

DANA and DRC Workshops with SA Advocates - 8 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 organized for live captioning of this discussion by The Captioning Studio. Care has been taken but errors may exist in the transcription.

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

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

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Transcript of Zoom Workshop – 8 December 2020

Siobhan: Welcome, everyone. We'll just wait for everyone to come on to get started.

Mary: Hi, everyone. We'll just give people a couple of minutes to come on. We know all the people who have registered to attend, so we'll just watch as people Join in. So everyone can just wait for a minute while everybody else comes on. P4, we can see you today. The last one you were just Joined by phone. It's good that we can see you in person today.

P3: Mary, can you hear me okay?

Mary: I can. That's fine, yes. We'll just wait for another minute while a couple of other people Join in.

P4: Can you hear me okay too, Mary?

Mary: Yes, I can, P4. Thank you. Siobhan, have you tested yours on Zoom to see if you --

Siobhan: Can you hear me.

Mary: Yes, fine, it's working. Good, excellent. We might get started. There may be a few more people who might Join in as we go along, but we've got lots to talk about, so I think we'll get going.

My name is Mary Mallett, I'm the CEO of DANA, and I'll start with an acknowledgment of country. I'd like to acknowledge the traditional custodians of the various lands we're meeting on today. I wish to acknowledge and respect their continuing culture and the contribution they make to the life of our communities. I'd like to acknowledge and welcome any Aboriginal and Torres Strait Islander people who may be attending today's event.

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

Mary: That's great. Thanks, P4. I think that's all the advocates that we've got on. We have five of the six South Australian advocacy organisations joined us today. We don't have anybody at the moment on from [SA Advocacy organisation], but we have the other five organisations, and thank you very much, everyone, for joining us today.

So we're going to talk about two topics and the first one is restrictive practices and I'm going to start by just asking you all do you all deal with or see people who are under restrictive practices in your everyday advocacy work? I can see nods, some nods. Just wave your hand or give me a nod if it's kind of a normal part of your work. Certainly some people are nodding.

And I'd be interested to know, for those of you who are not nodding, is it because it's not common in the advocacy that you do or for some other reason which might be just your role in the organisation? I'm going to ask P5 and P6 and - oh, P7, you're in the same room now, P5, P6 and P7. P8 - you're all the same organisation as P8. P8 was nodding vigorously and the three of you were looking very deadpan, so I'm interested in why that is.

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P5: I used to advocate for someone who was under quite a lot of restrictive practices, but less so in current times, but it varies among us.

P6: I was nodding.

P7: I'm collecting stories from everyone, so I guess I do have an experience of everyone else's people I suppose.

Mary: Yes.

P8: I might just add to that. We've got a number of advocates who advocate across a number of different people and I guess I'm nodding vigorously because I know about all of them.

Mary: Yes, right, okay. So we've got some of the questions - I'll almost apologise in advance, because some of these are the bleeding obvious, okay? And the first one is what are the effects of restrictive practices on people with disability? So feel free to dive in. You can have... anybody can have the first go and others just join in in response to any of the questions, just join in as things occur to you.

P8: I'm always happy to leap in. I've written down a couple of things in particular, but it limits access to other people and so many people that we're aware of are restricted to institutions, including institutions of one, so the only people they get to see are paid support persons who may well be the people who might be abusing, exploiting or neglecting them. And the other issue that I've written down here is the use of medications, which restrict capacity and ability for people to ask for or seek help, just as two things.

Mary: Yes, yes, thanks. Thanks, P8. And how do those restrictive practices... P8 has touched on one aspect, but how do restrictive practices lead to further violence, abuse and neglect?

P6: Because they're often implemented not as a last resort measure, they're normally the first response by services, and they use positive... Sorry, they're often used to justify behaviours and not used in the way it's intended is what I've seen.

Mary: Yes, thanks. That's P6. So do you see... somebody else had their hand up a minute ago, I think P9. Did you have your hand up and you were going to speak or were you just adjusting something?

P9: A bit of adjustment as well. I think I do have... seen situations where institutional, which is not a very appropriate word, but practices in restrictive practices where new staff come in to organisations, see various ways of working, working with people and in fact it's learned practices and 'this is an acceptable way of working, responding to people' and almost the accepted norm and that becomes very difficult to challenge and to relearn more positive strategies for people with disability. So yeah, I think that's an aspect of restrictive practice we need to be aware of.

Mary: P10?

P10: Yes, I was just going to... further on from what P9 was saying, I know I've seen historically PR [physical restraint] and medications being used as a form of restrictive practice. It's kind of developed this dependence on PR and medications to manage behaviours instead of like a last

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resort, you know like we were saying before it just becoming normalised, which isn't great for the individual.

Mary: No. I'll just follow up that... to pursue a bit further the issue that both you and P9 have just mentioned about that it becomes the accepted norm. So P9, you described it as a learned practice and that means by the staff of a group home or whatever, of an organisation that this just becomes the way that they deal with this person. So has there been... have any of you seen any difference since the NDIS, the advent of the NDIS, and supposedly people are having behaviour support plans written and there's lots more reporting that they have to do to the Quality and Safeguards Commission? Has that made any difference? In theory it should, but is it making any difference on the ground.

P8: Mary, just from I guess our observation, I think there's a couple of things I want to say about that and one is that people are ascribed a very negative reputation through all of these kinds of things, including positive behaviour support plans, and I think that P6 talked before about these things being used as a first resort rather than a last resort and when they're used as a first resort, then what they don't do and what we observe is they don't have actually good support plans, like ordinary support plans, how is it that you support a person around something that might be a behaviour of concern is sometimes just what it is... is protest behaviour, it's protest behaviour about that you're living a shit life, you're not treated well, that you are excluded from the rest of the community, et cetera, et cetera, et cetera, and a lot of these - from again our observation with positive behaviour support plans that these are instituted very often in congregated settings and they're not implemented generally in the way that they ought be, but again it's around we would see that people are protesting at what their living conditions and arrangements are and that the support in those kinds of places, SILs [Supported Independent Living], supported accommodation services group homes are driven by rosters, not by the individual needs of people. So we can't expect people to behave in ordinary ways when we put them into settings that are not ordinary.

Mary: Thanks, P8. P10, I'll come to you in a second and then I think P6 as well, but P11, were you wanting to say something a minute ago or somebody was at... I think we didn't pick you up in time.

P12: A couple of things, we might be going back, so sorry.

Mary: That's fine. It's a circular discussion. It doesn't matter.

P13: One of the things that I've seen is the use of psychotic medication and used inappropriately and I have examples of this with people that we support and these psychotic medications were given at a younger age and have never been reviewed and when you ask for a review, it's like, "Well, why would you do that, this is what's been needed and required."

I have one case in particular where we did ask for a review ... where we did ask for a review and it took numerous meetings with multi panel of people to actually have that person's rights adhered to, to actually ask for a review and when we did get a review by a psychiatrist, the psychiatrist couldn't believe that the person was actually on the medication, it was inappropriate. It wasn't even related to what the person needed. It was just a form of restraint. So I think that's one of the things.

The other things - now we've got our fire alarm. Sorry. We're having lots of background noises. The other thing that I think needs to be addressed is if you are in a group home situation, if one person has restrictive practices, that could actually impact on the rest of the people in the home and they are actually not required - they're not actually needing the restrictive practice, but because of the

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person, the individual needs, it actually impacts on the whole group and that can have negative connotations I guess for other people and their access to other things. Does that make sense?

Mary: Yes, yes, it does, thanks. Is it P13?

P13: Yes, it is P13.

Mary: Thanks, P13. Yes, it does and we should probably pay a bit more attention to that, shouldn't we, the consequences of the impact on other people as well as the individual themselves? Now, a couple of people had their hands up a minute ago and I leapt past them. P10 and her cat. Then I think P6.

P10: Sorry, I was just trying to remember what I was going to say. I think it was something along the lines of there being such a significant demand as well for disability support services that then in turn leads to quite a high number of either turnover of support workers or people being employed at such a fast rate that then they perhaps, for a whole range of compounding factors, aren't given maybe the appropriate kind of training or don't have that kind of understanding that reactive behaviours aren't always I guess person centred. So you might have staff who haven't been working with that individual for very long a time who then see quite high-risk behaviours occurring and then immediately leap to restrictive practices instead of.... like as a reaction instead of like making informed decisions about how to manage that.

Mary: Yes. Thanks, P10. And P6, was it, I think --

P6: Yes, so since the introduction of the NDIS and the Quality & Safeguards (Commission), on a couple of occasions services don't actually understand what a 'behaviour of concern' is and they're seeking positive behaviour support plans to try to get, I guess, better training on how to do a particular issue and in order to get that, they're using language that's quite harmful to a person's reputation. They're bringing out past behaviours and they are also describing things in a way that makes it sound like a behaviour of concern but when you put it in context it isn't.

So a couple of examples of that is someone I advocate for potentially has a tic and this person has done this particular involuntary movement for a long time and they're describing this tic as a behaviour of concern because it's becoming more apparent. And when I tried to challenge that it wasn't actually a behaviour of concern, it was just something the person did to communicate or was an involuntary movement, the NDIS still provided a positive behaviour support plan and lots of the issues they raised in the interim support were the person was communicating when they had no other way of doing so.

And so another example was the person was trying to get out of a car at stopped traffic lights but this person didn't understand that the vehicle had stopped, because of their disability, they didn't understand they hadn't arrived at their destination but were stopped at a traffic light.

Those were the sorts of things when you put it in context, it's not a behaviour of concern, but that's what they got the positive behaviour support plan for. So while there's extra measures in place, the services are still inappropriately describing and referring people for those plans when actually what they want is perhaps more training to deal with particular issues.

Mary: Yes. Thanks, P6. That was a really good description of what... I'll just mention-, so we've been discussing the same topics across the different states and territories, of course the experiences

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that advocates-, you know, what they are seeing on the ground is very similar across all the states and territories and we will pull together what is coming out of each of these and provide the information back to you, but we need to do a bit of analysis and theming of it before we send it back. But there's nothing that makes it seem as if the situation is either significantly worse or significantly better in any state or territory. It's pretty bad- everywhere. P5, did you want to...? --

P5: I wanted to also raise the issue where for people in group home situations or more institutional settings there seems there may be more pressure on services to seek guardianship orders for people that may not have had one in place so that they can be within the guidelines of having restrictive practices in place and how that sort of is affecting people's experience of guardianship overall and also maybe takes some of the pressure off services to actively work with people around skill development in some areas where instead the restrictive practice is put in place, so like locked houses, for example, where a person might be able to be supported to learn how to be a bit street smart but instead a restrictive practice is put in place through guardianship.

Mary: Mmm. Yes, thanks, P5, and there's lots of strands of this that need - each need pursuing in their own right. That particular one is one of them.

We're wondering whether - in the first place, I'm interested as to your view about - most of the people that you see who have restrictive practices in place, has it been explained to them? Would they know the term "restrictive practice"? Do they understand what it's about? Do they know why these particular restrictions apply to them? Just generally, has anybody got a comment on that?

P8: Mary, I think that P5, P6 and P7 probably agree that no, I don't think that people do understand that it is restrictive practice, what a restrictive practice is or even really understand that word. If it's difficult for service providers and other people to actually figure out what is and is not a restrictive practice, I don't know how we expect people to understand that because what is being put in place is actually not a restrictive - is being used as a restrictive practice but doesn't actually meet the criteria either. So I think it's complex.

Mary: And the reason why I asked that question really was a lead up to... we've got a question that we want to ask about whether people can make complaints, do they make complaints about the use of restrictive practices, but I'm inclined to think that of course they may not make complaints if they don't understand that this is a restrictive practice or that it's inappropriate or what to make a complaint about it. So do you see – P10, you wanted to make a comment about that?

P10: Just commenting quickly in terms of making complaints about the use of restrictive practice on an individual, I know from my own history working in supported accommodation there would be plenty of times that the individual doesn't understand that restrictive practice is being used, but also wouldn't have the capacity to complain about it either and it just kind of becomes, yeah, normalised, like we were saying before, so they don't necessarily agree with what's going on but they wouldn't have the capacity to kind of formally disagree with it either, without using maybe physical aggression or something like that.

Mary: Yes, yes, it probably means – P5, I'll go to you next - that the same people, the very people who are most likely to have restrictive practices in place, are also the people least likely to be able to make a complaint about anything?

P5: I think in the situations where people are very active in complaining and speaking out against restrictive practices, even though they may be able to go through the motions, so to speak, of being

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granted review hearings for SACAT [South Australian Civil and Administrative Tribunal] and that sort of thing, I think it's really difficult for people who in that setting have had a proven mental incapacity and especially if there's a psychiatric element to that - they may be able to go through that process of complaining, but I think it's very difficult to actually be heard in that setting. So for someone I'm thinking of specifically that experience just meant that the restrictive practice was viewed as the support trying to hurt them and so that created more problematic situations and that person was very persistent in trying to overturn those orders and trying to be heard, but the systems themselves weren't on board with that.

Mary: Yes. Thanks, P5. Do you think that - if we just think about access to advocacy for people who have restrictive practices in place, and it's a bit hard to tell because of course you know the people you do provide advocacy for and you don't necessarily know always about the other people, but do you think that - is it common or usual for people who have restrictive practices in place to be able to - are they able to get an advocate easily, readily? What is the access like to advocacy for people who are under restrictive practices?

P8: Mary, I think again from our perspective that those people who are most likely to be under restrictive practices - they don't get access to advocacy. I mean, we are advocating for people who are under restrictive practices. That's come to us because it's a complex matter, but we have limited capacity to take those things up, as I know that all advocacy organisations do. But if there hadn't been a person in that person's life who was an ally and able to stand up and say, "This is wrong" and then they've contacted advocacy, I think there's only probably one person and the other people might be able to - other advocates might be able to say something about that, but I can only off the top of my head think of one person we advocate for that's subject to restrictive practices that referred themselves and I think any other person we advocate for has come via some other method and typically that would be not a service provider, it would be a family member often.

Mary: Yes. Thanks, P8. P13?

P13: I think from our perspective I agree with P8 that predominantly family or support workers, other than with psychosocial, mental health, we get referrals directly from people, and particularly around treatment orders. So I've supported a lot of people with the treatment orders. And a lot of it is actually attending SACAT hearings and then helping them to understand the restrictive practice so they then understand why it's been in place and trying to link them in to suitable services often outside of community mental health so that they can get their own individualised access to people that they can build a trusting relationship with outside of community health sometimes, community mental health, so that they don't - it feels less forced and that they have more choice. That's what I find I do a lot of work around. I don't know how the other advocacy agencies work, but that's what I tend to do. So they have a voice, their own voice as well.

Mary: Yes. P13, just to clarify, when you're talking about community mental health there, you're talking about the government system, the government provided system?

P13: Yes.

Mary: Okay.

P8: Mary, just in regard to whether people complain about restrictive practices, I think for the people that we advocate for, they complain all the time about things not right in their life, formal complaints about things less readily, but people I think are very good at identifying what's not okay

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in their life. And again I think, as a number of people have said, it's actually about listening to people and listening to people means listening to behaviour. It means listening to utterances, it means listening to in all sorts of ways and we're not good at that.

Mary: When you say, "We're not good at that", you mean the system, the service?

P8: Yes, I think services are not good - I think that lots and lots of people, the majority of people that are in the life of a person who's marginalised don't listen.

Mary: Yes. So what can - now you've told us about all the problems, what are the things that are going to help to minimise or reduce the number of restrictive practices that people are under or the number of people that are under restrictive practices? What is it that can - what are the things that are going to help avoid or reduce them? P13?

P13: I think, like what was mentioned before, definitely training more in looking at people holistically so that you're looking at people particularly like in the Education Department around sensory issues and addressing - rather than reacting to behaviour, it's being proactive, like upskilling teachers. They haven't got enough training and particularly understanding ASD [Autism Spectrum Disorders] I would say in particular, what we've come across, it's up-skilling people and not just to tick it off to say well, they've got some training in this, but really putting in an effort to work on okay, the behaviour is the end result, so what's the need and coming at it from that perspective and working on that and trying to fulfil that part of it rather than just reacting and then right, you need a restrictive practice. So identify the needs, work as a team and address that and there will be a reduction in behaviour, but that's upskilling as far as I'm concerned.

Mary: Yes. Thanks, P13. I'll just make a side comment here. Obviously these suggestions and things that we're talking about - the reason we want the Royal Commission to be listening in and hearing this is because besides the fact that the Royal Commission is doing a whole series of hearings on specific issues where they want to gather evidence and there's responses to issues papers and the Royal Commission is through all of its different channels gathering material and evidence and submissions, but what will come out of that at the end by the time the Royal Commission is doing its final report will be serious recommendations about the things that have to change in the systems and we want to channel what's in your heads really into the Royal Commission because advocates have an almost unique perspective really because you see inside the systems and you see the problems that the people you're working with experience in the various systems and we need to get that out of your heads and into the Royal Commission to help build those recommendations that they will make which we would then hope that governments will act on.

So has anybody else got suggestions then in any other way? So P13 was talking about the education system there, but in education or health or justice or disability support system - P7 and P5?

P7: So I think training and education of supports and people who are around people with disability is important, but I feel like if the focus is too much on education and guidelines and rules, regulations, it all becomes a bit of a tick a box exercise. It needs to be a cultural change because again most of the people you know, as someone was saying earlier, I can't remember who, but essentially people will Join an organisation, they'll get taught this is the way we do things and then do it that way regardless (inaudible). If you focus too much on the training, we focus too much on these other guidelines you have to adhere to, we'll miss the true goal which is actually supporting people as best we can. I don't want to use the term 'common sense', but yes.

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Mary: Yes, thanks, P7. P8, you've got your hand up.

P8: This sort of cuts across... I know we've got conversation about segregated settings coming up as well, but I guess the thing that bothers me the most about this is it's the support that's in place for people and they are very roster driven and I think what we've got... the NDIS came along. What we hoped to see was the going away of block funding, but I think that what we've got effectively is the continuation of block funding. And so we see this happening in group homes... all sorts of congregated settings where what's being delivered to people is being delivered to a group of people rather than being delivered to individual people. So what people are receiving is a service that's aimed at people with disability, not a service that's aimed at Jenny or John or Tom or Bill.

So there can be... we want this to happen for people, that is the whole idea why we've got an NDIS because we want to see that people are able to live better lives and you can't live a better life if your life is contingent upon something that might happen in the congregated setting that you live in. So for instance you've got somebody who really loves to swim and on a schedule of support during that week that person is scheduled to go swimming on Thursdays at 2 o'clock. So Jenny is really excited about going swimming at 2 o'clock on Thursday and then Bill for some reason has a really bad day and so support says "We can't go out of the house now", so Jenny misses out on going swimming. Jenny misses out on going swimming and she then has a reaction to the fact she can't go swimming because she loves it, it's something very calming for her, it means she's out doing things, and she is now restricted and forced to stay in her house.

And this happens over and over again. We see it happening that people have got schedules of activities that they never get to because the model of support denies them the opportunity to do that. So what then happens is that Jenny starts to get a reputation as somebody who's very difficult to work with or in fact a reputation that Jenny doesn't actually like going swimming because she has a conniption on Thursdays when swimming is supposed to happen and the kinds of things that happen for people is that Jenny is now anticipating that she's not going to get to go swimming, so she starts to have a bit of a conniption before swimming whether it's going to happen or not because that's a pattern that she gets to experience and that gets reinforced week after week after week. Then we end up with a positive behaviour support plan which ends up on a shelf and Jenny still doesn't go swimming on Thursdays.

So we need to get rid of this kind of service delivery which is about rosters. Rosters are the things that keep people tied to their homes, it denies them opportunity to be out doing very ordinary things and the NDIS, we know as advocates, I think that you would all know, that the kinds of supports that come, and talking particularly about supported independent living, what a misnomer that is, that people are in these SIL arrangements and those SIL arrangements only and I've just been talking to somebody yesterday who's in a SIL arrangement and their SIL support only provides for in-home support going to a doctor's appointment and going shopping, that's it, and there is no other support available to them to be able to go out and just do the ordinary things I do. I go out and have drinks with my mates on a Friday night. All of those kinds of things are not available to people. If people were able to live better lives, we wouldn't be having these kinds of things happening, we wouldn't be having to tell these stories to the Royal Commission, we wouldn't have to be constantly advocating for the same thing day after day, week after week, month after month, decade after bloody decade. Off my soap box, thanks.

Mary: Thanks, P8. I'm going to go to P6 first and then P13. But P8, I just want to follow up push that a little bit further because what I want to know is do you think... you say it's based on the

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roster. Is that about convenience or is it about cost? Would it actually cost significantly more for people to have that more flexibility about being able to go to the things that are important to them?

P8: I'm sure in some situations it would be about money, but I think actually what it's about, a lot of it, is about mindsets and that even people who live in SIL type arrangements and they've got money in their plans for community and civic access to the community, et cetera, that doesn't get used in that way because again what often happens is that SIL arrangements - so when they've put their quote in, they've quoted for social and community participation and so there's some additional money in there, but their mindsets are that we do that and so unless it sits with a different provider, then very commonly it doesn't happen because that money gets used up in some other way.

Now, I don't know the accountability around those things and it's very hard to really get a handle on some of this stuff, but it is our understanding that quotes go in, money is allocated and then services just get that money every month. There's no accounting for it in any particular way. So even if there's money in there for social and community participation, that is no guarantee at all that the person will get access to a support worker to take them out because they only get workers from the roster or very occasionally another young woman who has got this additional money on a Thursday and her SIL provider fills that up with appointments and she says "I just want to go and hang out at the shopping centre", she likes to go window shopping because she doesn't have a lot of money, but they put in other things so that now what was really the responsibility of that in-home support has now been transferred over to social and community participation which is about going to appointments.

So that woman has contacted us on a number of occasions about these kinds of things and so the service provider says, "Oh, yes, well, we couldn't make that appointment on a different day because that was the only time that the doctor was available." Well, then make the social and community support on a different day that suits her. If you can't possibly go to the doctor on a different day and this is a usual appointment, then you need to negotiate that stuff, but they don't. So I think that there's a mix of people perhaps not having enough funding to do that but also that funding is not being used in the way that it should.

Mary: Yes, thanks, P8. We've sort of segued naturally anyway into the discussion about the segregated settings, so we'll continue that. I know a couple of you, P6 and P13, had your hands up and then P4 and P14, we'll come to you so you can tell us a bit about [your organisation]'s experience as well in this area. But P6, I think you had your hand up a minute ago.

P6: I just wanted to add to what P8 was saying in that while the NDIS's intention is meant to be individual based and really look at these things, the administration doesn't work that way and to me it's really evident in a way that the NDIS or NDIA is very happy to fund group setting bowling, but if someone wanted to go out with their friends bowling that's an out-of-pocket experience and to me that really shows that they're continuing to fund the same thing and this is where the cost is coming in.

I've had a couple of instances where I'm trying to separate out the SIL and get two different providers in to provide different support and it has been two years to negotiate that and has had to involve higher up people in the NDIS because the people at the bottom who do plans don't understand. In my instances, the support has been cheaper. SIL is an over-delivery of services that someone doesn't need and then what will often happen is you need more money to actually get support you want and need. Whereas if they just really have a look at what the person wants to do

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and then do the SIL afterwards you're probably actually going to find it's going to be about the same if not cheaper. It's just this wanting to ensure that they have this income coming in.

I think it's very service based, even the process of producing a SIL is very service based. They get to put in what they want, the NDIS don't question and when you challenge in an internal review, they kind of go, well, you negotiate with the service provider and there's no power there to do that, especially for someone who has an intellectual disability who is continuing to live in the home of the support they provide. They're going to hear negative feedback about them challenging wanting to use a different service.

It's just not conducive of individuals. There just needs to be certain things in place that are done differently in the administration to allow for some things to happen. I said that example of the bowling, why will they come bowling as a day option but not if you want to go Join a local bowling club. To me that really shows the true colours of the administration of the NDIS.

Mary: Yes. Thanks, P6. P13, I'll come to you next and then I'll go to P4 and P14 and remembering of course we're talking about segregated settings here, but in the context of the Royal Commission. So what is it about...- what are the features of the segregated settings, including the group homes that we're talking about at the minute, that foster the violence, abuse and neglect and exploitation that people are experiencing. P13, did you want to --

P13: I agree with everything P8 and her team were saying there. You were asking before about change. This is just a thought, I don't know where this fits in but it came to me. But we're so focused in on the disability. Have we ever looked at or outlined what an ordinary life is? Have we had enough conversation around that because that should be our goal and I'm wondering whether that needs to be addressed a bit because we've focused so much on what... particularly with the NDIS and particularly in segregated systems in restriction, it's all about what people are not able to do because of a disability and I'm wondering whether there's not been enough looks at what is an ordinary life. We talk about it, we live it, but has it actually really been discussed, is there conversation around that, enough conversation? That was just a thought. I don't know what other people were thinking.

Mary: Yes, thanks, P13. It's useful to think in the terms of the context of segregated settings - in an ordinary life people don't leave work and inhabit settings where they are cut off from other people. So it isn't very ordinary. P4 and P14, did you want to come in?

P4: Yes, I guess absolutely agree with P8 and the others. One of the issues in terms of the Disability Royal Commission is that access to people who are experiencing restrictive practices. However, we have another area that I don't think has been raised is we've had reports come to us from really concerned service providers about individuals living in family settings where restrictive practices are in place and they don't want to jeopardise their relationship with the family by intervening too strongly but are really concerned because the person clearly would benefit from more say in what's happening in their lives, and I think that's an area that we certainly have come across and would like to do some more work in.

And I'm just wondering in terms of how do we address that, I guess regulations are always really tricky but it's about having that independent observation of the person's situation to ensure that their rights are being upheld, yeah. But yeah, we've had difficulty accessing people in supported accommodation settings to tell their stories because the service providers do act as the gatekeepers and I think they would have concerns about issues that might be reported by residents.

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Mary: Yes. Thanks, P4. We might follow that up separately because that's all about how the Royal Commission is going to hear submissions, you know, get submissions from people if service providers are gatekeeping advocates out.

As you were speaking then, P4, I must say, because it's South Australian advocates that we're talking to today, Ann Marie Smith is in my mind and, you know, she lived by herself independently in her own house, didn't she? She wasn't living in a segregated setting, but she was in that situation of having only one worker looking after her.

Now, there's already been multiple reviews and investigations and reports and we hope that situation doesn't arise for anybody else and the Quality and Safeguards Commission is doing work and has changed some of the rules and the compliance stuff for the providers, so it's being addressed. But I just thought, given that you are the South Australian advocacy sector, that situation that she was in which was exploitation and neglect absolutely, what else do you see on the ground that can prevent her situation happening to other people and is there a specific role for advocates in dealing with that, and I suppose I'm not talking about - I'm talking about people who either are living with family or independently, because it's harder, it's hard, isn't it, to in some ways - service providers can be gatekeepers but also they have to be registered and they have to comply, so there are some levers there and that's harder with families. Does anybody want to make a comment?

P4: I know this has been raised before in the context of Ann Marie Smith, but the community visiting scheme.... if there was some scope for people living in private settings to have access to that and again, you're always going to need someone to alert those services or something and that's always going to be tricky, but if there was some regular service that could go and just do a check on people living in those types of situations, it might be able to assist those people to access supports that they need to ensure that they're not living with restrictive practices.

Mary: Yes. Thank you.

P8: Mary, I think it is a really complex thing and I think that people sort of and I'm not wanting to trivialise in any way at all. People have really lost their minds in regards to 'oh, we can't have people living in their own homes'. The failing in this, as I understand it and I don't have all of that information because of course there's lots of information to be had, but it appears on the surface at least to be that because there was only one single person going into that house as a service provider for somebody who needed supports, that it feels like that's the major failing here, that as advocates with people that we know that live on their own, advocacy is a part of that kind of check in and making sure that people are okay. Again, we have luxury in that we advocate for people over the long term, and we get to know them very well, but we also... a lot of our work is to try to help people to be embedded in their local community because when you are missed, then people are more likely to ask questions.

So it seems like there's a couple of things that we need to be thinking about. One is that... and again there's this choice thing that gets lauded all the time, but perhaps there needs to be something in place... I mean, in Ann Marie Smith's situation, that service provider, not that support worker, but that service provider, needed to be making sure that the support that was provided to Ann Marie Smith was being done appropriately and it appears that that didn't happen. So it was a major failing there because there is just this one single person in a similar way to somebody who's living in a family home, things can be happening to them that nobody else knows about.

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So we would always encourage that people are a part of their local community - you know, they shop in the same place, they become known to people. And we see lots of people, we certainly do, who do live in their local community, they have gone to their local schools, they go shopping whether that's on their own, whether that's with a support person, they are a part of their community. They haven't been bussed out of their community as kids to go to special school, they haven't been... or some have certainly on that parallel universe where special school, special housing, special work.

These are the kind of tracks that people get on and so ordinary community members just assume that the person is okay or they just assume that they don't need to be involved, whereas somebody who's living in their local community, and we do see this all the time "Where's Jack? We haven't seen him for a while, is he okay?"

I don't know... again, not knowing Ann Marie Smith's situation, but these are the things that keep people safer by being known and not just known to people who are paid to be in your life but known in ordinary ways. So that's kind of the pathway that we would want to see and as P13 said, you know, what is a good life or what is an ordinary life? That's the kind of thing that we want for people, not where the only people in your life are people who are paid to be there, and that's not a criticism of individual workers, it is a criticism of the system, however.

Mary: Mmm. Yes, thanks, P8. It's a slightly side issue, but it is relevant and there's been at least some little bit of discussion or sort of wondering about whether or not it's not how advocacy works now, but is there... can you imagine a system or a something where there are people particularly some people who are more likely to be more at risk who might be consciously and deliberately connected with an advocacy organisation that might have a role an outreach role which is less likely at the minute because you kind of mostly you're waiting for you get referrals in, but I can see that there could be some kind of outreach advocacy as well that might have to be funded as a separate program, and it's not really for today to sort of go through it but I'm just planting the seed really. P4, did you want to comment?

P4: Yes. I think as part of our promotion of the DRC we've actually managed to meet with service providers and that's actually been a really, really good connection in various regions and locations in terms of I guess getting them to understand about the Royal Commission. But as a side issue they know that advocacy is available and whether it be for SACAT matters or other matters they are learning about the fact that they can refer clients to our services across the board. So that outreach is really important, that letting those providers know about our advocacy services has been really valuable.

Mary: Yes, that's really useful. Thanks, P4.

P8: Mary, just to say that there actually is an outreach advocacy that happens and that's citizen advocacy and citizen advocacy don't receive referrals, they go looking for people and that's fantastic.

Mary: Yes, right. Yes. Unfortunately there aren't very many citizen... there's one program in South Australia, but there isn't one everywhere and, yes, I agree, I'd love to see more.

P8: And they don't all operate in the same way but that kind of purist, if I can use that word, model certainly does it in that way.

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Mary: I can see, P15, you have to go to something, but thanks for joining in today. Thank you.

So let's think about restrictive practices in other... sorry, segregated settings, I'll stick to my topic, do you... to what extent do any of you or your advocates work with people in the justice system so that absolutely the most segregated settings that you can have really, are people who are in prison and who are quite cut off for long periods of time from the rest of the community. Do any of your organisations do much work in and around the justice system?

P8: It looks like P12 is trying to get in there. Just for independent advocacy, it's referrals that come to us. It's... we're not out there in the justice system, but we've certainly done work with people who have been incarcerated.

Mary: P12, were you wanting to speak.

P12: I was going to say my background is I was a criminal lawyer for a lot of years and so we've been really mindful of the limited access that people in custodial settings are going to have to the Royal Commission. So we've been negotiating with the Department for Correctional Services in South Australia and they've said they'll allow us access to prisoners and we're just about to embark upon that and in fact now have a number of referrals from prisoners wanting us to go in and talk with them and the recent COVID outbreak has prevented that from happening in the short term. But we will be getting into the prisons and talking with prisoners hopefully early in the new year and I think that will raise awareness not just about the Royal Commission but about the availability of advocacy services for people in those settings as well.

Mary: That's really good, P12. That sounds great and, yes, we'd be keen to stay in the loop and see how that goes as you're doing that work.

So the other segregated settings... we've talked a bit about group homes, the justice system, education we touched on a bit and I'm not familiar... actually in South Australia, to what extent children with disability are in special schools as opposed to mainstream schools, I'm not on top of it and I don't know whether many of you do education or schools-based advocacy to any large extent. It's kind of a gap everywhere. P13?

P13: We do a lot of work with the education system. What we find, I'm sure other advocates find, again it seems to be primarily around the ASD diagnosis and also trauma. Children often with behaviours that are considered challenging can find themselves excluded from schools quite often or under RAAP [Resource Allocation and Adjustment Panel] funding where they have a one-on-one teacher and not actually... maybe even off site, so there's that sort of segregation that you might want to consider as well, or not being able to access what the other kids are accessing. Again it goes around those behaviours, 'challenging behaviours'.- --

P12: Even having restricted hours they're allowed to attend school and some of them being segregated from class and placed out in the corridor or in the gym or in the library, but not being allowed to participate in the classroom activities, and often we're finding with the DRC submissions we're doing it's when there's been an end behaviour that's been the outcome of a whole lot of bullying or things leading up to it and the school doesn't look at what led to the final incident, they just respond to the incident and the child with disability that's exhibited some behaviour, that's what's come to the notice of the principal or the teacher and they just don't - they might have

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anti-bullying policies or whatever, but they don't look beyond the final behaviour, they don't look to what's happening and trying to address that to prevent these things happening in the first place.

P13: On the side of that the perpetual placement in different schools and trauma children experience from that, again it's the department not taking responsibility for and what I'm finding in the secondary schools now is a coercion to get children into the FLO [Flexible Learning Options] program and often they're trying to be placed outside of the school into a community program where they don't have the proper training to manage these people. It's looked at... a reactive... they look at the behaviour as naughty children or naughty teenagers and they're not actually looking at their education needs, they're not being addressed, they're not providing individualised program, they're not looking at again what their needs are, the underlying needs and what they're seeing is the behaviour, but they're not addressing... it could be a sensory need, it could be all sorts of things that are coming into play. So there's lots of different segregation that's happening within the education system and particularly around ASD and trauma we're noticing.

Mary: Thanks, P13. You mentioned the FLO program. Is that a particular South Australian... --

P13: It's Flexible Learning Options. It's in secondary. We've got a few cases where normally people around 16 go into FLO program. They're putting them straight in from primary school now and it's really concerning. I don't know if the other advocates are seeing this, but we're getting an influx of that and I think it's been purposely driven from year 7 and that's a concern because kids are getting segregated into smaller areas off school site without the proper support.

Mary: Mmm, thanks, P13. And the Royal Commission of course is doing specific hearings into education and it's one of the topics they're pursuing quite deeply, so I'm sure that those issues will be coming out.

Can I just... quite a few of you have referred to examples, you know, examples of particular people. Some of you have talked about submissions that you're helping people to put in. So just a reminder that any of those examples that you've referred to or people's stories and cases, they're all useful to get them into the Royal Commission.

We'll be doing a case study project where some case studies will be being written up by a professional writer and if any of you have a case study that you think is worthy of doing that, please let us know. We want to get some of these things... there's a specific angle that DANA wants to have on it which is to show the story that happens to someone and at what point does an advocate become involved and then what's the influence and impact that advocacy has over that person's story. So that's the particular thing that we're interested in. If you have case studies that you think would fit that, come back to Siobhan and myself.

I was just going to ask, ADEs [Australian Disability Enterprises] are a segregated setting. In South Australia, do advocates .. are you in and out of the ADEs, do you have much to do with them, do you support, provide advocacy for people who work there? What's the general go with the ADEs in South Australia? P4, did you want to comment?

P4: Yes. We've had self-referrals actually from, by ADE, you mean assisted employment?

Mary: Yes, the Australian Disability Enterprises, yes.

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P4: Yes, so people have self-referred generally around having an independent advocate present when they're having their annual employment assessment, yes. And we've also worked with people because of the wages structure and people who believe that their work and it definitely would be comparable to an able-bodied person which is how they do their assessments and we've been to the Fair Work Commission with clients in the past. It's a real struggle. The whole way it's set up is confusing and really, really hard for people to fight in terms of wage discrimination.

Mary: Yes, and would you categorise it as exploitation if you were --

P4: Oh, absolutely, yes, absolutely.

Mary: So the Royal Commission of course, there is a hearing this week about employment, but it is about open employment and the Commissioner Sackville I think specifically said at the opening of this hearing that there will be further opportunity, another hearing, which will look at the issues to do with segregated employment. So they're not dealing with it this week in this hearing, but it will be dealt with. So if you do have examples or if you have people who you know who work in ADEs who would like to or you think their story should be told, then it would be great if you could get to help some of them to write in a submission because they might be the right person to give evidence at a future hearing.

P8: Mary, I just had a comment. In regards to referrals around ADEs, what I find really interesting we sometimes get self-referrals and I guess that the majority of people we advocate for aren't in any kind of employment, but I have had many referrals from ADEs who'd like an advocate along while they sack a person, so they don't look for advocates prior to that but they've now decided that whatever is going on in that ADE and so that's kind of mind blowing for me that these are congregated settings where people with disability, this has been created for people with disability, yet they can be sacked from those places. So, yeah, I think that's a huge problem in regards to them not believing or seeing that advocacy might be a helpful way... before the person gets to a situation where they're trying to push them out the door.

Mary: That's interesting. It absolutely gives the impression that they just want the advocate there to tick a box so they can look as if they've done something to provide some fairness.

P8: That is exactly what they want to do.

Mary: Yes. So another segregated area of accommodation is the boarding houses and hostels. What's that situation in South Australia and do advocates have... do you get referrals in from people or are you dealing with people who are living in those accommodation settings? No? Yes, P13, I can see you waving there.

P13: I feel like I'm talking a lot. I have had experience in...- I can't remember what they're called here, RE --

Mary: I can't either actually.

P13: What are they called?

P8: SRFs [Supported Residential Facilities]

P13: Yes.

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Mary: SRSs in Victoria, SRFs in South Australia.

P13: I've had a couple of... I know I'm not the only person, I know some of our other advocates have had some contact with some people in that sort of segregated environment. What I have found is that the so-called 'caretakers', a couple of issues was the NDIS wasn't covering very much of their expenses while in those places. I don't know how other people but I remember that was one case here. They were really struggling to get NDIS funding, suitable NDIS funding.

And the other thing is you can really see... the ones I've been in, the actual even just the aesthetics of the place is very run down, lacking in resources and people - it felt really institutionalised walking around with no purpose, the dining room situation was everybody sort of again that it felt very institutionalised, everybody is just sitting, you've got your meals and you walked out. It didn't feel - if we're looking at ordinary life or what would be expected, I wouldn't want to be in one of those places, of my experience. And I know the other worker that's done a lot in it... she's done it in mental health as well, so she's had a lot more experience than me. She could probably give you more examples. Yes, it was very wanting.

Mary: We'll go to P6, but I'm just wanting to know are those settings, the SRFs, settings where violence, abuse, neglect and exploitation are happening?

P13: Absolutely, yes, even just from other people, you know, other people that are living in those homes.

Mary: The other residents, yes.

P13: Other residents, a lot of violence there, yes, absolutely.

Mary: We'll go to P6 and then... the last few minutes I'm just interested in more of the solutions, what is it that's going to fix or help change these... what is it, what legislation, what policies, what is it that's going to need to be changed to change the lives of people who inhabit these segregated settings? P6?

P6: I've advocated for someone who until very recently has lived in an SRF their whole life since they were about 18 and they're about 50 something now and I was very disappointed to see that the Disability Royal Commission was separating out that issue of housing from group homes because what I have seen is it has very similar set-up and issues and risks that are associated with group homes and SIL settings.

I also have the experience where the costs weren't sufficient that the internal review was very quick at adjusting those cost difference, but all the other issues that exist for SIL definitely exist for people in boarding houses. I think they're more at risk because the support is even less sufficient so when they have a hospital appointment, ambulance and no-one goes with them.

With intellectual disability, it's very tricky to communicate those... some of the important information and the support just wasn't available. The NDIS and the increasing plan that we were successful in getting resolved a lot of that, but again it had to be fought for because for some reason there was distinction between boarding houses and group and SIL environments and I don't really understand why that is and why it has to be that way because they're very similar, very similar.

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Mary: Mmm, thanks, P6. That's really interesting and is a systemic issue that's definitely worth pursuing with the NDIA, isn't it, and kind of the obvious response is in the SIL... the structure of the way they've created that supported independent living - well, you've got a provider who's got a direct interest in putting in this large quote to get all the money and those SRFs are not the same kind of... it's not the same financial setup.

P8: Mary, I just want to add around SRFs that we've been involved in. These are places where people are forced to live in the same room as another person. They are forced to eat the food that's given to them. So if you decide that you would prefer to cook your own meal, you can't because you're not allowed to use the kitchen. If you wanted to go out for dinner, you still have to pay, so the ones we're aware of it's a percentage of your income. So you're paying 83, 85% of your income and then you don't have any money left over to be able to go out and have a decent meal.

We know somebody who loves to cook and loves to go out and have lunch at their local hotel or whatever and that person had to scrape money together every fortnight to be able to do that once every so often. And I think they are very appalling places and they certainly affect people with intellectual disability, but also people with psychosocial disability who are forced into those kinds of environments. Lack of housing, lack of housing, lack of housing.

Mary: Yes. Anyway, the Royal Commission have heard it loud and clear today and at other times and I think that will absolutely get picked up as an issue.

Just in the last couple of minutes, has anybody got any sort of closing things or anything else that we haven't touched on that you think is important that you want to just mention either to do with restrictive practices or the segregated settings in any context?

P4: Just in relation to restrictive practices, if we happen to, either in an SRF or segregated setting, if we do happen to observe that and we're concerned about it, you can take it up with the organisation and often that's really tricky because they will always have a reason as to what you might have observed or heard from your client or the person that you're dealing with. We can report those things to the Quality and Safeguards Commission. Again, from my observations of what they do, they take it up with the organisation and then they will accept an explanation as to what's occurred. We can feel really limited... and I'm not sure how other advocacy agencies deal with that, in terms of getting some action in relation to those restrictive practices that we do observe.

Mary: Thanks, P4. I think there's more interaction needed between the advocacy sector and the Quality and Safeguards Commission I think to deal more... dive in deeper on some of these issues. Has anybody else got a last thing you're burning to say in any P13?

P13: Sorry, I can't help myself.

Mary: No worries.

P13: I'm wondering if there's any thought around hospitals. A couple of areas around that. With restrictive practices, a person's capacity to make choice and also family input - I think that might be something that you might want to consider and get some input around.

And then the other side of it would also be around... this may have been looked into, but just around the NDIS, people not having appropriate funding and then being kept in hospital because

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there's no place for them to go and then advocating for them to get NDIS funding because of their needs. And that might have resulted from lots of things. I mean, they might not have had disability to start off with. It might have been a result of an accident or just that family members are no longer able to care for them. But I think that the hospitals could be considered that segregated sort of environment and that might need to be considered because there are people in hospital situations who've been in there a long time. We know of a couple of cases and they're waiting to get appropriate funding.

Mary: Yes. Thanks, P13, because I think traditionally, other than perhaps the psychiatric units, but the hospitals themselves don't... they're not normally neatly sitting in that list, are they, of segregated settings. That's useful to think about.

P8: Just to add to that. Very recently the South Australian Government funded placements for people who had been in hospital, people with disability who did not have a medical need to be there. It was a housing need. And they were moved into what was rehabilitation hospital, so it was just moved into a ward setting with a mix of people mostly older people but a couple of very young people as well and again just confined to single rooms. I've been there to visit on a number of occasions and it's bloody appalling. That was the South Australian Government's response to there not being, yes, any response to those people, in regards to housing and NDIS supports.

Mary: And the other area that you've reminded me of course is nursing homes and some of you may very well have clients who are younger people or, indeed, older people with disability who are residents in nursing homes and that's a fairly segregated environment as well, of course.

We've come to the end of the time, so we will wind it up. I'll just see if anybody from the Royal Commission wants to make any comments as we are finishing up.

P3: Hi, Mary, P3 here. Thank you. Look, just before we finish, I just wanted to say thank you to yourself and P1 for all your hard work in pulling together these workshops. We want to say thank you today for such an insightful discussion. I might just pass to P4. P4, do you have any final comments?

P4: It's just really been really engaging and to hear from advocates on the ground and the work that you're doing is just so important and certainly the importance of ongoing funding for individual advocacy is something that is regularly being raised with us.

I guess also just in the South Australian context, I think it's interesting that one of the unintended consequences of the NDIS is the growth of the SRFs and how owners and operators have been able to use funds through NDIS and also very involved and quite coercive in terms of maintaining and keeping people living in their facilities and I think it's a concern, especially given that the South Australian Government reduced the scope and prevented community visitor schemes now being able to go into supported residential facilities and all the non-Government organisations who are providing care in group homes here in South Australia. So there is a lot of... 2,200 people who were previously receiving that visitation are no longer doing it, which is of great concern and it just puts so much more pressure back on individual advocacy services trying to fill that gap. So thank you, everyone, for your great participation and many stories, they're so important.

Mary: Thanks, P4. That was interesting and it's obviously a systemic issue that needs to be picked back up in South Australia really about that and the reduction in the community visitors hasn't been matched by increased support of advocacy. The South Australian Government has for the first time

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in 12 years maybe put up a little bit of money for advocacy, but it's minuscule, to be honest, and I don't think the actual result has been announced yet.

So we'll wind it up there. Thank you very much, everybody. That's been a really useful and interesting discussion and nice to hear from you all about your work and you will... once we've pulled some of this together and done a little bit of tidying up and analysis, we will provide back to you all the themes and some of the issues that have come out of all of these discussions that we've had with advocates. So thanks very much, everyone. See you all later. Bye.

Comments typed in Zoom chat function

P8:

In addition if a person is seeking a different arrangement their housing is a risk because the SIL provider only supports people with '24' hour supports :(

P15:

I'm sorry but I have to go to another meeting. This discussion has been very interesting and I appreciate the invitation to listen. Thank you!