

DANA and DRC Workshops with ACT Advocates – 13 October 2020

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

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

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

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

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Transcript of Zoom Workshop - 13 October 2020

P1: Acknowledgement of country and then and then we'll do some introductions.

I am here in the ACT, so we acknowledge the traditional custodians of the ACT the Ngunnawal people, and we acknowledge and respect their continuing culture and their elders, past, present and emerging and any Aboriginal people who are with us today.

So my name is Mary Mallett, I am the CEO of DANA, Disability Advocacy Network Australia - Peak for the independent disability advocacy organizations. This is the first of a series of workshops that we will be doing that we have invited the Royal Commission to attend to hear directly from advocates about their experiences on a couple of topics, and we'll get to the topics in a minute. We've sent a little bit of information out beforehand, but we'll just start by asking everyone to introduce themselves. We'll go around the advocacy sector first, so we'll start with P5 and P9, who

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are both from DANA. Then we go to the [ACT Advocacy organisation] advocates and then the [ACT Advocacy Organisation] advocates.

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

P1: So just reminding everyone there is a chat function. Feel free if somebody else is talking and saying something and it reminds you of something you want to say. Just put it in the chat function. It's a useful addition to what we talk about. So as I said, this is the first in a series of workshops. I feel personally guilty because last year we did a series of workshops about the Royal Commission and we went to the six States and we didn't get to do it in either of the territories so we didn't do one in ACT and we didn't do one in the NT and I've felt guilty about that ever since. Those original workshops weren't like this one today. They were introductory workshops where people from the Royal Commission and Blue Knot and the other support services came along to just talk about what they do and what the functions of the Commission were. And we're not repeating that today. Today is specifically to have a focused discussion on the topics that we'll get to in a second. So we know, and the Royal Commission has learned, that advocates have this enormous, almost untapped wisdom and experience about some topics and they know more about them almost than anybody else in the sector. And we want to try and make sure that the Royal Commission gets to hear the experiences that you deal with all the time because some of the people that you work with, it will be hard for their stories to be heard at the Royal Commission otherwise. So, that's why we're focusing on the topics we've selected, which are segregated settings and restrictive practices because they're topics that are not widely discussed but advocates know about them. And I can just see that P2 has joined.

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

P1: Thanks, P2, so we're going to have 1/2 an hour discussion now on segregated settings and we've got some questions. There were some questions that were circulated beforehand, and the survey that you can do. There's a range of ways that you can put your views in, but today is the opportunity for you to talk about whatever is important to you about these issues, so we're starting with them.

Segregated settings, I'm not sure if that's back to front from what we had in the agenda, but anyway regardless, we're going to talk about segregated settings for half an hour. We will have a very quick five minute break, and then we'll talk about restrictive practices. I just wanted to explain a little bit about the role of the Royal Commission staff in the workshop. It's a DANA workshop with advocates from funded advocacy organizations, but the Royal Commission staff which includes some engagement and policy staff. They're here really kind of as observers. They're interested observers, they want to listen and hear what you all have to say. They might have some questions, so depending on how the discussion goes, and AJ, feel free to dive in with a question. Or you can put it in the chat and if some things don't get discussed, it might be that that we might share some questions around afterwards that come up from the Royal Commission people but their role today really is to listen and learn from the advocates... Feel free then you don't have to hang back. Whoever wants to respond, just, you know, put your hand up and dive in, OK?

The first question about the segregated settings is: What are the common features that you observe in in the environments that have fostered violence, abuse, neglect, and exploitation?

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You don't need to word your answers as if you're writing a thesis, OK, we just want to hear what it is that you know from your everyday work about the features of those segregated settings that mean that there tends to be more violence and abuse in those settings.

P2: Um, look, I don't know if this is within the remit of what we're discussing today, but I have seen it frequently in residential aged care facilities, so I'm talking about older people who have disabilities, and I think the common denominator tends to be people who are very isolated, who don't have an advocate or a family member or someone close to them looking in on them and checking that things are OK. That's where I believe, abuse tends to flourish or can flourish.

P1: Yep, thanks P2. Anybody else about other segregated settings? P3?

P3: So in my experience, group homes in themselves are segregated settings and I find that people are isolated even within those group homes into their rooms. I find people have been left in their chairs. Their chairs have been turned off. I'm talking about a motorized wheelchair and if they are nonverbal then they're stuck in that chair facing a wall for the day without any ability to mobilize themselves, I've witnessed that.

Well, also within the educational settings, I find that teachers who are not trained in working with children with disabilities will segregate the children from the rest of the class, either that being in time out, suspension, or sending home. Even though it's not necessarily segregated, it is removing the problem in inverted commas away so it becomes non inclusive and in that environment, bullying and neglect flourish.

P1: Thanks P3, P4?

P4: Yes, just like P3 said, I would like to add on how group homes operate. I think there is high chances of neglect, especially where in a group home the people are misplaced. They have older people and then, let's say, three older people then one very young person, so the younger person tends to face lots of neglect and isolation, because more focus is always placed on the older person.

P1: Thanks P4 and anybody else want to respond to that one?

P5: Yeah. I might actually jump in, not so much representing DANA, but just mentioning some of the work that I know that both [ACT Advocacy Organisation] and [ACT Advocacy organisation] have done in the area of supported decision making and that really comes from recognition of the lack of choice and control in group homes and similar settings where people first of all, don't even know that they have the right to make a decision. And often their control over their lives is so limited down to certain choices that it doesn't really amount to true autonomy. And I know that the Control and Choice report that [ACT Advocacy organisation] wrote was really eye opening for me. It's often well intentioned and you know there's a lot of gatekeeping, and people think they're just protecting people and keeping them safe, but really, limiting their control over their lives to such a degree and also keeping them so isolated from the world that it's incredibly disempowering, and I think that's a common factor across segregated settings is that they're disempowering to people - and their natural right to be able to make decisions.

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And I'll just read out what P6 has said. "A major factor is people living with others that they have not chosen to live with. And where they may be a lack of support or an imbalance of support between residents."

P1: That's interesting, the imbalance of support because I'm sure you've probably all seen examples of that where a person in a sort of congregated setting is the one who either has the most needs or demands more of the time of support staff and other people get left to themselves, really or not supported. Yeah, would you say that that's something that you notice or observe in the group homes in particular?

P3: Yes, absolutely. Group homes as P6 said, not having a choice of who you live with. This is one of the major factors for people's dissatisfaction in their living arrangements and the different levels of support that people get is dependent on whether a support worker likes them or not. It comes down to as personal as that. If they like you then you'll get the support. If they don't like you then you may not and we've seen that quite clearly.

P1: That's a really interesting point, because people then behave in particular ways to make staff like them, don't they? They think they have to. They feel obliged to do that.

P3: That's right. I don't think, therefore, we've actually moved away from the old way of how it was. It's not changed.

P1: Sorry, can I just follow up that specific example you gave when you spoke first about the person literally being parked you know towards the wall and the chair turned off and they're not able to move. And I presume that's with the person who's unable to articulate, you know that they need to or to ask, am I assuming that's correct? Or that either they can't ask to move, or that if they do, that everybody ignores them.

P3: They do, they have a quite a profound speech impediment, but I mean it's not hard to interpret what they're saying. It really is a choice of support workers to ignore them because they don't like that person. And so yes, that person has been parked and ignored and so behaviours then arise from that that may be not appropriate, aggression and then we then go into the territory of restrictive practices, using psychotropic medications and or intimidation. You know, bullying, standing over, the power imbalance is very much there.

P1: Yeah, um, thanks P3 and I think that that story is one that should go in as a submission so that the Royal Commission actually gets to hear that one is as an example.

P3: Yes, and we are. We've taken that person's submission. Yep.

P1: Thanks P3. One of the things that strikes me about it is...What's the role of the other people who share that group home with that person and who observe how that person is treated by staff? Because it almost means that they don't, even they're very unlikely to try and stand up for themselves as well, aren't they? If they see what happens to people who go against what the staff want. So it's almost like it doesn't have to be said, yeah? Staff can wield this power by treating one person in that way and it will make everybody fall into line.

P3: That's correct, and the power that the organization that runs a group home can have over a person who's living there, to threaten them with eviction. We've had a particular provider of group

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homes - I've now experienced them give immediate notice to two residents, and these people have nowhere to go, and they are high needs, so that power imbalance is still very much present in the abled and disabled worlds.

P1 Well, let's move us on to the next question. What do any and all of you think can be done to prevent violence, abuse, neglect, and exploitation occurring in those segregated settings? Any and all suggestions are welcome. P2?

P2: Well, I think we've really got to start with educating people; service providers and support workers. About you know what is a strict, restrictive practice and what is abuse? Because sometimes people think that what they're doing is normal and acceptable. So for example. Just sorry, go back to the residential aged care facility example, but this also happens in other more younger disability settings. You know, thinking it's OK to give people dosages of drugs to sedate them because there's not enough staff to support them is a form of restraint and people might not think giving someone a sedative is restraint. So it's really fundamental that people have education and understanding about these issues so that they can differentiate and they can understand what is abusive behaviour and what is accept acceptable legal behaviour. And that education also extends to all people, including people with disabilities, so that they know: 'Look, this is not right. I shouldn't be treated like this and I really deserve better.' So education and information on this is fundamental on all levels, and putting in place, systems of policies and processes that safeguard against this, this kind of behaviour happening is also pretty important I think.

P1: Thanks P2, P3?

P3: I actually believe that the treatment that disabled people receive is a reflection of society's culture as a whole. So, for me it needs to actually happen on the ground with empathy and compassion; training if we want to go there. We've lived it. People with lived experience being able to tell their stories and have experiential training so that support workers actually get the opportunity, as limited as it would be, to feel and experience trauma or situational experiences... scenarios is, I suppose, what I'm trying to find. Trauma-informed care in practice should be mandatory for anyone dealing with someone with disability. And I say that because the majority of people with disability as we know the disgusting statistics of women with disability suffering sexual abuse and assault. So for anyone dealing with people with disability, I believe that there should be mandatory trauma-informed care so that they're understanding how trauma affects the brain and therefore how it affects behaviours and what type then of support a person with disability needs and wants... and then we go back to the supported decision making. I think that's also an imperative form of training that people need to have that just to rise out of that: 'Oh but I know what's best for you', that paternal attitude that comes with a lot of care for people that aren't perceived as having capacity.

P1: Yes, thanks P3. Anybody else want to dive in? OK. One of the things that occurred to me, P3 when you were talking about that experiential training. This training process is in place, isn't it? Most disability support workers will have done, a Cert 3 or a Cert 4 or further training. So the existing training needs to be looked at properly. It really needs to be interrogated to see why are those workers not learning? What is it about the current training courses or you know where are the gaps, what's happening there? And that's not just a new thing, that's been the same for a while.

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P3: I would agree and having done Cert 3 and 4 in Community Services and then when you're out in the field on the ground, it is chalk and cheese. It does not train you adequately to be in those environments. And so, yes, you're quite right, P1, I think those current trainings need to be interrogated and to identify the gaps. And one of those gaps as I say, is experiential learning, as in getting people with lived experience to engage support workers as far as we can, but at an on the ground level, experiential level, people with lived experience people of disability so that it's not a big shock when someone goes into the sector and works with a person with disability because they've already met a person with disability. And the current training does not do trauma informed care and that's something that organisations may provide once they have started employment. So I just think yes, the training needs to be completely overhauled because it's not satisfactory.

P1: P2? Thanks P3.

P2: I would agree and add to what P3 has to say. I think that the focus for my understanding of Cert 4 type training is very practical, focused, and that's of course very important. But there needs to be an isolated, not isolated, but a very clear focus - On caring for people with disability and supporting them from a rights-based approach or focus. And I don't think that that's currently there. And this kind of thing is not something that should be implemented once and then you know it. It's kind of like cross-cultural capacity building skills. It's something that should be ongoing. And should be part of someone's mandatory professional training. They have to keep up to date with those kind of skills and knowledge and understanding. And I would also refocus things in terms of recruitment of appropriate staff. From what I have seen in my professional career, there are some people who should not be working in this field. And you just cannot impart or teach them things about, you know, basic human dignity - Either you understand things like that, or you don't. So there also needs to be an overhaul about recruitment practices of people who come and work with people with disabilities. It really needs someone who has those values and characteristics and are able to do that work with integrity. And that's not saying all people, support workers, I'm just talking about those ones have been highlighted in the Royal Commission.

P1: Thanks P2, P4?

P4: Yeah, I know P1, you mentioned that support workers need to get training through their Cert 3 and Cert 4 and get their qualifications. However, I have to say, given the nature of how the NDIS works, there's so many pop-up service providers and the like, one-man-show service providers, they run things, you know, the way they want and I have to say there are support workers that don't actually have any form of qualifications. It's somebody's nephew, somebody's friend, that gets employed as a support worker and I have gone through the Quality and Safeguards Commission audit process, and it could be better. Honestly what they ask? I don't see any screening being done for support workers, so really anybody could just go in there and do whatever they want to do and, you know, land on the job. But I think it really needs to be screened 'cause there are so many people that don't have those qualifications. So to add on to what P2 and P3 are saying, Can you imagine someone that has no idea at all? And yes, so I think there needs to be a better process on how support workers actually are screened and start working with people with disabilities.

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P1: Yeah, thanks P4. ... I know the Quality and Safeguards Commission are doing a whole piece of work called a Workforce Capability Framework and there's been quite a few bits and pieces of work done about workforce capacity and other things, in the last few years, but a lot of it seems to be about just getting bodies on the ground, doesn't it - just getting enough of a workforce and I think some of those otherall of what you've all been talking about, about the quality of the workforce is being left to the side I reckon while they just try and focus on literally getting enough people into the sector.

That was great about the workforce and highlights for me how important it is and that we should perhaps pick that up a bit more strongly.

P1: P5 put up in the in the chat function a little while ago about some of the videos that are on the DANA website. There are links from VALID in Victoria and from QAI in Brisbane.

What else do you think needs to change in regards to settings that segregate people with disability? I know that's an enormous question, so you can pick anything, any area really, but anything else that you think needs to change in regard to any of the segregated settings. So that might include group homes or employment. You know, segregated employment like ADEs or school settings or aged care, any of the segregated settings. P2?

P2: I think there's been many advances and improvements in terms of the architecture, the design aesthetics, we still need to focus from moving away from the look and feel of a setting that is like a prison cell and more to something that is what any person would expect and would enjoy, that really promotes healthy living from a physical and mental health perspective. And also really promotes social interaction with the other residents of the place or people who come to visit, an ability to get around to be independent, to get outside, so we really need to ensure that to the greatest extent possible, all those standards continue to be achieved. Or improved upon.

P1: Yep, thanks P2, that's interesting. The balance between people having their own privacy and their own space and then having enough opportunity to interact with other people where they wish to. P3?

P3: I was just going to just sort of follow on from what P2 said then. Particularly about the architecture space, so I don't know how many people have gone to the high dependency unit and the adult mental health unit here in Canberra - But it is like a jail cell and it has very disgusting, dirty linoleum on the floor. It is dark, there are no plants there, it's false grass on the floor. Now, while I understand most people are in the high dependency unit because of aggression, aggressive behaviours, it is not a therapeutic space. And neither is the general ward of the Mental Health Unit. And one thing about if you are in a place of unwellness psychologically, psychiatrically, then your environment is extremely important to regain a sense of equilibrium. The lighting, the smells, the colours, the textures, all of these need to be considered, and they're not, and so I believe that architectural space, as P2 says, is extremely important in segregated settings, particularly for therapeutic value.

P1: Thanks P3, anybody else want to add anything into that part of the discussion? I can see P6's put something about, as we're pushing people to live in their own houses with support that people

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with more high complex needs should not be segregated away from the community. And she's used Anne Marie Smith there as the example. P2?

P2: Yeah, yeah, just to link it all back once again to education and capacity building of service providers to understand about how design of where people live is really important. I think that that should be included and I just kind of reflect back when I was representing a group of family carers at a residential aged care facility in Canberra because the management had created this dementia unit. And it was just like completely locked away dark and I know what they were thinking. They were thinking 'they have dementia. They're not gonna notice' which was absolutely wrong. Of course, they're going to notice, and that's why people with cognitive impairment tend to inverted brackets. Inverted commas ("wander") like they move around. It's because they're really unsettled and unhappy. And it was really showing in the behaviours, I don't want to use the term behaviours, but the way they were reacting to that setting. So I think it's fundamental that the people that manage these different facilities are educated about what is needed.

P1: Yep, thanks P2. Just a couple of minutes before we have a short break. Are there any laws and policies that that any of you think should absolutely be changed so that that we will get some change in segregated settings? Is there any particular thing that that comes to mind for anybody?

P2: Maybe the Human Rights Act in the ACT could be strengthened to specifically relate to this issue. I don't think it's there at the moment.

P3: You're right P2, it was my very thought, the Human Rights Act.

P2: Like minds, yeah?

P7: I thought that as well, like more, focused on disability in the Act, but also like greater focus on gender like as we've already discussed there's an overlap there between vulnerabilities. And so I think adding that into the Human Rights Act as well would be important.

P1: That's interesting because of course you know ACT is one of three jurisdictions now that have a Human Rights Act. You know, Victoria has the Charter and then Queensland the Act more recently. So I think the other states think 'Oh well, those of you that have Human Rights Acts, everything must be fine.' And so it's useful to see some lessons about what happens when you have one, and then what? What difference does it make actually, that would be an interesting thing to kind of think about offline, I think - so ACT has a Human Rights Act - What difference has that made to anybody's life, and in particular to the lives of people with disability who live in segregated settings. We want to, you know, put forward to the Royal Commission, the change that we all want to see happen. It's important to try and get that as specific as possible. which might mean you know, specific changes that could be made to the ACT Human Rights Act is a good example of that.

BREAK

P1: All right, I think people are coming gradually coming back in. I've got a couple of quick follow up questions before we go on to formally talk about restrictive practices.

P2: I'm back.

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Oh yeah, thanks P2. So I noticed P6 put up on the chat about making people more aware of and strengthening the role of the official visitor scheme and that [ACT Advocacy Organisation] have had referrals through them for advocacy support, so as a safeguard mechanism, are they a useful one in the ACT? Are they effective? Just quick off the top of your head view about that - about the official visitor scheme in the ACT. Yes, P2?

P2: I think it's active. I know it's a different jurisdiction. I would like to see an older person's official visitors scheme 'cause older people have disabilities but that comes under the Commonwealth jurisdiction and it's a bit disappointing, but that's where I believe it needs to be expanded.

P1: OK, so you think it's OK but needs to be expanded, P3?

P3: You know my experience with the official visitor scheme is: They come in, which is really great, and they're very responsive and really across all the issues and it gives the provider a good scare, but that's it. Yeah, just a scare, doesn't actually change behaviour.

P1: Doesn't change behaviour. OK, that's interesting. Are there other safeguards or what are the safeguards that you think should be built into or strengthened in the ACT that would help do more to prevent violence, abuse and neglect.

P7: I think more appropriate screening of situations of domestic violence would be really useful. I think that when a number of clients have been having their family involved or had different, I guess like family supports or family based therapies or things like that, yeah, that providers or health care workers or those kind of people have tried to involve families inappropriately.

P1: OK, um, that sounds like it's an issue that needs a bit of further exploration P7, so do you think the workers who were working in those parts of the sector in domestic violence or health and other providers that they might be unaware of the fact that there potentially is violence and abuse happening within those family settings?

P7: Yeah, Absolutely. I think there's a failure to be able to notice and recognize domestic violence and therefore respond appropriately...

P1: OK, that that needs some thinking in its own right. But yeah, thanks for raising that. Anybody else quickly about safeguards, any other safeguards that you think, and you can include advocacy here, you don't have to hold back. If you think advocacy is part of the solution, please say so.

P3: Advocacy's part of the solution without doubt. When someone has a disability advocate, walking side by side, then people... because advocates are able to stay for a certain period of time far longer than, say, an official visitor. Then behaviour does change or can change in a way that is not necessarily able to be done by other mechanisms, so yes, disability advocates, advocates in that space are able to educate providers as to the gaps in their services or the legislation that then they require, or are meant to be responding to and abiding by. So yes, without advocates it would be a poorer world for people with disability, and not only that, we should be funded more, just saying.

P5: I just want to read out a couple of comments, that P6's made, 'we have also had issues with people being able to provide consent for an advocate to be involved when they are non verbal'. So there are people that advocacy you know has trouble reaching.

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And P7 said, “The other thing I would quickly add around legal changes is to strengthen the availability of the NDIS to people in custodial settings - as this would hopefully set them up with supports on release and thus render them less vulnerable to neglect and abuse whilst also improving their social health determinants”

P1: And so do you think in the ACT that that isn't working as well as it should, that interface between people with disability who are in custody and the NDIS?

P7: Yeah, absolutely. I think a lot of people are being told that they can't get access to the NDIS while they're in prison, and it's a really gray area because then only getting that application process rolling once they're already released so they were going out without accommodation or without support. So those kinds of things, I don't think the interface is working very well and I think that, yeah, that's a big issue.

P1: What that reminds me of is, and I don't have the link at hand to put it up, but there's a video I just watched the other day which was from one of the citizen advocacy organizations in Queensland. I think the Capricorn Citizen advocacy in Rockhampton. They matched a citizen advocate, so a volunteer in the community, with a man who was about to transition out after 17 years in prison and there's an interview with the two of them talking about how that process worked. So he had a citizen advocate with him on the journey who did help all of that process, you know, to help him get stable accommodation and all of that. Now, unfortunately ACT doesn't have a citizen advocacy service and so even if an advocate was involved, they wouldn't be able to stay alongside that person, two, three years, you know, to help them through that process.

P2: I would agree citizen advocacy would be very good and my understanding is that you know, apparently it's based on Wolfensberger's theory but the person's not just a volunteer, but they kind of stay there throughout their life.

P1: Yep,

P2: So you know the way it is now, advocacy has a limited time, once you finish the issue then you kind of close the case. So I think there would be a lot of added benefit to having citizens advocacy in the lives of very vulnerable people.

P7: Just coming back to that interface between NDIS and custodial settings the ACT Corrective services is, I think, releasing in December, the Disability action and inclusion plan, and I think they're going to be commenting on the interface between the NDIS and AMC [Alexander Maconochie Centre - ACT correctional centre] in that - I don't know how deeply they'll dive into it. But just if anyone's interested in reading more, there might be some stuff in there.

P1: Thanks P7. That's useful. Of course, the ACT disability sector, I'm sure you were all involved in the whole justice plan. Certainly on paper it looks fantastic. It looks better than anything in any other state or territory, but interesting to see how that's playing out on the ground. It certainly looks good, P3?

P3: The Disability Justice Strategy. I've been able to quote that, refer to it when trying to have access to justice for clients, when they've been turned away by either a Legal Aid Commission or

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the Pro Bono Clearinghouse, that sort of thing. So it's getting there. It's getting legs, but we're in early days.

P1: Thanks, we might move on to a few questions on restrictive practices. So, from your observations of restrictive practices, can you just say what are the effects of restrictive practices on people with disability?

P2: It can actually decrease their capacity rather than build it. So, for example, chemical restraint is a restrictive practice, and it can really affect the mind to go to a place it wasn't there before in a bad way, and it can hurt people, it can restrict their ability. For example, mobility, I had a client who was kind of chained to a chair, it can make it even more difficult to increase that mobility, so it can actually make the disability even more exacerbated and it can adversely affect them, and it can also affect a person's confidence to be able to do different things and it can make people anxious and depressed. Those are some of the things I've observed, thanks.

P7: Yeah, I was gonna say following on from that I think just fundamentally a lot of the time it causes trauma and then a lot more issues down the track. We had a particular client who was locked up and who is now living alone, but she's having a lot of behavioural manifestations of that trauma which is making it really difficult, which is distinct to her disability, but which occurred because of the abuse that she obviously experienced as a result of her disability. So I think that's kind of the most fundamental aspect I think I've seen, just the trauma that it brings about.

P3: And following on from that, that point that P7's bringing up, which is the trauma - people with autism or autistic people- because they're neurodiverse, medications that neurotypical people think will manage behaviour actually has a paradoxical reaction causing in itself either injury, harm, and or trauma. And I've seen clients who have level two and three autism being given ketamine to sedate when in fact it doesn't do that and it makes them extremely unwell. It's like night terrors, being trapped and completely conscious, but being unable to move, so that's what I've seen.

P1: Thanks, thanks P3. Can I just ask, of the people that you see who are under restrictive practices, how many of them understand what is going on, or understand that what's being used is a restrictive practice? And how many people have it explained to them and actually understand it? What's your sense about that? P2.

P2: Many of them would articulate it in terms of this is not restrictive practice, but I would say that they are aware of what is going on and they don't like it and they realise sometimes that it is wrong and that shouldn't happen so they might not be able to articulate that, they might have difficulties of communication, and they might not know the technical legislative framework, but I believe that they know at some level.

P1: And the reason why I ask that is because the next question is actually about people making complaints. It's what barriers do people with disability facing making complaints about the use of restrictive practices, but it just occurred to me, Of course, if you don't know that it's restrictive practice or it's wrong, why would you even think to make a complaint? So in thinking about that, do you think people who are under restrictive practices make complaints? Are they able to make complaints? Do they know that they could make a complaint? Do they know who to complain to?

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Are some people worse off than others in terms of making a complaint? So any response is really about the capacity or opportunity for them to make a complaint about a restrictive practice.

P2: I think many of them are so institutionalised they wouldn't know that they have a right to complain. They wouldn't know where to go to. I mean, some work has been done in that area to improve it, but there's a long way to go, and that's why advocates are so essential to the whole process.

P3: And I was going to say if a person has had an experience with an advocate, they're more inclined to understand their own rights and be empowered. And there's that word to Self-Advocate. And the purpose of having a disability advocate is to build capacity and someone to help them understand that they have rights. They are entitled to be treated as all citizens are treated - equally, equitably. I'm not saying that that actually happens on the ground and in real life, but yes, with an advocate by their side - If they've had that, they will have more capacity to understand their rights and self advocate.

P1: Have any of you seen somebody successfully make a complaint about a restrictive practice and have it dealt with properly? Anybody seen an example of that? ...No? That's pretty telling, isn't it?

P2: It's always brought, for example by the nurse in the hospital or it's brought by the family member who's really angry about it. But it's really by the person themselves saying, you know, please don't do this. This is wrong.

P1: Right, so other people might be making complaints on their behalf, but not very likely that it's the person themselves

P7: yeah, I was gonna say as well where people have experienced trauma and stuff like that, as a result of that particular restrictive practice. They can present quite difficultly inter- personally, and I think that can create a lot of issues. So even though they're making a complaint, if they get that far, the way that they are responded to is, almost that, they're part of the problem because of the way that they behave, or the way that they, I guess like, their anger, or the manifestation of the trauma, however, that might be, can kind of...you end up, I think with decisions by organisations which are based more on personality then the actual situation, in some instances. I don't know if that's making any sense. Yeah, I don't know how to describe that.

P1: Thanks P7.

P8: Can I just ask a quick question, I think you mentioned before that some work had been done to improve things in the area. I'm just wondering whether you would mind touching a bit more on what those improvements have looked like.

P2: I believe that, for example, letting people know about official visitors and putting posters in different places has been one way, but I specialise in advocating for people from multicultural backgrounds. And I tell you that they don't read that and the best kind of communication is someone that a person knows who is able to communicate in a way that that particular person can understand - might not even be verbally. There are different ways to communicate, so there has been some work, but we need to move away from just posters on the wall.

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P1: OK, thank you. Thanks P2. In thinking about people under restrictive practices - what happens to people who have a Guardian? People have a public Guardian? People who are under guardianship - Are they more or less likely to have restrictive practices? Does having a public Guardian either protect them in some way, or does it not do that at all, when it comes to restrictive practices - just interested if you have a view or seen any examples?

P3: My experience is that the Public Guardian is constrained in how much attention or participation they can have in the protected person's life and that that constraint can... it leads to restrictive practices being implemented and not oversights just because of those constraints - if they have a private Guardian, like a family member who is their Guardian, there's more likely to be a complaint... if the family member is upset by the restrictive practice.

P2: And I'll also add to that, that I think that the public guardian aspect is an added extra set of eyes that can only do good in looking at the situation and recognizing that there's some issues that need to be resolved. This is not the context of a restricted practice example, but I do remember one example where the public trustee contacted me and said 'P2 this client is dying, has advanced cognitive impairment, doesn't speak English, has reverted to Italian and there's whole end of life issues here that we need to help with.' And so I was able to help to make sure that she had a very peaceful and rights focused passing, so that's just an example where it's really helpful to have a government agency. It's an extra set of eyes, and the advocates need to do the extra legwork to make sure that the rights are realised and properly exercised and enjoyed.

P1: Yeah, P2 thinks that's a useful example about the kind of interaction between advocates, guardians, and a range of other people which all adds up to sort of safeguarding people's rights. So to reduce restrictive practices, what needs to change in the ACT specifically? Is there anything specifically in the ACT that needs to be improved in terms of laws and policies?

And if it's not because maybe it's a national level legislation. What happens in the ACT? So you can consider both, either in the ACT or, in regards to the NDIS or the quality and safeguards Commission? Or is there any legislative change or policy change that you think could help reduce the number of restrictive practices?

P2: Well, I think that there are pieces of legislation already in place in the ACT which are useful. But as we discussed need to be developed even further like the Human Rights Act and also there was a piece of legislation. The elder abuse. I can't remember the name of it, but the elder abuse and vulnerable persons focused legislation. Now there's been some outcry from the community that there wasn't enough consultation with the community in terms of developing that legislation, that it needs to be improved. But there are vehicles there, that can be used and developed and amended and expanded on that can really help in this space, I believe. We need some of those focuses that we discussed as a group in this forum are really important that we elaborate and they go back to training of people who work with people with disability. Making sure that people with disability, carers and families and advocates know what restrictive practices are and what they can do. What are the alternatives that are rights focused and that move away from these practices that are really outdated and can be quite abusive. Making sure that the training that we implement here in the ACT is relevant and is rights focused and doesn't just happen at one level, but happens regularly throughout the person's professional life, and making sure that the information is out

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there so that people know the role of the official visitor, the role of advocates, how they can be contacted and that more visits take place with the official visitor so they're aware of what's going on.

P1: Thanks P2, what I'm just thinking there is what leads me to think, what mechanism is going to be the most effective for the ACT for the advocacy sector and the other allies that sit around it in the ACT, to allow you all to get together and discuss these things and then put them forward to the Royal Commission as changes that need to happen, but then start pushing them in the ACT to, you know, have a have a kind of a medium and longer term sort of advocacy plan, I suppose about how to how to get these changes happening. Does it need a focused semi regular sort of round table? Some of this group plus some others ...And maybe the [ACT Disability Reference Group](#) - Anybody got a view on that? How would we progress this further? Yep, P2.

P2: I think a submission to the Royal Commission led by DANA encapsulating all of our views could be really good to formalize that. And I'm mindful that on Saturday there is an election in the ACT. So who knows what's going to happen? But after that and we realized what government is in power, perhaps a roundtable discussion. Not summit, but where we get the relevant, you know, MLAs at the table and we bring these issues, to their attention and also some meaningful solutions. And we ensure that people with disability sit at that table.

P1: Yep thanks. Thanks P2, 'cause I can see and this is, you know this is our first example of one of these workshops. There's some really good stuff that's coming out, but we have to bear in mind, 'How do we progress it?' And there will be common themes that come out across the country, but there will be specific things that in your case need to be done and pushed and lobbied for and campaigns, to do some systemic advocacy in the ACT and that has to be planned and agreed on by everybody. And then you know, take action on it.

We're coming towards the end of the time, so going back to restrictive practices. Anybody got any other things that they'd like to say about restrictive practices and in what way do restrictive practices lead to further violence, abuse, neglect? Anything else that you want to say about restrictive practices and what you've seen?

And one quick question then, is to what extent, of the restrictive practices that you see as you're doing your advocacy work, how many do you think are authorized restrictive practices and how many are unauthorized, or sort of invisible, almost the people don't even realize, the families might not know that they're even using or implementing a restrictive practice. Do you think, is that an issue in the ACT?

P2: Like the chemical restraint, they think it's normal, they are told by the managers it's normal and they're too scared to say anything in case there's retribution against their loved one. Yeah, I'm talking about the nursing home context. I'll give you another example. It was one of the hospitals, one of the nurses rang us up and said, do you know this person who has cognitive impairment is being belted to a chair so he doesn't wander because the nurses are too busy? They probably thought that's OK. 'Look, we don't have time. The ward's really busy, this person is wandering around and we can't constantly babysit them.' No, you can't and you know they had to be educated that this was not acceptable. You can't belt someone to a chair. Yeah. So they don't even know.

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P1: Yeah, yeah, they don't know. Thanks P2 - P3, did you have something?

P3: Once again, with mental health and autism and that intersection of those disabilities and restrictive practices in regards to the medications. People don't realize that they're restrictive practices - they're just ... it's "calming the behaviour", and so that's why they're used, I just think it's a matter of education. Also, there's a culture because it's been so longstanding to choose particular medications to sedate people, in a mental health crisis or similar, such that it's become normalised and no education round that there are other ways.

P7: Yeah, I think education is important. An important part of that. But I also think then that needs to be backed up with more resources available for nurses and carers because if you have more than one or two people on a ward in crisis and you do very quickly run out of staff who are able to attend to the other people on the ward. So while education, I think is really, really important, I think those resources actually need to be there to allow them to use the other options.

P1: Or additional supports being able to be called upon.

P7: Yeah,

P1: If a person who requires them is in hospital. Yeah thanks P7 and we're going to go to our sort of wind up there. Was there was a question that came through from somebody from the Royal Commission during the break. It's something you said earlier about the design, the architectural design, and the bad examples of architectural design that you've seen, and they'd be interested in knowing. Are there good examples in the ACT? Are there any good examples of architectural design that allows for better settings I suppose? Or a better life for people who do have to live in in congregate settings so we don't have to answer that now, but you can if there's an example you can think of if you want to share it with us, you can send us an email afterwards and we will share it on to the Royal Commission -if you either know already or come across an example. I might pass back to Sue in the Royal Commission engagement team to just make some closing remarks, and then we'll wind up in a moment.

P8: Thanks Mary, and thanks to all of you for your input this morning. It's been really very enlightening to hear your unique insights from the work that you do directly with people with disability, and we can't express how much we appreciated hearing first hand from you all as a Commission, and I'm sure I speak for our policy colleagues as well.

In particular, I'd like to express thanks to P1 and P5, who held this workshop. Together we have been, I guess, working with them to bring it to fruition, but definitely a lot of work has been done by them. So thank you very much and thank you all for spending the time to come together today. We know that you've got some really busy jobs, and particularly during this COVID-19 period, the impact on your workload and the sector in general has been enormous. So once again, we appreciate you taking the time out to share your experiences and insights with us.

I think that's probably all I really need to say. Unless our policy colleagues have got anything to add to that. But we look forward to hearing from other jurisdictions across the country, you might be aware that this is the first of many that we've got planned or that P1 and P5 have got planned. So we look forward to hearing the insights of your colleagues across each of the states and territories.

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And at the end of that drawing the themes and the threads from all of those workshops. Thank you again.

P2: I'd like to say, thank you on our behalf because our clients are so vulnerable they can't tell you the things that we're telling you and we really appreciate the time that you've taken to invest in this process and get those viewpoints. So thank you.

P1: Thanks P2, And the thing that became really clear to me through this discussion, and that I just hadn't been thinking before hand, is that it's all very well having the discussions, but then what do we do about it? So how do we pick up on all those useful ideas that you all have about what it is that needs to be done? What changes need to happen? And yes, we need to tell the Royal Commission, but that's a channel isn't it, and that's what we're here today for, but the Royal Commission, you know that there. That's a process and it will take a bit of time. It will, you know, get into the final report of the Royal Commission at the ACT level. Collectively, you could start already, you know, understanding when the various pieces of legislation that might need some changes are due for review anyway - What's the process that would be involved in getting some changes in and then starting to build a bit of systemic action to get those changes happening? So I think I haven't thought before and I'm now going to. We will build it into the rest of these workshops to get each state and territory group of advocates to start thinking about that systemic advocacy that's going to be required to make improvements, not just at national level, but in each state and territory as well. So thank you very much everybody for joining in today. It's been really useful, and I'm sure we will have more of these, so thanks very much and we hope to talk to you all again soon. Thank you.

Comments typed in Zoom chat function

P6: hi everyone, I have no video or mic. But I'm P6 from [ACT advocacy organisation]. I am representing the DRC team who were unable to come today

A major factor is people living with others that they have not chosen to live with, and where there may be a lack of support or an imbalance of support between residents

P5: In terms of educating about rights and what is abuse/neglect/restrictive practices I've been quite impressed by VALID's Staying Safe videos and QAI's videos too feature some great dramatizations by performers with disability, plus more: <https://www.dana.org.au/disability-royal-commission/violence-resources/> (Let me know of any other resources I should add to this page)

P6: I think as well, as we push for people to live in their own houses with support that people with more high and complex needs are not segregated away from the community - Anne Marie Smith style.

P7: The other thing I would quickly add around legal changes is to strengthen the availability of the NDIS to people in custodial settings - as this would hopefully set them up with supports on release and thus render them less vulnerable to neglect and abuse whilst also improving their social health determinants

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P6: I think also to make people aware and strengthen the role of the Official Visitors Scheme, we have had a number of referrals through them for advocacy support.

We have also had issues with people being able to provide consent for an advocate to be involved when they are non-verbal