

DANA and DRC Workshops with VIC Advocates – 12 & 15 February 2021

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

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

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

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

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Transcript of Zoom Workshop – 12 February 2021

[DANA CEO, Mary]:

Hi, everyone. It's Mary here and we will get started. I had to pick which of the three Zoom links I had was the right one to get me into this meeting. For some reason it's never straightforward. So it's nice to see quite a few people here and I think there will be some more people joining us and we'll just allow another minute or two for people to do that.

Siobhan and I for the first time ever since we have started doing these workshops, we are actually in the same room. ... Right, I'll just give another minute or two. We've got quite a long list of advocates who have registered. We know from our past workshops that not everyone ends up being able to come on at the time and some people will join in as they can, but I can see more boxes opening up as people join.

It's nice to see you all. Zoom doesn't quite make up for the face to face real life contact, does it, but we're getting better at feeling a sense of warmth towards people we see in these little boxes on the screen...

I'll start with acknowledging the traditional custodians of the various lands that we are all meeting on today and I'd like to acknowledge that DANA respects their traditional and continuing culture and contribution of those communities and acknowledge and welcome any Aboriginal people who may be joining us today.

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

[DANA CEO, Mary]:

So what we're going to do is we're going to divide our time in two. We're going to start off by talking about restrictive practices. Just for those of you who have your cameras on, put your hand up, if you regularly in the work that you and your organisation do, if you deal with people who are under restrictive practices. Just wave your hand in the air if that's a common experience within your organisation. All right. Many of you are waving, not everybody, but most people are.

Does anybody want to have a stab at how common you think the use of restrictive practices is? When I'm talking about restrictive practices, I'm really talking about authorised and unauthorised. Does anybody want to have a first go from the work that you do, how common is the use of restrictive practices?

[Advocate 1]:

Certainly in my cohort, my clients, it would be close to 100%, maybe a little less than that. But right now if we're looking across the board at all forms of restrictive practice, it's very high.

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[DANA CEO, Mary]:

Yes, and the specific cohort, [Advocate 1], that you're talking about are generally people with intellectual disability and possibly other complex needs as well.

[Advocate 1]:

Well, predominantly they are young men with autism.

[DANA CEO, Mary]:

Okay, right. Does anybody else want to comment generally on that for you in your work or for your organisation? [Advocate 2]?

[Advocate 2]:

I'd say, if you're talking about people in group homes or other circumstances where they are effectively under the control of a service provider, you'd be heading towards 100%. The more the person's living circumstances are part of the community and are determined by the person and their close family and friends, you start to move way down and you start to approach zero, but the more service providers have control of the person's life, the higher it is.

[DANA CEO, Mary]:

Yes. [Advocate 3] and [Advocate 4], from [VIC Advocacy organisation]?

[Advocate 3]:

Yes, I was going to say exactly what [Advocate 2] just said, that that's what we've found in advocacy is that the more services are involved, and I feel that a lot of it is around lack of training and lack of insight and lack of attitude and just thinking that a pill is going to fix everything and that locking everything is going to be great and we're going to get no behaviours. So, it's very frustrating. I agree with everything that [Advocate 2] was just saying.

[DANA CEO, Mary]:

Yes, [Advocate 5]?

[Advocate 5]:

We find it across all age groups and lots of different sectors, from kindergarten, preschool, in mainstream education, special education settings. We find it in group homes, we find it in aged care settings and we find it in private residential situations and family situations. So, it's across the whole sector. It seems to be focused more and more on people who have complex, challenging behaviours associated with their disability and it's the inability to manage those complex, challenging behaviours and the lack of support and training for people, service providers, parents, schools, teachers, whatever, that is largely the problem.

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We recently had one of our clients was evicted by a State Government housing authority and the eviction notice said that it was temporary while the place was being refurbished, but there were no plans to refurbish it and he was being evicted and was going to be homeless. We had to use our powers under human rights and VCAT [Victorian Civil and Administrative Tribunal] to get that order taken out, that eviction notice taken out, because under their own housing responsibilities, the state authority was supposed to provide him with temporary accommodation while they were rebuilding it, but they didn't have that and they didn't put a date when he could come back. In effect they were making him homeless. We had to intervene with that.

There's been lots of other examples where children on the autism spectrum with complex, challenging behaviours are put in locked rooms, separate rooms from the other kids, or they're restricted from school completely because their behaviours are so complex and challenging. Bus companies won't take them on the bus anymore and some parents have been forced to relinquish, even though they've got money, NDIS money to support their children, they are still relinquishing into state care because they can't cope - the respite facilities that are around, there is not enough training within the respite facilities or places available to put young people with complex, challenging behaviours into the respite facilities that are available because they're all full. In fact, I know of three in Melbourne that are already full of people, children, who have been relinquished. The NDIS was supposed to stop relinquishment, but although parents have got money and funding for short term, overnight accommodation, which is a euphemism for respite, trying to find somewhere to put their child to have a break is almost impossible.

[DANA CEO, Mary]:

Thanks, [Advocate 5]. What we'll do, I think, in this discussion, remembering we've done these similar discussions with each state and territory - today and on Monday we're doing Victoria and then we have New South Wales as the last state and we'll be doing again two groups in March. So, a lot of the questions Siobhan will have provided them to you beforehand. Some of those we've explored quite well with other advocacy organisations.

What I'd like to pursue and go down a few rabbit holes with you guys is probably before the NDIS came in, collectively we would have hoped that some of this would have changed, would have improved by now. Now, my sense is, from what you're saying and what we hear anecdotally from around the place, there hasn't been much shift. So let's try to discuss what's that about? There's this enormous additional injection of money now into the sector. There are service providers all over the place saying that they do this work, there's behaviour support plans, you know, left, right and centre. What is it that's not working and what needs to change?

So, you can pick any aspect of that that you want to comment on really, but there's a process for managing, authorising, dealing with restrictive practices. There are experts, supposed experts, who are meant to be writing behaviour support plans. Who would like to have a go at that first?

[Advocate 3], yes, I think you have your hand up first.

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[Advocate 3]:

I'll hand over to [Advocate 4].

[Advocate 4]:

What used to happen previously was there used to be some training allocated within the service provision, especially within the homes, the supported homes. So there used to be funding from DHS to enable some extra training to be done for teams and then the teams would go away and they'd start recording and they'd start working together. But from a conversation that I had only a few days ago with a service provider is that, well, we don't have the funding to do that anymore. It has to come out of the NDIS plan. So, if that person doesn't have enough funding, then sorry, but you can't get a behavioural specialist, you can't get extra training, because that's not allocated to that person.

So it seems to have gone backwards because it's all about money and it's all about... there doesn't seem to be... just from just knowing, working in the sector for a really long time, it seems to have gone backwards in that it's almost like I call it a babysitting service, especially in the group homes, that it's just there for a job and then they're just there to supervise and there doesn't seem to be a collaborative approach by the teams to actually want to know why that person is behaving the way they are to actually really figure it out and work with the behavioural specialist and really get to know. They seem to just..... let's go to the doctor's and let's get a pill to pop. It just.... yeah, I guess it goes down to funding and the way that the system is set up. It seems to be very siloed now.

[DANA CEO, Mary]:

Thanks, [Advocate 4]. [Advocate 2], I think you were wanting to speak.

[Advocate 2]:

If I think about an example we've been looking at this week, it's multiple factors. It's organisations just doing what they've always done and not really changing the way they think about things. It's overestimation of risk. It's a failure of Quality and Safeguards to respond not only in a timely manner but in this case at all. So, we're talking about somebody whose original complaint was that during the COVID lockdown in regional Victoria, so he's in regional and the lockdown was in Melbourne, he wasn't allowed to do his usual community access. The reason given was COVID, but that didn't apply in the area where he was. He could see other people doing exactly what it was he wanted to do and was told, "Well, there's too many people doing it, so you can't do it." So effectively, "The rest of the community is going, therefore it's too risky for you to go", which makes no sense at all. A complaint was made to Quality and Safeguards Commission. That's eight months... eight months...and nothing.

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So, the service provider believes fully that they are in the right because nothing ever happened. Our client feels like, well, there's no point even complaining about it because nobody does anything.

I went to visit and there's a gate running along the side of the property which is closed all day every day so that there's no visibility out on to the street. He asks to have the gate open. The reason why the gate is closed....privacy, security, all these words are thrown around, but they don't actually mean anything. The only person who is at home in the residence wants the gate open. Why can't the gate be open? They don't have space in the house to do their personal hobbies, so everything is locked in a shed. They each have a designated area in the shed. That's where they go and do their thing, whether it's craft or whatever.

That shed is locked. They can't get into that shed when they want to. They have to ask a staff member and if that staff member says, "I'm busy", then they can't access it.

All of these restrictions are just treated as absolutely normal, and any complaint made about them goes nowhere. So, when you're talking about the higher levels of restrictions, the medications and the locked rooms, if you think it's normal to stop somebody accessing a part of their house or seeing outside on to the street or going where everyone else in the community is going, it's not such a big leap to think the other things are normal as well.

This individual also had an issue where an appointment needed to be rescheduled, a medical appointment, a very low level, non-urgent medical appointment, and when an advocate attempted to assist him to call the clinic to reschedule, they actually said they won't speak to him because his "carers", translation support staff from the house, make his appointments and they get to have a say about when he has his appointment.

If you can't even make your own medical appointment, how do you get to have a say in what medication you're given? How is that doctor respecting your rights as an individual to make your own choices? That just tells me that that medical practice understands that the service provider has complete and absolute control over this person's choices, which is just not true.

[DANA CEO, Mary]:

Thanks, [Advocate 2]. It's so disheartening, isn't it, to listen to this stuff? I think we might have hoped some years ago that there would have been significant changes, you know, by now

...

[DANA CEO, Mary]:

... [Advocate 5]?

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[Advocate 5]:

Yes, look, there's lots of examples I can give you. The most recent one, which is going to be in one of our submissions to the Royal Commission, involved a young woman with cerebral palsy, completely reliant on her NDIS supports to get her in and out of bed, in a wheelchair, feed, all that sort of stuff. The problem happened when her electric wheelchair broke. It wouldn't work, and the agency's response to that, the service provider's response to that was it's a state-wide equipment program which does these repairs on these things in Victoria.

They came and got the wheelchair, but our client was in bed for a week and wasn't able to get out of bed and was left for six hours a day, incontinent with no supports over summer. Nobody in that organisation had thought about hiring one temporarily or approaching the NDIS to use some of her funds to hire another wheelchair so she could at least get out of bed. She spent seven days over summer in bed until [someone] found out about it and that was so discriminatory to leave her in bed like that when it would be easy to hire one to replace it, but they didn't do it. So, she was restricted to bed for a week over summer, no air conditioning – appalling abuse!

One of our board members has legal capacity but lives in a group home. When the pandemic started, state disaster was invoked, not only wasn't he allowed out of his group home to get in a taxi to attend our meetings, but we weren't allowed to send in our support worker that's trained to work with him and participate in board meetings to go into the group home in his bedroom, set up his laptop and participate. We weren't able to get permission from the group home to allow our support worker in. So, he was restricted from participating in board meetings. And because we couldn't make the reasonable adjustment for him to participate, we had to cancel two of them and the law allowed the group home to do that under the state-wide pandemic regulations. They allowed it. And it was only until I kicked up such a stink after the second monthly meeting was cancelled and threatened them with all sorts of dire consequences if they didn't provide someone within that group home to support him to participate that suddenly, "Oh, yeah, we can probably do that".

Then we ran into confidentiality issues sending out board papers about our organisation. We needed to know which one of your workers is going to be there in the room when he's participating and whether they're willing to sign a confidentiality agreement. None of the staff in the house were. So again, we were stuck. These are examples.

[DANA CEO, Mary]:

Thanks, [Advocate 5]. I want to get a sense from all of you, any of you who would like to respond to this. The NDIS Quality and Safeguards Commission, that's the place, isn't it? They're the ones who should be on top of all this, should be leading the charge, you know, out there waving the flag and making sure that everybody understands about restrictive practices, you know, all of that stuff. Do you think they're doing that job adequately? No? Okay, everybody is shaking their head madly.

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[Advocate 3]:

Mary, from our experience, we're finding that it's in the favour of the service provider rather than the participant. It's educating and hand holding, and they forget that there needs to be compliance and there's nobody coming and actually checking from the Safeguards Commission to actually visit the person and actually spend some time actually getting to know what the issues are and what's going on in the houses.

[DANA CEO, Mary]:

Yes. Does anybody else want to say anything about your interaction with the Commission or what you see them doing or not doing and I'll just....[Advocate 2], I'll come to you in a second. Obviously, the reason I'm asking this, out of these discussions we want the Royal Commission to understand what are the things that they need to be making recommendations about, but what do we as the advocacy sector need to be advocating for, what changes do we need to be pushing for in the way in this case the NDIS Commission is operating?

[Advocate 5]:

The Quality and Safeguards Commissioner has made it clear through some of their workshops that complaints from advocates, advocacy organisations, directly to the Commission get no priority over any other complaints and yet we are at the frontline of supporting people when they come into contact with restrictive practices, but their position is we don't prioritise complaints from advocates. They go into the mix, and they're processed the same as everybody else. So, if we complain, they don't get prioritised.

[DANA CEO, Mary]:

Yes, thanks, [Advocate 5], and I've heard the same, about them treating advocates the same as any other third party. [Advocate 2], I think you wanted to pick up on that issue.

[Advocate 2]:

Yes, thanks, Mary. My experience with them is that you have to actually hound them repeatedly to get them to do anything. They don't seem to feel any obligation whatsoever to get back to the complainant and tell them anything. The complaint goes in and then all of the activity after that is behind the scenes presumably to the service provider, but you don't get told anything that happens after that unless you chase and chase and chase, make complaints, escalate, make more complaints, but even then, the latest that I'm getting on the one I mentioned is it's gone to our compliance team. Okay, well, it's been there since September. What does that mean? What are they doing? What's happening? What is that? Nobody from the compliance team will talk to us. I don't even know who the compliance team is. Nobody will tell us what's... that's effectively the end of it.

It's gone to a complaint to the Commonwealth Ombudsman. They're not getting any answers. It's just a big black hole. And I just have to question what's the purpose of a process that does that?

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The person making the complaint has had no outcome whatsoever, no communication back. Why bother?

[DANA CEO, Mary]:

Yes, thanks, [Advocate 2]. In the previous versions of these that we've done, when we've asked a question about the barriers that people with disability face if they are under restrictive practices and they want to make complaints about that and what we've heard from lots of advocates is, well, many of the people who have restrictive practices in place, they're not necessarily aware themselves that these are restrictive practices. So does anybody want to comment on that and therefore they don't even know that they could or should complain about them because this is the life that they are used to. [Advocate 1]?

[Advocate 1]:

Yes, look, I think this issue goes across the board, so I think in some family situations as well. I think the problem actually needs to be looked at from a whole of life perspective and the reality is that the trajectory for these individuals is that they're living at home, their behaviour is becoming more and more challenging, you know, there's all sorts of dynamics going on in the home. It eventually leads to the family reaching out for some sort of support and that not being great. There's certainly nobody standing beside them saying, "Look, when your son or daughter does this, this is what it means, this is how is probably the best way for you to respond," or they're not saying, "You see what he did there, that's an early sign of escalation, this is a great strategy." There's not a lot of that across the board.

So that then leads to these individuals ending up in supported accommodation in a very rushed way. They have no rights over where they go, how that process occurs, who they live with, what's done to them. There's just no control over any of it. So, if we take away their disability, of course anybody going through that will end up with post-traumatic stress disorder as well as whatever their condition is.

So, I think the problem is quite complex and my experience is that I've actually never come across a service provider yet who's able to respond to that in an effective way where the outcome for the individual improves their rights, reduces the use of restrictive practice. I have a client at the moment who has lived in a group home, he's in his 50s. Somebody else has been moved into that environment and keeps assaulting him and his sister is advocating, and the restrictive practices are going on there big time. He's stressed out, so he's being medicated. And these scenarios are repeated over and over again in supported accommodation.

So, it's complex, it's a systemic issue, and I can't see...so I'm now running my son's service myself. I've set up a service for one because service providers just kept walking away because it was too hard and I'm aware of some other families, because I run a peer action group at [VIC Advocacy organisation] and there's certainly other families who have done the same.

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I'd like to see some of the tertiary institutions doing some research projects around these issues and coming up with solutions, solutions for families, solutions for providers, because right now and certainly since the NDIS I'm seeing more resources. I'm thinking of one young person I'm supporting, there's a very reputable behaviour support organisation involved and there's some great reports that have been written, but it's not actually playing out at the coalface of the support and there's lots of transient workers. It's problematic. So, I'm seeing a lot more resources in some respects, but it's not leading to the outcomes that it should.

[DANA CEO, Mary]:

I'm going to go to [Advocate 6] next, but [Advocate 1], the last thing that you said there - are there sufficient pricing incentives or whatever for there to be or is there a need for better trained staff, but support workers who specialise in working with that particular cohort of people with disability does that exist anywhere? Did it exist previously in Victoria? Can it be done or is it that the whole of the support workforce needs to be lifted?

[Advocate 1]:

There certainly needs to be when I think about some examples of situations in the mental health sector, you know, a lot of them have a nursing background or, you know, some higher level of understanding. And certainly, working with my son's own team, you know, I'm seeing it from another perspective, and it requires constant training, constant, you know, on call support. So, these workers are put in these situations, given very little understanding of the person that they're working with and they can't necessarily ring somebody and say, "Okay, this is what's happening, what should I do in this moment?"

But yes, I think we definitely need to look at how can we deliver a higher qualification or understanding. Look, it's a tough one because some of the workers that I use haven't got like a full tertiary qualification, but they instinctively pick up what's needed and see my son as somebody of value, as a peer. So, I'm not sure how you do that in a bureaucratic environment. Bureaucracy is the issue here. It's the big blocker.

[DANA CEO, Mary]:

Right. We have to bulldoze the bureaucracy, don't we, to help find some solutions. [Advocate 6], you were wanting to say something?

[Advocate 6]:

I just wanted to go on from what [Advocate 1] said about employing behavioural support specialists. We've had some in participants' plans where having a proper behavioural support plan to prevent restrictive practices has worked really well with some of our clients, although they're very expensive, they're hard to get into plans, you know, to get a behavioural support plan is extraordinarily expensive. It's also hard to get one funded in someone's plan.

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But we have had success with behavioural support specialists who will go in and train support staff if there's enough money and that has worked really well with some of our complex needs clients, but then again, you need to have a lot of money in your plan, but that has worked successfully for us. But yeah, it's only for clients that have a lot of funding in their plan, basically. But then other clients that don't have a lot of funding in their plan, there really is that gap with support staff having experience or training and all those kinds of things and the staff that don't often resort to restrictive practices. That's what we've found, yes.

[DANA CEO, Mary]:

Now, some of these issues of course have been and are being explored within the work the Royal Commission is doing, but it's really useful to hear you collectively telling us what you're seeing and, [Advocate 6], or any of you, in terms of formally submitting any of this to the Royal Commission, it is really useful if you have a good example that you've seen on the ground of what has made a difference.

If a good behaviour support plan, good training of the workers, if you've seen that make a really big difference in someone's life, I think that's well worth putting in as a submission to the Commission as an exemplar of what it is that can be done because there's obviously.... several of you have made the point now that people don't have enough money in their plans and can't get it into their plans to get this happening. So in one of the hearings the NDIS is going to be the focus of one of the hearings I forget which month. Siobhan might put a link in the chat to the hearings that are going to be happening during the year. But yes, there's so much that we need to get the Commission to be looking at with regards to the NDIS.

We'll just take another few minutes on this before we switch to the segregated settings. Siobhan has added in the link there on the Royal Commission's website about the schedule of hearings for this year. As we move into the other part of the discussion, which is about segregated settings, of course there's crossovers and links between these two topics anyway. So, what suggestions do any of you have about what needs to change? Are there any laws or policies that you think could or should be changed that would make a difference to do with restrictive practices? [Advocate 5] and then [Advocate 1].

[Advocate 5]:

Yes, I think there's some jurisdictional issues between Victoria police and the NDIS and the Federal Police, where the misuse of funds, NDIS money, results in restrictive practices or abuse and neglect or violence towards a person with disability because police claim they have no jurisdiction because it's federal money. And at times when we've had to get welfare checks because we're concerned about some of our clients in private residences, we now use triple 0 because before when we rang the local police station, they would go around and if no one answered the door, they'd leave their

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business card under the door for the perpetrator to see when they got home. So, it was a terrible situation.

So, this jurisdictional issue between Victoria Police and Federal Police when there's money involved that creates these abusive situations needs to be much clearer. If it involves an assault where someone has an NDIS plan, that's a different matter. Victoria police can investigate that. But when the money is being used to restrict somebody and prevent them from participating in normal life, Victoria Police have no jurisdiction.

[DANA CEO, Mary]:

Thanks, [Advocate 5]. That's not an issue that's been raised before. [Advocate 1] and then back to [Advocate 3] and [Advocate 4].

[Advocate 1]:

I think one of the issues that's concerning me that I'm seeing with the rolling out of the NDIS and especially SDA and Robust Build is that we're seeing a resistance from the NDIA to fund single dwelling options for people with complex needs that lack capacity. So if they need 24 hours of care, there needs to be another room for support staff to use when they're on shift.

There appears to be a pushback from that obviously for... I certainly had a discussion with somebody yesterday and the reason that they were given was that it's not value for money if the person is supported... if they're the only one being supported. But the reality is that there are some SDA approvals coming through for single dwelling situations. So there needs to be consistency with that.

I have many clients in CRUs [Community Residential Units], and some of them were part of the early NDIS rollout, where in fact their life had deteriorated and the NDIA were saying at the start that with an NDIS plan people's lives should improve. So I think across the board in most cases the funding has changed, but they've still got the same support workers, they've still often got the same management structures and the same culture, the same approaches exist and my main concern is that what that leads to is that they have preferred medical professionals that they use who will write a script for anything without question because they're being given.....fed the information from support workers in some cases. While ever that can happen, then certainly chemical restraint will continue and there's no accountability at all and putting individuals with complex support needs, particularly with autism, with sensory issues as part of their everyday life, housing them together will lead to higher levels of restrictive practice.

[DANA CEO, Mary]:

Thanks, [Advocate 1]. We'll go to [Advocate 3] and [Advocate 4] and this will probably be the last comment before we move on to the discussion about segregated settings.

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[Advocate 4]:

I actually have a bit of a list, if that's okay, that it's become a culture, actually, and that often, and I'm speaking really probably in the supported accommodation, so it kind of crosses over around that segregated sort of or secluded sort of places. But there doesn't seem to be strong leadership within a lot of the houses as well. Like there's some models out there that have a very big gap between the boots on the ground to the management. So, the manager might manage five houses, but there's no one on the ground actually working with the staff actually giving that sort of mentoring or that sort of leadership to make sure that things are happening.

I think one of the big questions that I'm constantly... we're constantly talking about in our office is that it's relying on good staff to report this stuff as well. We're relying on people being honest with this stuff. They're going to protect themselves. It's very subjective.

I recently had a conversation with an APO [Authorised Program Officer], with an organisation, around a behaviour support plan around restrictive practices and the conversation went like.... that it's reliant on ... that it's a process that they're following through the behaviour support plan, that we've tried all of these strategies and we're using this as a last resort. However, we're reliant on people being honest to do that and I don't trust a lot of staff in saying that they've actually done all the strategies prior to just popping a pill and thinking that that's okay or locking a door because they don't want that person causing any sort of ruckus.

So it is that control, that power and control, over our most vulnerable people that are in systems that they don't know any different. They can't say, "I'm really upset because", "And I need to go outside out into the garden". They will, if they're non-verbal, they'll bang things, they'll try to say to the staff who aren't taking the time really to get to know that person about why they're doing that behaviour. The whys are never answered.

When somebody is behaving a certain way, don't just assume that, oh, they're going to go off track and they're not going to be okay. There's not a lot of consultation, I don't believe with the staff, with their management. Management have it all perfectly written out. They have it all detailed, everything looks wonderful on reports, but the staff on the ground have no idea these things are in place and there's no communication down below.

So, it all looks wonderful up the top and when you make a complaint to the Quality and Safeguards Commission, it all looks wonderful to them because everything is ticked off and it looks like a neat little package. However, in reality, it's not happening. Why would people make a complaint if things were okay? If it's not investigated, then there's no point.

[Advocate 2] was right in saying there is no reason, there is no purpose for the Quality and Safeguards Commission. We thought as organisations and people with disabilities that I've spoken to thought that this was a really good win, and it was great, they were going to have some teeth,

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they were going to actually be on the side of the person with the disability and they were actually going to dig up things and actually get things right and fixed. But it's actually not happening. It's completely the opposite. It's, "Oh, I'll need to send off to the organisation or the service provider and find out what they're doing about that" and then they send back all in their nice little neat package yes, we're doing all these things, but on the ground, it's not happening at all, and the staff often don't even know what is even... what they're supposed to be doing either.

That's a big gap to me. Yes, we're honest people, I'm sorry, but there's a lot of dishonest people working in these fields that there is no accountability at all. It's disgraceful.

[DANA CEO, Mary]:

Thanks, [Advocate 4].

[Advocate 4]:

Sorry.

[DANA CEO, Mary]:

No, it's just that the issue of the training and the culture stuff in organisations, what is it that will make organisations change? NDS, their industry body had that Zero Tolerance program running for years. Now, that wasn't specifically about restrictive practices, it was about broader prevention of violence and abuse, but whether it made any difference I don't know.

[Advocate 4]:

Sorry to interrupt, but I just wanted to throw out there that with Worksafe they have penalties. I think there needs to be sharp and very severe penalties because what the service providers are doing are saying, "Oh, yes, okay, we're going to fix all of this stuff", but nothing happens, nothing changes, it's just all words.

Actions speak louder than words and honestly, there is no law against unless someone dies, and this is what I've been told as well by the Commission, unless someone is actually... someone dies ... we do not want another case like Ann Marie Smith, we do not want another case like that. I'm sorry, there's going to be more and more of those because there's no protection and no safeguarding for these people.

[DANA CEO, Mary]:

Yes. Thanks very much, [Advocate 4]. In the meantime, there's been some great stuff put in the chat. [Advocate 2] has put in some stuff about the issues to do with medical professionals, prescribing inappropriate medication. Siobhan has put a link to some of the evidence that some of you on the chat have given at past hearings and [Advocate 11] has put up something about behavioural plans and the funding. So, as you get a chance, pay attention to what's in the chat as well and feel free to add to the discussion in there.

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We'll continue the focus, I suppose, because as you've pointed out really, the restrictive practices are mainly an issue to some extent at home, as [Advocate 1] pointed out, but also primarily in segregated settings. So, the usual segregated settings that we've discussed previously, we focused on group homes and other accommodation settings and also on ADEs [Australian Disability Enterprises] and to a much smaller extent on special schools.

One of the areas we haven't touched on at all in previous discussions in other states are day programs and that's something that was... we were prompted to think about it and to ask you all about day programs today by the policy people in the Royal Commission who would like to hear and understand a bit more about how those settings work. Are they the same as they always were, are they still operating in the traditional way, has there been any improvement, what are the issues that arise, is there violence, abuse, neglect happening in those settings or... yes, or what is being done to sort of make any changes there? So, let's start with the day programs issue in Victoria. Does anybody want to fire off about day programs?

[Advocate 1]:

I don't have a lot to say because a lot of my clients don't access day programs because of the extent of their behaviours, but certainly I have had some direct experience in a situation where a young man, eventually the day service got rid of him, basically. They just kept putting up barriers, raising his behaviour as an issue.

So, I would say that one of the challenges I think is day programs being resourced enough to be able to support individuals who present with complex needs and particularly behaviours of concern, where there's a risk factor, so my cohort eventually end up not going and staying in whatever environment they're in, either at home or in a CRU all day.

[DANA CEO, Mary]:

[Advocate 2], you unmuted yourself. Does that mean you want to speak to this?

[Advocate 2]:

I think in some areas this is... this has improved under NDIS. Having access to funding that allows people to determine what they want to do and to have more individualised arrangements certainly has helped some.

I am sitting here at my front window; next door is a cafe and about four doors down there is a disability service provider and more and more I see the groups leaving that building are smaller. A person or two in the cafe next door will be somebody that others stop for a chat with. 20 people with a disability sitting around a table is a group that people will avoid. So, the more you are getting people out in much smaller groups or with just another person, the more they're actually interacting with the community, the more they are known by the community, the more the

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community is accustomed to seeing them around and considers them part of that community. There's a couple of people that live locally that I see in the shops and they're chatting to everybody because everybody sees them around and knows who they are.

The settings that are completely segregated and are going out in large groups are doing the same activities as forever, they're going bowling still. I don't understand how that hasn't changed. I think a lot of their clients don't know that they can ask for it to change. They've done the same thing for so long. And those are also the environments where we get people reporting abuse because it's separate, it seems like different rules apply, it seems like it's not what you would assume anywhere else in the community and things go wrong.

[DANA CEO, Mary]:

I can see [Advocate 3] or [Advocate 4] made the point in the chat about cherry picking and being selective about who they take on, picking up on [Advocate 1]'s point that people with more complex needs, day programs don't want them. [Advocate 5]?

[Advocate 5]:

There's one area of the relationship between day services and day programs and group homes where the landlord is also the provider of the same services, particularly if the person in the group home is not eligible for the NDIS. We recently had a case where someone who wasn't on the NDIS was over..... well over 65, wanted to retire from going to day services and he was restricted from doing so by his landlord, who not only was his landlord, but was also the service provider that provided the day programs. He was not able to retire because they wouldn't provide a worker to be in the house with him during the day and there were no funds for him to go out in the community to what he didn't want to do in the day services.

It's a gap that has fallen through where you have a conflict of interest where the same service provider is actually the landlord, and the person is over the age where they don't qualify for the NDIS. They're stuck because most of their pension goes towards the accommodation and there's no money left to employ a worker to stay behind allegedly while that person is able to go out, say go to the museum. He wanted to go to museums, wanted to go to concerts, he wanted to just sit in the middle of Federation Square on a sunny day for a couple of hours. Not allowed to do it.

[DANA CEO, Mary]:

Just clarifying, [Advocate 5], when you talk about retire, you're meaning not retiring from work at an ADE, but actually retiring from going every day of the week to a day program.

[Advocate 5]:

He wanted to retire from going to the day program, but he couldn't.

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[DANA CEO, Mary]:

Yes. [Advocate 7], yes.

[Advocate 7]:

We've got the same thing up here similar to what [Advocate 5] is saying to a point that the day staff are actually controlling individuals' lives. This particular family has now moved to the Bendigo area because they've been unsuccessful in challenging and making life better from where he was living. I'm also finding that a lot of the staff are still very archaic in the ways that they're running the day service. So, the day service provides the programs, not the clients providing the programs for what they would like to do.

And the other thing is staff are out there doing what they want to do and dragging the client along. So, an example is, "My child is in the Little Athletics swimming competition today, so we're not going to do the cooking program, but we're all going to go and sit and watch my child swim today." So, the clients are paying for a service and the day services aren't providing them with their choice, control and the activities that they wish to participate in.

[DANA CEO, Mary]:

[Advocate 7], is that an actual example where one of the workers, instead of working at the day program and taking, or asking for time off or whatever and someone to replace them, they actually dragged the group of people they were meant to be doing activities with to watch that person's child doing swimming?

[Advocate 7]:

Absolutely, yes, that's exactly what happened.

[DANA CEO, Mary]:

Yes. [Advocate 8], can I pick on you for a second. From the perspective of the Citizen Advocacy Program, which of course operates a bit differently and you have citizen advocates working with people, but do many of the people that the citizen advocates are working with, are many of them involved in day programs? Is that a common scenario? Is it an issue you hear about?

[Advocate 8]:

It varies, but I guess the benefit of having a citizen advocate is an independent person and the people in our program who are part of a day program more often than not the citizen advocate will get involved with the day program to just find out exactly what goes on there and how they're faring there and if that is a good place and, importantly, if that's their choice to go there because we've had a couple of situations where the person in the group home has no informal supports, just been told day service, with the citizen advocate's involvement they've found that's not what they want to do. So, yeah, then that's given that person some choice and control over their life not to go to a day service.

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[DANA CEO, Mary]:

That's only because there is, in their case, a citizen advocate in the role. I'll just shift to that a little bit. Because, of course, when advocates get involved in these issues, I wonder, to what extent do these issues about day programs..... are they high enough in the priority order of what an advocate is going to get to deal with for a day program issue to even.... for that person to get an advocate to deal with issues they've got with the day program? Does that even happen much, because I'm trying to elicit, I suppose, something about the capacity of advocacy, of individual advocacy, to deal with the issues that people have and are some of these issues maybe somehow seen as lower order issues? Just anybody who wants to pick up on that.

[Advocate 6]:

Sorry, maybe.... I guess we don't have the capacity because we don't have the capacity to do a lot of things that we'd like to do

[DANA CEO, Mary]:

Sorry, I'll just say I don't mean.... I clearly do not mean that the lack of capacity is your fault.

[Advocate 6]:

I know you don't. I would hope, would like to think that it's something the support coordinators would resolve. I would like to think that that's a support coordinator issue, but then quite often it isn't, so it does come to advocacy. It's not captured.....as in the support coordinators don't resolve those areas or local coordinators don't resolve all those issues, so it comes to us. We do a lot of the NDIS's work. That's just another thing that we do I think, you know.

[Advocate 1]:

I believe support coordinators and LACs are not supposed to advocate or work as advocates.

[Advocate 6]:

Yes, but I guess I mean it should be fixed before it becomes an advocacy issue, I guess is what I'm trying to say. We always come in..... things should be resolved long before they come to us, I guess is what I mean. You would hope that things get resolved at the start before it becomes an advocacy issue. It always seems to come to us, you know, when it comes to crisis.

...

[DANA CEO, Mary]:

Okay. So, there's more comments in the chat about other examples, you know, the community access going to visit the support worker's auntie for a cup of tea. [Advocate 3] and [Advocate 4], did you want to come in?

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[Advocate 4]:

I was just going to say that unless the workers or the organisation or the service provider with the day services is actually going to offer advocacy and actually explains to people that they can access advocacy, then it's controlled by the [gatekeeper]. They're not going to.... I find organisations that invite advocacy in, I think that's transparent and it can be a very good thing. But I find that very few and far between, especially with day services. They're very protective and I find that when we talk about choice and control, I get sick of hearing about choice and control because I don't believe conversations are had with people around their choices and control. So, it ends up being, "Oh, but that person has chosen that jumper." Well, of course they've chosen that jumper, but did you have a talk to them about it's really hot outside and that it may be really dirty, or it may be really old, or it's been shrunk in the dryer? Did you have those conversations? Because everybody wants to do whatever they want to do, but unless someone really has these conversations with people, it's just.....it is guarded very carefully about any sort of complaints. People don't know that they can do it.

[DANA CEO, Mary]:

Yes, yes. Thanks, [Advocate 4]. I might just.... that's been really useful about the day programs and day services. So just for a few minutes come back to..... thanks, [Advocate 2]. I'm sure the Royal Commission people will be madly grabbing all those great comments that people are putting in the chat.

So, let's broaden it out to other segregated settings, and this is a big question. What can be done to prevent violence, abuse, neglect and exploitation in any or all of these segregated settings? Whatever is top of your mind.

[Advocate 5]:

The biggest problem is getting the conflicts of rights in balance. Anywhere you've got a segregated setting, you've got the rights of the residents who live there versus the rights of the workers under OH&S laws to a safe workplace and in almost every case that we get involved the balance is tipped towards the worker and that means segregating or some sort of abuse or neglect in relation to the client or the resident that lives there.

It's largely got a lot to do with insurance, WorkCover insurance, because they are very insistent on things like providing a safe workplace for employees. The trouble is that many of these segregated settings are also residences, they're people's homes, it's where they live, and their rights to come and go and do what they want in their own home are restricted because it's also a workplace and OH&S insurance is very, very strict with service providers who don't put in the protections that make their workers safe and this is always a problem, always, and every time you get a situation like that in our case it's always tipped towards the balance of the workers.

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[DANA CEO, Mary]:

Thanks, [Advocate 5]. [Advocate 3] and [Advocate 4], did you want to pick that issue up or another one?

[Advocate 3]:

No, Mary, in the past I worked in apprenticeships and what we had in apprenticeships in Victoria was what was called the apprenticeship field officers. These apprenticeship field officers had very good powers who were able to walk into any employer's business and demand to see payroll, working conditions, et cetera, et cetera. Whenever an apprenticeship field officer walked into an employer.... this is for apprenticeships and trainees..... you were jumpy, the powers were quite great.

I would like to see something like that introduced, where we've got... I mean, we've got community visitors, but they just don't have the powers. I think we need people on the ground that can walk in at any time to any service provider and demand to see records and see how things are. It will be a cost, but I think that would help and then at least then they can see what's happening on the ground as well.

Now, those apprenticeship field officers back in the day were then able to go back and there was a list of banned employers ... this is after investigation of course... banned employers or employers that when they took on an apprentice or trainee then had to have some consultation around taking on this person, what their requirements will be from an employer and going to trade school and things like that. But the system worked really well. Again, it all comes down to funding. But something similar would work.

[DANA CEO, Mary]:

Can I ask, is there a view among you whether advocates themselves in the roles that you play should have something like those powers? Now, getting to that point is a whole other thing, but generally?

[Advocate 4]:

I think, Mary, there would be no supported accommodation houses out there. I'm just saying I'd shut everybody down, there would be just a total shutdown, and I don't know where I would fit everybody in their happy places.

So, I was just saying to [Advocate 3] before that institutions closed down for a reason. We understand that. But I feel like we're going back the other way where there's control and power and it isn't what it was meant to be.

When I was working in houses, we were really striving towards that community participation. We were trying to sort of work with behaviours that were concerning, and we actually worked as a

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team within those facilities to be able to get things happening, but there seems to have been a really big shift I reckon in the last even 10 or so years that just seems to have gone back to that thought process around institutions, we're just here to supervise, do no work.

[Advocate 6]:

Do you mean something akin to Community Visitors, Mary?

[DANA CEO, Mary]:

Possibly, [Advocate 6]. In Victoria you've got a large volunteer Community Visitors Scheme sitting under the OPA, but they don't exist at all in some states or there are a small number of paid community visitors, so there's no consistency.

[Advocate 6]:

I'm a community visitor and we have issues again with the NDIS as a federal body. There's also those kinds of issues as well.

[DANA CEO, Mary]:

It's not a resolved issue yet, community visitors, but it's just whether the advocacy in its current form should start..... is it possible that advocacy moves towards something that gives it additional powers and what should they be? It's a bigger picture discussion.

[Advocate 3]:

Mary, I like your thinking. I think it has to be definitely independent, but what that looks like I'm not quite sure. But I think there's an opportunity there for the NDAP providers to be able to step into that space.

[DANA CEO, Mary]:

Yes. [Advocate 2], did you want to come in?

[Advocate 2]:

I think, Mary, part of the issue with segregation is the differentiation that it creates, employee vs. person with disability and there's this hard line between the two categories of people which in any other place doesn't exist. I can be an employee one place and a customer of another place. I can be a co resident that blurring of boundaries is what actually allows people to get a better understanding of us all having the same rights.

And that I think leads into your question about accessing closed environments because the people who need to be accessing those environments..... advocates are important but Self Advocates are even more important. They see the things we don't see and know what they mean. They see the micro aggressions; they see the closed door. They understand the context in a way that somebody who has never lived or worked or spent significant time in such a setting does not understand it.

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We need to be breaking down the barriers between who is a trusted person and who is some charitable object of a service provider and see people with disabilities as having useful and valuable experience that they should be able to be paid to provide to others and get out in the community and do that. Stop segregating full stop.

[Advocate 1]:

Yes, and can I say I believe what's missing is there's nobody measuring this stuff. So, if you look at the values that the NDIS or NDIA talk about, if we look at just basic human rights, nobody is measuring this for people in CRUs and I think that if that was literally measured and quantified, people would be horrified at what the data would tell us. So, if there's nobody picking up that work, I just think we just keep talking in circles and no real significant change could happen. It's a very complex issue. There's complexity for the providers, there's complexity for the actual support workers, but nobody is actually measuring the outcomes for these individuals.

[DANA CEO, Mary]:

[Advocate 1], one of the things about that is the new next 10 year National Disability Strategy is being refined at the moment and it won't be out in public I think until later in the year and DSS, who are running this, are trying to have measurable KPIs, whatever, but indicators that can be measured over the length of the 10 year National Disability Strategy that will show how people's lives are improving or not and I don't think there's anything in there along the lines that you're talking about. So, I'm going to pick that issue up and feed it back to them.

We're almost... we're running towards the end of the time. There's a few more issues in the chat of star rating kind of thing, yes, whether it works or doesn't in the job services, the DESs and others is an issue.

We'll wind up very shortly. So, I'll just give you a last sort of collective go at any other thing that you think that the Royal Commission should be thinking about in terms of any of the segregated settings, just top of mind, anything else that you want the Royal Commission to..... any sector setting area that you think they should pay particular attention to, weave into the hearings, be looking for evidence about, anything in particular?

[Advocate 5]:

Why is it that some group homes, every single resident in the group home has an identical NDIS plan? How does that happen, when they're all supposed to be individualised to meet the needs of the individual? How can they possibly all have the same NDIS plan? It shows you just how much power the landlord, the service provider, has over the residents in group homes. And why doesn't the NDIS realise that that is happening and do something about it? Why do they approve plans that are identical? Go figure.

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[DANA CEO, Mary]:

Yes, thanks, [Advocate 5]. We might... nobody else is dying to come in, so we might... [Advocate 2]?

[Advocate 1]:

Can I just say one area I'd like work to be done and that is informed consent and particularly for these people that have challenge in getting their information out. And particularly those who are under a chemical restraint as well.

So, some of the work that I'm doing in my son's support is I realised that he was taking some medications, and nobody had ever explained to him why and what they are for and what are the potential side effects. So, we're sort of trying to improve his ability to communicate symptomology and what might be going on for him without actually giving that context behind it. And I'll guarantee that there will be no participant, or very few, who've ever been given information around their medications in a way that they can... there's this assumption that they won't understand, but there's no effort in delivering the information in a way. We've had to go to significant lengths to deliver him that information, but we are seeing that it is actually making a difference. So how many of these individuals have participated in their plan reviews in any way at all? How many of them even know that there's a review happening right now? This is really basic stuff around informed consent and it's not happening.

[DANA CEO, Mary]:

Thanks, [Advocate 1], and I expect the Commission will pick up exactly that issue. [Advocate 7], did you want to.... I think maybe I missed you earlier. There was a comment you wanted to make? Sorry, can't hear you now. Maybe put it in the chat if you can. For some reason your microphone isn't working, I think. I can see you're talking, but I can't hear you. Sorry about that.

So, we'll wind up now I think. Thank you, everybody, for your attention, for your participation, for sharing your wisdom and expertise. If you've got more you want to say about these topics, Siobhan sent out some links to some quick, quite brief surveys, but you can put anything, any responses, into those.

And send submissions into the Commission. So any of these topics, and if you just want to focus on one aspect, one story, one particular thing, and it doesn't have to be perfect, just get it into the Commission as a submission in a short, succinct form, any of these issues that you want them to pay attention to and, in particular, if you think your organisation and in your advocacy work you've got a client whose evidence should be heard by the Commission, then if you look ahead at the hearings, the schedule of hearings for the rest of the year Siobhan has put the link in the chat earlier on but it's on the Commission's website have a look at the hearings schedule, see which of the hearings you think your organisation or your clients have you've got the perfect client who could give evidence. The best way for that to happen, for them to be selected, is.... it needs to go in

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as a submission. So, you need to write a very short.... you can keep it brief but point out exactly what it is.... why that evidence should be heard in that particular hearing.

Get that into the Commission as soon as possible so that they can start thinking about who they're going to use to give evidence at the future hearings. The office of the Solicitors Assisting will come back to you if they think that the evidence you're talking about from that person will be useful.

Now, no matter how good the evidence is that you're talking about, there may be somebody that's better from another organisation, so there is a little bit of competition there, but get yours in. And you don't have to spend two weeks writing up a case study. Just put it in a short form, dot points, whatever, get it into the Commission.

Can I just clarify, I think it's just the DRC inquiries email address that you send it to? Can somebody from the Commission give me a nod to see if that's right, [Person 1]?

[Person 1]:

Yes. That's right, yes. People can also call. You can call and quickly make the submission over the phone. There's also an online form. So, like Mary said, it doesn't have to be perfect, it can be short and sharp. The Commission appreciates anything you'd like to send in. Thanks, Mary.

[DANA CEO, Mary]:

I'll just clarify, because [Advocate 1] asked the question in the chat, yes, the contents of the chat, Siobhan will send that back out to everybody and once we've got the deidentified whole piece of work from today, that can come back out to everybody as well. Thank you very much.

[Closing remarks and wrap up]

[DANA CEO, Mary]:

And actually [Advocate 10], from [NSW organisation], has been lurking in the background today because I think, presumably, she can't join the New South Wales one. Hi, [Advocate 10]. Sorry, I didn't come to you. So [Advocate 10] is, yes, one of the [NSW organisation] advocates. So, she's been a ring in today. But you can do the same thing, or your colleagues. If they can't take part in the other Victorian one on Monday, they are welcome to register for one of the two that will happen in March. Siobhan, those dates are... where will they get that link? Is it in the email? It would have been in an email we sent out. Maybe we'll resend it just to make sure that people get the opportunity.

Thanks again, everyone, and yes, let's hope this bloody COVID will get sorted sooner rather than later and the vaccines start rolling out quickly. Thanks, everyone. Bye.

(End of workshop)

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Comments typed in Zoom chat function

[Advocate 2]:

Education of medical professionals - they do not recognise their responsibility to ensure there is informed consent. Agree with [Advocate 1] re dangerous prescribing
Anytime there is increase in medication there needs to be accountability for that. Have seen a person's medication tripled over the course of a year. Reports went to Senior Practitioner as required. Not even a question asked. Meanwhile client was groggy, unwell, and other side effects. All prescribing was based on account of support worker - in one instance the SW [Support Worker] was on their first shift ever, and took client who they had just met, to GP. GP prescribed additional medication based on SW report.

[Advocate 11]:

there are issues with maintaining funding, I have worked with a couple of clients who had the amazing behavioural plans and 2:1 funding to ensure support. after 12 months there have been no behavioural concerns, due to them being well supported. no incidents reported means the NDIS funding will be cut and then they are no longer able to be supported well enough.

[Advocate 2]:

Only a financial penalty will make service providers take it seriously. Once their insurers get involved, the internal mechanisms are triggered to prevent recurrence.

[Advocate 3] & [Advocate 4]:

We are seeing some providers are 'cherry picking' and being selective on who they take on

[Advocate 12]:

I've heard of similar situations happen down here

[In relation to day service worker taking to child's swimming race]

[Advocate 2]:

or the classic of going to do the sw's [support worker's] personal grocery shopping - which is called "capacity building"! following someone around a supermarket is not capacity building!

[Advocate 7]:

the examples are long

[Advocate 2]:

we need more focus on the possibility of small business setups by pwd, rather than just going to day program to paste icypole sticks together

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[Advocate 13]:

or community access with a SW - going to visit the SW's aunty for a cup of tea.

[Advocate 7]:

There's a thin market in the rural areas and don't give alternative opportunities. Families don't wish to complain

[Advocate 2]:

also need financial incentives for service providers to innovate and do new things

[Advocate 1]:

Stop using segregated settings and follow international models of individualized true community based settings which has been shown to reduce abuse and neglect and restrictive practice use.

[Advocate 12]:

it just smaller institutions now

[Advocate 3] & [Advocate 4]:

Maybe service providers should have a star rating like job actives do. this is made public and participants, family or carers can view before selecting a provider

[Advocate 2]:

why do they exist at all? They should be required to justify the existence of disability apartheid, and demonstrate what they are doing to reduce it

Transcript of Zoom Workshop - 15 February

...

[DANA CEO, Mary]:

Hello. Sorry about the delay at the beginning of this. Just let me sort out my sound so I can hear you, hear everyone.

... Huge apologies, everyone. A technical glitch that's happened before, so apologies for that. You've all been waiting patiently and thank you very much for hanging on and not giving up on us. I just need to turn my phone down.

So, first of all, I'll start with our acknowledgment of country. So, DANA would like to acknowledge the Aboriginal lands upon which all of us are meeting today, mostly in Victoria but there are some

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people in Queensland and scattered around the country to some extent. So, we would like to acknowledge the traditional custodians of all those lands and any Aboriginal people who are with us today.

Today's meeting is one of a series. We had the first Victorian one on Friday and this is the second with Victorian advocates and we've done all the other states and territories, except New South Wales, which we'll be doing in March. These forums are an opportunity for disability advocates in a state or territory to get together and discuss some topics with some of the policy people from the Royal Commission listening in really and they have found it incredibly valuable so far to hear the issues raised by advocates. ...

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

[DANA CEO, Mary]:

Right. Okay. And is that in relation to other previous issues or particularly around the restrictive practices?

[Advocate 14]:

Particularly around the restrictive practice during COVID, but, I mean, there certainly are other issues as well.

[DANA CEO, Mary]:

Yes.

[Advocate 14]:

Ongoing.

[DANA CEO, Mary]:

[Advocate 15]:

[Advocate 15]:

Mary, just to... I think in responding to your question, my sense of a bit about restrictive practice, and this is a little bit more historical, is that sometimes it is coming from a place of control or a place of what is best for staff or what is best for the environment, for example, that people might be a part of, whether that be residential or another environment, rather than necessarily being viewed as what's best for the individual, and I think there's been some historical culture around that restrictive practice is just another tool or another approach to take when working with people with disability and it's never been seen as something that's a breach of somebody's rights. So, I think some of that is changing, but my sense is because of that history, because of that understanding, it can very quickly lead to experiences of abuse or neglect or issues where more power and control is influential within that relationship or within that environment.

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And I think, sadly, that can also include families as well, where chemical restraint in particular is seen as being something that's just part of the everyday practice and I think there's a real concern about changing from using chemical restraint to looking at environments that are influential to behaviour support.

[DANA CEO, Mary]:

Thanks, [Advocate 15]. There's a whole lot of things sort of inside what you just said then. I think we'll pick up a few of them. Can I ask - you said you think it's changing. Does anybody else agree, disagree, what do you think? Are you seeing, or have you seen over your years of being an advocate - have you seen positive changes in terms of the use of restrictive practices or you're not seeing anything much yet? [Advocate 16] I think first and then [Advocate 14], we'll come to you.

[Advocate 16]:

I'll briefly say I think in some cases I've seen with positive behaviour support practitioners coming on board, a fresh set of eyes coming in to, say, a group home accommodation setting and seeking, you know..... establishing alternative avenues so there isn't such a reliance on restrictive practices where there are perceived dangers, I suppose, or risks. So some positives there, but then still numerous situations where it's clear that what's needed is more allied health professional involvement, but having difficulty securing funds or whatever it may be.

[DANA CEO, Mary]:

Thanks, [Advocate 16]. [Advocate 14]?

[Advocate 14]:

Look, I've only been in the job as an advocate for a shorter time, but I've worked in disability for a number of years and I really think it varies. You know, different organisations have different cultures. So obviously as an advocate I see, and that feeds into what someone else said before, there certainly is a culture in certain organisations and in this particular organisation, you know, it's not changing, and it is a cultural issue I think.

[DANA CEO, Mary]:

[Advocate 17]? Don't forget to put your microphone back on.

[Advocate 17]:

Sorry about that, folks. Thank you, Mary. Yeah, I don't think that we're seeing a lot of change at all, to be honest. What [Advocate 15] was saying I very much agree with, that a lot of times it seems to be that the practices are implemented because it's convenient for staff, it suits them and it's obviously a way of controlling the person. But to get back to the point, I've not really seen much reduction, if any, in the use of restraints. Thanks very much, Mary.

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[DANA CEO, Mary]:

Thanks, [Advocate 17]. And [Advocate 15] has put a comment in the chat about that because there is increased oversight. So [Advocate 15], do you mean that some of the positive change is because you think there is increased oversight, so people are more careful?

[Advocate 15]:

Yes. I think look, I don't disagree with what people are saying that I think the change is very slow, but I think because of the increased oversight, there is vigilance, or there's greater vigilance, and there's more dialogue in understanding what restrictive practice is and because they need to appoint people in the organisation if somebody is on a BSP [Behaviour Support Plan], or restrictive practice, where that type of oversight wasn't previously there and, you know, there's monitoring that's occurring. So, I think that there's a few more measures in place that are making people aware. So, I hope it's a pathway for greater understanding around restrictive practice.

And it's similar to I think abuse, neglect, exploitation. I'd like to think... I'm not convinced, but I'd like to think that something like the Disability Royal Commission is raising the profile and that even the subtle things that actually occur in environments is called out as abuse, neglect, exploitation, you know.

[DANA CEO, Mary]:

So, do you think that the way that the NDIS Commission, NDIS Quality and Safeguards Commission how do you view their contribution to this area? Are they having a positive impact that you might have hoped [Advocate 14]?

[Advocate 14]:

No sorry, no, and this is a longstanding like, you know, experience I've got for the last two years, both as a specialist support coordinator and also as an advocate. Complaints to the Quality and Safeguards Commission, you know, have gone nowhere and in one case we've even had to complain about the Commission because there are no outcomes and no tangible sort of investigations, you know. Even on our advice sort of saying this is what you need to look at and this is what we want, you know, to be looked at, it's just like a chat. It's pretty toothless. I don't know if it's because they haven't got the resources or what it is, it might be.

[DANA CEO, Mary]:

[Advocate 15] has just added in a comment that they don't have the legislative power, but this is a recurring theme in these workshops, and we will be picking it up..... we are working with the NDIS Quality and Safeguards Commission to have a one-day forum with advocates and the Commission in a few months' time and we need to do some teasing out of what.... they come across as an incredibly sort of defensive body and somehow, we need them to open up a little bit to advocates, I think. [Advocate 18], you had your hand up.

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[Advocate 18]:

Yes, I was just going to quickly add that I've known some people that I'm supporting, and their families just choose not at all to even submit a complaint to the Commission because they have heard about their reputation of not having teeth.

[DANA CEO, Mary]:

Yes, that's not good, no. Okay. Thanks, [Advocate 18]. One of the things so for people..... given that the use of restrictive practices, in the people you work with, is relatively common, a thing that I'd like to explore is then how do people get an advocate? How do the people who are under restrictive practices and who really do need someone else to be aware of their situation and keeping an eye on things do you have a sense that there are people who are in that situation who just are not getting advocacy? Has anybody got any views about that, the people who are missing out on advocacy and have no way of contacting an advocate and the people who might otherwise link them to an advocate have no interest in doing that? Does anybody want to have a go at exploring that issue? [Advocate 19]?

[Advocate 19]:

I think that's a real concern because we don't know what we don't know and the case that we're looking at, the use of chemical restraints and the over prescription of medication used incorrectly in some of the group homes, they're certainly not going to be seeking an advocate for the resident. So, I just think we don't know..... I think the problem is probably worse than we think in a lot of senses because again, as everyone said, the NDIS Commission is a toothless tiger, so people don't even bother going to report to them. So where do you go? I think that's a real issue that we don't know, we can only speculate how big the problem is because the person themselves is not in a position to seek out advocacy.

[DANA CEO, Mary]:

So, a couple of questions that occur to me in the Victorian context: has the Disability Services Commission in Victoria..... is that still operating or is it completely wound up now? [Advocate 15]? Sorry, just unmute yourself again.

[Advocate 15]:

Yes, it's still present, yes, but you'll find that they.... so I suppose they're a gateway and then they'll refer on. But again, I think this does come down to a bit of culture. I think that we're hearing about issues of concern or access to advocates by default maybe rather than by design, but again it's culture. There's a cohort I think of people that aren't even recognising that it's restrictive practice. Then there's people that are recognising it and might be too fearful to speak out and then there are people who might be slightly detached and recognising it and are very prepared to whistle blow or to connect with advocates or to find someone independent and I'm sure there's a whole range of other folk in between that are covering the system. It's just not seen as being something that I

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think people don't see it's worthy sometimes of correcting or that it's in fact a breach of somebody's human rights. I'm just not convinced that people view it that way.

[DANA CEO, Mary]:

So, what is it that needs to change? What do we want the Royal Commission to be picking up as an issue, you know, to be eliciting in evidence in some of the hearings this year and then being able to put into the reports, you know, especially the final report but including progress reports that come out of the Royal Commission for what needs to change? What is it that is going to make a difference? All ideas welcome. Now, it's interesting and a bit depressing that there isn't a sort of flood of, "Oh, yes, we could do this, this and this to fix it" and that's because it's a complex issue. [Advocate 18]?

[Advocate 18]:

Yes, I think there's lots of things that need to be done to work on improving the situation. I think what a few people have touched on here is that in many segregated settings you're in this closed environment where there's a limited amount of people involved and seeing the situation and they may have negative attitudes but also, they may just be unaware that what they're doing is not okay or unauthorised.

Yeah, I think [Advocate 15] touched on kind of the history of restrictive practice and it being normalised in the disability sector as something that you just do and it's just a tool and that is really still ever present and widespread in many spaces, even with NDIS coming into the picture and putting into place, you know, many kind of like clear descriptions of what restrictive practice is, authorised, unauthorised.

But in many group homes I've seen staff members and even house supervisors just really not... it's just not computing in their head that what they're doing is restrictive practice and that it is a breach of a person's human rights if it's not part of a behaviour support plan, if there's no positive behaviour support practitioner involved.

I had one sibling of a resident call me about one issue of abuse occurring in the home and she just happened to mention that the resident had also had her electric wheelchair taken off her and had been put in a manual wheelchair and I followed that up, but that wasn't her inquiry or concern that she was even raising and her, the sibling, wasn't aware that if that wasn't authorised that that wasn't okay and it was only when we followed it up we found out that it was absolutely inappropriate for the house to be doing that and it was not an appropriate restrictive practice to be used.

So just that kind of closed segregated setting, people that have their eyes on that setting maybe not necessarily being aware that what's happening cannot happen and isn't appropriate and therefore risk of it just perpetuating and continuing.

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[DANA CEO, Mary]:

Thanks, [Advocate 18]. There are a few things in the chat from [Advocate 20], a couple of things about indirect restrictive practice for a person because of environmental restrictive practices for another person in the group home so that impacts on everybody who lives there, new organisations popping up not aware of what they're required to do, and of course the NDIS Commission has a job to make sure that those organisations do know what they're required to do. From [Advocate 15], the education of the disability workers entering the sector is critical. And another follow-up from [Advocate 15] about a need for a campaign that highlights the rights of people and including restrictive practices. And then [Advocate 20] about behaviour support practitioners having massive waitlists. That's interesting for me that that applies in Victoria because we hear about that in more remote areas, but maybe it is the same everywhere.

A specific question I wanted to ask about, well, it's related to the education and professional development of disability support workers. National Disability Services, NDS, have had over a number of years a thing called a Zero Tolerance Framework that... a Zero Tolerance project, maybe, but it seemed to work in phases over a number of years and they had resources available. Did it have a good impact in Victoria? Did it make any difference when it was in operation? Do you think it helped support workers understand any of these issues? Did anybody see it be beneficial? [Advocate 15]?

[Advocate 15]:

Yes, look, I think that there was quite a bit of energy around zero tolerance to abuse, not only the framework but the conversation if you like. But again, it's a little.... it reminds me a bit about the health sector, that it's obviously (inaudible) that go to the health environment. It's the people already engaged and interested and probably those practitioners that have some foundation, support and knowledge of people's rights that actually probably attend it, the zero tolerance to abuse training.

It's about, we've talked about it, but it's about how do you do it systemically, but it's about changing cultures, it's about getting those that set the culture in organisations to be committed to things like zero tolerance to abuse. Is it reflected in every disability service provider's strategic plan? That would be interesting, wouldn't it, as a measure? Why doesn't the funding body set a benchmark around the percentage of people on restrictive practice, you know, those types of things that are not punitive, but they urge organisations to stand up and take notice of different ways of practising.

[DANA CEO, Mary]:

Yes. Thanks, [Advocate 15], and I can see [Advocate 18] saying that she was involved in the making of one of those zero tolerance programs, one of those videos they had, but no worker at the day program she worked at at the time was shown any of the videos that were produced. That's an

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issue, isn't it? You can produce the best resources but if they are not made available and made compulsory for staff to look at them and engage with them.

The other resource materials that I'm remembering is when the NDIS Quality and Safeguards Commission came in first, so it came in in New South Wales and South Australia in the first year and then it rolled out to every other state the following year, except WA, which came in afterwards, but they had something like a compulsory worker module that all disability support workers were meant to look at. Now, I think I glanced at the beginning of it and didn't ever watch the whole thing, but the Commission were very proudly saying that every worker in the country, or words to that effect, had watched this thing and it had a huge impact and was very positively received. Did any of you ever see it? No? [Advocate 20], yes, you're nodding. [Person 2] looks like he has, [Advocate 16]. It was maybe a one-hour module, though, I'm not sure it's enough to change the world, but I think the NDIS Commission have put a lot of store in that thinking that it was..... they think it's been incredibly successful. Has anybody got a view on that? [Advocate 18] is saying it was quite good.

[Advocate 20]:

I think a lot of organisations actually mandate you have to do that. It's part of their blurb that everyone needs to do this particular course online. I did do it VALID also has this mandate, so we all have to do it and I remember it being quite good. It covers a lot of ground, but then you forget about it when it's gone. I wonder how it's applied in every day. I guess that's where the challenge is with disability support organisations, is how do they then apply that in their everyday practice.

[DANA CEO, Mary]:

Yes. [Person 2], did you want to come in?

[Person 2]:

I'd be interested in the advocates' response in relation to what about the role of GPs and doctors for continuing to prescribe medication and reviewing people's medication if they're under chemical restraint but also pharmacy and the role of chemists and pharmacists continuing to prescribe medications, et cetera. I know in South Australia we had a real focus on the chemical restraint project where we found that people had been receiving polypharmacy and a whole range of medications for sometimes 10, 20 years without proper review. So, in terms of principles and practices of pharmacists and doctors, have any advocates had experience where complaints have called pharmacists or doctors out on this?

[Advocate 14]:

I've certainly had a case, it's quite a while ago, where a doctor, you know, just prescribed it, you know, because the health staff asked for it and there's also a problem, a person with intellectual disability not being allowed by the GP surgery to even call and make their own appointments. That's a recent one, you know. So, the culture in those GP surgeries, for example, you know, is so

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that no, no, no, this person can't do that, the carers can only make the appointment. The person can't make the appointment and the person cannot inquire about an appointment. So, I tried to add my client into a call with the surgery so that he could inquire about the appointment. No, wouldn't let me do that. So, there's a cultural issue there and a view of people with intellectual disability that they have no capacity.

[DANA CEO, Mary]:

Thanks, [Advocate 14]. [Advocate 19], you wanted to come in?

[Advocate 19]:

We had a similar case, a client with an intellectual disability and being prescribed Valium but that being used for other reasons in the group home they were living in, and it took a lot of persistence with the advocate and the NDIS support coordinator to have that revisited. So, it's overt use and the misuse of medication too.

[DANA CEO, Mary]:

It definitely [Person 2], it does seem to me that needs to be picked up with the AMA [Australian Medical Association] and the Pharmacy Guild and the other... those organisations that represent those sectors, they should be taking this on seriously, shouldn't they, yes.

Is there any other... I did notice there was a comment that one of you had put in the chat about waiting lists for everything, including behaviour support but including advocacy. So sometimes we're skipping over things in these discussions just because it's so bleedin'ly obvious and that difficulty in people getting access to advocacy is one of the ones that..... feel free to put something in the chat or to raise it as you're discussing any of these other things because yes, it's an incredible frustration for all of us in the sector. I think that we, and all of you, are seeing people who could benefit by having an advocate and just are not able to get one.

It's not that we're just taking that for granted, but it's sort of become so commonplace that maybe we're not even mentioning it and we should be and there are things that we should start to consider about whether people who are under authorised restrictive practices, people in some circumstances anyway, should there be some sort of formal allocation of an advocate to them, an advocate or somebody else? It could be a community visitor if a state has a scheme that works appropriately, but there just are some things that need to be explored and some new solutions maybe that need to be found to some of this. [Advocate 15], yes, you want to go next.

[Advocate 15]:

I would support that, Mary. I think that's a really interesting concept, that in fact in environments it became the norm that if somebody was... God knows how you would resource it, but anyway, if somebody has a BSP, then they have an advocate, it's as simple as that. So, one goes in hand with the other. Again, I don't know how you resource that.

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But look, it's an interesting concept because then there is - and I know that we get asked regularly around the new forming or shaping up of BSPs and there's meant to be an independent person involved, but most of the time they just want you there to meet an obligation or a requirement and then, "If you don't mind, we don't require you", and also if you challenge things, "No, that's not what you're meant to be there for." So I think there is a role to suggest that advocates are commonplace and funded, but commonplace alongside somebody who has a BSP in place.

[DANA CEO, Mary]:

Yes, thanks, [Advocate 15]. And as I said, in these forums we haven't got time to kind of go into the detail, the nitty gritty, of how some of these potential solutions might be resourced, but the ideas I think need to be flagged and then we look at the resourcing. There are a couple of other people joining now. Would you like to quickly introduce yourself and your organisation and then we'll continue with the discussion and then [Advocate 22] as well.

[Advocate 21]:

Hi, everyone, I'm [Advocate 21]. ...I'm an advocate with [VIC Advocacy organisation]. I've recently started. My sincere apologies, I had some technical issues, so I do apologise for any disruption. But I'm currently working on providing information sessions for the Disability Royal Commission for various community groups, culturally diverse community groups, and I guess I'm participating this morning because I am interested in gaining much more information, insight and also understanding on the areas of concern and issues. So, yeah, I look forward to learning and sharing.

[DANA CEO, Mary]:

Thanks very much, [Advocate 21]. We might come back to you on another day for a separate thing because we're going to do something else with the Royal Commission, I think with CALD advocates, so we'll separately talk to you about that. [Advocate 22], would you like to introduce yourself quickly as well?

[ADVOCATE 22]: Hi. Sorry, I always have trouble with that. Hi, I'm [Advocate 22], from [VIC Advocacy organisation]. I'm the coordinator of the advocacy team and also an advocate.

[DANA CEO, Mary]:

Thanks, [Advocate 22].

[Advocate 22]:

Sorry I'm late.

[DANA CEO, Mary]:

No worries. Just everyone, yes, keep your microphone muted until you're speaking. We might switch away from restrictive practices into the other very linked topic of - [Person 1], yes.

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[Person 1]:

I was going to check in with [Person 4] and [Person 3] and [Person 2], any more questions regarding restrictive practices, is that okay?

[DANA CEO, Mary]:

Thanks, yes.

[Person 1]:

Thanks, team.

[DANA CEO, Mary]:

[Person 3]?

[Person 3]:

Hi, everyone, this is [Person 3]. So I had a question ...if I were to put the proposition that some have made that restrictive practices are often driven by unmet need and if advocates do consider unmet need as one of the main drivers of the use of restrictive practices, do we need to think about broader solutions to addressing restrictive practices in terms of broader transformation than just monitoring or accountability mechanisms? Thanks.

[DANA CEO, Mary]:

[Person 2] has his hand up as well.

[Person 2]:

Yes, look, just wanting to clarify. I heard a number of advocates say that when they've either tried to report to the Quality and Safeguards Commission but had very little or poor responses, I just think that in itself... I'd like to know whether, when that happens, is there another avenue for advocates to take and/or how are we sort of recording or how are they, the agencies, recording or monitoring this lack of appropriate response or investigation into restrictive practices?

[DANA CEO, Mary]:

Thanks, [Person 2]. [Person 4], you've got something as well? Yes.

[Person 4]:

Thank you. I'm interested in the discussion that's come up around culture and how do we change cultures of segregated settings and otherwise and more generally. And I appreciate that there's a funding constraint issue, but I'd like to hear more about the visionary aims of transformative social change in this space and what you'd like to see in recommendations that the Royal Commission makes in terms of achieving prevention at the primary level, it not occurring in the first place.

Thanks.

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[DANA CEO, Mary]:

Nice easy question there, [Person 4].

[Person 4]:

Yes.

[DANA CEO, Mary]:

That's a short one. So what I'll do ... we'll go back through those in order. [Person 3]'s question about whether restrictive practices are reflecting unmet need and about the broader transformations that are required, does anybody want to have a go at answering that one?

[Advocate 22]?

[Advocate 22]:

I would say that one of the areas that we see really frequently with restrictive practice and unmet need is in the area of sex and sexuality, that we work with a number of men who well, we have done over the past few years, who are on supervised treatment orders under the Disability Act in Victoria and, you know, they're people who have sexually offended in the past, but they are now subject to really extreme restriction and yet there's absolutely no sexual outlet, there's no acknowledgment of sexuality, there are no opportunities. And I guess it's something that we see that is certainly a cultural issue still, the belief that people with intellectual disability in particular don't have sexual desires or experience any form of sexuality. So, we see inappropriate public or private sexual behaviours as a justification for restrictive practice all the time and if it's not... if someone is able to say well, hang on, that's a completely normal thing, then often in a care team of people there will be several people who think it warrants some sort of restriction.

[DANA CEO, Mary]:

Thanks, [Advocate 22]. My screen was freezing briefly while you were speaking, but I got the gist of it and that's a topic that needs to be pursued, absolutely. I'm going to go to [Person 2]'s question about the Quality and Safeguards Commission, I noticed that [Advocate 15] responded in the chat that sometimes you will take those issues to the Human Rights Commission. And [Person 2], you were asking were people sort of keeping tabs on these things, are they recording when they're trying to take something to the Commission and sort of getting knocked back? Has anybody got a response to that aspect?

[Advocate 16]:

Yes, we are at [VIC Advocacy organisation]. We've made direct complaints to the Commission, yes.

[DANA CEO, Mary]:

Yes, thanks, [Advocate 16]. [Person 2], what you've prompted me to bring back to the front of my mind again - and we met with the research people at the Royal Commission actually ... (frozen)

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[Audio issues]

[DANA CEO, Mary]:

...Anyway, so I don't know whether you heard what I said, which is that we're going to do a survey this year of all advocacy organisations and other stakeholders in the sector about their use of and experience of using all the complaints mechanisms, including the Quality and Safeguards Commission. So happy to come back and talk to you about that, [Person 2], at some stage.

[Person 4]'s question about the culture and the cultural change, that's a huge one, [Person 4], and one of the thoughts that occurs to me... once these series of state-based workshops are over, we are planning to do something that we haven't quite formulated yet but to bring together a number of advocates at a national forum and I'm happy to receive any suggestions from any of you if you'd particularly like to be involved. We want to bring... we want to do another... a sort of a follow-on to this, where we are looking at the solutions and at the things that need to change because mostly when we're ... (frozen)

[...Audio issues...]

[DANA CEO, Mary]:

Yes, sorry. All right. I'll just have to stop talking is the solution, I think. I am actually locked down in Melbourne as well as the rest of you, by the way, because I couldn't get out of here on Friday, so I am currently in Parkville.

[Advocate 15]:

Mary, sometimes if you turn your screen off - if you turn your video off, Mary, that can help.

[DANA CEO, Mary]:

Yes, it's a good idea except I won't be able to see who wants to speak. But yes, that is good in theory. I'd like to move us [Person 4], we might put your question to one side. I think it's a big question that deserves some serious attention and we will try to work out how do we gather from advocates this issue about how to do the culture change that's required in the sector.

If anybody wants to have one quick response now, anybody put your hand up if you've got any ideas about this change (inaudible) in organisations, in the providers. There's no instant response - yes, [Advocate 15] is going to have a go.

[Advocate 15]:

Sorry, I can't help myself. I think for me a part of it is just the intrinsic value of people with disability, you know. I think that if we can address that right from the start.

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[DANA CEO, Mary]:

Yes. Okay. You can lead the campaign, [Advocate 15]. So, I've turned my own camera off, just in case that makes any difference to my own link into here.

We're going to switch to the other topic, which is about segregated settings. They've already been mentioned. You've mentioned them several times during the previous part about restrictive practices. But what we're trying to think of is what can be done to prevent violence, abuse, neglect or exploitation in any of the segregated settings and what do you think needs to change? What are the laws and policies or practices that need to change to get a shift in what happens in segregated settings or indeed to have fewer people in segregated settings?

I'd like to start with day programs because we asked Victorian advocates about it on Friday, but we hadn't in our previous state sessions. Day programs hadn't been mentioned, and so we want to pick up a little bit about what you're seeing happening in day programs. Do you all still consider them to be segregated settings? Are they still old fashioned and traditional or have any of them improved, are there some good ones, are there good and bad? Has anybody got a view or anything you'd like to tell us about the day programs? [Advocate 18].

[Advocate 18]:

Hi. Yes, just as someone that's worked in day program for about three and a half years, I think a huge issue in terms of trying to create a great culture and also living out a good culture in practice as well is there's really limitations on... kind of high limitations on admin time. The manager always talked about how there was really limited funds for training, and he'd jam six days' worth of training into one day at the start of the year and so you'd never get any quality training, you were just kind of being force fed information but in a way that wasn't quality, you weren't able to ask questions, you weren't able to really learn. And also, you were expected to keep notes on important things that happened in the day. You were expected to make reports on anything that happened that was concerning or risky, but you were given little to no time to do that and so that meant that people's supports were taken away for a while to do that or it meant that it drove people to do things that made things quicker and easier for themselves because they didn't have time to do things properly. And I guess, yeah, because I think there's lots of issues with culture as well, but there's also issues with resources which drive a problem in culture because if you're not resourced to support someone properly, you're forced into a situation where you have to work out how to do your "job" in a way that just gets you through the day and then that forces a bad culture.

Yeah, so I would say in terms of day programs, I see them as a segregated setting, see them as being under resourced, see them as having a real trouble of actually being able to provide something that's of quality to people when they have very little planning time and very little resources and, yeah, being able to provide people proper support and also risky for abuse when you're under resourced.

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[DANA CEO, Mary]:

Thanks, [Advocate 18]. [Advocate 20] has made a similar comment in the chat about the underresources. [Advocate 22], we'll come to you next, but it just strikes me that in all the work about the NDIS pricing, is that being covered off properly in the way that the prices are set in all of the NDIS pricing categories, but maybe particularly in this case for the day programs? [Advocate 22], did you want to speak to this?

[Advocate 22]:

Right, I've managed to do it. I guess, you know, from my perspective, and I'm always talking about people with intellectual disability I don't really understand why we still force people into day programs which is sort of, you know, essentially like babysitting and we don't allow people choice to do other activities in the community. And if people want to do a day program-like thing where they want to go somewhere, like to a community centre and do activities then, you know, go for your life but why we're still forcing this kind of, you know, segregated... this segregation I find absolutely mind boggling, and some of the stuff that you see in day programs, just the meaninglessness of it and the fact that the staff aren't resourced and the staff are basically just getting through.

So, I went to a day program a couple of years ago for a client who had enormous behaviours of concern and there were huge problems with toileting, hygiene, all sorts of stuff, him hitting people, anger, and then when I got there, the guy was sitting in the carpark in the rain. And I said to the staff, "Why is he there?" And they said, "He likes it there" and I kind of said, "You're telling me that somebody likes to come to a day program and sit in the carpark in the rain?" And they said, "Yeah, he always does it."

And just that kind of, you know... like this is a man who wants to go home or go anywhere but not be in this place and nobody was able to recognise that because it was framed as, "He's a really difficult client, we need more resources to control him", not actually, "My God, we need to get this guy out of here, he obviously hates it."

And that's one of the things that really concerns me that kind of links restrictive practices with segregation is that we look at people and we go 'well, in this setting they behave in a way that we consider to be really bad' and we don't recognise that what they're telling us is actually "this place is really horrible, and I hate it". We look at it and go well, he hits the staff, therefore maybe we'll take him to a psychiatrist and try to get him on something to control that, maybe we'll get him on an antipsychotic to try to control that behaviour, you know, we'll get a BSP to try to get some strategies for managing that behaviour without listening to the very human person saying, "I hate this crap". I just find... any kind of segregation where the person doesn't make a choice to be with people, I just find absolutely mind boggling in 2020.

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[DANA CEO, Mary]:

Thanks very much, [Advocate 22], and [Advocate 20] has added to the chat about that during the planning process and people's NDIS programs day programs are just approved without question, there's no other options thought about and many people attending the day programs expect.... well, it would be interesting to know how many of them are actually taking part in the planning meetings anyway or being asked anything about whether they're interested in them.

Let's pull it back to another segregated setting actually that I'm specifically interested in in the Victorian context is the Victorian version of boarding houses, rooming houses, I think SRSs [Supported Residential Services] maybe is the term used in Victoria as well, isn't it? Are there, and I haven't gone back and looked at the stats about this, but from your context, are there still lots of people with disability living in those settings? Yes. And do advocates get to go into those settings? Do they get access to advocates? How does that play out in Victoria? Does anybody want to give me a view? Lots here in Bendigo, according to [Advocate 14]. Yes, [Advocate 15].

[Advocate 15]:

We have a number of people that we work alongside from an advocacy point of view that reside in SRS. How do they come to us it's very mixed, but often it's an external provider that might be raising a concern about the SRS. And again, it's a little bit of... it's about oversight. They're private proprietors. They can tend to operate by themselves, and they don't sometimes they don't believe that they have to meet any particular requirements. So, it's open to potential for abuse and neglect and one of the biggest ones we've found as a bit of a trend, if you like, is financial exploitation. So, people are certainly taking advantage of what's in front of them. So yeah.

[DANA CEO, Mary]:

Yes. Thanks, [Advocate 15]. So schools we haven't touched on and I don't know how many of you in your usual advocacy work deal with children or issues for children in schools. Put your hand up if you do. Generally not. Okay.

[Advocate 20] is pointing out in the chat that some SRSs have started to provide NDIS services. Yes, that's right, some have now registered as providers. That needs a whole piece of work I think and hopefully the Royal Commission will look into that area. Different regulations in every state and territory and it's kind of a black hole really of where the people who have no other options sort of end up.

So, in regard to segregated settings, I might ask about ADEs. Do you have... any or all of you have clients who work in ADEs and has any of the typical old-fashioned stuff that happened in ADEs, has any of that improved or changed in recent years since the NDIS came in? No, no, no. Shaking heads or shrugging. Does anybody want to make any comment about people who are working in ADEs and they're now paying through their own NDIS plans to go to work in the ADEs? Have any of them... have you seen anybody make a change, shift to a different type of employment, move out

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of an ADE to work somewhere else? Has anybody that you've known been able to capitalise on the fact that they should have more choice now under the NDIS? No, no.

[Advocate 20] says it sounds like it's getting worse, they've become even more protective of their client. That's referring to the ADEs I'm presuming, yes, and they're hanging on to them tightly. Okay. So, then the segregated setting that you're predominantly dealing with I presume is group homes I would imagine. What... and this reflects what we... any other suggestions for things that you think need to change to reduce the amount of violence and abuse that happens in those group settings? Is it about giving people options so they don't have to live somewhere they don't want to be, or are there other things? Has anybody got a suggestion around that?

[Advocate 16]:

Certainly, part of it, I think, is what you just identified, as in alternative living options. I think we're all very sensitive to the fact that, yeah, the availability of alternative accommodation as opposed to group homes where often people just end up in living alongside people they don't want to live alongside that might trigger behaviours of concern, and so on, just the lack of availability of well-supported, independent living options certainly I think is a driver of very negative outcomes and people being victims of violence for sure.

[DANA CEO, Mary]:

Yes. Thanks, [Advocate 16], and people are putting some of the sort of obvious ideal solutions to that, so there needs to be more housing options, address the disability housing crisis. Thanks, [Advocate 18]. Yes, it's huge, isn't it? Needs to be more housing options, let people choose their housemates, let people choose their own staff. Some of those are things that... they're not new suggestions, are they? They're things that even the providers have been actually saying for a long time that... sometimes they're saying that they are doing those things, but in reality they probably are not. [Advocate 15]?

[Advocate 15]:

I still think that there is.... I can't help but coming down to culture again, sorry, but I still think there's a bit of a culture that people are treated like it's a chessboard and we need to move pawns around, if somebody is disruptive here, we need to move that person there, and it might be a risk-averse decision, "Oh, let's have a look at who's in the house and whose parents might complain or who's going to be the most vocal, so let's move this person and these folk can't speak out, so let's pop this person in here". It's like a little roulette.... it's like a little chessboard.

That was I think when DHHS had a number of houses, but you're seeing it potentially on a more micro level particularly in Victoria with the six or so providers managing the housing. There's still this sense of we have a right to move people around wherever we like because it's problematic and where's the consultation? So, again, it's cultural. This is someone's home. How dare you move just because you feel like it? Okay.

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[DANA CEO, Mary]:

So just pursuing that a second, [Advocate 15]. Do you mean that within those providers now in Victoria have you seen... have any of you seen examples where they're sort of swapping people between themselves, do you think that's happening, or is it within the provider that they move them from one house to the other within the houses that they run? [Advocate 19]?

[Advocate 19]:

I have to agree with [Advocate 15]. It reminds me, sadly, of what's happened in the Catholic Church. They moved the perpetrator, the priest, around to another parish. If you're moving the perpetrator who's bullying or being abusive to another resident, you're just moving them around to another house. The problem is not solved that way. We need there to be intervention programs, you know, positive programs to assist that person. Just moving them around like a chess piece doesn't work.

[DANA CEO, Mary]:

Yes. Thanks. [Advocate 16]?

[Advocate 16]:

I guess my experience is somewhat limited, but I'd say in both cases it happens, Mary, sometimes between, within the organisation, but sometimes there's a lot of pressure seemingly just to get rid of a problematic customer, is what it seems like.

[DANA CEO, Mary]:

[Advocate 17].

[Advocate 17]:

Mine is just an echo of what's already been said, but I have found that organisations are moving people across their various houses just to shuffle the client so that they are moving to places where they think they won't be a problem or that they'll be less of a problem. So the solution is basically to, if they have a number of houses or accommodation places, they'll move them to where they might, where they think the problem will be minimised or swept under the carpet or something of that nature. So I see that sort of fairly regularly. So thanks, Mary.

[DANA CEO, Mary]:

Yes, thanks, [Advocate 17]. Again, it's one of those sort of obvious things, isn't it, that... and I expect they're probably doing, as one of you already mentioned, moving the people who won't complain or haven't got family who'll complain so something like having an advocate that has to be brought in when somebody, when they're going to do something as significant as move somebody's place of residence, there'll have to be something to come in I think about that.

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[Advocate 20], you're raising that issue in inverted commas, "'Problematic' customers are being declined SDA places and people who have a high-risk profile have their SDA applications rejected again and again." Do you want to speak to that again?

[Advocate 20]:

I've encountered this issue for some time, that the providers seem to be able to pick and choose who they want to provide services to and they look at the potential risk profile of the client and potentially make decisions based on that, whether the person is suitable first of all to even come into their service and then obviously then there's a question over which property or what are the potential risks, can we manage this person? It often seems easier just to say no rather than look at how can we support the person.

So, I've certainly worked with many clients who have been on this roundabout of even trying to find a place. NDIA have approved funding, so SDA funding has been approved, but just so many rejections from applications.

[DANA CEO, Mary]:

Thanks, [Advocate 20]. ...So going back to the big picture about segregated settings, for the people who are... so there's still a reasonably large cohort of people who are NDIS participants who are stuck, aren't they, in that almost everywhere they live or attend or go is a segregated setting. So, there would have to be changes in all of the segregated settings for there to be much difference to their lives.

Does anybody want to speak to that? You are the advocates that work with these people, with that cohort of people. For there to be changes made in segregated settings, would any of you put priorities or what's the big picture thing that should be tackled first? Just any views at all really about that.

[Advocate 21]:

I can say something. I kind of feel maybe it's not my place because I haven't had much experience working in the sector. Can everyone hear me (audio breaking up).

[DANA CEO, Mary]:

Yes.

[Advocate 21]:

I guess from the little time that I've been here I see - it's going to sound very simplistic and straightforward, but I can see a problem in the settings of the disability service (inaudible) (audio breaking up).

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[DANA CEO, Mary]:

[Advocate 21], your sound is breaking up a bit... In the meantime, in the chat, the Victorian Housing Hub, something I'm not familiar with so I need to learn what that was about, but the LACs [Advocate 20] is pointing out were meant to increase the capacity of the local communities but it's a big ask, isn't it, and of course the LACs were drawn into doing all the planning conversations. You've come back to us. Do you want to pick that thought up again?

[Advocate 21]:

I guess just from the little experience that I've had, as I said, what the advocate previously mentioned about lack of resources, lack of training support for staff, I'm seeing really unqualified from.... and I don't want to generalise, it's not all my experience so far, but I'm gathering a sense of the wrong qualifications and people being in certain settings with power and I think what happens is when you don't align the right people with the right skill sets and qualifications with the importance in these services and settings, you create a cultural inequity. We create.... it's a culture of, you know, I guess not seeing people as assets that includes staff members, that includes managers, that includes also the people with the disability, so not putting them at the centre as human beings and having a right to a safe, equitable space where there is potential for wellbeing and growth. I think from my experience it's very much a sense of there's a structural problem, there's a systemic problem, and there's been research and the Royal Commission at the moment is doing so much work in gathering the data and information in targeting these gaps, but nothing seems to be really being done on the grassroots level.

I think as long as staff in every capacity, whether it's on the ground, you know, frontline workers, or whether it's advocates like us or management if there isn't the right qualifications and training, if we're not being taken care of and we're not constantly trained, whether it's cross-cultural training in disability or what have you, there's always going to be systemic problems in the sector and I think for me what I would like to see is more emphasis on organisational responsibility for addressing those issues, systemic issues, and also families that are working with the children or with the clients also need to be respected. There are some instances yes, there is some abuse with family members, but I also see a lot of family members are being neglected and abused by the system as well.

So I think, you know, it's very complex from where I'm standing at the moment, but as an advocate, being new in this sector, I can already identify gaps in our skill sets and I think that's a real huge detriment to basically voicing and addressing issues of concern and knowing who to go to and then if you don't have the right skill sets, you're not going to be able to take issues that are being failed to be addressed by management or by the sector you're not going to know who to take that to and how to proceed in ensuring that you're doing the advocacy on all levels, whether it's individual, family, systemic, and I think for me that's my concern.

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I do feel sometimes very frustrated when I am challenged with a systemic issue with a service that just basically like I've heard so far, you know, it's too hard, we've done what we can, and the onus of responsibility is always back on the client who is in a very vulnerable position and therefore as an advocate I feel like there's very little, you know, support systems around to provide us with the right access and resources to support the client. So that's just what-....- that's the only thing --

[DANA CEO, Mary]:

Thanks, [Advocate 21]. That's been really useful, and I think some of that stuff that you touched on there was actually the beginnings of a response back to [Person 4] about your culture question earlier on, so that's been useful.

As we go through the transcripts of these sessions, we are picking up some issues that we will do some other forums or workshops on during this year, and that won't necessarily be Victorian advocates or New South Wales or whatever, it might be everyone together. So that issue we will pick back up on.

We've actually come very close to our finishing time and so there are a couple of things that I wanted to mention. We will do the same thing and check whether the Royal Commission people do you have any specific or other questions that you'd like to ask the advocates now? [Person 2], have you got anything?

[Person 4]:

Thanks, Mary. I think I've asked the big question, so I'll leave it at that for now.

[DANA CEO, Mary]:

Thanks, [Person 4], yes.

[Person 4]:

Thank you.

[DANA CEO, Mary]:

[Person 3] or [Person 2], anything that you wanted to particularly ask at the moment?

[Person 3]:

This might be a broader question. Given that there are systemic issues that have been identified in relation to segregated settings, might this solution not necessarily be entirely part of changing some aspects of segregated settings but also getting rid of segregation in at least some forms?

[DANA CEO, Mary]:

Yes, thanks, [Person 3]. [Person 2]?

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[Person 2]:

Just wondering whether one of the unintended consequences of some of the supported residential facilities and these larger facilities - I'd be interesting in seeing whether the advocates have noticed that the owners, managers of these places have been able to get NDIS packages for a number of their residents and therefore have more funds but maintaining and almost getting people who've got the largest packages that they try to keep and recruit others who've got big packages? Just wondering whether - I hope that's not too much of a leading question, but are they seeing that happen more and more?

[DANA CEO, Mary]:

[Advocate 22] is nodding furiously in agreement there. [Advocate 22], do you want to respond to that?

[Advocate 22]:

There's one particular place in Melbourne who have always charged well above what people could afford, so you know I don't know about in other places, but in Victoria SRSs charge almost up to a person's full pension. So often there are lots of SRSs in Melbourne where you'll find the residents begging on the street close to the SRS because they can't afford cigarettes and the food is disgusting and that kind of thing.

That's not an uncommon thing, but there are SRSs now who are kind of.... they're capturing clients, so they provide all the services. They've opened up as support coordinators, they've registered with NDIS, nobody seems to be questioning their practices or anything. And there's one particular place in Melbourne who have always charged well above the usual rate and either DHHS or corrections have always paid to have clients with justice system involvement live there and that service provider has now yeah, they do support coordination, they do everything now, and, yeah, they just capture clients and they you know, some of the clients who live there are incredibly vulnerable and, you know, have had substance use issues. And there's one man I know who lives in that place who it's really hard to even get him on the phone because whenever you ring up, they want to know who you are, why you're calling and they stay in the room when he's having a phone call. They're really suspicious of everything and they are very..... he says to me, "Oh, my order finishes here and I want to move out, but they've told me I can't" and they control everything. They take him to every doctor's appointment; they tell him he can't go off certain medications he doesn't want to take. Everything is just controlled and they're making huge amounts of money doing this and the staff are..... the facilities are still grotty, the food is terrible, the staff are minimally, if at all, qualified and they treat the residents quite poorly, but now those people you know, there's nothing stopping them making huge amounts of money through NDIS.

[Person 2]:

The profits are growing.

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[Advocate 22]:

Yes.

[DANA CEO, Mary]:

Thanks, [Advocate 22], and that's a useful segue into my sort of winding up remarks anyway. Sorry, [Person 3], your question about getting rid of segregation, let's take it as a comment because everyone would be in agreement with you I think, and we haven't got time to pick it up further now, but we will in our next series of workshops.

So that little example there, [Advocate 22], you gave of the man who lives in that particular setting, that kind of story, but any others that you have that any and all of you have the time to put into the Royal Commission as a submission is incredibly useful. It doesn't have to have all the detail. It doesn't have to have all the relevant dates attached about when a particular thing happened. It just has to be even dot points, you know. But capture these things, write them down, throw some dot points together, put it in to the Royal Commission as a submission.

[wrap up and closing words of thanks]

[DANA CEO, Mary]:

But it is really clear that advocates have.... you've all got heads packed full of useful information, examples, stories, and the Royal Commission needs to hear them. Don't think you have to wait and turn something into a properly annotated case study, you don't. You just need to get the basics in and the sooner you can do that, the better.

Okay. Thanks, everyone, and thank you for being patient enough at the beginning as we had our tech problems and then hanging on a little bit longer at the end. So, thanks, everyone, and hope the lockdown that you're suffering through will be over shortly. Okay, bye.

(End of workshop)

Comments typed in Zoom chat function

[Advocate 15]:

Because there is increased oversight

[Advocate 15]:

They don't have the legislative power

[Advocate 20]:

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In many cases I have had there has been 'indirect' restrictive practise to a person due to environmental restrictive practise needed for another person in a group home.

[Advocate 20]:

New organisations are popping up that are just not aware of what they are required to do

[Advocate 15]:

The education of the disability workers when entering into the sector is critical

[Advocate 20]:

Most behaviours support practitioners have massive waitlists

[Advocate 15]:

having a campaign that highlights the rights of all people with disability and includes restrictive practice being exposed

[Advocate 14]:

[Advocate 18] you are right, I have had a brother not realising that his sister being hit by another resident was a big deal. He called about other issues.

[Advocate 19]:

Waitlists are problematic. This new environment is causing backlog including a waitlist for advocacy.

[Advocate 20]:

Yes, but it seems to have fizzled out

NDS was active when NDIS was being rolled out but I'm not sure what they are doing now?

[Advocate 18]:

I was involved in the making of one of the series in the 'zero tolerance program' yet no worker at the day program I worked at was shown any of the videos that were produced.

[Advocate 20]:

It is quite good

[Advocate 18]:

I agree, it was quite good

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[Advocate 15]:

If funding bodies attached funding to the reduction of restrictive practice or the increasing of positive practice maybe useful

[Advocate 18]:

Definitely an issue with many doctors holding a view that people with intellectual disability lack capacity - writing evidence that hold in VCAT Guardianship orders without proper investigation and understanding into the persons capacity - leading to them to potentially unnecessarily being appointed Guardianship

[Advocate 20]:

I wonder if organisations realise they are still required to use an independent person

[Advocate 15]:

Sometimes we would take then the concern to the Human Rights Commission

[Advocate 20]:

day programs are under resourced

I've also worked in one, i was way too busy sometimes just trying to keep people safe

during the planning process day program quotes are approved without question, no thinking outside the box, no other options offered or thought about

[Advocate 14]:

I have seen very sick people being forced to go to day program as there were no SIL staff available.

Lots 70 here in Bendigo. Yes, been in

As in 70 person SRS old aged care home..

[Advocate 20]:

some SRS's have started to provide NDIS services

They have become even more protective of their clients

[Advocate 22]:

Strangely enough, ADEs and day programs turn up to NDIS planning meetings to tell planners how much the client loves it. Why? Because they have been doing the same thing for 20 years, therefore they must love it!

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[Advocate 18]:

Address the disability housing crisis

[Advocate 15]:

Need to mention that there needs to be more housing options

[Advocate 18]:

Let people choose their housemates

[Advocate 15]:

Let people choose their own staff

[Advocate 20]:

Rostering is hard when people are on different levels of funding living in the same house

[Advocate 19]:

We have been talking about the lack of appropriate housing for 20 plus years and nothing has changed.

[Advocate 22]:

And there's still very much a sense that people can be moved and they shouldn't complain.

[Advocate 20]:

'Problematic' customers are being declined SDA places

People who have a high risk profile have their SDA applications rejected again and again

[Advocate 15]:

The Victorian Housing Hub was meant to be a more transparent way of viewing options

[Advocate 20]:

LAC's were meant to work in increasing the capacity of the local communities to be able to support people in more mainstream settings

[Advocate 15]:

Sorry have to leave thankyou Mary and Siobhan

[Advocate 18]:

Attending a day program, living in a group home or being a part of any segregated setting should be a choice alongside many other options - however for many people there really isn't many other options out there, which is a real issue as there is no real choice for these people.

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[Advocate 22]:

For so many people in group homes and go to day programs - they have no one in their life outside of a closed service system. If everyone in the service system agrees on the quality of the person's life, it takes for them to have 'behaviours of concern' to be able to protest. It means that people who don't protest may be incredibly unhappy and no one recognises it. The lack of outside people, or connection the community is a huge problem. Safeguarding is a different thing as it focusses and service failure. There needs to be monitoring of quality of life - and it has to be external and independent.