DANA and DRC Workshops with QLD Advocates – 1 December 2020

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

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

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

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

Contents

Transcript of Zoom Workshop – 1 December

Mary: Hello, it's Mary Mallett from DANA and I apologise for being late for our own meeting… So welcome, everyone.

[Zoom housekeeping]

So we'll open with an acknowledgment of country. So I wish to acknowledge the traditional custodians of the various lands that we're meeting on. I wish to acknowledge and respect their continuing culture and the contribution they make to the life of our communities. I would like to acknowledge and welcome any Aboriginal and Torres Strait Islander people who may be attending with us today.

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

Mary: Right. I think I've managed to get everybody. So we're going to first talk about restrictive practices. The questions are a bit bland, but it's to pick up really your experiences in your advocacy. So it's about your observations of restrictive practices in your advocacy work to share perspectives and examples that come to mind, and the first question is what are the effects of restrictive practices on people with disability.

P3: I'm happy to go first. Pretty much they'd be the same effects they'd have on any of us if we had to deal with that, but of course people with disability who have heightened vulnerability, and particularly if they have communication difficulties or have difficulties expressing how they're feeling - even worse it would be tantamount to torture.

We're almost in the final stages of our submission to this Royal Commission and I guess my concern, biggest concern, is that we start doing this to children while they're in school and at home and if this continues, their life is mapped out for them in ever increasing levels of severity and harshness and more than likely to end up in indefinite detention somewhere with multiple layers of restriction. So there's nothing to prove that applying restrictive practices on anyone does anything to help them.

I would say, though, that where people have very minimal restrictions because of certain compulsions of their disability, that where they are included in decision making and their capacities are scaffolded so that they take part in that and that they have an understanding almost to the point where they have been able to agree that in certain circumstances and at some points in time the most minimal restriction may be employed, then they're part of that process and therefore it's much more likely that those restrictive practices would be reduced immensely almost to the point... or are reduced and eliminated and we know of a couple of people where that's happened. But that is not what usually happens for people.

Mary: Thanks, P3, and I had that question about whether and how they can be reduced or minimised actually as a further follow-up question that we would come to if there's time, so thank you for bringing that in there. Just something I probably should have asked at the very beginning, so for those of you who are on the screen, you can just raise your hand, to give an indication in your everyday advocacy work ... is it a regular part of your work that you're working with people who are under restrictive practices? Yes, okay, people are nodding, they're waving their hands. So it's normal in a terrible way this is a normal part of your work because the people you work with are under restrictive practices. So lots of people are nodding. Is there anybody whose experience is different than that, who doesn't find they work with people who are under restrictive practices? No?

Okay, I was going to say, for the people whose cameras are not on and who we can't see, remember if you want to say something just unmute yourself and dive in in response to any of the questions. For the people I can see, mostly I'll be able to see if you're waving your hand. Sorry, that's the interpreter, not someone waving their hands. It's very specific waving.

So for people who are under restrictive practices, are they able to make complaints, and in particular complaints about the restrictive practices they're under? Do you see that happen? Does it happen at all, does it happen for anybody? And maybe I should pull back and ask another question before that really, which is of the people who are under restrictive practices, would they know - do they know they are? Are they conscious or aware that ….is it used when - does somebody explain to them what it means or why particular things are being put in place? Is that common or not?

P4: Mary, I can talk a bit about that. The person that I was working with most recently with restrictive practices, they were on increasing levels of medication and they had a new provider who decided to put huge amounts of wood in the area around their kitchen so that he couldn't actually access the kitchen unless staff wanted him to. And he had an acquired brain injury and really had little understanding as to why that was happening and certainly wouldn't have understood the reasons for his increasing levels of medication and therefore he wouldn't have been able to and he was nonverbal, so he wouldn't have been able to question why that was happening or to provide any response for that at all.

Mary: P4, just keep going on that exact client for a second. So in that case, was the provider doing all the things they're meant to do - you know, presumably the medication was being prescribed by an appropriate --

P4: I think it had been provided over the years by multiple different psychiatrists and it had just been added to by the next one that they saw or by the GP in response to the service requests regarding his behaviour. Once he was moved out of that service and he was connected with one psychiatrist, the level of medication was reduced considerably and also he was moved to a service who - there have been cases of him eating inappropriate materials from the kitchen, which is why the service had closed the kitchen area, but with the new service they left the kitchen completely open and the fridge open and through discussions with him - and obviously dangerous materials weren't put in the kitchen, like bleach or whatever, but everything else was left open and safe. There wasn't stuff left that wasn't safe in the kitchen, but he had access to his whole house.

So, yeah, it was a change in service, or a couple of changes in services, that eventually led to his medications being really radically reduced and also to the restrictive practices being removed in terms of access to the kitchen.

Mary: And to what extent was advocacy involved in the push for him to move to a different service and to change his situation?

P4: Oh, fully, fully involved. It involved us for two changes in service. Until that was got right, and the first removal of service resulted in, because they couldn't find anywhere appropriate for him to go, he went from Brisbane to the Sunshine Coast and then we had to advocate for him to come back from there and then for a further change for him to be close to his family. And eventually he had a good service and a home through Department of Housing, so that was another thing that we did so that then he could be more flexible in terms of the service provider he had. He didn't have to have a service that provided accommodation and then, so yes, so that was accommodation through housing, which meant he could get a good service provider and advocacy for connection to a private psychiatrist that bulk billed. So then he didn't have to have the continual changeover in psychiatrist from Department of Health he had had previously, people stay six months and then moved on, or whatever. He now has a long-term psychiatrist who's been working with him for, I don't know, three or four years now who knows. has a complete overview of the medication he's on.

Mary: Thanks, P4, and the reason for everybody else's benefit, the reason why I asked P4 to keep going on that story really is because I think what I'm realising more and more is that that gentleman's story may not be heard by the Royal Commission or may not get to the Royal Commission, unless an advocate writes it up. And this will be the case for all of you and I'm interested if any of you want to speak to this because when you write it up, you need to spell out what it was that the advocates did because I see otherwise sometimes there's some examples of so that question which P3 touched on about minimising restrictive practices and reducing them, they can be done but they don't happen magically and that doesn't happen just because service providers out of the goodness of their heart decide to do it. It requires significant advocacy and collectively we have to spell that out so that it's clear to the Royal Commission the level and the amount of time in advocacy that's required to make changes to people's lives. P5?

P5: Thank you, Mary. I'd like to hear from the Community Engagement team just in relation to how we can support advocates to clearly communicate. One of our strategies during COVID was a citizen advocate and, P1, you remember the situation, he included the Royal Commission submissions into a group email and letter where he named all the public guardians, all of the NDIS staff, the nursing home, everyone that was involved in the restraints and a person against their will.

This was about a man who had been locked for 26 years in a room in a dementia ward because he has cerebral palsy and that actually just that advocate cc'ing the Royal Commission lawyers in had a big impact on changing N's life, but I don't know if that's gone any further in the Royal Commission or what happened with that after that. I don't think [colleague] heard anything from the Royal Commission after that. Do you need me to talk any more?

Mary: No, it looks like P6 and P1 are ...that theirs has frozen.

[Zoom and audio issues]

P6: Thanks for that question. If it was lodged as a submission, there should have been a response from our submissions team. So if that hasn't happened, maybe we could have a chat offline after this. Is that okay? Yes, okay, awesome. Thanks.

Mary: Good, thanks. Let's go back to the restrictive practices issue. Does anybody else want to – P9- or, no, I think it was - not P9.

P10: Yes, P10 I was going to speak to the issue about some of the barriers to making complaints and in my experience people that are under a public guardian can have difficulty sometimes accessing a disability advocate to even get that assistance to perhaps try to put in a complaint or bring about change, and I think that's a real barrier that needs to be addressed and recognised by the Royal Commission, some of those practices at the Public Guardian that in some situations they can deny a person access to an advocate citing privacy reasons or deny the advocate access to any of the person's allied health professionals or support teams that are going to be key to them working successfully with the person. I wonder if others have experienced that issue as well.

Mary: I can see P5 is nodding. P11 is waving. P12 is nodding. Did any of you want to follow up on that particular one? I'll go to P11 first, P5, because you spoke just a second ago.

P11: Yes, I agree with what P10 is saying, it raises the bigger issue around advocacy in general, rather than just restrictive practices. The public trust here in Rockhampton won't allow an advocate to go in with one of her - with her protege to do a will and I want to follow that up with P3's team, [QLD advocacy organisation], with their human rights staff - I haven't done that yet - because in general, whether it's a public trustee, public guardian, service providers, they do not understand the rights of people to have an independent advocate. They just don't get it, even though it's in the NDIS Act. And if there's one opportunity to try to address the role of independent advocacy that we need to all jump at, it's the Royal Commission to put in these stories that demonstrate the legitimacy of the sector in general and the need for not just service providers but people in key decision making roles in non-government organisations or all government, including the NDIS, to understand advocacy and understand the role of independent advocates.

I don't think they really feel comfortable with someone announcing themselves as an advocate. They want some proof of their bona fides and I can understand that, but we've got to grapple with that because at the moment I think we're seen as being part of the fringe, not the mainstream. We're not seen as the right of anybody.

I guess I'm on my little soap box here, but I think the Royal Commission needs to hear from advocacy programs of every model.

Mary: Yes, thanks, P11, and P3 had put a comment in the chat that the Office of the Public Guardian [OPG] often think their appointment means that advocacy is a service. P3, you mean that it's like yes, treated the same as other services, other service providers.

P3: Yes, they say that - and even though - we've taken this up with the Public Guardian and their office. We tried to get a protocol of engagement drawn up between their office and all of the advocacy organisations, not particularly naming them because we were saying that there would be lots of informal advocates who equally should be recognised because we're obviously speaking or working with the person that they have a - a person has a right to an informal supporter or an advocate.

And OPG's response was that they didn't want to sign up to an MOU or a protocol of engagement between guardians and advocates. Instead they wanted every advocate every time that they ran into a problem to take it up with... escalate it through the regional manager at the relevant location. They see this as a way of improving their practice. But quite often when advocates need decisions from guardians that have to be timely, people are losing out on housing and a whole range of services because guardians don't make timely decisions, obviously they have too many people to see or to even read up on what they're doing, but that's part of a problem, doing things on the papers and then preventing an advocate from doing the work and we've tried to make the point that advocates can actually make life a whole lot easier for guardians.

Mary: It sounds like obviously that's still a live issue in Queensland that isn't improving. P13?

P13: I wanted to also raise the fact that recently a member at QCAT [Queensland Civil and Administrative Tribunal] actually spoke about advocacy in a very poor way. She actually said that she didn't have a clue what an advocate did and actually belittled my role so that the other people who were making the application refused to even speak with me or work with me at all. And also it's not just the Public Guardian and QCAT members, it can also be the hospitals, and I have strong evidence where the hospital just absolutely would not work with the advocacy worker under any condition.

I think it's - not only is it a breach of the national Charter of Health Rights, but Queensland's Charter of Health Rights, so Queensland's Human Rights Act, that despite these tools that we still have major bodies, CEOs of hospitals and individual doctors, who decide that they don't want to work with an advocate, especially when they're trying to discharge someone out of hospital on restrictive practices and behaviour problems into nursing homes, into locked dementia wards of nursing homes, you know, and an advocate is only trying to do their job. So we have lots of problems in Queensland.

Mary: Thanks, P13, and there's clearly a need for some more resources about people's rights to have an independent advocate and perhaps targeted, specifically targeted towards the health system I think. It's another issue that we'd need to come back to. P15, you've got your hand up?

P15: Yes, I want to second that. Unfortunately, … another advocate with us, has had very serious issues with OPG and unfortunately he's sick today, but he certainly has experienced that deliberate refusing to allow an advocate to be involved and also from a child legal representative through that same system.

The other thing that I would add is that it's not just the institutional advocates. Sometimes when the guardian is a family member, we've had issues with that guardian actually being more interested in controlling the behaviour of their family member and not understanding restrictive practices and behaviour support and if this has been going on for years, the family is happy to have them still medicated, still locked up. So we've had issues with other guardians, guardians generally not just OPG and organisations like that.

Mary: Yes, thanks, P15. We'll run out of time in a minute on the restrictive practices issue, but the behaviour support plans, another forum that we were involved with Queensland advocates some time ago, there was a theme that quite a few people raised about the poor quality of the behaviour support plans that advocates were seeing because of course there's a link there to restrictive practices because obviously people need to move away from restrictive practices if they're an NDIS participant, then they need to have a behaviour support plan, they have to have the appropriate practitioners.

So just a quick indication - and if anybody wants to make a comment about it - is that true in Queensland? Is there an issue with the people who are writing the plans, the quality of the plans, the cost of them? Does anybody want to just make a comment about that? P13?

P13: I can only - I've raised this before with the Royal Commission, the quality of the plans. Sometimes I think I could do as good a job as some of these clinical psychologists, no creativity, very little tool - you know, tools that can be used to help bring behaviours back into line without resorting to chemical restraint and that's why you always see chemical restraint as first line, first line of use.

Mary: Yes. Thanks, P13. P17, did you want to say something?

P17: I didn't want to interrupt, but yeah, just to follow on from what P13 was saying, I guess there's also the impact of the NDIS funding to implement some of those positive behaviour support plans in terms of having the correct amount of intervention by the specialists to be able to go in and provide training for direct support workers who are supposed to implement that plan.

I guess another issue that is attached to that as well is that often when you're getting into the more complex areas of behaviour support having a dedicated team that is trained as well to be able to implement those plans to the extent that they're supposed to be I think is also another issue that affects the effectiveness of those plans other than sometimes those plans not being adequate enough in terms of the data that's collected around behaviour and I mean in terms of the function of that behaviour that they're trying to support or manage as well. So there is some inadequacies in the system itself that makes those plans ineffective or less effective than what they need to be as well.

So you've got those issues as well as the... in terms of the level of training of staff being able to correctly gather the data to give back to the specialist so that that specialist can make changes to the plan in time is also another issue. So there's a level of skill that the staff need that seems to be lacking as well, so not only is the fact that staff aren't remunerated to a level that is I guess commensurate with what they're doing in terms of the level of skill required and then the training that they need and also to be able to understand those plans and what the actual purpose of them is I think I've found as well. Sorry to take up so much of your time.

Mary: Thanks, P17, that's good.

P4: Can I add one point with that? With the culturally and linguistically diverse community, we've had not under restrictive practices but somebody who needed a behavioural support plan to be put in place for them for the training device for staff and the like and one - there wasn't enough funding in the NDIS plan for that detailed report to be written and then when we asked for the report - the plan, funding for the plan to be translated so that the family could understand what was written, there was no funding available for that, so with a child with a behavioural support plan that the family couldn't understand was a real problem.

Mary: Yes. Thank you. P14, you had your hand up.

P14: I did, Mary, thank you. One of the things I found concerning was some of the bigger service providers, they're actually writing and prescribing the positive behaviour support plan all in house, so there's no sort of - you can't see what's happening, no transparency.

Mary: Yes. Thanks for that. P3, you've got your hand up, yes.

P3: Yes, I started to type it up. The thing is, going on from what P17 said, more often than not the use of restrictive practices indicates poor quality supports, support workers who don't know or understand the person, so they cannot interpret what the person's communication is trying to convey, they misread the person, they try to control them, and quite often because they don't have those skills and they don't have that relationship with the person, the fallback position is "we need to manage this so we'll use restrictive practices" and once that starts then of course you've got a clinician writing these things. And, as P14 said, it often happens with the bigger services doing it in house because they've got their own psychologist, so they wrap up the person, they often provide all other supports as well. It behoves them to have a huge plan then around a person so quite often a reputation that is completely undeserved is built up around somebody simply because people don't understand them.

...I'm going to spell out my own daughter's situation. We are self-managed. We have been for 10 years. I know that if my daughter was in a traditional service provider situation they would look to have her locked in and possibly have her medicated. She doesn't need it. We train her workers really, really well so that they get to know her and understand her. She is verbal, but she doesn't understand how to communicate her emotions and doesn't always react the best way and she's certainly not the most difficult person to work with at all, but I can see how she could be perceived that way and how this would build up over time and by the time she was in the hands of the service provider for a couple of years, oh my goodness, she would have a million dollar package, totally unnecessary.

Mary: Thanks, P3.

P21: If I can add to that. In our experience, [our organisation's] experience, a lot of people we're working with, the service providers are not providing interpreters. Even people who do have NDIS, the NDIS participants, they don't have access to free interpreters. Services are not providing interpreters and I heard very often when people saying, "I tried to communicate with him". How? How did you try to communicate if you don't speak the language and the person don't understand the English and cannot provide interpreters?

Mary: Thanks, P21, really good point and yes, I think that's a huge issue for all kinds of things, in particular as we're talking about now restrictive practices.

Mary: As we just move on from the restrictive practices, one last question which is just a nice easy one. What needs to change? To make any difference in Queensland for people who are under restrictive practices, what are the policies or the laws that need to change for there to be any difference? Has anybody got anything they'd like to suggest?

P3: Yes, I do. I think even going back to before the review in 2014, first of all take out the immunity provisions. That makes it all too easy for service providers. Take the short-term approvals back to what they were, which is half the duration they are now, and I think the big thing is, which happened to a couple of people just as NDIS was rolling out here, people who live with restrictive practices should be able to self-manage and hire their own workers, not have to have them registered as providers as long as they do the same things that they did under Your Life Your Choice, which is the data collection and the reporting, so the number type frequency and the situations around the use of restrictive practices.

That should be monitored by ... well, it used to be the Centre of Excellence, but I can't say that we could rely on the Quality and Safeguards Commission because they're hopeless. I think that there should be a separate independent mechanism that does collect that data and that they do monitor it and that they then say they step in when they see that either the use is not coming down or it's even escalated and look at why, whether it's mandatory retraining of staff or even then a forced change of provider.

Mary: Thanks, P3. P15, you had your hand up. Do you want to just comment on that as well?

P15: Yes. The other thing that I would say - it kind of harks back to P3's original comment - the regime in Queensland should apply to people who are under 18 as well as people who are over 18 because it's when people are under 18 that they get set in this pattern of chemical restraint and restrictive practices that they end up in for the rest of their life. That's one thing that I think really needs to change.

A second thing would be this skills deficit exemption, which is just an absolute - or has in the past been an absolute rort for providers - "Oh, this person doesn't understand how to cross the road, therefore we need to lock everything", but there's never really been any plan in place to say well, how about we teach this person about road safety and then we won't need to lock them in because they will be able to cross the road. So I think there's too many loopholes in the Queensland legislation.

I've already said in a previous submission and in my evidence to the Royal Commission that I'm concerned about the fact that in respite, if a person in Queensland was only receiving respite, then you can give them fixed dose chemical restraint with only the permission of their guardian and with no further investigation of whether this restraint was appropriate or not.

So I suppose too many loopholes in Queensland and too many exemptions that I would like to see removed. The NDIS partially gets there, but as P3 said, they're hopeless in terms of their supervision of restrictive practices, so we can't just rely on them looking after the under 18s because I don't think they've got the resources to do it.

Mary: Thanks - thanks, P15. We might move on to the other issue that we want to have a bit of discussion about is segregated settings. I'm going to ask you the same question that I did about the restrictive practices. In your everyday advocacy work, are you working with people who are living and/or working or spending time in segregated settings? There's some nods, some people looking at each other, debating. P5, yes.

P5: So segregated settings including group homes, particularly those that now come under SIL, which then impacts on restrictive practices because what happens to one person in the household has to happen to all and the issues around is it about individuals or is it a financial issue of the service around what's happening.

We have a lot of interaction around hostels where people are prevented to have advocates if they're speaking to their advocates about their situation, they're prevented from having access to the community if they're telling people in the community what's happening to them in the hostels, and also these are people who have public guardians in place.

P3, as you were saying, the safeguarding commission in Queensland has been useless. They refuse to even participate in any complaint process if there are guardians involved or even if there's an EPA [Enduring Power of Attorney] and the other issue for us that really segregated setting of course is nursing homes, where talk, talk, talk, but people are still there.

Mary: Thanks, P5. Obviously the reason we're talking about segregated settings in the Royal Commission context is because of the increased risk of people experiencing violence, abuse, neglect and/or exploitation in segregated settings. The question sounds ridiculous when I ask some of these questions to experienced advocates, I think oh my God, the questions are so - what can be done to prevent people's experiences, so people who live or work in segregated settings? What do you see or think can be done to prevent people in those settings experiencing violence, abuse and neglect? P11?

P11: I think in the absence of a really well resourced, independent advocacy sector we've got to see more community visitors, people that can come in unannounced any time and look at the conditions in that particular setting and ask about restrictive practices. I think the problem with the current practice with community visitors is that they almost, not saying toothless tigers, they're more kind of in the pocket of some of the providers, they don't want to get too controversial and providers can work them - game them. I think that needs to be beefed up. There needs to be more of them and they need to be going hard if they have to.

And part and parcel with the lack of resourcing with community visitors is the lack of resourcing of independent advocates to come in and I'm not talking about our model (Citizen Advocacy), but anybody who needs an independent advocate should be able to get one. It's just not possible now to follow things through, particularly with the Office of the Public Guardian overseeing a lot of these clients but not on the spot. They might visit them once a year or twice if they're lucky.

In Rockhampton, people rarely see their decision maker from the Office of the Public Guardian because they don't have the staff and they don't have the budget, so they rely on community visitors. I believe there needs to be a lot more effort put into monitoring these settings because there's going to be more and more of them as money pours in through the NDIS.

Mary: Thanks, P11. There's some comments in the chat. P14 has put a comment in about people in ACFs. I don't know what ACF stands for, actually. What is it?

P14: ACF - aged care facilities. There's no positive support plan for people who are in aged care facilities and if you're a person with disability in an aged care facility, it's so easy, they slap on a restrictive practice like that. It's like the respite centre scenario.

Mary: Thanks, P14. Then P3 has listed SIL group homes, hostels, nursing homes, boarding houses, FDS [Forensic Disability Services] and AMHS [Authorised Mental Health Services], that's mental health service, the forensic disability service I presume is FDS, special schools and units, special classes in schools too, so all of them. P3 is saying get rid of all segregated settings as a suggestion for the solution.

As it happens, there's a paper on segregation which the national peaks have had written recently and sent to the Royal Commission and you'll be getting an email today actually looking to see if any advocacy organisations want to endorse some sort of public campaign about ending segregation, but having a campaign is one thing. Actually making significant change is another. There's a lot of resistance.

In Queensland - and so, going back to my point about the question about what can be done to prevent violence, abuse and neglect in segregated settings, and P11, you've said more advocacy and more community visitors, has anybody else got anything else that they want to respond to that issue about how to reduce people's experience of violence and abuse in those settings? P3, did you turn your camera on because you wanted to speak?

P3: I did, but I can see P14 has his hand up.

Mary: Oh, yes. Sorry, P14.

P14: That's all right.

Mary: You need to put your hand higher above your hand or something. I keep missing you.

P14: I was just going to say segregation in the education sector is something that I come across a fair bit. And that's not regulated at all. I just think greater transparency in the schools would be a good thing.

Mary: And P14, are you seeing that in special schools or in mainstream schools?

P14: Mainstream.

Mary: Right.

P14: Well, my experience has only been with people on autism spectrum and it's not a complete segregation 100% of the time but they're often taken away and placed segregated and by themselves and that just causes more behaviours for them and it just exacerbates the situation and by the end of the term they're quite often frazzled.

Mary: Yes. Thanks, P14. P3, you had your hand up again?

P3: I was just going to extrapolate on the idea of getting rid of segregated settings. By having them in the first place you send a clear message to everyone else in community that people don't belong, that they're not good enough or somehow they're different, inferior or problematic. So if we want to have higher scrutiny, more protections for people from abuse, violence, neglect and exploitation, then they need to belong in community. When you belong in community and you're well known in community, you have more eyes on you and potentially more relationships.

Even if you don't have relationships and you're known, at least you have eyes on you and people will step in if they see something untoward or report something untoward - not everyone, let's face it, people stand by when anyone is experiencing something horrible at times, but all the while you're closed away, hidden away or even out in groups you're someone else's responsibility. People assume that if there's a group of people with disabilities and a group of workers with them and there's a kerfuffle or somebody is upset, people look away. They just assume that they'll be taken care of. But if a person is walking around the shops or the community with one worker and there's a kerfuffle and someone is upset, people might stop and ask, "Are you okay?", intervene, check out what's going on and see if there's something bad happening. That won't happen in segregated settings.

Mary: Thanks, P3. Just for people who can't read what's written in the chat function, P15 has made a point that she has a client who wants to go into a 2 to 1 shared living setting because she's frightened to be alone with a support worker because of trauma she's experienced in the past. Yes, a single worker, a single individual supported by one person, as we saw in Ann Marie Smith's case wasn't good, didn't lead to a good outcome for --

P21: I just wanted to make a point about what P3 was saying. I think it's now changing that, it will be a long process, but I think the segregation is starting at schools and that's what we're teaching kids, that it is okay to put children in disability in one place and children without disability in the mainstream schools and that is going further with every single part of our life and that is a culture that we created and I think if we want to change anything (inaudible).

P16: Can I say something just about segregated settings in education and in particular with autism. So in Queensland there are two main autism schools which would be segregated settings, so there's the autism Queensland school at Sunnybank and Autism Queensland school at Brighton. Both those schools have waiting lists that are probably about three years long. There is a long line-up of parents that are just desperate for their children to get into these schools.

If we were to close those schools, what's the solution, what is the practical solution in terms of addressing the desperation that these parents are practically facing in terms of achieving inclusion in mainstream schools because it's all well and good to say let's just shut down these settings, but why is there such a demand for them in the first place?

Mary: Thanks, P16, and P11 I can see has his hand up possibly in response to that. P11, do you want to respond?

P11: Yes. P16, I don't believe those schools are what I call segregated settings. It's like schools - there's one here in Rockhampton for disengaged kids, they're in a segregated setting, but these are a special school or a special education development unit is a segregated setting. They're pulled out of the mainstream and they don't participate with the normal school community, with the everyday children and parents and teachers and teachers aide that teach kids who have special needs. So I think we've got to be careful about our definition of a segregated setting.

P16: So would you consider an autism school a segregated setting?

P11: No, I don't. I think those schools have got their place and I've got kids with autism and I would have loved to have had something like that --

P16: My daughter attends an autism Queensland school.

P11: My three boys went to an early intervention centre in Rockhampton run by Autism Queensland, so I don't consider that to be a segregated setting, P16.

P16: Because it is physically segregated, though. It is physically set apart from the local kids in the community and I agree with you that the teachers at these schools are highly, highly specialised, highly trained, incredible people that have allowed my daughter to access the full curriculum at a full-time participation.

My daughter is accessing education, there's no question. She's not going to school with her local kids, though, and I think that's the problem, that's the intrinsic problem, why in terms of - there's a very simplistic argument to say let's close these schools or stop these settings, but how do we combine the benefits that kids are gaining from these autism schools while also being able to access relationships and friendships with their local community children.

Mary: Thanks, P16 and P11. These are big issues. Unfortunately, the time we've got to discuss them is just not enough to go into exactly the real detail really of that point. But I might go to P3 because I know [QLD advocacy organisation] is part of the alliance on --

P3: Coalition for Inclusive Education.

Mary: Thank you, yes.

P3: The thing is, P16 and P11, there's always been the demand for these specialist settings and all the while there is a demand, there will always be, for segregated path unfortunately.

The thing is we understand that people choose that path because they recognise that the way schools are currently in their local area are not equipped or don't have the will and welcome for students with autism in particular. However, it is the system that needs to change. Having kids educated off site isn't the solution because it will still ‘other’ people, you know, it still ‘others’ them long term.

Autism Queensland schools have a high rate of non-acceptance of kids with autism and suspensions and exclusion, so they are part of the problem as well as the education system. Instead there has been some progress with autism coaches and inclusion coaches, but the problem stems, and the department is well aware of this, that back in the I guess it was the 80s, late 80s, early 90s, devolution of power to principals means that principals are allowed to say who comes and who doesn't. But the Queensland Human Rights Act is going to have an important role to play in that because the department is training principals so that they no longer can gatekeep, but then it is incumbent on the system to make sure that students with autism and any other disability are not only welcomed but supported and it also means that teachers need to upskill and they cannot just rely on the 40-, 50-year-old excuses that have gone on forever that good teaching is good teaching and we've seen teachers teach to all children, including across all the spectrums there are, when they're in a one teacher country school because they have to.

So it's that creativity and mindset that needs to be instilled in every teacher and it can be done, but yes, and I can understand parents are only concerned about their own child, but I battled for my child back in the 90s and I still see that nothing much has changed unless we drive the change by closing off that segregated path.

P16: It seems to me all I'm hearing from parents at the moment is they're wanting to build their own autism schools everywhere.

P3: Yes, I know.

P16: It's going in the opposite direction.

Mary: P16, I'll just make a comment about that. I think at some stage during next year we will look at doing something with advocates from all around Australia specifically around autism.

P16: It's so needed.

Mary: Increasing numbers of children with autism, so it's a little bit separate from what we're doing today.

P16: Yes.

Mary: But we'll come back to you about it because, yes, it's badly needed. Coming back to the segregated setting - sorry, somebody from [organisation with multiple people on screen] has their hand up.

P4: I wanted to go back to that segregated living issue. One of the things to do with affordable housing in Queensland, there's such a shortage of affordable housing and such long wait lists for people that to try to get people housing where they can be supported to live on their own if they wish or with another person if they wish is so difficult. So I just wanted to flag that.

Mary: Yes. Thanks, P4. Did anybody else have their hand up at the minute? No. The hostels, the boarding houses and hostels, they were mentioned. I think P5, maybe you mentioned them. There still are quite a number of them in Queensland. Does anybody have a view on how they can be changed to that it's almost like a non-system, but it sort of operates like a system. Has anybody got any experience or understanding about how changes can be made in that sector? P5?

P5: First up, I would immediately say NDIS planners and the public guardian not referring people to them because that's where it all starts, that original referral, the acknowledgment in the NDIS plan that this person is going to live in a level 3 hostel. I'm finding that quite mind blowing to what we were fighting a few years ago and getting people out of hostels and boarding houses where that agency was financially dependent on a person's pension, to now that agency is still getting that person's pension and at a minimum around 80,000 a year in NDIS funding and still not providing anything else to a person, people are still sharing bedrooms in hostels. P3, I'm sure you can speak to a lot of this around Brisbane. So I guess the referral, that initial assessment and the assumption that this is a service, that it's even seen as a service provision at all needs to be stopped.

Mary: Or the fact that they're actually allowed to register as NDIS providers even.

P5: And build day centres now on their properties as well.

P3: Oh, my God.

Mary: Building day centres?

P5: Yes.

Mary: I might follow that up with you separately, actually, P5. That does make it sound like it's getting worse. P2 has put a link in the chat function to the roadmap, the roadmap for achieving inclusive education in Australia, which was put out earlier this year, and it's a fairly tight and ambitious roadmap, but it does go into some detail about, at least in the education area, how segregation might be able to change for children with disability in education system.

I'm just conscious of the time, so I just want to see is there anybody who wants to say anything in particular about segregated settings that you deal with and have you seen any improvements in any of them, have you seen... people are shaking their heads.

P3: Oh my God, no.

Mary: And the advent of the NDIS into Queensland hasn't helped that, hasn't improved any of those settings - no? It's just shifted who the money is coming from and that's it?

P3: Mary, I would say that if anything it's brought more sharks out into the water. The way so many providers are gouging the system, gouging plans, gouging through the portal, and yet the scrutiny and the hoops that participants have to jump through is obscene.

I'm just looking at minutes from a meeting that [a colleague] and I were supposed to be at last week, but we couldn't go, it was our DSS audit, and it's the residential regulations reference group. It's a new thing within Department of Housing and Public Works and I think it was brought about by a lot of pressure from us as well as [interstate advocacy organisation] around the behaviour of boarding houses and hostels in particular, supported accommodation providers, during COVID.

Now, we had tried to raise this for over three years with the NDIA, with OPG, with housing, with QCOSS [Queensland Council of Social Service], very little interest in the problems arising because while they're accredited buildings under Department of Housing and Public Works, hostels are not accredited about their service provision of course unless they're an NDIS registered provider. But there are still hostels and boarding houses in Queensland that are not NDIS registered and people are still living there and they are still... even though they've got NDIS plans.

So there's a whole bunch of people who were really terribly treated during COVID and I think it was only - I know [interstate advocacy organisation] raised complaints and we had quite a lot of media interested in doing stories and digging around and we brought in the community visitors in quite readily as well and tried to escalate complaints. I think some of that made - and we've pushed Department of Housing as well as disability services to do something, especially when our DRC funding for our advocate says that part of their advocacy work was to "find housing for people", that was a bit laughable, and we thought that the powers that be should actually be the ones finding the housing.

So we were unable to be there…. It will be interesting to get the lowdown …about those minutes that I'm looking at because the President of the supported accommodation providers association was there as well as some other housing providers and just briefly looking at the minutes, it seems like they were saying oh, we're poorly understood.

Mary: Yes. Thanks, P3. I'll just see if anybody else wants to make any other comments about what needs to change and how on earth do we make that change and what is it that we want the Royal Commission to have by the time the Royal Commission is doing its final report - what are the really strong recommendations that you want to see in the Royal Commission's final report that will make some changes to the segregated settings that people live in? Yes, P5.

P5: More visual and proven independent advocacy, people having access to that advocacy and that advocacy not being prevented through the OPG or EPAs.

Mary: Yes. Thanks, P5. P3 is agreeing. P11, did you want to speak?

P11: Yes, hi. I wholeheartedly agree with what P5 is saying and I think we need better governance around the appointment of advocates so it's a clear process, people know where to go and advocates have got….. this is my idea and it probably isn't... it needs assessment, but I think we need a pool of people and they need accreditation so they have some bona fides. Not anybody can just put their hand up and rock up and say, "I'm an advocate." I think there's a lot of people who would be excellent advocates who don't have any bona fides, neighbours, friends, family members, but we've got to be able to prove in this world of bureaucracy that resourcing advocates means they're actually good advocates, they're people who have some skills, some knowledge particularly of the person they're advocating for and they can take it up to these decision makers and to any organisations that have control.

Anyway, again I'm probably going too far, but I really do think we need resources in advocacy, because we are seeing so much money poured into transactional systems into that client provider role. We need money that doesn't go into that: that oversees those and tries to separate all that from a real life person who's not just a creature of support providers.

Mary: Thanks very much, P11, and I completely take your point about skilling up and supporting friends, families, neighbours and others to also advocate. Advocacy isn't just for paid professional advocates. All sorts of people in the lives of people with disability can and do advocate for them and some people would be able to do that better if there was more support for them to be able to do that. So thanks, that's a really good point.

[Tribute to retiring advocacy manager and wrap up]

Mary: Thanks, P6, and P20, thank you for joining us today. It's really nice to have you along and listening in as well.

P20: Thank you very much for the opportunity and thanks to all the advocates on the hook-up. It's been great to hear.

Mary: Thanks. So as P6 said, we're working our way through the states and territories. The Victorian and New South Wales workshops won't happen until the beginning of next year, but we are now in the process of theming and analysing the material that comes out.

We've had some of you who have already taken part in the Zoom In On sessions that P2 has been running on Mondays on a whole lot of Royal Commission related topics and we're doing the same thing. We're now analysing those and we will provide that information back to the advocates so you can see what's come out of the sessions that you've been involved in at your state level but also the other topics. There's really rich information that we're receiving.

And I just should say for the benefit of the people in the Royal Commission, it's not that I - DANA doesn't send something out to the advocates beforehand saying, "You must say how important independent advocacy is" or, "You must say it needs to be better resourced." I'm not prompting people or giving them a bonus if they say that.

PB: We believe you, Mary, we believe you.

Mary: It's just obvious, isn't it, the work advocates do is so critical and that the organisations are extremely busy and feeling fairly under-resourced a lot of the time. So how to get that message through to governments is a challenge and the Royal Commission is one of the ways, one of the places that I want recommendation, number 1 in the final report should be about advocacy, yes, and that is important, isn't it, because the interim report of course has lots of information in there, but wasn't constructed in the form of recommendations. So it means that governments will sit back and just wait until the final report to make decisions about what they should spend money on or what they should do. So we have to keep fighting our corner, don't we?

Thank you very much. Thanks to all the Queenslanders who took part today and very nice to see some of you I haven't met before, but very nice to see all of those of you that I know already. We really value your involvement in these workshops. So thanks, everyone. Bye.

Comments typed in Zoom chat function

P3:
OPG often think that their appointment mean that advocacy is a service and they tell people they don't need an advocate. We have taken this up with the OPG but they say that advocates need to escalate this by complaining to the relevant regional manager.

P18:
P3, [our organisation] has had exactly the same experiences.

P3:
not surprised

P5:
NDIS QLD safeguard commission - OPG - EPA. Commission have advised they will not pursue if OPG or EPA involved.

P3:
There should be a means for the person and their advocate/informal supporter to reject any PBSP (Positive Behaviour Support Plan) that they do not feel is adequate.

P3:
The problem is also that SP do not follow the PBSP

WA Advocate:
Are restrictive practices being reported under governance structures, to monitor use of chemical restraints etc from an organisational perspective. Are organisations audited.

P14:
And people in ACFs

P3:
YES

SIL, group homes, hostels, nursing homes, boarding houses, FDS and AMHS

special schools and units special classes in schools too

People need to belong - get rid of all segregated settings

P15:
Some form of SIL is not always a bad thing for all clients. I have a client who actually WANTS to go into 2:1 SIL. She has experienced extreme trauma in the past and does not want 1:1 supports 24/7 because she is frightened to live alone with a support worker.

P3:
It would be better to fund supports out of CORE instead of SIL and choose her co-tenant rather than SIL which ends up as vacancy managed and the power in the hands of the service provider

WA Advocate:
great discussion

P2:
ACIE advocates a staged transition away from segregation to fully inclusive quality education https://acie.org.au/2020/09/30/driving-change-a-roadmap-for-achieving-inclusive-education-in-australia/

P3:

I would hope that the DRC report at the end of its term would be very firm on actually realising the CRPD and the National Disability Strategy that must have clear implementation procedures, and we need a national human rights act

P3:
thanks Mary

P19:
Thanks Mary