

# DANA and DRC Workshops with NSW Advocates - 16 & 18 March 2021

This document is a redacted and edited version (for privacy reasons) of live captioning transcripts from workshops held over Zoom during March 2021.

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 organized 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](http://www.dss.gov.au) for more information.

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## Transcript of Zoom Workshop - 16 March 2021

*[DANA CEO, Mary]:*

We might just get started and other people can join. There are other people registered but I am sure they will join as they can. So, first of all, I will start by introducing myself. For those who don't know me, my name is Mary Mallett, and I am the CEO of DANA, the national peak for the disability advocacy organisations.

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So, I would just like to acknowledge the Aboriginal lands that we are on today. I work on the lands of the Ngunnawal people, but there are various Aboriginal lands that you are all sitting on today and I wish to acknowledge the traditional custodians of all those various lands and acknowledge that we respect their continuing culture and the contributions they make to the life of our communities. I would like to welcome any Aboriginal people who are attending today's workshop.

So, this is part of a series of workshops we have done with advocates in different states and territories. This is the first of two New South Wales workshops. The second one is on Thursday, so those of you who have colleagues who weren't able to join today, you can please encourage them to join in Thursday's meeting.

We record these workshops. Now, we record them just to help us capture the quotes properly. We don't publish those recordings afterwards. We don't publish any video. Any material we use, we use it in a completely deidentified form. If you want to say something, just put your hand up and speak. For those of you who haven't got your cameras on but are listening in, you just have to dive in. Just interrupt and say something, but if you can all keep yourselves on mute when you're not speaking. You can use the chat function, so Siobhan is DANA's Royal Commission Policy Officer and Siobhan keeps an eye on what everybody is doing and who wants to speak and also manages the chat. Siobhan has already put the link to the captions in the chat box today for those who would like to use the captions. They open in a separate window from that link. But if while we're talking about an issue, you have something you want to say and you can't interrupt or for some reason can't get into the flow of speaking, then please add your comments into the chat box. That's been used extensively in the previous workshops and it's very useful.

So, these workshops are done with advocates and with people from the Royal Commission attending and listening in, I suppose, to learn from your experience in the sector.

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

*[DANA CEO, Mary]:*

Something that I haven't probably mentioned in these previous workshops, but it just struck me, as all the advocates were introducing themselves. The money that funds the work that these advocates do is a complete mix of federal and New South Wales state funding, and what's interesting is that's not particularly relevant to how the advocates introduce themselves or the work they do. It's relatively seamless. For the people on the ground, they just get free funded advocacy, but it is combined or a jumble, a mixture really of funding from both DSS at Federal level and from New South Wales State Government

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that is funding the work that's being done by these organisations.

So, we will divide our time in two and we're going to start with talking about restrictive practices. [Advocate 3], I think it was mentioned that you don't deal a lot with it but I'm interested to know from the rest of you: are restrictive practices a significant part of the work that you do? Do many of the clients that you deal with have restrictive practices in place? So, if you've got your camera on, just give me a wave, if that's the case, or just chime in if you just want to talk about it. I can see [Advocate 2] waving his hand, so that's true from [NSW Advocacy Organization]. Sorry, people, but things are moving --

*[Advocate 1]:*

Sorry, Mary. I didn't hear your question. It cut out.

*[DANA CEO, Mary]:*

OK. It was to do with whether restrictive practices are common. In the cohort of people that you provide advocacy for, that [NSW advocacy organisation] provides advocacy for, or any of your organisations, are restrictive practices something that you see commonly?

*[Advocate 1]:*

Yes, very common, I would say.

*[DANA CEO, Mary]:*

[Advocate 4] is waving and saying the same thing. And that's generally been the view across the sector in the other states as well, which is one of the reasons why it's particularly useful for the Royal Commission to hear from advocates on this issue because it can be a tricky subject to get to grips with. Another question then: of the people you see who have restrictive practices in place, are they authorised restrictive practices or are there as many unauthorised or even more perhaps? Anybody got a comment about authorised and unauthorised restrictive practices? [Advocate 2]?

*[Advocate 2]:*

Yes, I think one of the questions behind this is the fact of - what is restrictive practice because there's so much of a spectrum of ideas on what is a restrictive practice that it actually clouds everything that's going on. I'll speak a bit more. So, from the group home setting, it was interesting seeing what things were considered restrictive practice, particularly around locked doors, but then in the advocacy setting where I am, restrictive practice is not only when you lock a child into a classroom but it's also when you lock them out of an activity, which can happen in a whole lot of different range of things. So when is something a restrictive practice that needs to be authorised and when is it not even considered to be a restrictive practice?

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*[DANA CEO, Mary]:*

Thanks, [Advocate 2]. And I'll come back to something about that in a minute. I can see that [Advocate 16] put a comment in the chat there, so, yes, some of the people that you're working with have restrictive practices in place. They're mainly people with significant support needs and they are authorised restrictive practices. [Advocate 2], can I pick up on your comment there, which was about, I suppose, the understanding of what is a restrictive practice. So, for [Advocate 2] first, but then anybody else that wants to chime in: Do you think there is a good, solid understanding in the sector about what restrictive practices are or do you think it's confused? Is there confusion?

*[Advocate 2]:*

What do you mean "within the sector"? That would be my first question because we're not just talking about the sector; we're talking about every environment in which a person with a disability lives and works.

*[DANA CEO, Mary]:*

Absolutely, and we might tease out a few of those. So, I suppose one of the things in the first place is for the people with disability themselves who you see and advocate for who have restrictive practices in place, are they aware that that's the case? Are they aware or is it just part of their environment and it's not explained to them, they don't necessarily understand that there are restrictive practices?

*[Advocate 2]:*

What a question.

*[DANA CEO, Mary]:*

We can move quickly through the questions but that's come from something that came out of the previous workshops actually.

*[Advocate 2]:*

With a lot of my advocacy experience, I'm talking to parents, so we're talking about children who are experiencing these restrictive practices of a variety of ages, but it's not necessarily... I don't think it's classified separately as restrictive practices; it's just what they have to deal with and the restraints or the restrictions that they exist with. How that translates to an education setting from my experience, I'm not hearing that the student is involved in talking specifically about restrictive practices.

*[DANA CEO, Mary]:*

Thanks, [Advocate 2]. Anybody else want to comment more broadly about the disability support work force or disability providers and the support work force? -

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*[Advocate 3]:*

It's [Advocate 3] here from [NSW Organisation]. I just wanted to add a few things about the question that has been posed already. So in the few cases that we've come across at [our organization], I personally have realised that it's quite hard for families. Similar to [Advocate 2], I work with individuals, and predominantly in the NDIS space, so in a lot of the cases, families find it hard to differentiate what is behavioural support and where does that cross the line to restrictive practices. And then to also answer your question about is it authorised or not, without that really clear understanding from the families, the carers' perspective, well, there's a very high chance that lots of families out there are undertaking restrictive practices without knowing that it's actually restrictive practice, and then for them to be told after the fact, there's just a lot of confusion around how it's meant to work and who's responsible for what and whose responsibility is it then to work out who does the paperwork, who do I see first, who do I talk to first, and it's all just like a ball of mess in their mind, and carers become so overwhelmed with this idea of restrictive practice and all the finer details around the different environments that they're in and how that changes and what their role is, what they can and can't do, how that then varies from when their child turns 18. From my experiences, that's just been a really confusing situation and often enough it just flies under the radar. So, I guess in one way, for [our organization], we just haven't had a family who's really honed in on the advocacy aspect for restrictive practices because the behaviour in itself is just so all-consuming in any sort of advocacy matter.

*[DANA CEO, Mary]:*

Thanks, [Advocate 3]. That was a really useful description really of the issues that the families and your clients are dealing with. And I should have clarified at the beginning that: is there an advocate among you who would like to clarify for me properly the process in New South Wales of getting restrictive practices authorised? Who wants to have a go at that? Whatever you know about it is going to be more than I do, I have to say.

*[Advocate 3]:*

I'll give it a shot. So, what I understand is that somehow someone's going to recognise that restrictive practices are required in this family situation, and they'll bring in people who I believe are called a behavioural specialist, who would then prepare a behavioural support plan of sorts. If in that plan there obviously will be some sort of restrictive practice involved, they then have to take it to a board for it to be approved. I am not sure what they do there, but once the approvals come down, it's implementation. So that's my very basic understanding.

*[Advocate 1]:*

Mary, [Advocate 1] here from [NSW organization]. Can I speak to something about that, please? A recent experience that I had for a young man who I am the advocate for. He's now an adult but very recently turned 18 and has very significant behaviour support needs.

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He recently had his NDIS plan reviewed and, as part of that review process, during his 12-month plan, the family was requested to develop a behaviour support plan through a registered clinician, and they undertook that process. Restrictive practices were, I guess, highlighted as being undertaken with him by the clinician. The mother was outraged that the things that she does just to keep her son physically safe and alive were being labelled as a restrictive practice, so there was work around, I guess, explaining that situation to her.

Now, this young man, his NDIS plan review meeting took place and we explained clearly to the planner that within 48 hours he was going to be completely without any level of funding. He was left for 15 days with zero dollars in his plan, so no ability to provide any supports, because they said that they had to take time to have the restrictive practices lodged and approved. Now, this is despite the fact that the mother had willingly taken part in having a really comprehensive biz plan [Behaviour Support Plan] drawn up, had done everything right through every part of the process and had that done a month prior to the plan review meeting, and this young man was left with, as I said, no funding for 15 days and the NDIS were very aware of that. In the end, I had to raise the issue repeatedly with the state manager and they finally approved the plan 10 minutes past 5 on a Friday night after the mother had called me and said that she couldn't face going through the weekend without any overnight supports or support for her son.

*[DANA CEO, Mary]:*

Thanks, [Advocate 1]. A very good illustration of why advocates are required, to be honest. But you flagged a couple of good points there - sorry, I shouldn't refer to these things as 'good'. They're terrible stories about what happens to people and what systems do, but the language you used where you described the mother being "outraged" and the labelling issue around restrictive practices, that follows on some of what [Advocate 2] was saying, and [Advocate 3], that it feels like and anybody who wants to make a comment on it, feel free that there's a gap somewhere in the support for families in particular as their children are growing, and the children particularly who have behavioural challenges, to help families understand the way that the term that's used, what 'restrictive practices', that terminology, means and why it's used and then have plainer English and clearer explanations to help people understand it. To me, it highlights a gap in some states but not particularly in New South Wales. So, in a couple of states, there's an advocacy organisation called something like Association For Children With Disability. There's one in Victoria. There's one in Tasmania. New South Wales has Family Advocacy, which isn't really replicated anywhere else, but isn't the same as those ACD organisations and it's a gap, a gap in the funding of advocacy that we need to pick up and do something about.

Coming back to the restrictive practices, going back to what Alastair said at the beginning, does anybody want to comment about the effects of restrictive practices on people with disability and do you see examples where restrictive practices lead to further violence,

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abuse or neglect or exploitation of people with disability?

*[Advocate 4]:*

I'll throw something else in the mix there, Mary, something that came through to us this morning. We have had request for advocacy support from a support coordinator. The participant is in shared accommodation. They don't have any family members or appointed guardians. There is a behavioural support intervention which is funded through NDIS, and they need to have restrictive practices signed off. Who is going to do that? That's what the question is, and we've been asked for support on that. So that's something else to throw in the mix about restrictive practices and those practicalities about getting them signed off in the first instance.

*[DANA CEO, Mary]:*

Thanks, [Advocate 4]. It's not uncommon that advocates are sort of asked to be de facto consent givers or something for people with disability. It's not a role that advocates normally play and it's not meant to be your role but it is something that providers reach out to advocates for, as that sort of independent person, but it's another gap for people who, like you said, don't have family members or guardians.

We had put forward some questions that went around beforehand, and some of you may have had time to look at them or not. We were wondering about whether people who have restrictive practices in place are ever able to make complaints about that? But that goes perhaps to the earlier question about whether they are even aware that they are under restrictive practices. Please dive in if you have any comments or have seen people or you have helped anybody to make a complaint about restrictive practice that they're under.

One of the things that we're interested in ... is what are the improvements, what's the good practice that you see? So have any of you seen examples where somebody who has been under restrictive practices but that they've been able to be lifted or modified perhaps because of good behaviour support plans being implemented well? Has anybody ever seen an example, a positive, useful, good example?

*[Advocate 1]:*

Never.

*[DANA CEO, Mary]:*

That's what I was worried you would say.

*[Advocate 1]:*

Never. I don't think that that is the purpose for which they are designed, Mary, in my experience. I don't think that is ever thought of or in any way even a goal from anything I

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have ever experienced.

*[DANA CEO, Mary]:*

[Advocate 1], just to pursue that a bit, is that because you think the entire purpose is about managing people's behaviour for the convenience of other people, of the service support workers or others?

*[Advocate 1]:*

At times. I think often for the people who I'm providing advocacy for, it's a matter of physical safety. And it sounds dramatic, but for some of them, without the restrictive practice being in place, they would be at risk of being killed. So, in that instance, it's never even thought to review it or to look at a behaviour support plan. For the people that I support, Mary, living in supported accommodation, behaviour support plans seem to be a way of having any restrictive practice that they require authorised in perpetuity. That's been my experience across the board.

*[DANA CEO, Mary]:*

Thanks, [Advocate 1] . Anybody else want to comment on your experience?

*[Advocate 3]:*

I just wanted to add to what [Advocate 1] was saying. First of all, I completely agree with her, and from an individual advocacy perspective, the clients I have had, being the carers, often see it as a punitive measure, as if they haven't been doing the right thing. So, therefore, restrictive practices now have to be put in place. Everything that they have been doing in the past to manage; pretty much 'crisis management' for lack of a better word, must be put on hold because it's in a way seen as 'illegal' and wrong. So, what's left for them to do? It's almost like they've been put into a position where they will lose carers who are no longer able to provide the care they were doing because of these restrictive practices rules, and without themselves being informed, "What do I do next? How do I fix this situation?", they are then looking at the NDIS to say, "Well, I need help", but the NDIS is saying, "I'm going to put a hold on everything because you need to do X, Y and Z" but there is just not enough communication to facilitate that and for that to happen in a timely manner. There's always weeks and months of delay just for an understanding of what's happening to happen, let alone the actual implementation of restrictive practices.

*[DANA CEO, Mary]:*

Thanks, [Advocate 3]. Can I ask something else about access to advocacy for people who have restrictive practices in place or when restrictive practices are going to be implemented. Do people, providers or others, think of referring to an advocate? Do people get access to an advocate when they need one? Anybody got a comment about that?

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*[Advocate 4]:*

I think we only see the tip of the iceberg in advocacy. We wouldn't see that many at all, compared to what's going on out there. I guess the other point before was we probably don't see examples of when it's been a positive thing for people as well because it couldn't come across our desks necessarily.

*[Advocate 2]:*

Yes, I think it's interesting. Just going back to one of your earlier questions, what's happening in New South Wales at the moment is there is a draft Bill on the regulation of restrictive practices that's currently in draft stage, which is designed, I think, to expand the role of the function of the Ageing and Disability Commission around the authorisation of restrictive practices, and in that I believe it says that they should always be part of a behaviour management plan. And I think that when it comes to restrictive practices, the behaviour management consultant, or whatever the correct terminology is, would have more input into a restrictive practice than even the person with disability or the family members, and I think often families and carers, but particularly families or people close to them, are left out of a lot of this and in some ways they're the informal advocate in many cases and when they are shut out of the process, then that's already a problem. So, I think perhaps one way forward is to say when there are behaviour management plans put in place with restrictive practices, then people are at least informed about advocacy options around those things.

Just in terms of success stories, one of the things I find very interesting is that when I'm talking to a parent who has a child who has been subject to restrictive practices, authorised or unauthorised, that in a number of cases, it's not consistent every school year; that somebody might have better experiences in one school year than another school year or in one education setting than another education setting. So, I think that's potentially part of what needs to be explored in terms of what works and what doesn't. But usually, it's not about the quality of the authorisation or of the behaviour management plan, but it's about the approach of that school or that teacher or the communication between an educator or a system and a family who knows the person. Sorry, a lot there.

[Audio issues]

I've come back on now. I hope you can hear me.

[...]

It's my ambition to get through one of these with no technological hiccups at some stage.

[...]

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*[DANA CEO, Mary]:*

Good. OK, we will continue on. We will wind up the restrictive practices discussion in just a couple of minutes and we will move on to our other topic, which is segregated settings, but I just want to say that any thoughts you can send us, Siobhan will put in the chat her and my email addresses and any random, it doesn't matter how brief, any thoughts you have or any issues you are dealing with in the next while where restrictive practices are involved and you think, "Oh, I should have said that at the workshop" or whatever, please just send us it can be a two line email, just a couple of dot points, whatever, anything, if it just gets it out of your head and into this collection of information that we are gathering for the Royal Commission.

The other thing I should have said is that if there are particular examples that you provide today or ones you think of afterwards, again raise them with us. The Royal Commission and their submissions team and their Office of the Solicitors Assisting are always interested in examples and stories and case studies potentially that are really clear illustrations of the problems that happen across all of the issues that the Royal Commission is looking at. So, if there is something that you mentioned today and they would like to find some more information out about it, then they might come back to you about it. So apologies for dropping out.

*[Person 1]:*

Mary, can I just interrupt. Do you mind if I just ask perhaps one more question in relation to this topic? I'm conscious of time and I'll try to be brief. Is that OK?

*[DANA CEO, Mary]:*

Yes.

*[Person 1]:*

Just to expand a bit more on the role of advocates, and you have touched upon it briefly, some of you. I just want to get perhaps a clearer or better picture of your experiences working with service providers to... obviously, the aim will be to reduce and eliminate restrictive practices. Can any of you perhaps elaborate on your experiences with service providers to have genuine conversations about that aim? If not, that's fine. As Mary said, if you think of the answer later, please let us know. I'm interested to know that. If anyone would like to answer now, that would be great. If not, I'm very keen to know of your experiences in dealing and working with, or attempting to work with, service providers. Thank you.

*[Advocate 3]:*

[Advocate 3] here again. I would love to share what my limited experience is. I have just

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found that with a lot of behavioural specialists, registered ones, they're not always across restrictive practices. So, I have found that those who are great with preparing a behavioural support plan, they will then have to do their own research or speak to their managers or their team leaders in putting together the actual restrictive practice side of things. Often enough, part of the procedure, I believe, is they do need that two-person kind of check because it's part of the requirements, but I have just found... I just haven't really come across anyone who really understands the space really well, and that's a huge issue because there's hundreds and thousands of people, individuals, who might need it but if there are only a small handful of specialists out there who actually understand, it falls back on advocates. I found myself in a situation where I am trying to pore over the legislation on restrictive practices. I am going through websites trying to work out as to who does this and who does that and who do I talk to get to this set up for this family, and when I finally find that person, for example, a behavioural specialist or I'm speaking to the receptionist they kind of go, "Oh, we don't do that". So what do we do now? That's the biggest obstacle I have come across.

*[Person 2]:*

.... I'm very interested to hear from advocates about whether they're finding there are, if they go into group homes or congregate care facilities, A, whether they see or observe more restrictive practices, B, whether they liaise or get an opportunity or receive referrals from the official visitors, the community visitors in New South Wales? I would be interested to hear whether there is crosscommunication between advocacy services and the official visitors, especially in relation to group homes or congregate care.

*[DANA CEO, Mary]:*

Anybody want to comment on [Person 2]'s question and the link between advocates and the community visitors? Do you get referrals from them?

*[Advocate 2]:*

I can't comment directly on that but in terms of what I understand of the community visitor scheme, it's about referrals, so they refer things back to the Ageing and Disability Commissioner, I believe, but that doesn't necessarily go anywhere else. So they would never actually refer to an advocate in my understanding, from what I know of that. I think that's probably part of the issue. And I'm going to bounce off that to say I think there are three issues in terms of reducing restrictive practices, and the first one we have already commented on is timeliness. If something is not handled quickly, then how does it improve? So, if there's no assessment done quickly, if a school has got a restrictive behaviour support team and they don't actually provide data, which doesn't get processed quickly and things don't change, it means that something can continue for a long period of time. There is also the issue of independence. You need to go outside of the body in order for accountability to be happening, whether that's outside of the Department of

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Education, whether that's outside of the organisation that's actually managing the group home. You need that independence. You need that independent oversight and you need that independent accountability, and I think there is no accountability, there's no target set. There's restrictive practices in place. How will that change? And you see that particularly with suspensions, which I would say is a form of restrictive practice. So often suspensions are not followed up with improved changes. It's like, OK, your suspension is over; come back to the same status. And suspensions are designed to be a support ideally. The school takes a break so we can put in additional supports. So often they don't happen. So, you don't get a reduction in restrictive practice because nobody's collecting data, nobody's responding to it quickly and they don't have an independent accountability to encourage that to happen.

*[DANA CEO, Mary]:*

Thanks, [Advocate 2]. And what that...--

*[Advocate 1]:*

Mary, just to say as well... I was just going to say [our organization] has never received a referral from a community visitor.

*[DANA CEO, Mary]:*

Alright, thanks. And they're set up differently in each state and territory, or in the states where they exist, so that's something we should look into separately, the links between the community visitors and the advocates. [Advocate 2], what you were saying there made me think that if there's no-one who is held accountable, whose job it is to, like you said, collect the data and make sure something happens in a timely manner, that must be one of the issues behind the education system problems that you were talking about, that nobody's held accountable for those issues. And one last question before we move on to the segregated settings: have any of you in relation to restrictive practices had any dealings with the Quality and Safeguards Commission? No? OK. That's fine. We will move on to the restrictive practices.

*[Advocate 3]:*

Sorry, Mary, I was going to say I have, only in the instance of just trying to obtain information and to also speed up the delays involving funding approval for a behavioural support specialist to put together a behaviour support plan, and so the extensive time it takes for that plan to happen and the number of hours that the behavioural support specialist might need to put in until the restrictive practice is approved. It takes so much time, as [Advocate 2] said, and I have tried to reach out to many different avenues to make that happen. Very similar to [Advocate 1]'s example earlier on. And the response I receive is: "It's been escalated to the relevant team", and that's it. "We don't have any further information we can provide you," apart from "we're looking at it. We're looking into it."

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*[DANA CEO, Mary]:*

So that's the response you get from the Commission?

*[Advocate 3]:*

Yes.

*[DANA CEO, Mary]:*

And yet the Commission are meant to be providing leadership, aren't they, in terms of - well, that's my understanding in terms of restrictive practices. That is one of Jeffrey Chan and his team's roles, to be providing sector leadership on these issues. So that's another thing that needs to be picked up.

*[Advocate 2]:*

But the problem is the fact that restrictive practices are authorised by states.

*[DANA CEO, Mary]:*

Yes, that's right. Yes. There's something falling down in the middle there. Apologies, I now can't see any of you. I have some funny screen on my Zoom, so I can hear you all, but if anybody is waving their hand to talk, you have to just cut in on top of each other, because I can't see any of you at the minute.

So, we will move on to talk about segregated settings. We know, and the Royal Commission already knows, that those segregated environments are environments that have fostered and allowed abuse, violence, neglect and exploitation to occur, so we won't even ask about that. What we're interested in is what can be done; what should be done and what can be done to prevent violence, abuse and neglect happening in those segregated settings. We might just touch on a couple of the settings one by one. I'll ask about day services and day programs first, just because in our earlier series of workshops, we didn't talk about them at all, so I have picked them up now in the Victorian and now the New South Wales one. So, we'll go on to group homes, boarding houses and some other settings, but in the first place, I will just ask about whether the typical traditional day service or day program in New South Wales, are they the same as ever? Have they improved? Would you still class them as segregated settings? Is there any sense that you see where there are... are they better than they used to be?

*[Advocate 1]:*

That's a subjective question, I guess, Mary. So, it's very hard to answer. I mean, I can give my opinion purely on my -experience-,

*[DANA CEO, Mary]:*

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And that's fine, [Advocate 1]. Your opinion is completely fine. Your opinion based on your experience, on what you have seen, is exactly what we would like to know.

[Advocate 1]:

Then I would say that, by and large, no, they are not better. There are some that are. There are some new models of operating that have been developed but, by and large, for many of the traditional-style day programs that I am exposed to, many of them, a large percentage of them, I would say, are not better. They are still highly segregated and there's concern there, and a lack of access for advocates as well.

[DANA CEO, Mary]:

Thanks, [Advocate 1]. The lack of access to advocates, just explain that from your perspective.

[Advocate 1]:

Again, this is hard. I don't want to be too specific but there is a reasonably well-known provider in the northern Sydney region, and when we've attempted to have conversation with them or gain access to someone that we can see is potentially finding their experience there difficult, it's been hard to do so. There has been a resistance there.

[DANA CEO, Mary]:

A resistance to dealing with advocates or to allow advocates in?

[Advocate 1]:

Both.

[DANA CEO, Mary]:

You can be as specific as you like. Feel free to mention the name of any provider. It won't be used in any way, in any inappropriate way. So, feel free to mention them.

[Advocate 1]:

Yes, I know. It's just a bit of a tricky situation because I'm currently trying to sort that issue out.

[DANA CEO, Mary]:

Thanks, [Advocate 1]. And similar things have come up from some of the previous workshops, that if an advocate is attempting to develop a stronger relationship with a provider, then at the same time you can't or you don't want to be seen as whistleblowing on their practices. But you can, and this is a good example of something where either through us or separately somebody from the Royal Commission might have a separate chat to you about a way of finding a way to get that information that then doesn't reflect

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back on the work that you're doing.

I'm interested... you mentioned that there are some new models operating. I'm interested from anybody else as well, if you want to chime in on that, whether any of the new models that look like they're better, what is it that's driving those? What's making new models arise? Who's leading that?

*[Advocate 1]:*

If you want a specific organisation, I have many people... again, just because we're in the northern region of Sydney, who I have advocated for who have moved from a traditional day program model over to Fighting Chance. That is proving to be very successful. Anything that's got a community participation or a community based day program I find tends to have... the people that we support are far less segregated and happier than in the traditional setting. So those would be the two biggest examples I could think of, Mary.

*[DANA CEO, Mary]:*

Thanks, [Advocate 1]. Anybody else want to make a comment about day services or day programs? If not, we might go to special schools actually. [Advocate 2], in particular, but anybody else as well, if you want to make any comment about the New South Wales situation in regard to special schools or segregated settings sort of inside mainstream schools. Is there anything positive that you see that's happening to reduce violence and abuse in those settings or that has been successful in the last few years?

*[Advocate 2]:*

I can't point to anything that seems to have been successful. I think that NDIS has encouraged some of those schools to continue to build, but the issue is so often the fact that you are secluding people, you're actually developing cultures that not only condone but encourage seclusion and being separated from the rest of people's peers, people's community, and so often what it means is that people can be at greater risk in a secluded setting because there are less voices, there are less eyes, to see when abuse, neglect and exploitation actually occurs. So, the short answer is I am not seeing examples where moving into a segregated setting means that people have improved outcomes.

*[DANA CEO, Mary]:*

Yes. Thanks, [Advocate 2]. I'm interested, for any of you that are in the regional areas, [Advocate 4] or any of the rest of you who are covering advocacy in a regional area, because people's options might be slightly different, and continuing with schools for a minute, do children tend to travel further to go to special schools or do they go to their local school? Is there more inclusion and integration and less segregation just because there might be fewer schools available? Anybody got a view on that? And it may be that it's not part of your advocacy cohort that you're dealing with, but you can come back to us

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afterwards.

*[Advocate 1]:*

Sorry, I feel like I'm talking a lot. [Advocate 2] will probably have more examples but for many of the children we advocate for, they're travelling up to 40 minutes a day each way on a bus to attend a school for specific purposes. Is that what you mean, Mary?

*[DANA CEO, Mary]:*

Yes, that is kind of what I mean. I am assuming in the city that those options are available. Therefore, parents might choose them. It occurred to me that in regional areas maybe the options wouldn't be there, that children might by default almost be more likely to be in their local school but that might not be the case.

*[Advocate 1]:*

They're obviously not regional but people in [Greater Sydney], many of them, their children attend [School], so they are being transported each day a long way.

*[DANA CEO, Mary]:*

Yes.

*[Advocate 2]:*

Just even in that is the fact that even if they're not travelling a long way to another school, it just encourages that more tightly segregation within the school. I know of one regional school where there is a special class which is behind the fence which the other students call "the cage", and that's what's happening in one of the regional schools. So just because they're not on a different location doesn't mean that that segregation and that alienation and that labelling doesn't happen.

*[DANA CEO, Mary]:*

Yes. Thanks. Can I ask about boarding houses and hostels? A lot of people still live in them. Do any or all of you deal with people with disability who live in those settings, or you don't tend to much? We can move on from it if it's not [something] you cover much.

*[Advocate 2]:*

I have spoken to a couple of people who are in public housing. It's not a boarding house but, yeah, they often experience being treated differently because they are there.

*[DANA CEO, Mary]:*

Yes. And can I just pursue that a bit. In public housing, in a sort of public housing enclave if you know what I mean, or just scattered public housing where they are scattered through the rest of the population?

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*[Advocate 2]:*

Yeah, in larger scale public housing.

*[DANA CEO, Mary]:*

In larger scale public housing, OK. Actually, that's interesting because that's not particularly an issue that we have picked up on, so I'm just making a note of that to pursue that further separately. PWDA specifically do some boarding house advocacy and we will be talking to them about that particular issue. So we might touch on ADEs [Australian Disability Enterprises] and group homes. But ADEs first. I presume most of you would have ADEs on your patch somewhere. Are advocates brought in, welcomed in? Do you get referrals from the providers who provide the ADEs to bring advocates in when there are issues that need an independent advocate? What's the relationship like with the ADEs? Or there isn't one? Either way, you can tell me if it's not an area that you deal with much. OK, I'm taking the silence to mean that it's not. And we might move on to group homes then because I'm assuming that for most of you, you will have a reasonable number of clients who do live in group homes.

*[Advocate 1]:*

Yes, many.

*[DANA CEO, Mary]:*

OK. Can you see any or suggest any changes that could be made to improve... well, either can you see changes that should be made and/or have you any examples of positive changes that you have seen improvements in the segregation that happens of people in group homes?

*[Advocate 1]:*

Having access to an independent advocate greatly reduces the segregation someone experiences living in supported accommodation, and if there was a greater ability for every person with disability living in supported accommodation to have access to an independent advocate, I think we would see a huge reduction in the amount of segregation because, for myself, if I am advocating for someone who lives in a group home with four other people, I will ensure that that person - once I have dealt with the critical issue that I've come on board to advocate for, I will then look at everything else that's happening for them and ensure that they are accessing the community, that they are engaging in activities of their choice, in enriching. I will advocate for them to ensure that that is all set up before I will, I guess, view my job as done. And the problem is that there are so many people living in supported accommodation that don't have anyone to refer them to an advocate, that don't have an awareness of it or access to it. And if they did, it would improve the quality of their life, in my opinion.

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*[DANA CEO, Mary]:*

Thanks very much, [Advocate 1]. There's lots of stuff that we will make notes and follow up on because that thing about no-one to refer them to an advocate - anybody got a view on the reasons behind that? Is it that providers and support workers and others don't know that advocates exist? Is it partly to do with a lack of information about advocates, lack of promotion about advocacy or is it something else, which is that they don't necessarily want advocates coming in and telling them what they should be doing? Anybody got a thought about that?

*[Advocate 2]:*

An organisation doesn't view a group home as a home. It views it as a workplace.

*[Advocate 1]:*

Yes, and I would also add that it's a mixture of all three. I have had people who are in positions of management in supported accommodation saying, "I didn't know that the people living here could have an advocate", as well as people who are resistant to the idea because they know that the things that they do and put in place are going to be looked at and checked up on. So there is a resistance to that.

*[DANA CEO, Mary]:*

Yes.

*[Person 3]:*

Can I ask a question - Just following on from that, [Advocate 2] and [Advocate 1], for all the advocates, are there any examples you can provide where you have been doing some advocacy work in a group home and you have seen any cultural change within that organisation at all? Are there any improved experiences or it's always individual cases and you never see a cultural shift at all within the group homes?

*[Advocate 1]:*

Yes, absolutely. I guess a smaller example, but it only happened in the last two weeks so it's on my mind, is that I became an advocate for a young lady living in a group home in her mid-twenties who was living with three other co-residents, all aged under 30, and I would go around there sometimes to visit her on my way home from the office, so at 5pm, and they would all be in their pyjamas, having their dinner at 5 o'clock, having already been showered and wearing their pyjamas. I started speaking to the house manager about the fact that the young lady I am advocate for would like to go out for dinner, would like to attend a restaurant, go out for dinner with some friends and socialise during the week and not be in bed at 6.30pm. So, they have now introduced twice weekly dinners for the co-residents to go out in the community and have dinner together. That is a small

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example but it's a significant one for those ladies. They have all spoken to me separately about what a joy that is for them now and how much they're looking forward to that.

*[DANA CEO, Mary]:*

Thanks, [Advocate 1]. And oh, my God, the bar is low, isn't it. It's pretty desperate really that any provider would think that that was acceptable. Anyway, the Royal Commission have their work cut out for them, I have to say.

*[Advocate 1]:*

It's so common. It's so common.

[ADVOCATE 3]: I just wanted to add to that situation about every single service provider in that type of scenario is quite strapped and, as an advocate, when I'm in a situation where we're talking about group homes, supported independent living, and, yes, the NDIA is involved as well. My go-to has always been support coordinators to try to implement those things for an NDIS participant, but I just find that we all end up passing the buck because, like you said, the supported independent living providers, they're not there to case-manage. They're there to ensure supports are put in place and that everything is in order with the property and the carers as such. A support coordinator just shows up at the very beginning of someone's plan and says, "OK, you need X, Y and Z. Great, I'll check in with you maybe once or twice a year." And so advocates might get the referral but then our involvement is very limited because we're not funded to case manage. We're not funded to ensure that- --

[...Audio issues...]

*[DANA CEO, Mary]:*

I think it might be – [Advocate 3], in the background, when you were speaking, there is probably somebody else in the same room.

*[Advocate 3]:*

Yes, sorry, everyone. It's a small office. But I was just saying there's no accountability when it comes to looking at the segregation that an individual is put in when they don't have an informal carer who would step up to speak up, an informal advocate who has the time and effort to actually bring the services to do what they're supposed to do. So, the example [Advocate 1] gave is what I experience all the time when working with people in a group home scenario or in independent living because no-one is there to keep a support coordinator accountable, for example. And without the knowledge of what is available out there, without someone suggesting to this individual "How about dinners every other night or how about I take you to the library because you don't like being in a big group", you want to have that outdoor experience, but in a controlled environment. Without someone

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giving that suggestion, of course they're not going to ask for it. But who is responsible? Who will be accountable to do that for these individuals because otherwise they're left in that segregated setting indefinitely?

*[DANA CEO, Mary]:*

Thanks very much, [Advocate 3]. [Advocate 2], can we come back to you. You wanted to share a story.

*[Advocate 2]:*

Yes, I actually had a support worker give me a call because they wanted to talk to the Disability Royal Commission and theirs was a story of financial abuse. So, they worked in a group home and they had been told by the company, the group home manager, that nobody was allowed to spend money more than two coffees a week. Previously they'd been going out for meals on Friday evening but because of COVID, they weren't allowed to go shopping, they weren't able to go out for meals. In fact, there was no cash allowed in the house. The only money in the house was on the credit card held by the house manager. I support one of the men in the house. His parents gave him a house as part of his inheritance, and he gets rental income from that house. He actually works for the ADE of the accommodation provider and so he's working for them and he's supposedly getting a pay cheque from them. He also has his NDIS money. And he's being told, "No, you can't go out for a meal; no, you can't go shopping because you don't have any money." So even though this man is obviously entitled to be getting income, he's being told he can't have any access to money. I was talking with the support worker, and he says "What can I do? I can't go to the police because the police want evidence." I said, "Go to the Ageing and Disability Commissioner and definitely talk to the Disability Royal Commission." Then at the end of the phone call, I went how does this actually work? And I rang the abuse hotline, the Ageing and Disability Abuse hotline, which I'd referred the guy to, and they said, "Oh, is this service provider NDIS funded?" and I said yes. And they said, "Oh, we can't do anything. You need to ring the Quality and Safeguards Commission". OK, so I rang the Quality and Safeguards Commission. "Oh, is it about money? No, we can't help you at all. You need to ring the fraud hotline." So, I rang the fraud hotline and they said, "Yes, this is the right place to report it. I just need to let you know that we can't give you any information about any investigation that we do or even if we are going to do an investigation, for confidentiality reasons." And then they said, "So can we have your phone number and email address?". So, I said, "You're not actually ever going to give me anything?". "No, no, no, we can't give you anything." So there seemed to be no relevant reporting and accountability structure around this thing, this matter of financial abuse which wouldn't just refer to one resident but potentially would refer to all the residents in that particular organisation.

I wonder whether a way forward is to have some kind of anti-monopoly style law. So, a

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single service provider can provide no more than just one of accommodation, employment, financial services or planning services to any one individual, whether that's a way of helping to combat some of that potential for abuse, in this case financial abuse.

*[DANA CEO, Mary]:*

Thanks very much, [Advocate 2]. Really interesting story and that anti-monopoly thing used to exist in some of the states and territories prior to the NDIS, where providers were not allowed to be the sole provider in charge of every single aspect of a person's life. And, in theory, in the NDIS, that's the case, but in practice it is happening.

[...]

*[Person 4]:*

Actually, I did have a follow-up question to [Advocate 2]. Thank you for that scenario. It must be quite a feat to do that ring around. I do want to confirm that the person, the client that you are talking about, didn't have a guardianship order, that the group home manager wasn't actually his guardian and therefore had no legal right to inhibit his access to his funds? So, if you know anything about that.

*[Advocate 2]:*

I imagine that's the case. I don't have any information on that. But, yes, from my experience in working in a group home, you are talking about people, in some cases, people don't have necessarily the money skills. But, yes, the question of guardianship is quite fraught. I know one person who... it was under a public guardian who then said, "Actually we haven't made a decision for this person in three years. We think that they no longer need public guardianship" and it required the intervention of their key worker in the group home to say, "Actually, this person can't be making these decisions", but in that case, the public guardian just went, "Oh, well, we haven't made a decision for them; therefore, they don't need a public guardian" and that person had no family at all and I don't know where that person would have been left.

*[DANA CEO, Mary]:*

Thank you, [Advocate 2].

*[Advocate 2]:*

It's an issue.

*[DANA CEO, Mary]:*

Thanks, [Advocate 2]. Sorry, these conversations get very depressing, don't they? The realisation, which is true, that advocates are called in to try and help resolve issues where there are problems, so that's your normal work experience and work practice. Probably

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the depressing aspect is if you're not seeing positive change in the system more broadly, so that you're saving one person at a time or you're attempting to do that, but there's something that I hope the Royal Commission can tease out a bit about what is it that needs to be done to strengthen the work that advocates do for individuals and how do we bring that together to help cause systemic change. And the thing that particularly I am trying to think of, and I would like all of you to watch out for, is whether the way the NDIS is designed is causing the continuation of a lot of the practices that we might have hoped would be improving. There's about to be new NDIS legislation come in. Is any of that going to help any of the settings of any of the people that you are talking about? And, if not, what is it, what changes are there that need to happen in either legislation or policies or within organisations that will improve the lives of those people that you are working with who are living and working and spend their whole days in these segregated settings?

As I mentioned earlier, these are big topics but the Royal Commission is deeply interested in them, and we'll be happy to hear from you or any of the submissions that any of your organisations are helping people to put into the Royal Commission. Siobhan may have already put it in the chat, I am not sure; but if not, she will. She will put in a link to the scheduled hearings. It's worth having a look at the hearings that are scheduled for the rest of the year to see if there is a person you have been advocating for and you think that they might be interested in giving evidence at a hearing or that the example or the story of what happened to them would be something that the Royal Commission might be interested in.

So, the best way to do that is to put in a submission and it can be as brief as anything. It just can be informal. It doesn't have to be a fully worked up case study with everything chronologically described, but the sooner and the quicker you get something in, then that allows the submissions team to have a look. And if you've got someone who wants to, they can ring and they can make an audio recording, they can ring or speak to somebody at the Royal Commission, but we would strongly support you getting those submissions in. Yes?

*[Person 3]:*

I just want to jump in with a question of what you have just said in terms of changes. It's a broad question, without putting anyone on the spot, but have any of the advocates thought about what would improve and make the biggest changes, and, if so, what you think the Royal Commission should be recommending? We would be grateful to hear if you have any initial thoughts. Thanks.

*[Advocate 1]:*

I think I said it before and it sounds self-serving but it genuinely isn't, but again it's about introducing the ability to have that independent input from someone in a person with disability's life who is segregated or doesn't have that. So greater access to advocacy.

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And that's where it does sound self-serving but it's not, because we're the ones that see the difference that is made to people's lives once they do engage with an advocate. That would be the biggest thing that I can think of at the moment, as well as significant changes that are required to the NDIS. But I guess that's kind of outside of this.

*[Advocate 5]:*

I agree with [Advocate 1] on that but I think the way... instead of... I am not sure what [Advocate 1] means in terms of how she wants to get the word out, but I think it's really important to, you know, health professionals, GPs, podiatrists, people like that, because you think about who's going to go into these homes, who's going to see them? Because obviously the workers in there aren't going to be really reporting it to us or referring to us, but by getting the word out about advocacy and our services to, I guess, allied health professionals is really important. I find that makes a big difference in our referrals around these sorts of matters. That's where we find they come from, and so that's where we target when we go into community and we're talking to organisations, that's how we target who we target, so, therefore, we're making sure we're going to reach the clients because when that podiatrist goes to see that client, they will be sitting there and see something and then potentially refer to us.

*[DANA CEO, Mary]:*

Thanks very much, [Advocate 5]. That's a really useful description for all the other useful intermediaries and people who might be able to consider that an advocate is required. Anybody else want to comment on [Person 3]'s question about what would make the biggest change? Biggest improvements?

Can I ask a question, because we have to wind up shortly? We've flagged - with DSS, with the NDIA and with the Quality and Safeguards Commission, we have flagged the notion which hasn't been turned into formal proposals yet but we will be starting to work on something, which is that it does feel like there is a need for some people to have a formal allocation of an advocate, so some people who have - and they would be some of the people that you are already working with, but at the moment there's a kind of randomness about how those people get an advocate and we think there should be something more deliberate, where people who don't have family or friends or other connections and who are entirely within the segregated settings and who are relatively vulnerable, that some of those people should deliberately be allocated an advocate that obviously has to attach to some advocacy funding, so that there is a deliberate process of outreach from advocacy organisations to particular people instead of the current - or as well as, at least, the existing system of people being referred in for advocacy. Has anybody got any comments they want to make? It is a thing you can contact us afterwards about. But any quick comments from anybody about that notion?

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*[Advocate 1]:*

I would agree with you, Mary, that there is an absolute need for that and also I think to enable that to happen, there needs to be a cultural change in the way advocates are viewed in a lot of settings, that the input from an advocate isn't to create trouble or to make someone's workplace more difficult, but the actual reason that we're there and engaging in the work we are engaging in. So a bit of education for the sector as well as having people assigned an advocate. If someone's got a public guardian assigned to them and no-one else in their life, no level of informal supports, or if they don't have a guardian, I think it's absolutely a requirement that they should have an advocate appointed.

*[DANA CEO, Mary]:*

OK. Thanks, [Advocate 1]. Anybody else got a quick comment on that notion?

*[Advocate 2]:*

I would agree wholeheartedly with [Advocate 1]. It seems to make sense that everybody who has the public guardian also has funding allocated for advocacy in that regard, if not being assigned a particular advocate. But part of the difficulty is, we see the difficulty with family members or people... just the NDIS has a lot of difficulty in people being, the words are failing me, but being the nominated person [Nominee]. There's so many issues around that process, that if they can't get that right, then how on earth would they get advocacy right?

*[DANA CEO, Mary]:*

Yes, absolutely. Absolutely. Anyway, the NDIA doesn't fund advocacy, so funding for this is not likely to come out of the scheme. It has to come from elsewhere.

*[Advocate 1]:*

And we wouldn't want it to either. Ever.

*[Person 2]:*

Also, I just wanted to ask [Advocate 2] - he made a comment on the chat about community visitors and community visitor schemes and around their reporting, reporting some improvements, et cetera. Is he able to clarify? Are you able to clarify, [Advocate 2], what you mean by that?

*[Advocate 2]:*

Yes, when I was talking about this group home financial abuse thing, I went looking for what happens with the community visitors scheme and found a report that they apparently put out at least annually. I think it's an annual report and I just read through that and there's some very good stories in that about where that's been helpful. Very interesting statistics on that and me going, "Oh, that report also seems to highlight huge gaps in how

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many services actually get visited and how many issues don't necessarily get resolved." But it's an interesting read and it's something that's outside my scope but I think it would be good for the Commission to be looking at.

*[Person 2]:*

Thank you.

*[DANA CEO, Mary]:*

Thanks, [Advocate 2] . We've actually come to the end of the time. We're just over. So thanks very much, everyone, for your participation.

[...]

If you've got colleagues from your organisations who want to take part in Thursday's, the link should have been sent out already but if they come back to Siobhan at [policy@dana.org.au](mailto:policy@dana.org.au), she can send out the link again. Thanks, everyone, for taking part today and we appreciate all of your time. Thank you. Bye.

(End of workshop)

### Comments typed in Zoom chat function

*[Advocate 6]:*

As an advocate I have been to guardianship hearings to support clients but not ever contacted by a service regarding restrictive practices.

*[Advocate 2]:*

Restrictive practices that are often not thought of are of people being physically "locked out" of education including limited enrolment and suspensions

*[Advocate 6]:*

I have seen a day program consisting of clients just parked around a TV set. That is, secluded.

Day programs where clients do activities in public are best.

I worked for an organisation previously that assisted boarding house clients get out of boarding houses into better accommodation.

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*[Advocate 2]:*

In my experience, people in group homes are encouraged to have no outside relationships. Visitors to a home are determined by organisation policy and schedules rather than by the people who live there. With limited external connections and tight regulation by organisations there is little opportunity for abuse to be observed or reported on. There is little opportunity or support for people to make complaints about anything, particularly abuse, neglect, exploitation or violence.

*[Advocate 6]:*

In many group homes, clients are living in the next room to an abuser. In many cases, having their own home with supports in place would mean they would not be vulnerable to such abuse.

I have had some providers make referrals to advocacy but other providers are clearly wary of advocacy services.

*[Advocate 2]:*

There are some good stories of change in the reports of the Community support visitors

good news of the impact of community visitors

*[Advocate 6]:*

I have to go and I am having communication problems at any rate. Thank you for the forum.

*[Advocate 2]:*

Question:

Did I hear the CALD Issues paper is the last one?

Will there not be a separate paper on NDIS service provision??

*[Advocate 2]: (writing these as recommendations in response to the discussion at that time)*

- An advocate is engaged, in consultation with the person with disability, their family and close connections who is independent of any association with organisations that provide services to that person with disability.
- Independent Advocacy is funded to the level that all people in segregated settings can access an independent advocate.
- Opportunities and resources for trust building between advocates and those that require them is provided and funded.

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- Family members need to be formally recognised as important voices in people's lives. This needs to be formally recognised in policy.

*[Advocate 4]:*

Also agree with [Advocate 1] in regards to independent advocacy and how it is integrated more broadly into common practice

*[Advocate 2]:*

Agree with [Advocate 1] and [Advocate 5] - also the Community Visitors

e.g.

[https://www.ageingdisabilitycommission.nsw.gov.au/\\_data/assets/pdf\\_file/0005/781034/O CV-Annual-Report-2018-2019.pdf](https://www.ageingdisabilitycommission.nsw.gov.au/_data/assets/pdf_file/0005/781034/O CV-Annual-Report-2018-2019.pdf)

## Transcript of Zoom Workshop - 18 March 2021

*[DANA CEO, Mary]:*

It's Mary here. Good morning, everyone. Thank you for joining. I can see a few people. Others have their cameras off and that's fine. We will just give a couple of minutes as other people will be joining now over the next couple of minutes. So we will wait while people do that. I see more people joining so we will just keep hanging on.

[...]

So we might get started and then other people may join us as we go. So for those who I haven't met before, my name is Mary Mallett, the CEO of DANA, and I'm sitting in our Canberra office. I'll start with an Acknowledgment of Country before we get into the meeting proper. I'm on Ngunnawal country and the rest of you, you're not all in the same states. The advocates are in New South Wales but the Royal Commission staff are in various Aboriginal lands around the country, so we would like to acknowledge the traditional custodians of all those lands and the contribution that they make to the life of our communities and welcome any Aboriginal people who are taking part today.

This workshop is the last one in a series that started last year where we have had workshops with advocates in each state and territory. This is the second of two New South Wales workshops. We are doing them in conjunction with the Royal Commission. So Royal Commission staff are sitting in and listening and hearing what advocates are

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telling them about, are speaking to us about, and for the Royal Commission to be able to hear about in this case two particular topics, which is restrictive practices and segregated settings. These are issues that advocates are very familiar with and that can be hard sometimes to get other people to speak about.

So we will go through and spend half the time on each of the two topics. Feel free to use the chat function while other people are speaking, but if something occurs to you and you want to say it and you can't get in to say it, then please use the chat function and put your comment in there. As I mentioned, for anybody who needs or wants to use the captioning, the link to the captioning is there.

So I am sitting in our Canberra office. Siobhan is our Royal Commission Policy Officer, who most of you will have had some contact with, and Siobhan is sitting in Melbourne, and in case you can see that she's there twice, it's because she's joined by Zoom on the camera but is also, to get better sound, is joined by phone as well.

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

*[DANA CEO, Mary]:*

Previously you will have, in the process for registering for the workshop, you will have seen a few questions which Siobhan sent out, which were very broad questions about restrictive practices and the effects on people with disability and what we'll probably... so some of you may have already responded because there's also a small survey available. Siobhan, can you remind me, do you send that survey out again afterwards? Yes, you do. OK. So the survey questions, which are just some brief ones, will come back afterwards, so there is another opportunity that you will get or others in your teams will get if they want to make some comments about restrictive practices.

But what I'm interested in, and those of you who have your cameras on can respond to this with just a wave really, in your advocacy, your general every day advocacy really, are you seeing or dealing with restrictive practices? Is it common? Yes, common from [Advocate 12], [Advocate 14] is waving, [Advocate 9] is nodding and thumbs up, and [Advocate 7] I presume in your team, across the team, you would?

*[Advocate 7]:*

I would say, based on the fact that a lot of these restrictive practices occur in settings in which we don't have access, I'm only seeing the tip of the iceberg. That's part of the problem.

*[DANA CEO, Mary]:*

I couldn't hear you. Just say it a little bit louder.

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*[Advocate 7]:*

Sorry, we only see a small fraction of the restrictive practices out there. A lot of these occur in settings which we either don't have access to or people aren't able to access us.

*[DANA CEO, Mary]:*

Yes. OK. So [Advocate 7]'s point, if anybody couldn't hear that clearly, was that his belief is that we're only seeing, the advocacy sector is only seeing, a small section of the restrictive practices that are out there, and one of the reasons being that there are places that advocates don't have access to. And the reason why, as Maurice mentioned earlier, that it's important for the Royal Commission to hear from advocates is because many of those people who are under restrictive practices won't otherwise have their voices heard by the Royal Commission.

Does anyone want to start speaking about how do restrictive practices lead to further violence and abuse? Does anybody want to comment on that or do you think it's true anyway and have you seen where that applies? [Advocate 8]?

*[Advocate 8]:*

Sorry, I was just thinking about the question. I guess that I just think about exclusion and sort of like access to services and things in terms... and poverty and all of those. I'm thinking just generally. It's not really about a specific example about restrictive practices but just that access, for example, NDIS services, and how complex that can be and particularly I have had experiences with people with psychosocial disability who can be excluded on many levels just because of the complexity of systems to actually access support that they need. So I'm just thinking in terms of arrangements and service arrangements and how people are excluded. So that's not really talking about probably what you're thinking about.

*[DANA CEO, Mary]:*

Your responses really can be as broad or as narrow as you want, if you know what I mean. You can focus in on a particular example of a particular person or broadly on the issue. Do you think restrictive practices are more common in some settings than others? You don't have to keep answering it, [Advocate 8]. You can let somebody else pick it up if you want. I wasn't targeting you in particular.

*[Advocate 9]:*

I might make a comment and it is tricky in a way because personally I work across so many different areas and so I have been at [NSW Advocacy organization] for nearly three years. I feel like as [Advocate 7] was saying I have only just touched the tip of the iceberg in seeing some of this stuff and it's partly I think because of access issues and getting into

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places but also probably because I work in a general way. I certainly have seen a lot around recently, not a lot but I'm starting to see more people telling stories around issues around medication, so for behavioural control. So experiences in the mental health system of being zombified through medication that is really... it's been stated that it's for their treatment, not for behavioural reasons actually, but is sort of creating this stupefying effect that leads to things like people telling me experiences of being sexually assaulted and not being able to... or harassed and not being able to respond because of the medication.

So I don't know, I can't provide any definitive... this is not based on research or anything. This is obviously anecdotal from what I have seen, have been told, sorry. So medication certainly seems to be... and things like anti psychotic medication being not just used for behavioural control but treatment, but then creating further avenues for other forms of violence and abuse. And things then also being discredited and not believed after making complaints because the medication then prevents people from having proper memory recall and things like that. So the abuse being perpetrated and then being disbelieved through the complaints or reporting process because of that. So that is certainly coming up.

It comes across in all the work, restrictive practices across so much of what we do, but, again, it's hard to comment on it in a general way. I would have to spend more time... certainly things in ... boarding houses where, again, medication has been used, seeing people kind of sitting around and not being able to go anywhere, not because they're locked in or chained up but because they've been medicated to the point that they're kind of zombified and can't move and go anywhere. Things like we have seen in the Aged Care Royal Commission, the use of Clozapine and other medications, things like that. And examples in group homes where people have been locked in and not being able to kind of leave. That's not something I am hugely familiar with. It has come up in some of my client work, though.

*[DANA CEO, Mary]:*

[Advocate 7], you want to go?

*[Advocate 7]:*

Can I just back up what [Advocate 9] is saying about the abuse. Can people hear me?

*[DANA CEO, Mary]:*

It's a bit hard. You might have to yell a bit.

*[Advocate 7]:*

The issue of psychotropics is really problematic because they're used commonly certainly

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in assisted boarding houses here in New South Wales and they're used a lot in group homes as well and, of course, it's always, almost always, under the guise of mental illness. Now, the way Australia looks at that currently, if you use psychotropics, chemical restraint to treat a mental illness, that's acceptable but that's clearly in breach of the CRPD, and so then means you've got a situation where people's human rights are being abused, but there's actually nowhere to take that. I'm still unclear as to where the DRC stands on this matter. Do they take the CRPD approach or do they take the modified Australian approach where the use of psychotropics to treat a mental illness is acceptable?

I will quickly talk about the assisted boarding houses. You have a situation there where almost everybody is on some form of psychotropic, in the main mostly clozapine, which is a fairly toxic medication. Many of them aren't getting the sort of regular clinical review they should be getting. In many cases, the so-called positive symptoms of their so-called psychotic illness have long passed because they're in their 50s and 60s and so the need for that medication is questionable, and then they have a whole truckload of toxic side effects which accumulate and actually lead to all sorts of health problems. So we see that as a really significant problem that certainly the DRC would need to be addressing. And that... you can mirror that in other states and territories as well.

*[DANA CEO, Mary]:*

Thanks very much, [Advocate 7]. I am going to pick up and, as I said earlier, yes, sorry, [Advocate 10]

*[Advocate 10]:*

My experience has been extensively in the education department and I believe there is a significant issue in a lot of schools where they are not amending the curriculum and the environment for people with disabilities, with children with disabilities, and, therefore, they use that as an excuse when the children can't cope, to seclude them. I have had stints where children have been locked in rooms without adult supervision or put in a corner and left there to stand for hours on end, and I think that is a significant problem in the education department, that these measures are being used as a band-aid approach rather than looking at the curriculum and how we can adjust the curriculum for that child. I believe it's quite a significant issue across New South Wales.

*[DANA CEO, Mary]:*

Thank you, [Advocate 10]. Anybody else - yes, [Advocate 15]? No, did you want to speak?

*[Advocate 15]:*

How long have you got? [Advocate 10], I take your point. Obviously we hear from a lot of families. Over the last five years, our calls have doubled in relevance to education and

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specifically the lack of adjustments being made to account for a child's disability, and often it's that lack of adjustment that causes a reaction from a child, which they now call, they like to label it a behaviour of concern and then all the onus and blame becomes the child's problem, rather than looking at the environment around the child, the conditions around the child and what are the needs of that child, if we're sort of looking at the order of need, the hierarchy of needs, what are those needs? Are we meeting them? What adjustments can we make to really support this child to feel safe, to have a safe person to go to when they don't feel safe? So that even if they are nonverbal, they understand that there is somewhere for them to go or a person to see, where before an eruption takes place, which is really a form of communication to say "my needs are not being met and I don't feel safe".

So that's one issue in that particular space but I think across all settings, we just have got it all wrong. We're really looking obviously, first and foremost, we've got to look at it as a breach of human rights in accordance with the UNCRPD. It's a form of torture. But it's also a perceived problem from the people that are using the restrictive practice and the people that are permitting the use of that restrictive practice. So by that I mean it's the perception that there's something wrong with the person and that they are.... those deeper, subconscious biases that people have that a person with a disability is a menace, that they are violent, to just automatically make those negative assumptions, it clouds how we perceive that person and then it affects how we act with that person.

So I think we really need to dig a lot deeper and ask more questions of service providers, ask more questions of them about what are they doing to actually deeply reflect upon their actions, what are they doing with the conditions that they're providing for a person with a disability to ensure that a particular reaction, which is often a well-known reaction, continues to take place and why do those conditions continue to stay remain as they are, whether it's the space that they're in, not having the right person with them, continuing to put them on a bus, for example, if that is a trigger. There's so many things in so many spaces where we're looking at it in the wrong way entirely. This sort of blame game, I guess, rather than looking at what is the service provider's responsibility here to look deeply beyond seeing that person in that negative way.

I know we hear of families that come from - especially when they are transitioning, say, from a segregated setting to a day program or an ADE, they come with a file this big because of all the violent things that they've done, and that colours and affects the perception of the person that is going to be interacting with them in that next phase. Very often, if we just take some time to really deeply get to know that person and what it is that their needs are and meet those needs with the right conditions around them, the violence dissipates and often is just completely removed.

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*[DANA CEO, Mary]:*

[Advocate 15], I'll interrupt for one second and a couple of other people, [Advocate 12] and others had their hands up earlier, but just exactly where you were there, saying that with the right support and the time allowed, people can... there can be significant change made. Can you think or any of the rest of you think of an example where you have seen that happen? Have any of you actually seen-... -what [Advocate 15] is describing and what others are describing is commonplace. This is background for where some people have these... they get labelled and then it follows them their whole life and they then get medicated to manage it. Have you any examples of something better happening, of better practice of people whose lives have been significantly transformed and improved? You don't have to tell us the whole case study now but just interested to know whether- --

*[Advocate 15]:*

I definitely do but I will let others speak.

*[DANA CEO, Mary]:*

Thank you, [Advocate 15]. Happy to hear you afterwards. [Advocate 11]?

*[Advocate 11]:*

I actually do. In relation to the education, I think there should be an independent complaints board outside of the department because what happens is when people make a complaint, it stays within that system and then it just feeds backwards and comes back to the beginning. I have found that then that child is set up where they watch everything that they do and then they get suspended and it keeps going that way. So I really believe an independent complaints board should be made available for people with disability and their families to actually have it addressed properly and I have seen where it should not be up to the family and up to that person to do that but where they've actually moved schools or found a school that has a more supportive environment and become a completely different person.

*[DANA CEO, Mary]:*

Thank you, [Advocate 11].

[...]

[Advocate 12], I think you wanted to speak?

*[Advocate 12]:*

I wanted to speak before but I'll speak to this as well. It's a case study of a woman probably now well passed away actually. When I was in my 20s, I was a residential care worker and this was in New Zealand but I am a sure it will be the same here. There was

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deinstitutionalisation, so people who had lived in institutions since they were 5 or 6 or 7 were now suddenly living in group homes and going on trips in the community and going to supermarkets. Things that they hadn't ever done. And they were medicated to the eyeballs. They were on all sorts of temazepam and all that sort of high-level medications. Of course, initially when they came out into the community and those medications were reduced, there were a whole lot of things. We didn't know that you could call those things behaviours of concern and challenging behaviours and all that. I mean, they just were how they were when they weren't drugged up. It's probably why they got young 20 yearolds to look after them.

We would race after them and we had to learn various different sorts of strategies and we had to do specific training about how to work with these people, and over a period of sure, a few years, those people who were nonverbal, who had never had any experience from their childhood, and these individuals we working with were in their 40s, they had been institutionalised for a very long time, they were going to supermarkets and putting things they wanted in the trolley with the support worker. They were contributing in the kitchen and helping prepare their own meals. They were electing what things that they wanted to do, even though they weren't verbal, they would use cards and other mechanisms, and you go from an extreme where a person's reaction in the first week of her again, the specific woman the first week of her release into the community, she bit my arm I mean, she was half my height, but she bit my arm and also head butted me so she was obviously quite experienced at defending herself, and she went from those behaviours and then just was really intensive stuff. Training and just guiding her, she eventually trusted her environment. All of those behaviours vanished. And she was able to live in the community and have a really happy and enjoyable, it seemed, from what I saw, life.

One of the things that... so one of the things when I finished filled the survey out about restrictive practices was definitely I think number one is medication because , I am just going to add this, that the medical model is the first go-to for people. So people have got a 2-year-old and they are going this 2-year-old is not doing things other 2-year-olds are doing. They go to their GP and that's how they get into the medical model at a very, very early stage and they're not given information about their child and how their child might develop over time and the different kinds of things that they might have to do to adjust their lifestyle. And from the very first get-go, you're having very young children going on to medication. To my mind, that's one of the places it starts. So by the time they're old enough to go into a group home, they have been on medications for decades to "control", so-called, their behaviours because that's the starting point. I don't mean that to sound like a blame. I think parents are struggling "what do I do with this small child?".. how am I going to adapt? Then, of course, you go to your GP and doctors think in terms of medicines. They don't think in terms of behaviour modifications. That's not their training. So from my point of view, where the system could be improved drastically is better

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training, better training from the get-go from medical staff being able to appropriately refer very young children to more behaviour-based, and training for parents so that they know how to guide their small children so they don't end up being 15-year-olds that punch holes in walls.

*[DANA CEO, Mary]:*

Thank you. [Advocate 11] we will go to [Advocate 13] in a second. [Advocate 11], I could see you took yourself off silent. Did you want to say something there? Maybe not. OK.

*[Advocate 11]:*

Sorry, it's [Advocate 11] from [NSW organization]. Sorry, I can't see who is on because I'm on the phone. The only other things that I have thoughts on are... or feedback from, is in the prison system, people with disabilities and they've told me that they have been given a particular medication and it's a medication that's one fits all people, not the appropriate medication, and also in terms of with the guardianship orders, people with disability who have been put under guardianship orders and who have had contact with DOCS [Department of Community Services], not feeling that they've been able to have their say in what they're hoping for in terms of restoration or access to their children.

*[DANA CEO, Mary]:*

Thanks, [Advocate 11]. That's another issue that we'll be picking up as well. We did have one session, Zoom session, last year about some child protection issues, but it's one that needs to be picked back up again. [Advocate 13], I think, you wanted to speak, yes, go?

[...]

*[Advocate 13]:*

Thank you. I might be repeating what other people have said because I have to take other calls as well as attend this. I just can't avoid that, I'm sorry. In relation to what [Advocate 12] said about training, under the NDIS, I am not sure that service providers get paid to do training and I think there's an economic incentive to have agency staff and untrained staff and that's part of what privatisation of this service causes. So there is a real problem with training.

Our client group are people with intellectual disability and especially it concerns me, people in group homes. Our service has many incidents where the police get called in because untrained staff are not familiar with the clients or they're not familiar with de-escalating clients by just providing consistency in the same service each day. And what you get is that the client then has a behavioural reaction and then, because they're untrained, they call the police and our clients end up going to gaol.

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My second point is that in group homes, with untrained staff, and people who would know this, I am not aware that there's any signs about basic... what restrictive practices are. I think it would be a good idea if it was mandatory for there to be signs about a few principles about restrictive practices, especially that they should be used as a last resort, even if they are authorised by a restrictive practice panel. Also, to educate workers that small things like not letting residents go out into the community because they misbehaved in the morning is a restrictive practice. So I think we should work in that direction as well.

Two more points I am going to make, well, actually it's one more point, is that, yes, it could be that you have to train the staff, but the other real problem is that service providers know that they're not accountable. The NDIS Quality and Safeguards Commission does not have powers to act against service providers in individual complaints and the New South Wales Ageing and Disability Commission, who is now getting a function to what they call oversee restrictive practices, also does not have powers to make any penalties or findings against service providers in individual cases. So we now have two regulatory authorities that appear to be regulating but, in actual fact, do not have any powers against service providers in individual cases to stop things. I am not talking about the obvious things like assaults and sexual assaults and things like that. I am talking about the day-to-day things, like restricting diets, closing doors, not letting them go out into the community. What we really need is tribunals that you can go to that will listen to the complaints and deal with them in a very short period of time, and we haven't got it. Thank you.

*[DANA CEO, Mary]:*

Thanks very much, [Advocate 13]. I will just see is, there anybody else who had their hand up to speak?

[...]

*[Advocate 9]:*

I just wanted to say I agree with what [Advocate 13] was saying around the training. I have had quite a few examples where a client will have a BSP, a good behaviour support plan, and they have got quite complex needs and there's a lot of restrictive practices including in the BSP, and even though it is stated how they will be eliminated or reduced, there's absolutely no funding at all for implementation or training in the budget, in the NDIS budget, which is just ridiculous, and that does come up time and time again, and then restrictive practices are just used and that plan is then essentially rendered useless. So I just wanted to support [Advocate 13]'s comments around how not just training but how staff are valued, paid, trained, all of these things to do these jobs. I'm also interested in what funding there is for research in this area and if that's something that the DRC is looking into in terms of understanding behaviours from the perspective of things like these behaviours being adaptive behaviours, survival. I have had clients who later on have been

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six months and they have found out they have actually had infections and that's why they were behaving in certain ways and the brother has lobbied to get that person seen by a doctor and then that's been the root cause of that. So I am just curious about the funding and research that might be happening or could be proposed around this as well.

*[DANA CEO, Mary]:*

Thanks, [Advocate 9], and all of the things that you are raising, you are raising lots of issues that are the things that need to be resolved and some of the potential solutions. The research.. it's an interesting point about the research, though, just specifically the Royal Commission itself is commissioning some research in relation to some of the topics, but there's been broader research for a very long time done by various academics around these issues to do with restrictive practices. Probably the biggest issue is how... so it's not necessarily the shortage of research. How does the research get translated into things that service providers and support workers can use? I suspect that's one of the biggest gaps that needs to be looked at, not so much research, but the implementation of best practice and is that being funded and people, staff properly supported to do it? Clearly from all of your examples, it's not.

We want to move... there's lots of the issues that one of you mentioned that [Advocate 9], I think you mentioned the tip of the iceberg and that all of the stuff you're saying is anecdotal. It's true but the anecdotal you're saying is exactly what the Commission needs to hear, and I'll mention it now, which is... because it's you've touched on it, a few of you have touched on it. So the next hearing that is being held, I think it's the end of April, beginning of May, is about the NDIS and service provision, and I can't remember the exact name of it the hearing. Siobhan is going to put the hearing schedule in the chat, the link to the rest of the hearing schedule for the rest of the year in the chat box at some point. But if you have in the examples that are in your minds around these issues, if there's a story, a person who you can think of who sort of exemplifies exactly some of these issues and either they're an example of all the things that shouldn't be happening or if you happen to have a good example of something where the systems have worked properly, then it would be a great idea to put that in quickly, even as a very brief dot point submission into the Royal Commission because particularly in case it is something that the person a person or the advocate that they would like to hear from or enter row gate that provider, but if that is something that could come up in that NDIS and service providers hearing because the stuff about the lack of training and the training that isn't been provided in spite of the fancy behavioural support plans being written, that's a big gap and needs to be really properly looked at. So I would encourage you to... you don't have to spend two days writing a case study up fully. Just get the bare bones of it into the Commission and if they're interested, they will come straight back to you to get further details.

There's a lot of cross-over between what we have been talking about now about restrictive

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practices and segregated settings, and there were several mentions that a few of you made there and I would like to pick them up as we talk now about segregated settings. I think it was [Advocate 15], you made a very telling comment with you talked about families with children transitioning from segregated settings to a day program or an ADE, and, of course, you said that in such a matter of fact way because that's exactly what happens, because there's no choice, is there, for people who have been in the segregated settings to begin with, and they're in special schools, basically on a pathway that steers them directly into segregated settings for the rest of their lives, so that's something we really want this Royal Commission to bring that out in the hearings, in the final report, in the recommendations from the final report about how do we stop that trajectory being inevitable for people, and the earlier that it happens, those interventions happen, the better.

[...]

*[DANA CEO, Mary]:*

So that was one thing about segregated settings, and there was the boarding houses: I would like to come back to that issue particularly. I know PWDA as an organisation has lots of experience and has had some specific funding at times for working in the boarding houses. And you mentioned, [Advocate 7], I think it was you, talking about the assisted boarding houses. So let's pick up the segregated settings, particularly in that area, the boarding houses and assisted boarding houses, and what is it do you want to speak to that, about that setting? What is it that's wrong with it and what on earth can be done to improve the lives for the people who live in those places?

*[Advocate 7]:*

I can speak briefly to that element and others obviously will have their own views. Here in New South Wales, of course, we have fundamentally two different types of board housing settings the assisted boarding houses, of which there are around 17. The number varies because some new places come on board and others close. There's, of course, the far, far bigger issue of the general boarding house sector. This matter is currently all up for review by the New South Wales State Government, so they're sort of looking towards the future of the boarding house sector and ... but it does concern me that the NSW Government sees a future for the boarding house sector. It also concerns me greatly that it seems and I stand corrected that the NDIS sees the future for the boarding house sector, which really gets away from what the CRPD [United Nations Convention on the Rights of Persons with Disabilities] says around people with disability, being able to live in the community and participate in the community, and I think it also says how entrenched these problems become because this was a critical issue in terms of this sort of congregate living way back when Brian Burdekin did his Human Rights and Equal Opportunity Commission inquiry into mental health way back in the early 1990s. He

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specifically pointed to the problems of the rooming house sector, as it was called and still is called in Victoria, and he actually visited a place which had some bizarre name like Paradise Lost or something in Footscray and was outraged and talked about the need to get away from this sort of institutional living, and I think that's the critical issue.

Is this the boarding house sector... for the people that want to talk about the future of that, they really need to do some basic research around the context of institutions and how they institutionalise everyone within, and certainly our experience in that space over... the past almost 20 years has been basically that everyone within that setting is institutionalised and even now, you will get examples where people of course are supposed to get individualised support through the NDIS but things are basically then spread out across everybody in the residence. So everyone's doing the same activity. Everyone... as I said before, almost everyone is on the same medication. There's not the choice of meals. So it's a really critical issue and everybody ultimately is complicit in keeping that whole thing running, and so you're not in effect seeing... I'll give you an example, which is a case example.

Trying to get someone to transition from an assisted boarding house back into the community is extremely, extremely challenging for us as an individual advocacy organisation because it's assumed that assisted boarding houses are the end of the road. Many of these people, for example, have been screened out of long-term stays in places like Cumberland Hospital, which is a terrible, terrible institution here in Western Sydney, and everyone's saying, "Well, this is it". Now, I have worked in various settings .... with boarding house residents, and when I was at [another organization], we actually tried to bust out people from a particularly bad assisted boarding house and we failed. And when I say we failed it's because the whole system didn't support us doing that work. And that's even with the authority of government. So it's a really deeply entrenched problem and I would really compel the DRC to try and look at... start with looking at the research evidence around institutions and there's a whole legacy of stuff in terms of research evidence going back to things like the Callan Park inquiry back in I think 1960, 1961. We know what these things do to people. I suppose in terms of if we're going to look at this from a rights-based focus, we want to be looking forward to the future. How do we afford every citizen the right to participate and live in the community?

*[DANA CEO, Mary]:*

Thanks, [Advocate 7]. That's fantastic. [Advocate 10] and [Advocate 9] and [Advocate 14] have their hands up.

*[Advocate 10]:*

In our organisation, we deal a lot with people in supported accommodation who do not have any relatives and what I have found and what other advocates have found in our

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organisation is that these people are extremely vulnerable. They often have no choice in the care that they have. They often have no overseeing person to look after them and, in fact, one person got moved from one house to short-term accommodation and the only reason we knew about it was because the person who was running the house rang me and said that they needed an individual advocate for this person, she didn't want to move. And I think it's really important that people who are in supported living accommodation who do not have any relatives are allocated an advocate that has no vested interest either in accommodation or service provision to look after their needs because it's quite obvious to us from our experience that they are often left very vulnerable.

*[DANA CEO, Mary]:*

Thanks very much, [Advocate 10]. [Advocate 9]?

*[Advocate 9]:*

Just as [Advocate 7] was talking about the ABHs [Assisted Boarding Houses], I made a list of some of the issues I have come across. So medication was huge. Severe malnutrition and illness. Concerns around sexual violence where men and women were co located, often in shared... not shared rooms but there was still more than one person per room and easy access to different rooms. People having things stolen. Not being able to, [Advocate 7] said, we were told directly that we are not to encourage people to leave the boarding house. And to move into somewhere else, even if we did get someone out and maybe want to move them into social housing, that then brings up a whole lot of other issues, which is a separate conversation. ABH providers becoming NDIS providers themselves and then double dipping, so potentially. But also having more control by... we heard one case of a provider getting everyone to cease their other service agreements and sign up with them as the NDIS provider. A lot of people being under trustee and guardian in these environments as well, so another layer of control in that environment, having all their money controlled, also most of their DSP going to pay for boarding and lodging, and then very, very, very poor compliance or oversight mechanisms in those systems. So I just wanted to mention that was a list of just some of the stuff I had come across in those environments.

*[DANA CEO, Mary]:*

Thank you, [Advocate 9]. [Advocate 14], you had your hand up and then [Advocate 15].

*[Advocate 14]:*

Thanks, Mary, and thank you to the others who have spoken already. The thing I wanted to highlight is I think the real issue in these types of settlements is, just to make it very clear, the conflict and the moving away from informed choice and control over the provision of supports. While we're talking historically about the lack of choice, we have to turn our mind to emerging developments in the market that are perpetuating this for people with

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disability. I know Mary is aware of what I am going to talk about but what we're seeing, for instance, harking back to [Advocate 7]'s point about how the NDIS supports these types of settings, is the fact that we're suddenly seeing market development and encouraging these types of supports of housing.

One thing that we have raised to both the Commission and to the Agency has been the practice of homes where essentially it's a mini institution and where a single agency is providing both housing and supports to a person, how that then gives rise to inherent conflict of interest and the potential for a whole host of reportable incidences. The concern is the fact that there has never been that informed choice and this isn't meant to happen. According to the guidelines, housing shouldn't be provided by a sole provider but what we have noticed is that the guidelines allow for other agents to be able to put in place for excluded costs such as housing and those costs will be paid to other forms of funding such as personal income, DSP [Disability Support Pension], et cetera, Commonwealth rent assistance and other forms of income. What that then creates is a new model of housing that perpetuates in all the models that we're discussing where people don't have the informed choice to be able to live their lives fully, included in society, and that is something that needs to be addressed. What things are happening in the current system that are giving rise to outdated models? This is not just me speaking lyrical. The report from the Joint Standing Committee released last year highlighted this conflict and it's not necessarily something that is new and it's something that we need to address in terms of housing, as I said what can be done to address unintended and perverse outcomes with current systems and models that is creating and re-perpetuating of traditional older models of disability care to exist.

*[DANA CEO, Mary]:*

Thank you very much. We will go to [Advocate 15] next. I just want to make a point, so that you all realise, so you're all touching on a really wide range of issues, which need to be addressed in different ways, by different systems, by different places, but that will get teased out - so a de identified version of what you're talking about today will go into the Royal Commission as a submission, but the policy people in the Royal Commission trawl through these transcripts to pick up the specifics of the issues and where they need to be directed to. So it's good, really good, that you are ranging across a wide range of issues and potential solution, as we're talking today. There are also people putting very good contributions in the chat so please, as you have time, have a look at that, but we will capture that as well. [Advocate 15], you had your hand up?

*[Advocate 15]:*

Yes. Just wanted to say that the reason why we're always banging on about inclusive education is we feel like that is the first step. We need to start with that because that will lead to gaining employment, which will lead to being able to afford housing, et cetera. So

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we are really wanting to have a strong focus on inclusive education. I understand that those issues are there with the boarding houses and I don't want to take away from that at all but I really think we need to think about why are they there and make sure that people are disability are part of our society and belong to society and are within it and not just being thrown funding to do activities and essentially time waste. What can they do to genuinely have employment, so what can we do about the great divide between education and employment? And in terms of having customised employment and starting to really promote those models that are innovative and contemporary so that we can... people with a disability can actually afford to make choices about where they live and who they live with, et cetera.

*[DANA CEO, Mary]:*

Thank you, [Advocate 15]. You make a good point in what you're saying there. From the sector as a sector, of course, the individual advocates, and most of you on the line today are individual advocates, and you're working with one person at a time to resolve their issue, but there is something about the systemic advocacy that we collectively as a sector need to make sure it covers yes, that there is enough focus on inclusive education so that there are people working on that issue but, at the same time, all the issues that [Advocate 7] and others have talked about, and that depressing list that [Advocate 9] had about the assisted boarding houses, of course we have to find there has to be parallel work, doesn't there, so that those people don't get completely deserted and forgotten about, which in effect they have been for a long time already.

The point of today's discussion and a lot of the rest of the work of writing submissions into the Royal Commission, the other Royal Commission work happening at the minute, is to make sure that when this Royal Commission is finished, hopefully it gets an extension, but we want it to make a difference, and so we have to put forward all of the best ideas for what's going to make a difference for people. You talked about providers today, or various types. The providers generally speaking - they're not necessarily bad people, all of them, but they have significant conflicts, don't they? They benefit from the current system, so why would they be promoting changes to the systems that they benefit from? So there's this huge inertia that exists in all of the systems - the education system, the disability service provision, the boarding houses... all of those, there's this weight of the existing systems and structures and then how do we generate sufficient force and the Royal Commission is one of the ways that we can do that to try to put huge pressure back on to those that enormous inertia of the existing systems. So that's why any things that you come across or good examples, the tiniest of good examples that you see, where, especially for individual advocates where you're working with someone, I'll ask a specific question about that. If you have worked with someone on an advocacy issue and you have seen a shift, so you have won, you have helped the person get resolution to their issue, have you seen any example where that has shifted the culture of the organisation,

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of the provider organisation, where they have then in response to something that you have worked with and had success for an individual client, do you ever see that a provider changes their practice to improve the situation for other people as well? Does that ever happen? Have you ever seen that? [Advocate 10] and then [Advocate 15].

*[Advocate 10]:*

I have seen that specifically actually to do with my daughter and I will speak personally to that, in the education system, where for years we had a head mistress or a principal whose philosophy about education with disability was poor and continued to be poor. So we were working in an uphill battle where the teachers wanted to make the adjustments but the principal didn't. Sometimes I feel that this is the same process. We, as individual advocates, are trying to push up change from below up to the above and, yes, that can work in many circumstances, but the difference was when a new principal came on board who had the philosophy that all children with disabilities have equity of access to the curriculum, that they weren't doing me or my daughter a favour in changing the curriculum, and that not only changed things for her but it changed all our vision, equity of access, for the department of education.

My concern is, I believe that training is essential to get improvements but my fear is that whoever heads up any of these organisations has to have a philosophy about disability that's not one that I have seen a lot of, which is theirs... not essentially can we get these people better. It is about their inherent, independent role in society and how they are valued members of society and how society needs to treat them as valued members of society.

I fear that without that headstrong approach and philosophy from the heads of all government departments, anything that we suggest will not get very far because from what I can see from my role, if the head of a department is very, very on board with that philosophy, whether or not your staff are well trained, they will be well trained. It will get done, but if they don't have that philosophy and they have a self-interested philosophy and the philosophy of somewhat charitable philosophy about disability, it doesn't get done.

*[DANA CEO, Mary]:*

Thank you, [Advocate 10]. That's a really clear articulation of that issue. The next question in my mind is then how do we as a sector and what's the Royal Commission need to be recommending about how, how to get those leaders, as you're saying, the senior leaders to have their view or have them be accountable for what happens. That's the next step in that. [Advocate 15], did you want to speak?

*[Advocate 15]:*

Yes, I guess I can give... there's lots of examples but there is one example in particular at

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[a primary school]. We had a family member there whose daughter was forced into the support unit and the mum advocated really hard to get her into the regular classroom. After a period of time, not only did the teachers realise that it was working really well with good practice, that the principal started to see that as well and it ended up... it's ended up in that school that all the support units are now starting to be dismantled, but they're starting a movement called Collaborative Classrooms. So they're trying to ensure that there's a lot more proper engagement and inclusion with all children, so the children with disability are actually engaging with everybody and not just when it's the music class and then they pull them in and then they pull them out. So that's had an impact in a systemic way and in a really positive way. So that's just one example.

But just from what you were saying, I think with the issue of training and I think [Advocate 10] made a really good point, it's about mindset and it's attitude training that's needed, mindset training so that people with disability are actually perceived in a different light, not so much a skill idea but a will, the will idea, the will that they should be included and they should be part of our society, and that we need to actually look at things a lot more deeply than this sort of surface level kneejerk reactions that we often get, knee jerk surface level solutions that often come forward without really looking at a deeper level as to why things are happening, especially given the history that our society has in devaluing people with a disability.

*[DANA CEO, Mary]:*

Thank you, [Advocate 15]. [Advocate 9]?

*[Advocate 9]:*

I wish I had good examples. Unfortunately, I don't. I actually want to raise... we talk about the philosophy and the attitude people have and a good example recently of how bad this is that you look at the Minister Roberts' conversation recently about disability and prostitution and how I feel very disturbed personally about his framing of that, and I will give you one example. We talk about the problem around sexual violence against women and girls with intellectual disability. I have had a client in the past who was seeking out a relationship as a result was being sort of, it's a long story but was seeking out stuff in social media and in the community and was getting abused by men and I won't go into the details to of that but it's just a good example where if you can't have a conversation with clients around or with the NDIS around relationships and people with disability actually being seen as human and wanting to have sexual relationships and then have the Minister framing this as people with disability using their NDIS funding for prostitution, we've got a real problem on our hands. So I think that just showing some of the disgusting attitudes that we're battling against in this area particularly, and how that relates to extreme levels of violence and potentially perpetuates it further.

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*[DANA CEO, Mary]:*

Absolutely. I think everybody is nodding in agreement. And the fact that the Minister is in theory the leader on that issue, sorry, he's the Minister responsible for the NDIS and is running around the country talking rubbish. [Advocate 13], you wanted to speak?

[...]

*[Advocate 13]:*

I totally agree with [Advocate 10]. I don't think I agree so much with [Advocate 15].

We have had these issues about educating staff for 30 or 40 years, with all the stuff that's gone on in Victoria, with that big disability service provider down there. We've had tonnes of Royal Commissions. We've had tonnes of Senate inquiries. It's all very well to say people should be educated but we have said the same thing for donkey's years and it doesn't happen. People, I think, it's probably a pessimistic view of human nature. Many of them don't do things unless they're forced to do it. I would say, by the way, that I do think there are very many service providers out there that are very good service providers and do a really good job. So the complaints we hear are with the troublesome ones, and that's where you need effective regulation.

I think you are burying your head in the sand if you think nothing is going to change without having legal remedies. That's got to be the approach. There's no point in saying we've got courts and we've got tribunals. When our clients who don't have legal capacity and don't have funds can't access them. There's no point in having regulators like the NDIS Quality and Safeguards Commission or, in New South Wales, with restrictive practices now this Ageing and Disability Commission, if they're not actually given powers to hold regulators to account in individual cases. For 30 years we have had a complaints system that just says, "Give the complaint to the service provider; if they don't resolve it, maybe you can go to an Ombudsman". An Ombudsman has no power. They write a letter and say, "Well, this is what you should do", but you can't enforce it.

So unless you're going to actually give our clients legal rights, and I mean in a practical sense, where they can access a regulator who can hear the matters that are submitted for them perhaps on behalf of them by their parents or carers or their advocates, and hear the case and make a decision in a very short time which holds the regulator to account, you're never going to get change in this industry. It was set up to be privatised to make profits and, unless you're going to put in the legal machinery to make them accountable, it's never going to change. It's going to get worse.

*[Advocate 8]:*

I think there are real limits to the legal process. Not many people could actually manage

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that. It actually requires quite a lot of resources for individuals. Often in my experience, just working in advocacy, people have to have pretty organised sort of lives and have a sense of investment in the mainstream, have capacities to organise paperwork. I just think that we live more and more a legalistic system. I think that's one of the problems. We need to have a way of promoting exchange, of conversation, communication, that's not about all this administration. I think we've got into a world of technology and phenomenal legal wrangling actually, which I think is actually problematic for many people. But that's just a general point.

I just think that there are lots of systemic issues that are actually impacting on everybody's lives and making things more difficult. I think it's about... I guess it's how you look at how to communicate and then actually embrace complexity and really talk to each other and work out how we go forward and avoid actually blaming of particular sectors in society and really start to engage with some new and increasing issues that we have, daily issues.

*[Advocate 13]:*

Can I respond to that please?

*[DANA CEO, Mary]:*

Yes, absolutely, *[Advocate 13]*. But in my mind it's not that the two of you are at cross-purposes. It's that both of those responses are required. But, yes, *[Advocate 13]*, please go ahead.

*[Advocate 13]:*

I don't want to be legalistic. I don't want to be confrontational. Our centre, we always try to settle things. I would like to settle things with service providers. What I am saying is when it gets nowhere, as a last resort, our clients have got to have somewhere where they can go and get a remedy, and they can't do that. That's what I am talking about. They can't get a remedy in the courts or the Tribunals or from the Commission, so we actually need for them, at the end of the day, as a last resort, to have a legal remedy where someone can say, "Yes, service provider, you were wrong there, you denied our client Community Access 10 times in a row because you wouldn't fix your bus, and that's not acceptable, so you've now got to give him back his 10 Community Access visits". Things like that that can be fixed up. Or "you've let him - these are all cases I've got, "You haven't fixed his toilet in his room for six weeks". Now, a tenant could get an urgent repay and pay for it himself and go to the Tribunal and get compensation back. In a group home, you can't. So you should have a regulator that can say: "Mr Group home, you're at fault. He's gone and fixed up his own toilet or he hasn't has his toilet for so long, bang, you pay him a fine or compensation of \$2,000", as a last resort that's what you need.

*[DANA CEO, Mary]:*

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Thanks very much, [Advocate 13]. This part of the discussion is really useful because we talked to the Royal Commission policy and research people last year but we have just reached back into them again because we are strongly encouraging the Royal Commission to do a proper piece of work on complaints mechanisms and processes. You were all giving really clear examples there of how they're not working for people and I think you can see what some of the solutions should be. So it's a really important area that the Royal Commission should pick up and do some serious work on and we will come back to you, to you all, as we're hoping some of that happens.

We haven't got very much time left and I just want to touch on, I will just ask you about a couple of other segregated settings. Has anybody got any comments to make about ADEs? Anything good, bad or indifferent? Are you working with people in ADEs? Any quick comments to do with that setting? I can't see anybody leaping in.

What about day programs? Day programs, day services? Are they improving at all? Are there good examples that you know about? Are they still stuck in the Dark Ages and haven't changed? Has the transition to the NDIS made any difference at all to that day service model? [Advocate 14]?

*[Advocate 14]:*

I didn't get a chance to talk about the ADEs. Yes, [NSW Advocacy Organisation] has never supported segregated employment settings. However, I think what would be helpful, particularly through engaging with the policy and research team, is if the DRC is looking at what a transition away from those segregated settings look like. That's work I don't think many people in our sector have done and it's one that I want to do here at [this organization] but it's very hard to see how we can - for the ending of employment of segregated settings, we don't know what it looks like elsewhere. So it will be really interesting to see where it's worked well and what that transition looks like because that transition plan will be part of obviously ending those segregated settings but also it will address the concerns that people have around that pathway that I was alluding to earlier in this conversation where you have got a segregated setting from one to another. So we have to make sure that there is that conversation around that pathway from schooling to work, that that is factored into what that transition plan looks like. If we don't do that work, then ending those segregated settings won't happen.

*[DANA CEO, Mary]:*

Thanks, [Advocate 14]. [Advocate 10] has made another comment about there aren't outside bodies with the proper powers, so the organisations don't have to change because no-one makes them and are we looking overseas for best practice, has that work been done? I am hoping that the Royal Commission will be doing some of that work. I'm just going to go to [Advocate 13] who wants to comment again.

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*[Advocate 13]:*

I just want to say on day care, my brotherinlaw is in a very good day care and we're really happy with it. I just think there's a lot of pressure on service providers financially in trying to adjust their shifts and having to justify themselves to the NDIS to get paid. It does impact on our clients, especially the training seems to be on the cost for the service provider. You've got the issue of where at last minute services get cancelled and then the service provider is not sure if they're going to get repaid. They may have already committed for staff. So I know I'm on the other side here but this model of the service provider having to care for our clients and then billing the NDIS, in a lot of cases they get squeezed in the middle and sometimes they lose money and it causes themselves and their employers a lot of business stress, if they're doing the right thing, and sometimes in order to survive, our clients have got to miss out because they're not getting paid for stuff. So I just think that's the other argument, that this model of trying to guess when you're going to provide the services and when you're going to get paid, it makes it hard for a lot of service providers and a consequence of that could be that a lot of them are going to go to the wall, the smaller ones, and other services with our clients are going to miss out. So just making that comment.

*[DANA CEO, Mary]:*

Thank you. I think across some of these other workshops there have been a couple of other examples of newer, different, Community Access organisations that are providing that in a more modern, innovative way, and I'm hopeful that the Royal Commission will pick up and look into some of those examples and pay attention to whether the current system and pricing is actually working for people.

We might I might just ask if anybody has any last comments, things you wanted to say, things you wanted to say about... and it can be anything really to do with restrictive practices or segregated settings, just to see if any of the advocates have anything final [Person 2], have you got a question? [Person 2] looks like he has a question he wants to ask.

*[Person 2]:*

Yes, I'm just wondering whether, especially [Advocate 7] and others going into supported residential facilities and the larger hostels, et cetera, in South Australia, one of the unintended consequences has been that some of these larger providers for profit organisations have been able to get packages, quite substantial packages, big packages, for a lot of their residents and are expanding. They're not getting smaller. They're actually buying other properties and expanding. And I wonder whether if that's your observation in New South Wales? I would be interested to see whether an unintended consequence is that these individual for-profit organisations with large residential facilities are actually

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growing and creaming people who have got a good package, but also the coercion and being able to maintain and keep people who have got a decent package, that they exploit?

*[Advocate 7]:*

I can see that in New South Wales, it seems to be that the assisted boarding house sector is under considerable pressure in terms of their business model and so it's not actually working out perhaps the way that they thought it might in terms of the NDIS being some sort of cash cow. There's also an issue that not as many people are being screened in to assisted boarding houses as previously, so there's actually pressure there. There is a thing when people hit 65 in assisted boarding houses, so they no longer become, if you like, good for the business model, so there's pressure to move those people on, and I can give anecdotes of terrible situations where that's indeed happened. But I think because this is all a subliminal phase here in New South Wales until the NSW Government sort of settles on where it's going, it does seem that the goal is to reinvigorate the sector and I think hearing people speak, what really concerns me is we're still... I mean, I've been doing this for decades. We're still having these conversations when it comes to people with disability doing basic things like going out the front door and choosing what they want to do with their day, that is something people with disability have to wait for. They have to be on the bloody pathway and wait until everybody else decides it's actually OK. And I think that really gets to that attitudinal stuff that underpins all of this stuff in terms of restrictive practices and other acts of violence perpetrated against people with disability.

*[DANA CEO, Mary]:*

Thanks, [Advocate 7].

*[Advocate 9]:*

Can I make a quick comment because we didn't talk today at all about restrictive practices in the family home. It's not an area that I have much experience in, but I would be interested to hear from anyone who does. I have had clients who certainly have had issues around family members trying to take control of their finances. That's probably the thing I've come across most in my work. But I would be really interested... I think it's an important issue and I am wondering how the DRC are looking into it and what other advocates have come across in regards to that?

*[DANA CEO, Mary]:*

Thank you, [Advocate 9]. I'll just ask [Advocate 10] or [Advocate 15] from [NSW Advocacy organization] whether that's an issue that your organisation grapples with any more or differently than the other organisations because you're dealing with families a lot?

*[Advocate 10]:*

From my experience, I haven't had restrictive practices in families. If anything, I have

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had - I suppose, the opposite, where families have come under incredible pressure from outside groups not to medicate their children, with the idea that somehow they are trying to make them like zombies, and that they're not being good parents. So I have found actually the opposite from my experience.

In terms of financial abuse, I have had circumstances but not in families where independent people are living in supported accommodation and have been told that they need to give access to their cards to service providers to get them things like clothes, and although the financial guardianship has been involved and has told them to send the invoices to them, the service providers don't want to do that. They see it as a bit of a hassle. So I am sure there are restrictive practices in families. I personally haven't come across it, but, if anything, I have come across the opposite, where families are shamed about medication, about restraining their children, and really all that does is create a circle of fear for those families and a circle of fear for the actual child.

*[DANA CEO, Mary]:*

Thank you, [Advocate 10].

*[Person 3]:*

Mary, I have a question.

[...]

Picking up your point earlier, Mary, around change, I am interested in whether any of the advocates have given any thought to the recommendations they would want to see from the Royal Commission at the end of this Royal Commission in terms of those two areas of restrictive practices and segregated settings? I know they're big areas but I'm just interested if you've given any thought to that and happy to hear your thoughts if you have any. Thanks.

*[Advocate 7]:*

I can quickly say something. In terms of people alternatives to restrictive practices, obviously that entails a whole lot of researching, right down from the on the ground stuff in terms of getting, ascertaining people's will and preferences and being able to support those choices through to the high level support that people need, in many cases across their lifespan, and that's one of the issues we're not talking about today, that the disability sector is not properly resourced and so many of the things the concept of last resort, for example, is often first cab and only cab off the rank because nothing else is available. So if government was going to be genuine about this, they would actually make sure that the supports are there, not just decision making supports but the actual support services, and I could give a long story about what we are hearing in New South Wales, when the NSW

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Government exited the sector, particularly around that sort of clinical support that used to exist within ADHC [Ageing, Disability and Home Care NSW], and there's all sorts of problems that ensued from that. So I would say resourcing, Peter, would be a really critical issue to address.

*[DANA CEO, Mary]:*

Thanks, [Advocate 7], and that particular issue about the things that were lost as the State Government transitioned their services across to the NDIS is something that there's some of those specifics from each State and Territory about the things that have been lost and who is now responsible or is anybody responsible for them is something that I think will end up being recommendations in this through this whole process. We have chewed up past the time we said we were going to finish, but we could keep going on this all day but we'd better not. You're all busy people. I will just make a couple of points, and people are still putting things in the chat and thank you for that and we already gathering those comments.

We will provide so, as I mentioned at the beginning, we have done a series of those workshops. They have been incredibly valuable. So they will go in in a deidentified way into the Royal Commission anyway as submissions but we will provide back out to the sector, to all of you and all of the advocates, the compiled version of all the issues that advocates are raising, including some of the solutions that you have been suggesting. We are planning to do some more workshops..a couple that will evolve from these which are solutions focused workshops. They're still at the planning stage and there's a couple of other specific things that are thinking of. We did run a series of Zoom sessions last year and we haven't picked them back up again this year. They were on specific topics and specific systems and I think now we are at the stage where we will start planning some more of those this year. But please feel free to come back to DANA if you have other suggestions of any of the things we talked about today but other issues that you feel are not they're not getting enough air time, they're not being discussed enough, they need to be ventilated a bit more before the so that the Royal Commission can pick up on them. It is enormous and with all the different systems that need to be looked at, it's huge but it is an opportunity for the advocacy sector to try to influence what it is that comes out of the Royal Commission. It's a separate thing to influence how Government responds to the Royal Commission but at least let's get what the Royal Commission recommends at the end, get that to be the best that it can be.

I mentioned earlier that if you have particular stories that you think... lots of you touched on anecdotes today, but you mentioned in passing you have lots of other case studies and stories. Any of those that you think the Royal Commission should hear, please, as I said, send them in as a quick submission and so that they can... the Royal Commission can start to look into them in more detail if they want to hear more, and is there anything else I

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was meant to mention at the last minute? [Advocate 15] made her closing comment, proper resourcing for independent advocacy, and it's an issue that has been mentioned by a few of you today but I haven't asked you more questions about it but it is something that the advocacy sector does need to work on in the next few months really and develop some new resourcing and funding models for advocacy. It's such an obvious thing and we know you're all aware of it, that if advocacy isn't well resourced enough, it does make a big difference in the lives of people who manage to get an advocate, but there are so many who don't. I think [Advocate 10] or [Advocate 15], one of you mentioned earlier the issue that there are some people who should be allocated an advocate. That's absolutely a position that DANA has come to believe. Where we need to move forward on that now is to develop what those models are. If people should be allocated an advocate, which people in which settings and to what point? How many hours of advocacy and delivered by whom? Obviously by the advocacy sector and who is going to fund? That is a particular piece of work we will be working on and coming back to the whole advocacy sector about it in a few months because we have to put that to the Royal Commission as one of the potential solutions for some of these issues.

So thank you very much from DANA's perspective, and I'll pass you over to [Person 3] just to give you closing comments from the Royal Commission.

[Final words and thanks from DRC]

*[DANA CEO, Mary]:*

Thank you, Maurice. Thanks, everyone. Feel free to email myself, ceo@dana.org.au or Siobhan at policy@dana.org.au, if you have things that you thought afterwards, "Oh, I wish I had mentioned that", feel free to let us know. Thanks, everybody, for your time today.

### Comments typed in Zoom chat function

*[Advocate 15]:*

I would also mention another setting increasing the risk of restrictive practices, particularly seclusion through lack of access to supports and failures to act, would be in aged care facilities (for both younger and older people with disability). With low staffing levels and a lack of expertise in spinal or neuro care many nursing home residents are often left disempowered, with only recourse to a bell at the side of their bed to seek support. Many aged care service providers misinterpret peoples' needs and fail to appreciate their choice and control. Many people do not have the choice of chair that they use and many unscripted chairs cause pressure sores and present other health risks. It's particularly

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concerning for older people with disability as they often do not have support persons to advocate on their behalf.

*[Advocate 12]:*

[Advocate 10] that is exactly right. All people in group homes must have someone to advocate for them who is not employed by the service that provides the staff in their home. Along with this Support Coordinator should be accountable to their clients over and above the service that employs them.

*[Advocate 10]:*

Totally agree [Advocate 13], The Disability Discrimination Act needs to be reviewed.

*[Advocate 9]:*

How do we address restrictive practices in the family home?

*[Advocate 15]:*

Totally agree [Advocate 13]! Legislation/regulation with teeth.

*[Advocate 9]:*

I agree 👍

*[Advocate 7]:*

Totally agree, [Advocate 13]. This is not a problem that can be solved by more or better training. What we are talking about, in many instances, are acts of violence that should be treated as such.

*[Advocate 10]:*

The Issue is that both Education/NDIS and Aging are self regulated  
no outside bodies with any real power

These organisations don't have to change because no one makes them.

I am not sure why we are not looking Overseas for best practice with policy and procedure  
- has that work been done?

*[Advocate 15]:*

[Advocate 13], I did not mean attitude or trauma informed training was the panacea by any means, I was commenting on [Advocate 10]'s reflection about philosophy of decision makers. It's a part of a complex suite of solutions. Absolutely, service providers do need to be forced to behave properly. And creating legislation with teeth will help.

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One last point on segregated settings to get in - people with acquired injuries struggle to find appropriate employment (usually due to employers' attitudes) following rehab and are forced to turn to ADEs, but as many have said to them these settings reinforce a sense that they are defined by their disability. As one person said to me, "I live with disability, I don't want to work 'disability'" too. As has been said there needs to be attitudinal change by employers and workplaces, which can in part be facilitated by providing resources and subsidies to former employers to make reasonable adjustments following a person's rehab journey when they return to the workplace (i.e. greater resources for Job Access etc.).

[Advocate 10]:

Anyone who is in supported living accommodation that do not have family members should be allocated an independent advocate.

[Advocate 15]:

Proper resourcing for independent advocacy is also important

[Advocate 10]:

Any organisational change needs - strong vision, leadership, policy and procedures, legislation, independent auditing, independent advocacy,