how to actually have a discussion with an advocate about it to even sort of talk about it. So I think that's one of the great things about having a Self Advocacy group is that people can have those conversations with their peers or there's an advocate there as well, so that can be a good opportunity for people to do it directly.

MARY: Yes.

P8: But not everybody goes to Self Advocacy groups.

MARY: No.

P4: The other issue is, as P9 and P2 said, people are isolated so they wouldn't know, help them understand what's happening to them, so they don't have any avenue for complaints. Often if there's families involved, families are kept in the dark and they're not involved in what's happening with their loved one or siblings or their sons or daughters. So there's a double whammy. The third one is families sometimes get it wrong because they don't understand what's happening.

MARY: Can I just follow that up, P4? In the first place you were saying so families where their family member is with a service provider, the families are kept in the dark and they don't understand that there's restrictive practices being used. But was the second point families themselves might be using restrictive practices... is that where you were going with that second point?

P4: No, it wasn't where I was going but it's a very valid point. It is true that has happened as well. Family sees their son/daughters like two years old, when families still see adults like when they were little kids, exactly the same way they were when they were little, or other siblings, family, even though people are adults, feel the same and that's also why this can happen.

MARY: Yes. Thanks, P4. P2 put a comment about that many services have "whole of life", so in other words the same service provider is responsible for every aspect of the person's life. Now, that's meant to be changing. Is it changing in Tasmania or are there still, do you think, a reasonable number of people in that situation?

P8: I think it is frowned upon in Tasmania, but I do know of a few services in particular that have sort of grown really quickly, but also while they say that - they actively discourage other services coming in to group homes to provide day service, so for somebody who perhaps needs the infrastructure of their home, it means that they don't have another organisation coming in and being a witness to how things are for them within the home. So, there's some sort of structural barriers there.

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And I've also seen big services that provide whole of life not consulting with families around the way that they provide service and have made applications for restrictive practices without informing families even though they've been nominees.

MARY: I just want to ask a question about guardianship and people under guardianship. Does it protect people/not protect people... what's the sort of consensus? People who are under guardianship; official, formal guardianship, are they any less likely to have restrictive practices in place, or will guardians agree to any restrictive practices that a service provider says they want to use?

P7: I think in effect guardianship can, when misused, be a form of restrictive practice in and of itself. We've had a lot of reports not necessarily of guardians, although sometimes guardians, but more frequently public administrators of kind of overstepping their authority and restricting the client's access to their own finances and keeping information from them that would be used by the client to be better informed on the way that their finances are being handled and, yeah, we get a lot of those come through on a regular basis.

MARY: I have to say every conversation with a group of advocates who know what they're talking about is incredibly depressing really because these things change so slowly, if at all, you know. So the whole point of having the Royal Commission and the difference that we want the Royal Commission to make is to make some changes so that if we were having this same discussion in five years' time, if we can all hang on that long and survive in the advocacy sector for that length of time, we would like to come back to this in five years' time and things be better, wouldn't we? We would like that advocates might be working on other issues, but that restrictive practices would not be a daily thing that they see and recognise and have to help people to deal with. So, what has to change? What is it? What should we collectively be telling the Royal Commission that they need to... their interim report has just come out. We want to see some really hard recommendations in the final report the Royal Commission does.

P7: I think that's a very difficult one because you've got to balance duty of care versus dignity of risk and that's a very difficult thing to do, especially when you're dealing with guardians and administrators who would generally err on the side of caution when working with a client so that they'll generally try to keep the client safe and stable rather than acquiesce to their desires and wishes which they should within their rights be able to do.

For example, like a bloke that I worked with under a guardianship and administration order was - he was denied access to all of his finances just because the guardian administrator thought that he would go out and purchase copious amounts of alcohol and drink himself into a stupor, where like any regular person who's not under a guardianship order would be able to go and do that of their own free will. This person here was denied all of that and access to his finances to even make other purchases outside of alcohol or to buy gifts for his children or gifts for his family and, yeah, just because they were so scared of this person going out and kind of drinking himself into a state that they just completely limited his freedom by cutting off his finances directly.

MARY: Thanks, P7.

P2: MARY, there's... one of the other things is that people hide behind duty of care and they forget that upholding people's human rights is an aspect of duty of care, but they totally just don't

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get that, so people's right to take a risk. But one of the really fundamental problems is that people with disability are seen as less than and those who need to be protected, as opposed to, you know, risk takers like the rest of us and have that opportunity for risk.

The Public Trustee, you know... put a group of advocates in a room and mention the word Public Trustee... it's just a completely different standard. It's just they hold people with disability to a completely different standard than the rest of us are held. I can go and blow all my money on cartons of wine if I want to, but it's just a completely different standard that the Public Trustee hold people and really ridiculous statements.

There's an example that P6 had where the Public Trustee, actually in this NDIS environment purchased a wheelchair out of a person's money, own personal money. They purchased a wheelchair, where that's the role of the NDIS, and they say things like, "No, they've got to have this big nest egg because they might have to go to the hospital." Well, at the end of the day they can go to the public health system. It's a completely different standard that they're held. So it's this fundamental issue around they're seen as less than, need to be protected, yeah, and there's not enough focus certainly on rights.

P5: Mary, this very same group of advocates that you're talking to, we raised an unintended consequence when the NDIS came in because they made... they didn't look at their legislation and then how it impacted on other legislation. So we said at the time as a group that we were really worried about the unintended consequences of people taking guardianship, families taking guardianship, where they wouldn't necessarily have had to do that and they took guardianship so that they could be nominees in the NDIS world and have a say in their son or daughter's plan where they wouldn't have ordinarily taken guardianship before and that's been a serious consequence I think and totally unnecessary.

So when you think of what can be done, well, before governments legislate, they need to look at other legislation that they have and see how it's going to impact, what the impact will be on people with disability because I think that was something that could have easily not happened in the first place and advocates said that there was an issue and no-one really looked at it and therefore nothing was done. So here we are years down the track and we've got more and more people under guardianship unnecessarily.

MARY: Yes, thanks, P5. And the NDIA are supposedly doing a big piece of work internally about nominees, but of course they might be going to make the situation worse not better. We do need to kind of get in to have some discussions with them to understand that a bit better. P10 or P11, I just wanted to check whether, from the citizen advocacy perspective, you have any comments about restrictive practices and how citizen advocates see them, deal with them, talk about them.

P10: Certainly we've had a bit of a trend I guess, because the people we service don't often have many people in their lives so are often appointed a public guardian, and I've noticed a real trend recently with the public guardian's authority over all sorts of ridiculous things. So we had a person recently be arrested because she went to see her boyfriend at his house, even though she spends three days a week with him... she went on a different day, so the guardian sent the police to come around and arrest her.

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This poor girl was absolutely petrified. It's nothing to do with her guardian, her guardian obviously wants nothing to do with her either because she's made no effort in obtaining any of her choices or taking into account this longstanding relationship that's been going for over 20 years. So I don't know, I don't know whether there's this extra power that's existing at the moment.

So that's been a real trend with a lot of the people that we service, being appointed guardians, being appointed for whole-of-life decisions, not just important things that are supposed to be decided on at the time, like accommodation or crisis applications, and they don't ever seem to go away. They seem to just roll over year after year with no thought into why that needs to be.

MARY: Yes, thanks, P10. It looks like we do need to pay attention to that issue about, as somebody said, guardianship itself being used as a restrictive practice. P2 has made the point in there about the decision support pilot, which came through DSS and there's just one advocacy organisation in each state or territory that has some funding for this decision support pilot and P2 has made a point in the chat that because of the work they're doing through that pilot, the guardianship people are consulting more and refusing some orders. So that's a useful positive to see and there should be more of it.

Why else... any other things that you can see, either in terms of laws or policies or training for staff or other things that need to change to reduce the number of restrictive practices that you see in place?

P6: I think consequences for service providers around using unauthorised restrictive practices because they seem... I know I've worked on a case, the senior practitioner said, "You've got two weeks", because there's been complaints put in about unauthorised restrictive practices, "You've got two weeks to provide details to me" and it was eight weeks later before they provided the details to the senior practitioner. So the organisation thought they have law of their own to do whatever they like and they've taken away from this person having things that were dear to her or having milkshakes with no justification and it's like they were fined, or something like that, I don't know, but there was no consequence for it. They just did everything in their own time.

P9: I think there needs to be a real pushback too to make sure that there's evidence of many other things being trialled before jumping straight into a restrictive practice because in my experience it seems like it's almost the go-to and so long as you've got the paperwork, that makes it okay, but we know that then it increases sometimes in people more behaviours, more feelings of isolation, more behaviours. So, I think there needs to be more extensive evidence of what's been done prior and really having that as a last resort.

MARY: How else or in what way could and should advocates be used more in this context in any way, in any and every way that advocates can be useful?

P5: Advocates are an excellent safeguard, Mary, obviously, especially a rights-based safeguard and given that we've always struggled to keep funding or get enough funding, there's just not enough advocacy because advocates are also involved in general awareness raising about people's human rights. We're not just standing alongside people and advocating for them. We're doing a lot of that filling in the gaps, trying to make sure that there are clear pathways for people so that they can get their needs met as well as raising awareness.

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So, I think the safeguarding area could actually be reviewed and even if you look at the NDIS now, well, if you were worried about a provider, you can report to the Quality and Safeguards, but what about if you're worried about a family member or what about if you're worried about a neighbour exploiting someone? You know, we don't... we could see practices... you can actually see a lot of worrying things happen across mainstream universal services, but you can't... they're not all registered with the NDIS. So where are we going to go to safeguard people? What are the safeguards that exist? I don't think there are enough of them.

MARY: Yes. Thanks, P5. Anybody else got some quick tips about what else if advocates had the resourcing and there was more capacity in the advocacy sector, what else could advocates do advocates and/or Self Advocacy groups, to keep a rein on restrictive practices?

P10: It's been flagged before... I guess this isn't direct advocacy, but community visitors scheme being introduced to Tasmania.

MARY: So if there was one, you think that would be a useful addition?

P10: I think it would be a useful thing, you know, particularly we see people who don't have any family or friends involved in their life and they're often the people that aren't when restrictive practices are placed upon them, it isn't noticed because nobody is looking out for them. So, I think a community visitor scheme would be an extra benefit to know that people are going in and keeping an eye out on vulnerable people that are isolated.

P12: Mary, I agree totally with P10 and I think if you look at the experience of the decision support pilot and the number of... and the identification of unauthorised restrictive practices that came with that, it actually again shows that... it's evidence of the benefits of having that kind of outreach and tapping into people in that more proactive productive way.

MARY: Yes, thanks.

P2: Mary, lots of behaviours of concern or communication is because people feel powerless and you give them an advocate and you go through a process of helping them to determine what it is they actually want, you know, and a lot of the time you get to a place where it's just that that person actually wants something that the provider or whoever is saying that they can't have.

So, there's that... I think advocates should have right of entry and particularly around people who have no family. The services that I'm thinking of that have whole of life, they have so many people there who have no family or no significant other and yet they do everything. They go to their planning meeting, they determine who their coordinator of supports is, and usually that's someone who gets along with the provider and they make decisions for the person as opposed to them being part of making any of those decisions. So there needs to be some definite safeguards for those people who have nobody alongside them that can help them understand their rights and actually have a real meaningful say in things, in decisions.

MARY: So, P2, some kind of, sort of allocation of an advocate to certain people, people who don't have family, the same group you were talking about, P10, really, so people who are only looked after by a service provider, don't have family, don't have friends, don't have other supports.

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P2: Yes, and I doubt that... the Agency doesn't offer that. They go along with their service provider to their planning meeting and they're not going to say in front of them, "Yes, I want"... they don't even know they can change services or what that might mean. So absolutely it shouldn't be ... the power shouldn't be... you know, depressingly this seems like the power is moving back to the providers from what we see, yes.

MARY: We might move the discussion on to the other area, but it's linked and already some of the things that we've talked about of course are very relevant to segregated settings. So what are the common features that you observe in environments that foster abuse, neglect and violence and exploitation?

P2: For me, the people that... when I've seen things happening or people have raised concerns with me, it's conflicts between residents because there's no choice. They're lumped together with a group of people they've got nothing in common with... had no choice who they live with, no choice in the staff that work there. It's not a home. It's their workplace, you know. It's all taken away from them. And often staff are too busy... big turnover of staff.

MARY: Nods from people on the screen really.

P6: The organisations think they know what's best for people instead of consulting with other people as well. Like I know I had an incident in the segregated setting with a family member and they said, "Oh, we've changed worker because it was in the best interest of her to change that worker" and I'm like, "Who are you to make that decision to say that that's in her best interest? You've had no consultation with her and you've had no consultation with anybody else in relation to changing that." But they just said, "As an organisation, we think that's in her best interests."

MARY: I was just going to say, of course, threaded through everything that you're all saying is the lack of any broad understanding that all of the people that you work with have rights and have their rights to have their say about their lives. It is kind of fascinating and horrifying, isn't it, that we're seven years into the NDIS having started and supposedly all about choice and control? Would any of you have a sense that people have... have people's choice and control increased since the NDIS came in?

P6: I think people with a disability don't talk... they're not given the chance to have input into little things ... how they stand up to people and say we've been abused or neglected or exploited when they're too scared to say "I want to have that support worker" and they're told no. If they put in something to say this has happened, who's going to listen to them?

MARY: So, the segregated settings that you advocate for people in, what are those settings in Tasmania that you're mainly dealing with where you're supporting people with disability?

P4: In the north we've got a setting. In Perth [in Tasmania] there's 45 people living together that have been there for a long time and we haven't seen much changes with the NDIS other than there's more staff than people and people are even more overwhelmed by the amount of people living there. It's not a home. They've got nowhere to have a bit of space, absolutely nowhere. There's a lot of staff but people don't think people's lives have changed as far as decision making and where they want to live and what they can do.

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I went to a plan review for somebody last month and they assume on the plan of that person that that person was happy to stay there and when I got involved planning with this person and asked him what he would like, his goals, what he told me is, "Get me out of this hole, P4." But it goes on his plan because the service provider did it with him, he was happy to stay there.

We haven't witnessed much changes in those settings with the NDIS other than people being overwhelmed and more staff than they had before. It's fascinating to see hive of activities and there's nowhere for people to go for a little bit of privacy.

P8: I think what I've seen in service delivery in those big group homes or large living arrangements, conglomerate living arrangements, is that service providers are really, really preoccupied with their systems and how they're going to make their systems work within the NDIS and then how they're going to make that system look like it fits within the choice and control kind of paradigm. So I've seen services saying, "You can't have those extra hours of support to do this thing because your NDIS plan won't allow for it." Now, when I've talked with an LAC, they've said, "No, no, they've got lots and lots of hours left." It's really about the service not wanting to go back and do an extra - amend their service agreement, all of that extra admin.

I've also seen people who have been promised a particular selection of workers, so you'll have your own workers, you'll have your own team, it will all be about your preference, and so people saying, "Okay, can we interview my team?" "No, you can't, you can have a choice between these people because they're the ones that have got that line free." Then we can't guarantee that that team will stick with you because we might have to send them somewhere else and you can just about guarantee that as soon as somebody has got a stable team that is wrapped around them and working well, some of those team members are identified as being great so they've got the ability to go and work with someone else.

So that is a pattern and coming from service delivery, it's something that I was always fighting against. I've seen that really, really ramp up since the NDIS has been introduced.

P2: I think, Mary, there's been a real lack... certainly within Tasmania, a real lack of creativity in terms of other accommodation models. It's like the five-bedroom group home, that's it. There's lots of great creative different ways and the evidence says that people living with profound disability can live successfully in the community with the right support, but there's a lack of will within the NDIS to actually enable that to happen. So as a result, you just end up with your standard five-bedroom group homes, which is where lots of abuse happens.

The other thing that we've seen here, and particularly in the northwest coast, is people being evicted because if family start to become... ask questions, if they don't like questions, and where tenancy is tied to the provider, then people don't have a choice to change services if they're not happy and what happens is they're just asked to leave and pretty much they're evicted. We've had, what, three of those in the last really little... short time where people have just been asked because the families have said "this is not good enough" and have started to ask questions and demand for better.

MARY: P2, what happens then? So the provider says, "Right, you're out." Then what happens? Is that the point at which the family then comes looking for an advocate to help?

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P2: Yes, generally ... what's happened in every single one of those cases is that the family have been intimidated and they don't want to pursue it any further. There is two that's going to end up with so they've basically... basically they've said they don't want them, it's not going to be a very nice place for them to live anyway and so we're just going to find somewhere else because the families don't want to... they don't want their family member living in an environment where they think they're not welcome and that they might get a hard time. But at least two of those issues are in the process of making a submission to the Commission.

MARY: Oh, good.

P2: It seems to be it just seems to be that that's the go-to now for at least a couple of providers - "Oh, well, if they're not toeing the line, we'll just ask them to leave."

MARY: What I was just going to say, there's so many of the points that you're all raising that need proper follow-up and what I'm thinking, when we get the transcript of today's workshop, I think what we'll do is we will we'll send it back to you anyway, but we will also do some analysis of it to pick up the systemic advocacy issues because there's so many, so many, and we need to sort of analyse it and pick up which ones need to be taken to the NDIA, which ones are for the Guardianship Tribunal or Guardianship Board. So there's an extra piece of work that I think we will do and then sort of feed it back to you and some of these are national issues and some of them are specifically Tasmanian and need to be picked up.

But that one, P2, about the people being evicted, we are hearing that around the country. That's not just a Tasmanian one, that is something that seems to be very bad in Victoria for a while and there's something that... which means that the power imbalance really has got worse, hasn't it? Instead of improving with the NDIS coming in, it's got worse. It's given the service providers more power, not less, and we have to find a way to shift that.

P2: At least in one of those cases the safeguarding commission were completely useless. It was terrible. It was like you may as well save your energy.

MARY: Okay, it needs to go to them too.

P5: Can I give you an example for kids? So we meet a lot of children that just before they're transitioning out of foster care, a lot of kids that have got disability, and if we're lucky we'll get to meet them when they're 16, but often it's when they're 17 and they are now transitioning to somewhere, often the child safety system aren't sure. But coming back to what P12 said, there's often... if you look at the cases of those kids, then they could have... if they had the right services and supports initially and many years before, then they wouldn't even be in the child safety system in the first place.

In Tasmania we don't do prevention well. We don't do intervention well, but we definitely don't do prevention well. So many kids are ending up as a service of last resort in the hospital, in a hospital setting, which of course is a totally inappropriate setting, but then when they get there, that's because there is nowhere else for them to go, and then the State Government has nothing else to do other than to put them in a segregated setting from that point. So, it's way too late.

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There has to be a strategy for prevention because we know what happens with people with disability. From the time they're born, you can see indicators for children that will tell you that this child is going to require more assistance, that this family is going to require more wrap-around services and support so that that child doesn't end up in the hospital with the family totally broken down and someone saying they're going to walk them off into the bush and leave them there.

We keep on saying oh, we don't ... of course no-one wants an institution. We absolutely don't want one. But what the State Governments are almost doing here is forcing that to occur because more and more children are ending up at hospital because they haven't received the services and support that they required when they were young and everyone is kind of throwing their hands up and going, "Oh, well, no-one does it." We just don't have the right supports.

I think that there's a massive body of work that needs to be done and the State Government can't just say, "Well, because the NDIS is here, it's all over to them." They're responsible for a high number of people. You know, we've got about 10 children on our books at the moment that we're working with long term just as a safeguarding mechanism because they're really experiencing that ongoing neglect of a system and right across the community because we're not servicing them well, we're not providing them with any real assistance, and that means that they end up not being educated, being in their houses, you know, having increased challenging behaviour due to frustration.

One child yesterday was reported to me that they went into... they didn't want to go in a taxi and there was one taxi provider who was going to take them home, so to get them home eventually after half an hour, someone managed to get them in a taxi. But then when they were in the taxi, they ripped off the handle, they vomited and threw vomit on the taxi driver, all kind of things happened, and now that child won't be able to get any taxis.

And if you look back... because that child is 12 years old now. This child had indicators that we needed to really do something about when that child was 3 years old. You can see the writing on the wall now. You can see well, they're going to be at home more and more, they're already in danger when they're at home not from being abused by their family member because child safety look at them and say oh, no, they've done an assessment and they've said well, they're with their family, they're fine, but at some point because that child is getting more and more frustrated and they are going out less and less, then that's just going to blow. You know what's going to happen and it will again be that that child becomes segregated, and they'll have to go into care and it's all totally preventable.

MARY: Thanks, P5. I think there's a really useful piece of work some of which has been done, not by us but by other people, about which of the states and territories are doing any better with that group of children that you're talking about. Have any of them managed to get their system to do that wrap-around stuff? So it's a separate topic really. Like you said, the prevention and early intervention stuff is important.

Can I switch the topic to one of the other segregated settings, so the criminal justice system and sort of all aspects of it? Do all of you, any and all of you, have much involvement with people with disability who are involved in the criminal justice system? Are you brought in, asked in, push your way in and then do you have any success when you do manage to do that?

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P7: Not so much directly on our part. We often refer to free legal services when we get those types of cases come in. But when we're looking at clients who have had something perhaps done to them and they need to make reports regarding a crime that's been committed or something that they've witnessed, then they're often treated as unreliable and their thoughts and their observations and their witness testimony is often kind of seen as lesser than that of somebody without a disability. That's been a big concern for many clients that we've actually worked with in that particular area.

MARY: Yes. Thanks, P7. Does anybody else want to dive in about any part of the criminal justice system that you've seen people get brought into?

P2: Yes. When people - one of the recommendations from the UN was that all police lawyers, magistrates, everybody have disability training and it absolutely needs to happen because we do support people through the legal process and that's because solicitors largely don't know how to talk to people. And so, people can't make an informed decision about their legal issues because they don't actually understand what their choices are because of the way that the legal fraternity communicate with them.

I think we've built the capacity of a number of law firms over the last few years and so they're our go-to solicitors and they've done a fabulous job in modifying their language and making sure that people are actually understanding information. But again, where is the proactiveness in terms of where is the money to do that? There's been a lot of time and effort working with those firms and with clients over the years to get them to that stage. But the court process is so inaccessible to people. They don't understand what's happening when they get there. Half the time they can't hear because it's just the way that the courts are set up. It's really inequitable for people.

P7: I was just going to build on what P2 was saying. We've experienced a similar thing where a lot of our clients are finding, like, communicating with lawyers to be extremely difficult as they're not necessarily willing to kind of make the effort or are not trained in how to actually communicate with people with disabilities and often times the lawyers will get frustrated and either not act in the most optimal way or withdraw completely because they're unable to communicate with the client.

I've had an example where the lawyer themselves was actually trying to do so by communicating through a third party at the client's direction and the lawyer was then charging the client double for that time. So, they would charge for the original communication with the client and then the client would need the information communicated to their third party so then it could be explained in proper, understandable terms to the client and then the lawyer was charging them for that again, which didn't seem very fair to them at the time, and we've actually made a submission about that one a few months ago. So yes, there's definitely a lot of problems and there seems to be a very large gap in the support system for people with disability to engage in not just criminal justice legal services, but just legal services in general.

MARY: Thanks, P7. Does anyone want to dive in about any of your experiences of restrictive practices or the segregation of people with disability in the criminal justice system and any changes that you can see that need to happen?

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P8: Yes, I think that there's just such a huge reliance on literacy, isn't there? So, whenever I've had anything to do with the legal system and when I've been supporting people, a lot of it has been about being a point of contact because everything is via email now. If you don't have literacy, if you don't have an email address, and if you don't understand what the next step is or why it might take a little while, then that's an access issue. That's massive, it's massive.

And I guess the other thing is what P7 was saying, and P2 as well, just being there to be able to reframe or interpret for people so they can have a really clear understanding and also having no skin in the game saying do you need five minutes time out for people to know that they have time to consider their options and to be able to think about things.

P2: In Tasmania there's supposed to be within Tasmanian police policies in relation to how they deal with people with intellectual disability... we know because we helped them in the first instance develop it, but they're supposed to consult. When a person is identified as having a disability, they're supposed to call a third party to assist them, but they don't do it and they will just... people who are accused of serious crimes will just be video interviewed and have no idea about what they're agreeing to or what's happening.

We had one the day before yesterday and he just said, "Oh, well, because they're the police, you have to follow everything that they say." So, I informed them about their rights, you actually have to follow lawful direction, but you don't have to agree to be video interviewed. They weren't told that by the police.

So people just want to comply and when it comes to court, then they probably agreed to something they had no idea or they've asked someone about a timeframe and someone with an intellectual disability might have trouble knowing how long it took them to get from one place to the other or what time something in the day happened and the police had no idea around how to respond to ask questions to particularly people with intellectual disability.

But Tasmania had a review into communication assistance a couple of years ago and that's gone nowhere, so there's been absolutely nothing come of that.

MARY: Yes, did they trial them for a while in the court system.

P2: Not to my knowledge, no.

MARY: They thought about it and then didn't. Right, okay. Anybody else? We'll just continue on the criminal justice system for another couple of minutes.

P5: [3 TAS Advocacy organisations] are involved at the moment and it was prompted through the justice area and the Magistrate's Court, we were involved in making some videos to try to make the pathway before you go to the Magistrate's Court and then when you're at the Magistrate's Court more of a level playing field if that's possible for people with disability. And I know that that really came out of the disability justice plan in Tasmania that was updated only a couple of years ago and I know that the justice area is keen to improve and the lawyers that we've been working with are keen to make changes and to hear about what's wrong with the court system and is there anything that they can do, you know, quite easily to make changes and if there are more systemic concerns, what are they and that they'll start talking about them and doing some work across the

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justice area. So that's been fairly positive, I think. Because they came to us, you know, rather than us having to go to them to say this is an issue, they already know it's an issue for people with disability. So I think that's been positive.

MARY: Yes. Thanks, P5, That's a really good example of the kind of area where there's sort of potential for systemic advocacy to make a difference there because there's a kind of preparedness inside the system in some way.

So, I said earlier about the notes that we'll send back and that we'll try to pick out the systemic advocacy challenges and opportunities I suppose. What we might do is send it back and then ask all of you to kind of have some input because you'll have a clearer understanding of things you know about that might be... that you think or you've heard they're going to review that next year or whatever it is.

So I'm interested to know then, in the Tasmanian context, does the advocacy sector get together in any regular basis now in a way where you could look at systemic advocacy actions that you wanted to collectively act on, you know, over the next 12 months or do you have that sort of... is there a pre-existing sort of way that you could do that already?

P5: I think, Mary, that we probably need to do it outside the meetings that we're all invited to because we do all go to an NDIS advocacy network meeting and when we're invited, we're often all talking to agencies or, you know, people that invite us to go along to speak with them. But it's probably better for us as advocacy organisations to come together outside that and have some kind of strategic plan so that we can collect what is going on now and talk about what we're all doing about it and then what our plan is for doing something over the next 12 months and who we're working with on that collaboratively and then we might get some more traction, I suppose, for people with disability. We might make more progress.

MARY: And I think doing these groups has... we realised as soon as we started talking to the advocates in the ACT in the first one that there's kind of a missing piece and the missing piece is some sort of strategic look at these systemic actions that need to be taken or issues that need to be pursued. And the purpose of these workshops in the first place was deliberately and specifically to feed all of this into the Royal Commission, but it's obvious that regardless of whatever the Royal Commission does with all the information and the hearings and as they add evidence and put it into their reports, advocates will still have to keep working on these things.

So we're going to see how - for some of the issues that you're talking about, they have to be addressed in a Tasmanian context, but some of them can be looked at in a bigger picture across the country and there may be some good examples elsewhere of where the disability justice area is an example where there are some little beacons of light around the country that might be able to be brought or suggested in Tassie.

P2: Can I add, in terms of some of those national systemic advocacies, [our organisation's] members and Inclusion Australia, we contribute to their systemic work.

MARY: Yes, thanks, P2, that's a good point because looking at who addresses and which group of organisations works on them nationally is another sort of strand of this.

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We haven't got very much more time, so is there anything else about any part of segregated settings, we haven't talked about ADEs [Australian Disability Enterprises] at all. Do you see them as segregated settings? Are they getting any better, any worse than they were? Nobody looks like they think they're getting better. Just any quick feedback or input about anything to do with the ADEs as a segregated setting.

P2: I feel like I'm talking too much. There absolutely is still not an approach of 'this is a pathway to open employment'. Once they get their hands on people and they're productive workers, they keep them at all costs and there's still not enough focus on moving people and using that as a transition even though we think they shouldn't exist at all. So, yeah, that lack of opportunity to transition people into open employment or even talk to them about what it is they actually want in terms of their employment goals. It's very limited.

MARY: Yes. Thanks, P2.

P4: There is still definitely people... often just after college or high school for the rest of Australia and they work for an ADE and 20 years later they're still doing the same thing, they haven't moved, with no opening to open employment. I don't think that's changed. We can't see the ADE here that there's any effort for the ADE themselves to let people... try to get people open employment. They've got good workers who may be very, very successful in open employment that's for sure and they hang on to them because they are the ones who make them the most money with very little pay.

MARY: Do you see that ADEs are a place where violence, abuse and neglect and exploitation absolutely exploitation, but talking about the others - are they settings where people are vulnerable to violence, abuse and neglect or is it not quite that? Is it almost the opposite - that they're in this looked after sort of situation?

P12: Mary, the comments that I'll make probably come more from conversations through Self Advocacy groups and peer support groups, but I think certainly, yes, people are really vulnerable in the settings, again for all those reasons that it's closed off. There isn't the natural interactions with the community, there isn't the traffic that's going, you know, through.

I'm with P4 and his comment about how people go to an ADE and they get stuck there and often that's actually done in the name of 'it's their choice'. But the opportunities to actually revisit those kinds of... those sorts of impacts on their life just aren't there and the support to actually do that.

One of the things that people have raised often, though, really is about what happens in an ADE when there isn't enough work and when people are actually bored out of their brains and some of the kinds of... the impact that that actually has on people's behaviour, on their communications and the whole sort of interactions then that happen between people. And again, that kind of triggers off that whole thing again of, "Oh, the person really can't be here, they actually really need to be relocated somewhere else" rather than actually addressing some of those core issues.

It's a real... yes, it's a real worry to me that the language of the interactions that there actually are, around not only around ADEs but the whole sort of areas of restrictive practices too, and P2 raised this sort of earlier on, of it's consequences, it actually isn't about restrictive practices. I'd say exactly the same thing that people are actually told that it was their choice, or they're presented

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with choices that are only acceptable with the service provider. So, it really actually isn't a choice. I mean, it's not... it's a sort of blue socks or red socks and that kind of thing, not really bare foot in the sand running along the beach. I think that there's a lot of things around communication and its connection with people's values.

MARY: Thanks, P12. We're coming to the end of the time, and you've given up an hour and a half and I don't want to take up more of it. So, thank you all very much for your contribution today. As I said, we have got those surveys. If you have time and interest at some stage, feel free to go into there. P3 is there anywhere else you want to suggest to any advocates about where they can put in some feedback if they want to?

P3: The surveys and also created some surveys for Zoom-in discussions, which it was great to have P5 along talking about access to education and some of the other topics we're looking at.

MARY: So a quick plug for those Zoom in On sessions. We're doing them on Mondays at lunchtime, 12.30 to 1.30. There's a different topic each time. Again, they're prompted by the Royal Commission, and I think next Monday's might be child protection I think. There is a schedule of them. P3, we might get you to email that list of the Zoom-ins out to all the advocates that have joined in today so they can see them. They're for advocates from anywhere around the country, whoever wants to join to discuss those topics.

So I'll just say thanks very much to everyone. I'll just pass briefly quickly to the Royal Commission, P13, if you want to say something.

P13: I just wanted to say thank you for us being a part of the discussion. We greatly appreciate the opportunity to listen to you all as advocates share your experience and knowledge. We really appreciate it and thank you, P3 and Mary, once again for making today happen. Thank you.

MARY: Thanks, P13. So, thanks, everyone. That's been a probably slightly frustrating experience because I know you're talking about the same things that you have to keep talking about, but the Royal Commission has to hear them. They don't know it all and advocates need to tell them the truth of what happens on the ground.

And, as I said, we will send back – P3 and I will have a think about it and we'll see how we do some analysis and tease out some of these systemic advocacy issues, national ones, and Tasmanian specific ones, and then feed them back. And let's try to keep thinking about how we... what can we set up next year I'm not contemplating anything before Christmas, okay... what can we contemplate to set up next year where we have some way of doing some strategic thinking about some of these systemic advocacy issues that need to be worked on. Thanks very much, everyone.

(End of workshop)

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Comments typed in Zoom chat function

P2: Many services have whole of life, so they don't have any opportunity to make a complaint.

I can list the services who have whole of life, and who go to the planning meeting with them, so no option of changing services in the face of their SP

Decision Support pilot has been a game changer for Guardianship, they are consulting more and refusing orders

whole of life

For those who have an advocate or family maybe