

Solutions Focused Workshops by Disability Advocacy Network Australia

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. DANA then worked with the Engagement team to co-design these 'Solutions Focused Workshops', bringing together senior and experienced advocates from all states and territories to draw out their ideas and recommendations for seeing positive change at a national, state and local level.

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 (DSS) for DANA to provide DRC systemic advocacy support. Visit www.dss.gov.au for more information.

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Transcript of Zoom Workshop - 22 April 2021

MARY MALLETT: Welcome everyone as you're connecting in. I'll just ask you all to turn your microphones off just so we keep the background noise down. So, you can leave your cameras on, but turn your microphones off. That would be good. Thanks, everyone.

Siobhan, are there many more people we're expecting or have we got most people on by now?

SIOBHAN CLAIR: A few more, I think.

MARY MALLETT: Okay, I'll just give people another minute or two, a minute or so to come on, and then we'll get started. I can see more people joining now. We can see you in the middle of the screen, Amber Interpreter. No, no, that's fine. You stay right where you are.

We'll get started and it may be that a couple of other people will join in. Just a reminder to the people who've just joined to keep their microphones off unless we're actually speaking. Thanks.

So, I'll start with our acknowledgment of country. I'm here on the land of the Kulin Nation today and I wish to acknowledge the traditional custodians of the various lands that we're meeting on. I wish to acknowledge and respect their continuing culture and the contribution they make to the life of our communities. I'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 MALLETT: Thanks, [QLD Advocate 3], and thanks all the advocates and it's really a pleasure to realise that we have advocates from every state and territory joining here today, so that's really excellent and thanks very much.

So most of you took part in the earlier series of workshops which [Person 1] referenced earlier where we did them by state and Territory, and those workshops provided really rich insights and examples from you and your colleagues. And mostly around systemic problems and areas that needed improvement. And what this workshop is about is not about focusing in on the problems again so much, but trying to have a focus on the potential solutions. And advocates shared their views and ideas very readily in the other ones, and the Royal Commission found that incredibly useful.

So, I'll just sort of say a couple of points before we start discussing some questions. You don't have to all agree on ideas, so you don't need to put forward ideas that you think there'll be consensus on. Your idea might be yours alone, and the rest of the advocacy sector doesn't necessarily need to agree with you. and there isn't an expectation about that. So, this is about generating ideas that the Royal Commission can then absorb, especially into their recommendations for their report.

So, there's no bad ideas, there's no silly ideas. There's just ideas on the issues that you work on, which are complex issues, so there aren't necessarily simple solutions, but even

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the smallest potential solution can be useful. If there are stories or case studies that you're prompted to think about during this discussion, but you don't, they're either too personal or too complex to share in this context, then the best thing to do with those is to provide them as a submission, a submission into the Royal Commission, and Siobhan will put the email address for submissions into the chat so that you can pick it up from there. So, what we're focusing on today is moving towards what are the recommendations that the advocacy sector wants to see the Royal Commission put in their final report.

So, just to start off with, and this is obviously recommendations to address violence, abuse, neglect and exploitation of people with disability, so it's the whole spectrum, really, that we're talking about. Are there any sort of beginning ideas that anybody wants to mention. They can be high level, very specific, very broad, very focused, just to get us started. And again they could be either specific to your state or territory or on a national systemic issue. So, has anybody got any sort of initial thing that they'd like to put forward?

[QLD ADVOCATE 3]: Mary --

MARY MALLET: [QLD Advocate 3], yes. [QLD Advocate 3], I'll get you to put your microphone back on. [QLD Advocate 2] had her hand up, so I'll ask [QLD Advocate 2] first and then come back to you.

[QLD ADVOCATE 2]: Thanks, Mary. Thanks, [QLD Advocate 3]. [QLD Advocacy organisation] has made a recommendation already in our submission to the Royal Commission that both the Australian and state and territory governments should agree in principle that refugees and asylum seekers with disabilities currently on temporary protection visas or no visas should be given access to specialised disability supports while residing in Australia or its territories. This would include, of course, the National Disability Insurance Scheme and we understand that that would require the Act to be changed. So that's one to start off with.

MARY MALLET: Thanks, [QLD Advocate 2]. I'll go to [QLD Advocate 3] and then [SA Advocate 1] next. So, these are just your initial thoughts and then we'll work through some questions.

[QLD ADVOCATE 3]: Can you hear me?

MARY MALLET: Yes.

[QLD ADVOCATE 3]: I don't have a little hands up thing. Look, I just want to say because we're just kind of kicking this off that despite all the legislation, the principles in our acts regarding decision making, the Queensland Human Rights Act, the NDIS legislation, the principles decreeing choice and control, prevention, protection from abuse, neglect, our system, each and every day, unfolds very differently. The daily oppression, the harm being caused is largely hidden. It can be subtle, or it can be so clear and in your face that most of us would find it hard to believe that it could actually happen, but it does.

I think we have to think about how and why the mechanisms to protect the system itself are still far greater than the very weak mechanisms that exist to protect vulnerable individuals or the non-dominant groups, and I would suggest that advocacy workers are part of a

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nondominant group which the dominant groups try to control. As an advocacy worker, I'm forced to work in this arbitrarily set system of social hierarchy which includes our government institutions, such as QCAT [Queensland Civil and Administrative Tribunal], the office of the PG [Public Guardian], our health institutions, who often become the oppressors when they're supposed to be the protectors.

I've had repeat experience of how this powerful system obstructs and attempts to diminish the rights of people, and also the advocacy work that I do and the role I'm meant to fill. And I shudder to think what the system would get away with when there's no advocacy worker.

I think we need to identify the power dynamics of the current system, and identify who those dominant power groups are, and hone in on just how this institutional abuse of power and oppression occurs. We really need to understand those two things that I've mentioned.

MARY MALLET: Yes, thanks very much, [QLD Advocate 3]. That's a really useful prompt about the power imbalance which people with disability are always on the lowest rung of the power imbalance and advocates, even when they have advocates to help them, it still can be hard. Your description of how systems protect themselves is a very useful one. Thanks. So now let's try to find the answers to how do we unpack, how do we make the changes? [SA Advocate 1], I think you had your hand up.

[SA ADVOCATE 1]: Yes, I did. One of the primary things that our organisation feels very concerned about is the lack of affordable housing and that what happens to people is they're forced into congregated settings. I know that there's all sorts of ideas about what constitutes a group home. We would say that a house with, there can be group homes of one. However, what happens to people is that they are constrained by services. There are a whole bunch of SILs - Supported Independent Living - organisations that get a whole lot of money which looks like the old block funding model. Even though it comes from a participant's plan, it's actually not in the participant's plan, it's a quote that is done by the SIL provider. Very commonly, they don't involve the person or the family in that process. They then get allocated a whole bunch of money which is used to fund rosters. It does not fund individual support for people or meet their individual needs, and it has to stop, and what we need to be thinking about is home of your own.

Now, there will be people that definitely want to be living in a house on their own, but there'll be other people who want to be sharing and we need to think differently about sharing. And I know that there are programs in place in some states, like "homeshare". We don't have something similar to that in South Australia, but a place where you can be looking for somebody to share with you that doesn't have to be a person with disability. It might be a friend, a neighbour, a family member.

We have ILO [Individualised Living Options], which is a part of the NDIS. We need more and more and more of ILO being... people being engaged with ILO so that they can start to think about what home looks like for them. And we see this all the time where, for instance, somebody has an amount of money that's in that roster which is their one-to-one support that they get, and it's rostered from 5 o'clock to 7 o'clock every day. Well, what if I want to go swimming at 9 o'clock in the morning? What if I want to do something elsewhere, I want to do that on my own? The roster doesn't allow for that.

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Not only doesn't it allow for that, but if you have, let's say, swimming scheduled into the roster and the roster is the support staff and you're going on Tuesdays at 10 o'clock, if Fred, who you live with, who you don't actually know, but just somebody who lives in that house with you, has a really bad day, then those two support staff that are rostered on have to stay at home so you don't get to go swimming. All of these things over and over and over again are just a reflection of the old bad, sad, terrible block-funded model that creates the environment in which people experience violence, abuse, neglect and exploitation.

MARY MALLET: Thanks, [SA Advocate 1]. I'll just pause for a second because I'm going to ask you a follow-up question. [NSW Advocate 1] and [WA Advocate 1], I see you both have your hands up. I'll finish with [SA Advocate 1] and then I'll come to [NSW Advocate 1] first and then [WA Advocate 1].

[SA Advocate 1], that example you gave of the person who has that sort of inflexible use of the hours, what's the solution? What changes need to happen to what? Is it the NDIS pricing guide, is it the rostering processes of providers? What's the thing that would give that person the flexibility that you're talking about?

[SA ADVOCATE 1]: ILO [Individualised Living Options], I think is the thing that's going to give people more flexibility. I think that what happens, and this, no matter what the service provider, the SIL provider, might say that they want to do, the practicalities are that they cannot do that because they've got three or five people living in that house and the response to... so there's no way to respond to an individual need. So if I wake up in the morning and I go, "Oh, my God, there's a really good concert on" or "there's a really good band playing at the local pub and so I want to go up there" and the other people that I live with, they're not interested in rock music, or whatever it is, and I want to go, there is no capacity within those SIL arrangements for a support worker to be able to be rostered or provided to support that person. It takes weeks. So, if you want to make an arrangement to go to a concert, you've got to let your support service know with at least two weeks and quite often that doesn't happen because what they have to then do, because you might have a small amount of money in that SIL quote which is for social and community participation and so they then have to go to their pool of workers and work out who it is that's available to do that.

So, the person has no choice and control. I get really over that term, but this is about when a person has a plan. They need to be able to have choice and control within their plan. We know that they don't have it more broadly, but within a plan it should be there.

So, I think that the money needs to be in the person's plan, not paid to... I'm not real clear about how those things are paid, but I understand that SIL providers get their SIL money paid, I think it's probably on a monthly basis and it's on the basis of what they've been allocated. It's got nothing to do with how that support is provided to the person.

If it sat in the plan, even if you lived in a cluster environment... I think it's harder when you're living in a congregated environment, but if you're in a clustered environment, you would be able then to say to your service provider, who might be providing services to all of those people in there, you've got the money and you've got the power and so you can have... you might have a schedule for your week which you're then able to say to whoever that service provider is, "I need support on these days and now I want to buy some extra support", but you get the power and control over that, not the service provider who is constantly telling

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people, "Oh, I'm sorry, we don't have anybody to take you to swimming today" or, "How about you go to the movies next fortnight?", or, "Okay, every fortnight on a Wednesday we'll look at what your next fortnight is going to look like so that we can organise our roster around that." That is not access to the good things in life.

I get to decide when I want to go to the movies, when I want to go to the pool, when I want to drink wine, you know, all those sorts of things, and people who are living in those environments do not get those choices. No matter what people say, they do not get those choices.

MARY MALLET: Thanks very much, [SA Advocate 1], and yes, each one of these issues could, we could spend a workshop just on people having more freedom to do things. I see that [NT Advocate 1] has put a whole comment about poverty, which is very linked to this as well, in the chat. [NSW Advocate 1], can we come to you for your point and then we'll go to [WA Advocate 1]. Thanks.

[NSW ADVOCATE 1]: I was thinking of one way, one angle of looking at (inaudible). I was going through the questions, the five points that you sent out. One, I guess, angle is thinking of the problem from the view of a perpetrator. Why do perpetrators feel safe and confident when they commit their crimes against people with disability, what is going through their minds, and how can we make systems unsafe for perpetrators.

I'm just having a bit of, a little bit of research on the issue and the personal safety survey from the 2016 census. So, it indicated women without disability in terms of sexual violence, 16%, which is pretty horrifying, 33% for women with disability. That's from the age of 15 onwards. And I would suggest that part of that is to do with settings and environments where perpetrators feel safe, like group homes.

Somebody mentioned congregate settings or secluded settings and the experience for people with disability of course can be absolutely horrific, not to mention neglect as well, [like] that appalling case with that young woman in South Australia, I think it was, with severe cerebral palsy.

So yeah, I mean, seclusion and segregation... these are the sorts of things where some of the worst things that can happen, like neglect to the point of people dying, sexual violence, and so on, we need to, sort of, dismantle these things so perpetrators who abuse against people with disability don't feel as confident perhaps as they do in current settings, yes.

MARY MALLET: [NSW Advocate 1], do you personally have a view or any ideas about what is it that would make the perpetrators feel more unsafe? And somebody else can chime in as well if you have thoughts on this as well.

[NSW ADVOCATE 1]: Well, yes, I mean, one, I guess, sort of reiterating the point to start with, you have a grooming process often with sexual assault. Somebody in a group home, you know, employee who intends to abuse somebody, you know, a situation where they become [a] sort of special friend, special deals and so on and that person, yeah, sort of feels that the perpetrator is really sort of looking after them, whereas in fact the perpetrator is working up to sexual assault.

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I would suggest that if people were actually living in... and somebody mentioned this earlier... their own home rather than in this group setting, where they have no choice, real choice in the issue, that might be less conducive to forms of abuse. Yes, just to get away from this seclusion and this sort of segregation which, yeah, to me it just makes it easier for somebody who wants to do harm.

MARY MALLET: Yes. Thanks very much, [NSW Advocate 1]. There's some excellent contributions being put in on the chat. The last one I can see is from [QLD Advocate 1] about the OPCAT, the Optional Protocol to the Convention Against Torture, that needs to be more disability informed and aware and there's a plea from [VIC Advocate 1]... just needing more funding for advocacy services and horrifyingly, she's saying they now have a wait list that's blown out to more than six months, which is terrible.

We'll go to [WA Advocate 1], who had his hand up to ask a question. Then I'll move on to another area that we want to explore. Sorry, [WA Advocate 1], you wanted to make a point, yes.

[WA ADVOCATE 1]: Thank you for giving me this opportunity. Mine is not a question, but I just wanted to comment on some of the discussions, the possible submissions. My area is systemic advocacy. We've been working in this area, working personally, for more than 20 years in systemic advocacy. I'm finding quite a lot of issues we put up on submissions in relation to neglect and abuse and discriminations, and we find that there is no auditing system the Government is funding, and the funding is actually being reduced, funding in this sector, when we know it's a very important crucial service that is offered under the systemic advocacy. But we find that auditing system is not followed up, there's no mechanism. Agencies... there's no particular agencies that would be able to support the auditing process, and whatever submissions [are] just duplicated year to year and this makes it very difficult really to resolve some of the issues.

So, I will see that... the recommendations will be actually to strengthen the systemic advocacy and to put up an auditing mechanism that will really follow up cases that have been noted and also legislative agenda to resolve some of the issues. [Those] would be very strong recommendations we expect probably would be able to resolve that issue, and I really support the idea that individual advocates also [be] mandated reporters so that they can use... those mandatory reporters can be put into the books and those issues can be followed up by the same agency as part of the auditing mechanism. I think that would really help to solve the problems.

MARY MALLET: There are several suggestions there, strengthening systemic advocacy, the auditing system. So, you're talking about the Quality and Safeguards Commission and their capacity to check the compliance of the providers, is that what you're talking about?

[WA ADVOCATE 1]: Yes, exactly.

MARY MALLET: And they should be doing more follow-up and that that should be stronger?

[WA ADVOCATE 1]: Yes, exactly.

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MARY MALLET: Your last point about individual advocates being mandatory reporters, there's slightly different issues in different states and territories, aren't there, about how states view or look at vulnerable people and children yes, but not necessarily people with disability. Okay. Thanks very much, [WA Advocate 1]. [NSW Advocate 1] and [WA Advocate 1], if you can, you can take your hands back again on the thing if you've given your points.

What I'd like to ask about now is when you have worked with a service provider, so you're helping someone to resolve a situation, they've got a complaint or a problem with a service provider and you're helping them to resolve it, have you seen providers as a result of you working with an individual person with a provider, have you seen times where a provider has taken serious steps to make positive change, cultural change or change their practices across their organisation as a result of something that they've had to do to fix the issue for one person? Has anybody got examples or seen some good practice from providers? The silence perhaps means that you haven't.

[QLD ADVOCATE 3]: It's [QLD Advocate 3] here. I have no way of putting up my hand.

MARY MALLET: Thanks, [QLD Advocate 3].

[QLD ADVOCATE 3]: I have recently been working with a service provider who has performed beautifully in improving their practices and that is to work as an absolute part of a team with the advocate, the mother, the family, the support coordinator and another service provider that's working jointly. We work as a team together. Everyone is on the email list, including the family, and we have stakeholder meetings every two weeks, and all incident reports are shared with the family and the service and everyone works together in discussing approaches and strategies within the... (inaudible) provider who is willing to include the advocacy as well as everyone.

MARY MALLET: Thanks, [QLD Advocate 3]. I'm interested who initiated the bringing together of all of those players.

[QLD ADVOCATE 3]: I did. I worked very hard. I think people are a little bit frightened when you talk about transparency and openness, but there was a level of trust and it has been happening. We have a very good support coordinator who's very highly experienced and everybody just commits to it, and it's just the first time that this man has had a service - the longest that he's had it, you know. Usually services end in five weeks. For him he's had a history of failed services, but this time it was implemented very well.

MARY MALLET: Thanks, [QLD Advocate 3]. That's a good example, and just to take that through a little bit more, though, so they're doing really good work for implementing this service for that one person and they're cooperating with all of the other stakeholders? Do you think they are improving their practice across... --

[QLD ADVOCATE 3]: Yes. They have recognised that that's a good way to manage their things and I do have them with another service and they're very willing and open to doing the same thing with another person that they are providing that service to.

MARY MALLET: You can mention the name of the service if you want to.

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[QLD ADVOCATE 3]: [QLD provider]. They're located in Brisbane.

MARY MALLETT: Yes, okay, good. Thanks, [QLD Advocate 3]. A couple of other people had their hand up -- [SA Advocate 1], I think, and [NSW Advocate 2] wanted to. --

[SA ADVOCATE 1]: Very limited experience, but there was one I think is noteworthy and that's a very small organisation who I think do much better jobs. They changed their service agreement based on feedback from one participant. I think that was a really positive thing that they did.

MARY MALLETT: Absolutely. Do you want to name the service?

[SA ADVOCATE 1]: [SA provider] in South Australia. They're a boutique model of support and, yeah, I think they're very responsive.

MARY MALLETT: Yes, very good. Thanks, [SA Advocate 1]. [NSW Advocate 2]?

[NSW ADVOCATE 2]: Thank you. I just wanted to also mention in this example the issue was really with a family member wanting her daughter with an intellectual disability - she was in a support unit at a regular primary school, a local government primary school - and she wanted her daughter to be in the mainstream classroom. And so, through building the capacity of the family member, she had lots of meetings with the school and the principal and the teacher and they ended up transitioning her daughter across successfully to the point that now the principal has decided that the whole school would be changed, and he's started an initiative called Collaborative Classrooms so that all the children that are in those support units are now moving into the regular classroom as often as they can. And it's obviously a work in progress, but it's been a schoolwide change as a result of that one individual case.

And, yes, obviously that whole point is that we would like the Commission to be mindful about the importance of inclusive education at the very start of a child's life, to be included and to end the othering which seems to be a high-risk factor that is involved with any forms of abuse, neglect and exploitation. And we'd really like the Commission to be looking at, sort of, that long-term data on the impacts of life course, so when you are in a segregated setting versus being in a mainstream setting, if you are a child with a disability, what are those impacts when it comes to leaving school, getting a job, getting tertiary education, and things like that. That is something that's really lacking at the moment in this country.

The other point that I did want to raise, Mary, from your first question was just in relation to the Quality and Safeguards Commission and it ties into our discussions from yesterday's meeting, that the Commission didn't really look at the Quality and Safeguards Commission and that's not a criticism of the Commission, but just it would be good if they could make some recommendations, because at the moment it does seem very compliance-based and process-oriented rather than being actively preventing abuse and neglect, which is part of its terms of reference. So, looking at improving the complaints process so that it doesn't feel like you're looking into a black hole, for example.

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MARY MALLET: We'll add that into our feedback from yesterday. Can I ask, that example of the school, and you can name the school.

[NSW ADVOCATE 2]: Yes, we actually showcased the school at a parliamentary forum on inclusive education. It's called [NSW Primary School] and as a result, the Minister for Education did go out to visit that school the following week to have a look at the practices.

MARY MALLET: And have you provided... has [your organisation] provided that as a case study into the Royal Commission or spoken about it at a hearing? If not, do, make sure you do.

[NSW ADVOCATE 2]: Yes, will do.

MARY MALLET: If you haven't already. Yes, thanks. Was there someone else who had their hand up that I missed? I notice in the comments that people are saying, so they've seen some of these examples, but with small [organisations]. I think [QLD Advocate 2] said similar experiences with small new NDIS providers, not the same experience with the large providers, and then [SA Advocate 1] has also said the same thing.

I'm interested in, so larger providers resist change. Has anyone got any suggestions, notions, ideas [about] what is it that can make that change, because it does look and feel like, and you're saying that the bigger the provider, the harder it is to change and the more resistant they are. Where does that change need to start? What is it? What level, how can change be forced really, in those organisations? Has anyone got suggestions?

[QLD ADVOCATE 3]: It's [QLD Advocate 3] here. I require, if I'm going to engage with... pick a service provider or help a person pick a service provider, they must be willing to sign a memorandum of understanding with all of the principles for teamwork and partnership and inclusion that I want to see in that service as part of the service agreement.

So, I've developed wording in previous [agreements]. I guess it depends on, the actual wording depends on, the particular circumstances of the individual involved, but there is always, and I will always do it now, a memorandum of understanding that the service agrees to work within and where the family is included and advocacy is included and openness and transparency and all that. And the same if I'm involved in helping a participant pick their service coordinator, all of that again with the service coordinator. I think because this one is working really well for the last eight months, I'm definitely going to push for that sort of thing.

MARY MALLET: Thanks, [QLD Advocate 3]. I can see there's more comments in the chat. [QLD Advocate 3], I'll get you to put your microphone back on mute again for a second. [SA Advocate 2] from [SA Advocacy Organisation] has put the comment in the chat [that] once an advocate is involved, the organisation becomes more responsive. Of course, one of the problems about that is the insufficient supply of advocates and because of the lack of resourcing and that comment that then when services have seen some clients benefit by having an advocate, the service themselves then refers more people to advocacy, and she's given an example there of [SA provider].

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One of the things, and yes, [QLD Advocate 3], I agree. [QLD Advocate 2] has asked she'd love a copy of the principles that you're talking about, so we might get you to provide those and share them. Do you see or is there, do you currently see these examples of good practice done by any of the providers, are they shared? Would one provider ever see or know if another one of their providers, even in the same city, was doing? Is there something, is there anything that can be done through NDS [National Disability Services] as the peak, or if you as advocates are seeing good practice, how can that be shared further? Just a thought. You can put it in the chat if you have any thoughts on that. [QLD Advocate 2] I think has her hand up if you want to come in now, [QLD Advocate 2].

[QLD ADVOCATE 2]: I don't think I have the answers. I just wanted to say that I think cultural change in these very large, long-established organisations who've been delivering support to people with disability is a huge struggle. You see the same workers are there that have been there perhaps for the last 15 years, when they were supporting people with disabilities in very restrictive ways and choice and control was certainly not on their agenda - person centred, flexibility, responsiveness - none of that was on their agenda.

It's a bit like asking for cultural change in the police force in New York. Some of them are talking about "let's sack them all and start again," and countries have done that in ways with their police force. And I feel like that's almost what you need with some of these large services. I don't know how you can effect real meaningful cultural change with people who've been working in a way that's so restrictive for so long and it's embedded in all of their practices. They learn how to speak the language, but they're not delivering good support to people with disabilities.

So, we just blacklist many organisations and will actually recommend people don't go anywhere near them because they're so bad. And, as advocates, we have to be very careful about the options and choices that we give people so that they can decide which service or supports or approaches they want. But we find that quite difficult because many of them are just not suitable and we actually strongly recommend people don't have anything to do with them.

We've tried to advocate for people in those services in the past. We've gone through State Government complaints systems to try to effect change and we've had staff from those big organisations come to us and make complaints about what's happening, whistleblowers, about what's happening in those services and all that happens to those staff is they lose all their hours. They suddenly have no shifts when they report things to their supervisors about what they see, you know, very concerning abuse and neglect. So, yeah, I don't really know how you effect real change in those large organisations. So, I don't have any answers.

MARY MALLET: Thanks, [QLD Advocate 2]. All of that was really useful and your final point there about protecting the staff, the really good staff who do reach out to advocates and who become whistleblowers in their organisations, it often is to the detriment of their own jobs and how can they be protected? It would be useful if the Royal Commission can pay some particular attention to that.

[WA Advocate 2], I'll come to you in a second. There was another thing that you said there, [QLD Advocate 2], where you said you blacklist organisations. Now, I know exactly what you mean and somebody else referred to something [QLD Advocate 3], I think, also said

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something similar, and probably every advocacy organisation, each advocate has their own informal blacklist. These are not formal. You haven't got a list, well, you might have, but I don't think it's on the wall of your office. I think it's in everybody's head, and you do informally send people to the good providers and not the bad ones (inaudible) that alone that the advocacy sector should explore further I think about raising some of that to be at a more formal level.

[NT Advocate 1] made a point, oh, she made another point then about the new providers that are coming in that are more flexible. That's good that there's more positives and that should be encouraged more, but also [NT Advocate 1] made the point about maybe we should be nominating the good organisations for awards and [NT Advocate 1] mentioned the NDS Northern Territory Disability Services and Inclusion Awards. So, finding a way to do that where an advocate is not saying this is a perfect organisation, but is able to nominate or recommend an example of good practice, you know, would be a good thing. [WA Advocate 2], I think you had your hand up next, and then [SA Advocate 1].

[WA ADVOCATE 2]: I just wanted to go back to what [QLD Advocate 2] said because it's just a thought, maybe it will be an open-ended question but more of a thought really, in regards to the informally blacklisting organisations. So, naturally what we would do as best practice would be to refer the client or the person to the relevant service who would best be able to accommodate the supports they're after, the help that they need, [but] I do agree that along the track there should be a more formal implementation of blacklisting.

I'm not... I don't think it should be as formal as like credit blacklisting, but with that said, how do you... when all these good organisations get inundated with people needing help, [how]- do you get to find out that this organisation that you previously blacklisted... how do you know whether they -actually have done improvements, whether they have made some changes within the organisation to, say, undo the blacklisting almost? How does one actually come about finding that information out if we're blacklisting, "-blacklisting" those orgs. Yeah, that's just something I thought about. I just wanted to... --

MARY MALLET: And what you made me think, I have flagged something with the Royal Commission that we haven't yet acted on, but in this kind of area I feel like there is potential for the advocacy sector and the service provider sector, so possibly DANA working with NDS as the national peak, but DANA and other peaks maybe, but working with NDS to try to bring some of this into the open and see if we can find a joint project that we could do that would help share some of the improvements that are happening.

The quality audits that are done all the time of these providers, they're not publicly available and there are systems in other countries. If you were in the UK you can look up their Care Quality Commission and you can see the recent quality audits of every aged care home, every disability service provider. It's there. Now, that's not necessarily a perfect system either, but it's more visible than what we've got in Australia, so there are other improvements.

[SA Advocate 1] made the critical point which is - ask people with disability if a service has improved. That's obviously the people... asking people with disability, and it's completely the obvious thing to do, but it's probably the thing that happens least I reckon.

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I want to move on to something else, but feel free if you're diving in to put something in the chat or if you're making a comment --

[SA ADVOCATE 1]: Mary, I just wanted to give an example. It's not something where the organisation has done a shift and it shifts the conversation a little bit as well, but individual child protection workers sometimes, and our experience has been there have been individual workers who've actually been seeking advocacy input into written and verbal communication with parents with disability about their children who are in care and about access visits. It's rare, it's not supported by the child protection system, and it remains viable only when the individual worker or practitioner is prepared to work with advocacy, but maintaining consistent workers can help that continue.

So, there's a lot of shift and change. So, if the system was prepared to leave people in their work role, their social work role, whatever it is, with a family in the long term, you're more likely to get better outcomes for those parents with disability. But you also would have the opportunity to challenge that because what happens where we give good feedback to those workers, and I've been really impressed with a couple of those people, but we're talking about hundreds and hundreds of workers, and for some families they might have 26 workers across a period of years because workers change so much.

So, even when there's a good thing happening and you give that feedback, it's fantastic, the system undermines that good practice and I think that the reason is because these things take time. So, to do well by people with disability, particularly I think people with cognitive impairment, probably people with mental illness, you need to provide time to get to understand the person, to work out what it is in your practice that you can do differently, and I think [QLD Advocate 3] or somebody mentioned before about programs being five weeks long. When you get to the end of a program, our experience of the service kind of goes oh, you're too broke. Or it's your fault that it didn't work, but it's not the person's fault, it's the fault of the service or the worker or the system.

So, in the child protection system we see that as being a really significant problem, and we would be really keen for the DRC to be taking that stuff up in regards to the consistency of workers for people with intellectual disability, parents with intellectual disability, and the encouragement of workers having more time ... you know. It's probably a workload issue, but more time to actually pay attention and to engage better. And I really love that idea of an MOU... oh, gosh, wouldn't that be fantastic to have that across big systems.

MARY MALLET: Yes. Thanks, [SA Advocate 1]. Actually you've sort of led us on to - there was another question I was going to ask, I'll come back to another one in a minute - which was about if you've got any practice examples or case studies of positive change that you've seen that could be replicated across other systems or services, and so your example from the child protection system of trying to have stable, consistent workforce working with a family is one of those that potentially, obviously, would be a useful thing to see across other systems as well.

There's an important thing that I want to get your views on which is about advocacy. This is your bread and butter and it's something that we - the question I've got is - can you explain the preventative power of advocacy for people with disability? So, how does access to independent advocacy assist to prevent violence, abuse and neglect?

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Now, I know you know this, but we need the Royal Commission to hear this articulated again and again and again, so anything that any of you would like to say about what you see in your work about the preventative power or prevention of violence, abuse and neglect of having an advocate involved with someone. So, either put your hand up or dive in if you want to make a comment.

[QLD ADVOCATE 1]: My hand is not working on my screen, so I keep typing comments. I just wanted to say, I mean, yeah, it's obviously very apparent to all of us as part of this meeting, but it is a message that needs to go clearly to the DRC and that's about helping to address, to some small extent, the significant and innate power imbalance that invariably exists when you've got a vulnerable person dealing with an organisation or a system, and giving a voice to someone who's not going to otherwise have a voice. And I think that's really powerful, not only actually in being able to practically assist and in providing the support and capacity building and empowerment for the person, but sadly there actually often is a difference in response that you get from the organisation or service provider when an advocate is involved - when there is transparency, when there is support for the person.

MARY MALLET: Thanks.

[QLD ADVOCATE 3]: I could say something. I just wanted to say that about eight years ago I was rung up at 12 o'clock midnight to get to the hospital as quickly as I could to save a man's life because the doctor was going to take action that would cause him to be dead in the morning. I was called by his father, who was racing from Toowoomba to get to the hospital. The mother, who was dying of cancer, wanted her son to die at the same time or around her and this man had a bladder infection and the doctor had decided that he would withhold antibiotics because if he did so he would, the man would be dead in the morning.

So I raced to the hospital and had to stand up against a very abusive doctor who said what he was going to do and that I had no standing and I said I was representing the views of the person, the disabled person and his father and that I was authorised to do that and I threatened the doctor that if he did so, if he was making such a decision, it would have to be approved by QCAT and if he did so, it would be all over the media in the morning and that I knew how to do it. And I did threaten him, but I did end up saving that man's life and he's alive today. The mother is deceased, but the father is looking after him today and he's still very much enjoying life.

So there's been a number of times where I've had to stand up against a very scary system to prevent something really bad happening and I'm involved in something this very day as we speak which is very difficult, but advocates must be able to perform that role without the added difficulty of this power imbalance that I mentioned earlier. That we work within the system and we have to identify how this power imbalance is occurring and identify... hone in on how it happens, because it's difficult.

MARY MALLET: Thanks, [QLD Advocate 3], and that's a particularly dramatic example which we hear from time to time of - that intervention of an advocate in an actual lifesaving situation and that's probably... they're not all to that extent. So, I just note [NSW Advocate 1] had one in the chat there about he advocated for a client by just being with him at a

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Housing NSW office. He got respect and proper service just because someone else was present. "It's sad in a way, but unfortunately that's so often the case."

We have heard from advocates that even the threat of having an advocate present at a meeting, even if the advocate isn't able to attend, sometimes makes the provider or the system do the right thing. [SA Advocate 1], did you want to make a comment on this issue?

[SA ADVOCATE 1]: I did, and I think it really adds to what [QLD Advocate 3] has just said. From our perspective, advocacy can be the observer witnessing the behaviour and the practice of service workers and uncovering things from alongside the marginalised person. Others generally, when they go into a setting, they observe the person rather than observing what's happening around them, and so we get a whole lot of environmental stuff that impacts on what's happening for a person, particularly around when people use protest behaviours. And we see that a lot, protest behaviours are just a form of communication, and so when we're observing what's going on around, for instance, a fellow who didn't want to go swimming who loved swimming and the reason he didn't want to go swimming was because of the support worker that was taking him, advocacy could observe that because they'd observed that swimming stuff happening many times and this was what was different.

I also think that... I guess we would talk about that advocacy relates to the person and listens to their sort of wants and needs separate from service constraints. So, we don't have to think about programatic stuff, we're just listening to what people want and helping to influence the decisions that are made about that. Advocacy has no skin in the game, for want of a better word, in regards to being served by the outcome, so that's the independence.

[SA Advocate 2] had mentioned this before in her comments that when advocacy is watching, services are more likely to treat the person well. There's an inherent cookie cutter kind of response to the needs of people with disability within service and government systems and advocacy challenges them to do better. Advocacy is a human response I think to the lived experience of people with disability and advocacy will act.

MARY MALLET: Thanks very much, [SA Advocate 1]. I can see [QLD Advocate 2] has put in an example supporting someone against the hospital mental health system really for the person to get urgent health care.

So, I'll just... there's another couple of questions I want to move on to, so if anybody has any other particular things about the preventative effect of advocacy, [NSW Advocate 2] I think, and then I'll move on to the next topic. [NSW Advocate 2].

[NSW ADVOCATE 2]: Just from our perspective, family, we see time and again that family is imperative to the raising of awareness when it comes to abuse and neglect and holding that accountability - and so having the ability to build the capacity of the family through advocacy and actually acknowledging the importance of family as advocates is really imperative - one for the whistleblowing and naming, but also for when you're looking at the other side of the coin and making good things happen in a person's life - ultimately it usually comes down to the family. If they have better advocacy in talking with a school, for example, that leads to better outcomes for the student with a disability, and that student is seen as having a valued role as a student, and then they're treated in a different way by the teacher,

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and when they're treated more favourably by the teacher, they're treated more favourably by the child. And this is the thing that flows on from one setting to the next, when they then move on to their next phase of life, how they view themselves, how they are treated, et cetera, et cetera. So, advocacy is absolutely vital, but also recognising that nuance that the family's advocacy... needs to be recognised as well.

MARY MALLETT: Thanks very much, [NSW Advocate 2].

[NSW ADVOCATE 2]: Thank you.

MARY MALLETT: And I can see the point [NT Advocate 1] from Alice Springs is making in the chat about advocacy being critical for people with disability in remote Indigenous communities, and one of the particular reasons is because the systems themselves now are harder and harder to manage and to deal with because they're assuming everyone is literate in English and in using computers and those people need advocacy assistance to navigate the systems.

I want to see what your view is about the notion about primary prevention. Primary prevention is... it uses whole-of-population initiatives to prevent harm before it occurs, so upstream is the term that can be used. So, if you try to think about that, about whole-of-population changes that could be made, what is there that could form part of primary prevention of violence, abuse, neglect and exploitation? Are there some whole-of-population initiatives across any and all sectors that have been a driver for positive change, anything you can think of? Or is there anything that you think could be adapted into the context of increasing positive outcomes for people with disability, so not necessarily... we've talked about the sort of targeted in work that advocates do. If you pull way back out from that and look at the whole community, is there anything that pops into your minds about whole-of-population initiatives that would help be part of that primary prevention of violence, neglect and abuse?

It's a big question and you haven't had necessarily time to think about it, but I can see somebody put in a comment there which I don't know if it's related to this question or just coincidental, but investment in affordable housing and of course... so that's whole of population, but would support people with disability. Sorry, was somebody else wanting to dive in there? [SA Advocate 2]?

[SA ADVOCATE 2]: Sorry, I don't have a hand either. I was just going to say one of the things that we see all the time is the lack of knowledge in health professionals, Centrelink and other organisations when people with disability are trying to access services and [the] outcomes that people with disability receive depend on the knowledge of the particular practitioners that they're in contact with. And so having some consistent education across those institutions would be, is vital and we see our role as getting that information out to those various providers.

Again, you can only do it sort of within the scope that you're able. So, yeah, an example of that is if someone is applying for NDIS supports, but the doctor doesn't really understand what the NDIS require as evidence, we see that, time and time again, where people are rejected because there's been a lack of proper input from the medical practitioner.

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MARY MALLET: Thanks, [SA Advocate 2]. So that understanding, a better understanding about disability issues and the impact on people with disability but across lots and lots of sectors. I can see people putting comments in the chat. So, anybody who's putting in those comments, if you want to dive in and actually speak to them, take yourself off mute and speak to them, please feel free to do that.

[QLD ADVOCATE 1]: I haven't commented yet, but I was wanting to make a couple of points briefly. I think removing segregation across all systems, particularly education, housing, it's so important in this regard... divert from within the criminal justice system in a way that's appropriate so we're not diverting people for a forensic disability system which indefinitely detains them in prison-like conditions, but therapeutic rehabilitation and habilitation.

I also think the quality of the disability workforce is critical, making sure that the workforce is properly trained; is paid appropriately so it attracts and retains quality staff; that all workers have basic things like first aid training, et cetera. I think that's so vital.

MARY MALLET: Thanks, [QLD Advocate 1], and I can see there's some stuff about human rights training and trauma-informed practice training in some of those. in the comments.

One of the things, the National Disability Strategy has been bubbling away in the background and will come out into the public arena at some stage in the next few months. Some of you have probably been involved in workshops to do with that. I've been involved in some and one of the things that gets suggested all the time is campaigns, like advertising or promotional campaigns to do with changing attitudes, attitudinal change towards people with disability.

Does anybody have a view as to whether - do you think it would make any difference - is there a risk that governments will spend large amounts of money on terrible ad campaigns that won't be helpful to anybody? Has anybody got a view on that? Is it something we should stomp on as a terrible idea, do we encourage it, do we suggest, are there examples in any other context you can think of where that kind of big picture work to try to change attitudes, you know, has helped? Feel free to come back to us afterwards and tell us if you think that that's the case.

I can see [NT Advocate 1] has made the point in the chat that storytelling and video resources to tell the story about rights can be very powerful in Indigenous communities and that's a good, useful example of some targeted work.

We've only got a few minutes and there was something else that I was going to, [one] particular thing and I almost mentioned it earlier. Right back at the beginning, [SA Advocate 1], when you were talking about the person who might be interested in going to a rock concert, you know, but couldn't because there was no staff capacity to take them. But it prompted me about something that in our earlier workshops - what's been mentioned quite often is, it's kind of a recurring idea - how to increase participation of people with disability in their community and building relationships that help to naturally safeguard people. And it reminded me when you were talking about that example that there are those volunteer programs, like Bandmates in Melbourne and Gig Buddies in Sydney, who are designed to do those kinds of helping someone get to a rock concert, to match them up with a volunteer who has the same musical interests.

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So, does anybody, as we're starting to wind up, do you have any other suggestions or views or things that we should be putting forward to the Royal Commission about any measures at all that should be being taken to increase people's participation in the community?

[SA ADVOCATE 1]: Mary, this is the place that I live. I just want to tell a little story which might give a bit of an idea. So, this is a young man who lives in a, just an ordinary community, suburban community, but he's been very present in his community through school, through Scouts, through lots of different experience. So, he was a Cub, he was a Scout, Venturer, he was just a part of his ordinary community.

He doesn't have a depth of relationships with people, but he is very well known and he's got a very supportive family and has a very, very strong relationship with his mother, but on a particular occasion that his mother didn't know about until sometime later he had been at his home and there had been a commotion outside. He had gone outside and intervened in what was a domestic violence thing that was happening and there was a man and two women and he tried to intervene to say, for the bloke not to be assaulting the woman and for this other woman who was also being really abusive.

What happened was that... tragically, one of the women hit him. She kind hit him. She punched him and he was injured by that. What he did was not go back into his house, but he went immediately to his local supermarket, where he was very well known, and the workers in that supermarket called the police, sorry, called the ambulance and they stayed with him until all of that had happened and got him home and that had nothing to do with support services or close friends or family, because he had a feeling that what he had done was he'd put himself into a risky situation and so he was a bit concerned about telling his family. But that's what happens when you have somebody who lives their life in community.

The other thing that happened was that he went to the local pub to the drive-through thing and the guy that worked in the pub knew him and knew his neighbour. He rang the neighbour and he said, "Oh, Fred's here. What should I do?" The neighbour said, "Do your bloody job." So, again, it was another aspect of this is really ordinary life and that he had people in his life that knew about him and knew him much more intimately in the fact that it was a community that knew him.

So, it was, this is what we need to be happening for people, and you all know about what happened to Ann Marie Smith here in South Australia and this could have been prevented. All of those safeguards that we talk about and people have talked about, you know, all of that stuff that happens with service providers, [it] is actually a local community that's going to keep you safe and so people say, "How are you?", "How are you doing?" Or if they see somebody in distress that they know, they will step up. They're not necessarily saying, "Come home and have dinner with me", but they see you in the street and they know you and so they say... local cafe has a bloke that comes in, you know, he's homeless and he's got a mental illness and every week he goes in there and they just give him a drink. He's known there and they don't shoo him out the door, they invite him in, "Sit down, here's a drink, here's food, how are you doing this week, see you next week." That's what happens in ordinary community.

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MARY MALLET: Thank you very much, [SA Advocate 1], and that story is just, it just shows the power of a story about somebody's experience that is, it's better than 20 referenced submissions sometimes about showing the difference that ordinary people, other people in the community, can make to somebody's life. So, thank you very much for sharing that.

We've actually come to the end of our time today and thank you, all of you, so much for really participating today. We get to the end of these, and I always feel we could go on for hours because there's so much to discuss, but today has been very useful and we have another one of these next Thursday at the same time, actually, with another group of advocates from around the country.

[Closing remarks from DRC representative]

MARY MALLET: Thanks, [Person 1], and Siobhan has put the links to where to put your submissions in the form back there in the chat again if anybody wants to put, it can be a single story or it can be whatever, anything you want to put in. I think write it up briefly and get it in to the Commission. Okay, thanks, everybody, for your time today. Thank you.

[Person 1]: Thank you, bye bye.

Comments typed in Zoom chat function

[NT ADVOCATE 1]: Poverty provides the ideal environment for abuse, neglect & exploitation of people with disability in remote Indigenous communities. The poverty is largely caused by dependence on Centrelink income support payments which are inadequate particularly in situations where there is a cultural obligation for people with access to resources to share with their extended family. Often times people with disability are left without money for basic needs such as food, clothing & bedding. This is a complex and many layered matter but part of the solution is increasing Centrelink payments to support people to have a better standard of living.

[VIC ADVOCATE 1]: I would just like some more funding to provide Advocacy services. We now have a waitlist that has blown out to six months!

[QLD ADVOCATE 3]: I see exactly the same problems. The NDIA is also telling a man with severe GAD [Generalised Anxiety Disorder] who requires 24/7 that he will not get 24/7 without opening his personal home to a renter with disability to share his supports. He will have all the same problems as well. Most of the people I advocate for are in the very same problem housing as highlighted by [SA Advocate 1].

[QLD ADVOCATE 1]: On this point - the way in which the Optional Protocol to the Convention against Torture is implemented is critical - we need dedicated legislation, mandatory reporting obligations to the National Preventive Mechanisms, ensuring the inspection bodies are disability informed and aware

There is also a need for the NDIS Q&S Commission to be redesigned to be independent, proactive

I agree [VIC Advocate 1] - there is a need for a plan for sustainable advocacy funding, that properly reflects role of the NDIS and the need for independent advocacy

[SA ADVOCATE 1]: [QLD Advocate 3] that is horrifying and all too common

[SA ADVOCATE 2]: Further to [QLD Advocate 1]'s comment we also need properly resourced and empowered inspection bodies such as the Community Visitor Scheme in South Australia

Very broadly, there is a need for introduction of a redress scheme for the DRC, accompanied by waiver of time limitations for people who have experienced abuse – suggest adopting model of institutional sex abuse redress scheme, with addition of funded advice for people exploring common law claim so it is not purely no win, no fee model

[NT ADVOCATE 1]: Primary prevention in the form of community education is essential to begin the process of changing attitudes about violence and abuse. In remote communities we think the education should start with school children and then continue at all levels of the community. People in these communities are not necessarily aware of their human rights, they are struggling on a daily basis to have their basic needs met. It is important to ensure

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that people understand their rights and have support to have their rights championed. Advocacy is a critical aspect of educating and supporting people to access their rights.

[QLD ADVOCATE 1]: Not something we have experienced, but [our organization] has opted in to be bound by the Qld Human Rights Act, and is hopeful other organisations will do the same, to contribute to a stronger human rights culture in Queensland

[SA ADVOCATE 1]: very limited experience of this working as cultural service change :(

[QLD ADVOCATE 2]: [Our organisation's] Advocates have had similar experiences with small new NDIS providers. Not the same experience with large providers.

[NT ADVOCATE 1]: Provider Education is very important but there needs to be a strong commitment to people with disability at every level of the organisation. There should be representatives of the cohort on Management Committees and Boards as well as in leadership positions in the operational side of organisations. Just doing training once a year is not enough, staff turnover can be a big issue.

[SA ADVOCATE 1]: boutique services appear to be more likely to consider change. large services demonstrate significant resistance to changing policy and practice.....they prefer the person to change and if they don't the service asks for positive behaviour support plans

[SA ADVOCATE 2]: [Our organization] finds that once an Advocate is involved the relevant organisation will be much more responsive to an individual's requirements. Some organisations have then engaged our services for other clients as they have acknowledged the benefits of advocacy. Specific example [SA provider in regional centre].

[QLD ADVOCATE 1] : I agree with [NSW Advocate 2's] comments regarding education. Would also add that we would like the DRC to focus on disability training and awareness in the educational context and the regulation of Restrictive Practices within schools with a focus on reduction/elimination; strengthening compliance with Disability Standards and auditing schools, all schools to be bound by the Human Rights Act in Queensland (not only public schools)

[QLD ADVOCATE 2] : That's an interesting idea [QLD Advocate 3], would love a copy :)

[NT ADVOCATE 1]: Maybe we should be nominating these good organisations for awards like the NDS NT Disability Services & Inclusion Awards.

[SA ADVOCATE 1]: very often human service workers and services are themselves institutionalized in their thinking

[NT ADVOCATE 1]: Some new organisations have emerged since the NDIS started in NT and we have found them to be much more person centred and flexible in their approach to providing services for people with disability

[SA ADVOCATE 2]: Perhaps as part of the auditing system of providers - recommendations about improvements to problems that are identified in disability service provision could be part of the reporting process?

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[SA ADVOCATE 1]: ask people with disability if a service has improved

[SA ADVOCATE 2]: People can have very different experiences with the same organisation - often comes down to the individuals they are dealing with and agree with [SA Advocate 1]!

[QLD ADVOCATE 1]: As a related issue, there are significant limitations with worker screening that can mean problematic workers move between organisations

[QLD ADVOCATE 3]: I find that some of the new services can often be very inexperienced and ill informed and dangerous. Perhaps a joint project mentioned by Mary where a service has a quality tick by the advocacy national group. Black lists can be dangerous and services will pursue for deformation, although there are definitely specific organizations who are dangerous.

[SA ADVOCATE 1]: consistency of workers and time to be present to people with disability can be replicated across systems

[QLD ADVOCATE 2]: Advocacy so people have the type, level and quality of support they need,

Safeguarding close relationships around the person, often in relation to child safety issues.

[NSW ADVOCATE 1]: I have advocated for a client by just being with him at a Housing NSW office. He got respect and proper service just because someone else was present. It's sad in a way but unfortunately that is so often the case.

[SA ADVOCATE 1]: there is also a lack of clear communication between services and human service workers about the role of the human service worker in supporting the person with disability. what is most commonly conveyed is the daytime and length of the 'shift'. services and system need to listen more to the person with disability

[QLD ADVOCATE 2] : Ensuring a person who was unwell and deemed by hospital health professionals to have capacity to choose to die was admitted to hospital for urgent health care. Long story and involved fighting for a family member to be appointed as a guardian which was argued against by the hospital mental health team.

[NT ADVOCATE 1]: Advocacy is critical for people with disability in remote indigenous communities. Most people with disability in our region have English as a second or third language and literacy levels are very low. It would be almost impossible for people with disability to manage all the requirements of Government without advocacy support. The move away from having staff in offices that people can visit to get information and have problems resolved and toward having all systems eg. My Aged Care, NDIS, My Gov etc. online assumes that everyone has English literacy and computer literacy. There a cohorts of people in community who cannot navigate these systems and will consistently require advocacy.

[SA ADVOCATE 1]: a hospital kept a person in hospital against their wishes because they believed the person was at risk and because they assumed there was a guardian. this

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resulted in the person being invoiced for a non medical needed hospital stay. advocacy was able to ensure that the person was able to act on their own wishes, challenge the charges and ensure that services and supports were available for the person to return home

Investment in affordable housing will better serve people with disability and others who are congregated, homeless, poor etc

[NT ADVOCATE 1]: In remote Indigenous communities there is an important role for Champions in primary prevention. Senior, respected people with good knowledge and understanding about Human Rights and disability Rights who take every opportunity to educate and support people in the community about these matters

[SA ADVOCATE 1]: a real home of your own is a primary protection from violence abuse neglect and exploitation....it is a place in which you can choose who enters, it is a place you can retreat to if needed, with relevant and appropriate support you can exercise your human rights in the context of citizenship and ordinary life

[NSW ADVOCATE 2]: whole of population initiatives - trauma informed practice training

removing segregation in all settings but inclusive education is critical

[NT ADVOCATE 1]: Storytelling and using video resources to tell the story about rights can be very powerful in Indigenous communities

[SA ADVOCATE 1]: students with disability truly present and participating in ordinary schools and classrooms means that the future support persons/practitioners will have direct experience that can inform their work. schools are a microcosm of society and that is where we need to start with meaningful inclusion

[NSW ADVOCATE 1]: Community rather than seclusion truly is a way of preventing abuse and neglect.

[QLD ADVOCATE 2]: The power of informal supports and close relationships in safeguarding the wellbeing and rights of people with disability. Such a powerful story thank you

Transcript of Zoom Workshop - 29 April 2021

MARY MALLETT: Good morning, everyone. I'll just say hello to those people that are joining and we'll give people just a few minutes to join in. We've got quite a few people who are going to join, so we'll wait while they all run from their previous meeting to this one.

It's nice to see you've joined from WA, [WA Advocate 4]. You're not in lockdown, I presume. Wait a minute, take yourself off silent for a second.

[WA ADVOCATE 4]: Yes, we're out of the lockdown part. We've got another week of masks, but yes. Thanks, Mary.

MARY MALLETT: That's all good, yes. Obviously from time to time this is going to happen everywhere, so we all have to be prepared for it. I can see a few more people have joined. We'll just give people another minute or two. They're all leaping in at the moment.

All right, we've got quite a few people on already and I think others will just join in, so we will get under way.

So, I'd like to start with an acknowledgment of country. I'm here in Canberra on Ngunnawal lands and I wish to acknowledge the traditional custodians of the various lands that we're meeting on around the country. I'd like to acknowledge and respect their continuing culture and the contribution they make to the life of our communities and I'd like to acknowledge and welcome any Aboriginal and Torres Strait Islander people that are joining us today.

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

MARY MALLETT: Thanks, [P4]. One of the things that [P4] has touched on, that the Commission is looking at recommendations that will go in the final report. So the Commission is still working on hearings, and they've got a whole schedule of work that is still happening, but they have turned - they are turning - their attention to the final report. Now, we don't know yet, the Commission hasn't been told whether or not they're going to get the extension that the Commission have asked for, so the Chair asked for, but either way the final report and the focus on it still has to play out, even if there is an extension granted.

One of the things that's completely clear in all of the discussions that we have with advocates is that this Royal Commission has to be a serious disrupter. Nobody wants more of the same, you know, the terrible everyday work that advocates, the problems that advocates see every day, we just do not want that stuff to continue. So, we have to... our sector has to push as far as we can into how can this Royal Commission really seriously disrupt what's been a longstanding practice, a longstanding practice in the sector.

Just a few things, a few other things. You don't all have to agree on ideas. So, when you're putting something forward, you don't have to think oh, well, will this get consensus? It doesn't matter. Your idea is as valid as anybody else's. There [are] no silly or bad ideas. All ideas and potential solutions are useful and ,even if they're not because they might be a

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solution to something in your jurisdiction even if they're not more broadly of value, so just put forward your thoughts and ideas. That's important to kind of generate those ideas, and you don't need to think about or be held back about whether or not everybody else is going to agree with you.

If there are case studies or stories at any point when you're dealing with the Royal Commission, if there's particular case studies or stories that are very difficult for you to talk about or deal with - and we're all very conscious of the traumatising nature and the vicarious trauma that advocates deal with over the long term - so if you find them too difficult to speak to and you would prefer to write it or you want to talk about it in a one-on-one situation, then please, you can put it in as a brief submission into the Royal Commission. Siobhan will put the submissions link in the chat or you can have somebody from the Commission call you and you can just have a one-on-one conversation about something.

During these workshops, we're asking you to suggest ideas, innovations or solutions that the Royal Commission... you want to see them consider in terms of their recommendations about addressing violence, abuse, neglect and exploitation. So, what ideas do you have to get the discussion started today? They can be very broad or focused, they can be high-level ideas or very specific or just specific to where you operate and provide advocacy. So just an open throw really to everyone to see if anyone wants to start with potential solutions.

[VIC ADVOCATE 2]: [VIC Advocate 2] from [VIC Advocacy organisation]. I have solicited feedback from fellow advocates in our organisation and one of the issues... one of the... not issues, one of the suggestions made is in relation to people with disability living in the community in supported environments and to have something that is... what's the word, to have some other system apart from community visitors, so where there can be potentially... obviously, there's issues of privacy, but with the client's agreement or with the householder's agreement... unannounced visits and potentially, yes, support around that because of concerns that this particular worker raised that community visitors where they have been utilised... it is announced, and it hasn't always been that effective when there have been concerns raised about the levels and the type of supports that people have been receiving. I'm not being very articulate today. I hope you grabbed the guts of that.

[VIC ADVOCATE 3]: Can I jump in there, [VIC Advocate 2]? I think what I'm hearing about looking at community visitors, et cetera, is that probably a lot of us feel like the safeguarding mechanisms that we currently have are probably not strong enough, or effective enough, and the fact that it's not done in a kind of outreach model, that it's very much a 'you come to us' inaccessible model for people with cognitive disability. I think having a huge amount of work... policy work and remodelling of the safeguarding mechanisms we have is really, really important to make sure that safeguarding actually outreaches into the community and into all settings, it's not just a sort of inaccessible phone number but actually they're going into group homes, prisons, closed settings. That's a really important thing that really, really needs to be strengthened I think.

[TAS ADVOCATE 2]: Can I just give the perfect example of the importance of that? As a private citizen, I was going to the supermarket, drove past a group home that I, as an advocate, knew was a group home, witnessed abuse, went in, knocked on the door and I was... a complaint was made about me so I diffused the situation, ensured the client was

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safe. A complaint was made about me because I did not ring the office and make an appointment to go to visit that home.

Now, when you've got a provider who has that sort of attitude, that actually 'we don't welcome anyone to visit these homes because we want to make sure everything is squeaky clean and people are...' before they enter, I think that's a perfect example of we can't just wait and be invited, there needs to be stronger safeguards. And sorry, I have to add in here as well, advocacy funding because [TAS Advocacy organisation]'s statewide, we've had our books closed for the whole of April because we are working completely at over-capacity all the time. So yes.

MARY MALLET: Thanks, [TAS Advocate 2]. I'm going to just... there's three others that have joined us and I'll quickly ask them to introduce themselves and then we'll continue with this conversation, and we might come back to a couple of those points. We've got [SA Advocate 4], [VIC Advocate 4] and [SA Advocate 3]. In that order, you can quickly introduce yourselves, thanks. [SA Advocate 4]? Maybe not. [VIC Advocate 4], can you hear us? Do you want to just introduce yourself and your organisation? Okay, I can see [VIC Advocate 4] in the chat struggling to get his or her mic working. [SA Advocate 3]?

[SA ADVOCATE 3]: Hi, everybody. I'm [SA Advocate 3] from [SA Advocacy organisation] in South Australia. Apologies for being late.

MARY MALLET: No worries. Thanks, [SA Advocate 3]. Lovely that you could join... So [VIC Advocate 4] from [VIC Advocacy organisation] and [SA Advocate 4] from [SA Advocacy organisation]. I'll just go to... so let's continue on that topic. We may come back to that exact issue that was raised at the beginning, but I just want to give people an opportunity to see if there are other areas that you want to throw in the mix for solutions to any of the issues that you are grappling with. Yes, thanks, [VIC Advocate 5].

[VIC ADVOCATE 5]: I suppose I just want to join the chorus of bolstering the NDIS Commission and the outreach program now. I think that's an important point to emphasise.

Another thing that may have been touched on previously is promoting diversity of providers, so there's increased risk when everything is under the same roof, going on a white bus from the house to the day service all under the one roof. And safeguarding through inclusion and community access I think is a bit of a no-brainer that might have been mentioned a bit as well, but I think it's important to emphasise that. Yeah, they're key themes that come up time and time again amongst our team. So, I just thought I'd mention [those].

MARY MALLET: Thanks, [VIC Advocate 5]. Can I ask you, promoting the diversity of providers, how would you enforce that? Have you got an idea, or see if anybody else has as well. What should be done to stop a single provider having that total sort of control of a person?

[VIC ADVOCATE 5]: I can't give you the full details, but I know at one point - I think it was last year - there was discussion around changing the guidelines or such that you couldn't have a support coordinator who worked at the same organisation as the SIL provider. I don't know what came of that, but it was at least acknowledged at a broader level, at the NDIA level, that this was an issue.

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[NSW ADVOCATE 4]: Can I add something, Mary?

MARY MALLETT: Go ahead.

[NSW ADVOCATE 4]: This is [NSW Advocate 4]. I just wanted to add to that that's a big problem in this area as well, the Northern Rivers area, that there's providers that provide everything, support coordination, plan management, there's even SIL homes... It's full control and it doesn't work well and then the client... I know one person in particular, they thought where do I go? They feel they're obliged to stay with that service. I said, "No, you can go somewhere else", but that makes it very tricky for that person to go, "Hang on, I've got a complaint against the support coordinator" or someone in the house, because everything is controlled by the one organisation. It's a real problem.

I would think, having a law background, the best way around that would be for the Parliament to pass legislation to say that that's... to rule it out basically, to say that can't happen in the future because that is a real problem. People need choice and control. They shouldn't be controlled by one service, especially if they don't have parents or a person responsible to give them a voice. Then they really... they just stay there, and they don't realise that there's other options. So that's all I want to say.

MARY MALLETT: Thanks, [NSW Advocate 4]. Now, other people who want to come in were [VIC Advocate 6], [WA Advocate 4] and [VIC Advocate 2]. So [VIC Advocate 6], we'll go to you next.

[VIC ADVOCATE 6]: Thanks, Mary. I think, if I'm understanding, what you're asking is around the final report is coming up, how do we want to influence, if you like, the look of that report. From my perspective, firstly I'd like to see that there's almost a declaration that this is a crisis, this is something that needs to be addressed - the number of people with disability that are living in a situation or have been exposed to abuse, violence, exploitation.

The second thing I'd be pointing out is, what does the future look like? Succinctly spell out the future, and it could have key elements in it... for example, that people with disability should be involved in all levels of decision making, and I'm particularly talking about people with cognitive disability here. There's some involvement of people with cognitive disability, but there needs to be a cultural and a community shift, that there needs to be not only the exposure, because I think this is what we've done. I think we've exposed, we've talked about it, so now we need to set up systems that ensure transparency, which I think a few people have spoken about here - that transparency, that safeguarding. I think COVID has been another example of all of this being exacerbated and the most vulnerable people ... and so that needs to be highlighted.

Then I suppose one of the last things is ensuring that we continue to declare, or we continue to highlight, the value of advocacy as a safeguard or an oversight measure and it's a critical component.... it's not an add-value, it's a critical component to the outcome of any recommendations.

And then, in fact, that we've got... I can't think of a better word, but power, but we've got respect or something in place. Particularly in situations where advocates, I mean, there's

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no legal right of an advocate, and I think that that is problematic when you're endeavouring to work alongside someone around some of these issues. So, it might be about changing the legal rights of advocates, similar to guardianship, but something needs to shift that's going to be sustainable, that needs to be in place for the future. This is a golden opportunity to change our future and I would not want to see this lost. Thank you.

MARY MALLET: Thanks very much, [VIC Advocate 6]. You've covered a broad range of issues there. That's great. Thank you. [WA Advocate 4]?

[WA ADVOCATE 4]: Yes. In fact, following on maybe a bit from that about the standing of advocates with regard to their right to be involved in advocacy work, citizen advocacy is primarily focused on cognitive disability as well. We've surveyed our advocates about concerns that they think we should consider in making a submission to the Royal Commission. A couple of areas that have come up for us from that survey are access to information, perhaps also some concerns around health care access and delivery, and I'd say a common thread might be what can be done to prevent and mitigate the problems.

One of the concerns that I have is the application of privacy and confidentiality provisions in the management of disability services. So whether there's something that can be done from a training or an orientation point of view to, sort of, clarify what the limits of that are and what the reasonable expectations are for advocates to have access to information, whether it's about disability service provision or the NDIS planning and management process.

MARY MALLET: Thank you. Thanks, [WA Advocate 4]. I think it was [VIC Advocate 2] I think maybe was the other person who had their hand up earlier to speak.

[VIC ADVOCATE 2]: Thank you. Just wanting to add in there, I think it was back to... sorry, I'm not sure who talked about the decision making, people with disability being involved in decision making at all levels. Yes, it's a significant concern amongst the people that I work with that this doesn't occur and the focus on that. Particularly from our ATSI [Aboriginal and Torres Strait Islander] worker, [there is] concern about the lack of understanding around some forms of abuse, particularly financial abuse, so yes, abuse occurring without intentionality.

And then, in regards to the workforce, where are the real checks and balances in this sector? We have the Safeguards Commission and in Victoria the Disability Worker Commission, but my experience of them, and again speaking with colleagues, has been extremely disappointing, very slow moving and, in some cases, actually add to the harm and the situation because of their lack of response or their... Yeah, one situation I'm working with, we're now four months down the track and the investigation still hasn't been completed and the lead investigator is not returning my phone calls and not responding to my emails.

So, we have these things in place, but they are not effective, they are not actually supporting people with disability. I'm sure there are experiences where they have, but that's been my overwhelming... yes, both with National Safeguards and the Disability Worker Commission, they don't seem to have any real teeth.

And then... yes, concerns about the workforce and the level of skill, effective education and training and then leadership, such a lack of oversight in so many scenarios where there's

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one-on-one sole providers even in large organisations. So, yes, that's the swag of my list, thank you.

MARY MALLETT: Thanks, [VIC Advocate 2]. I can see [VIC Advocate 3], [SA Advocate 4] and [TAS Advocate 2] have got things to say, but can I pursue this particular point about the workforce stuff just for a second. So, everybody else hold the thoughts or scribble them down if there's other stuff you wanted to say. I can see [P5] from the Royal Commission has put a point in the chat, which is, "Has the introduction of 'zero tolerance' approaches in workforce training had any impact?" Does anybody want to comment on that, zero tolerance I think being the NDS sort of project that has waxed and waned over some years, but don't know whether it's doing anything at the moment.

[VIC Advocate 2] is shaking her head. I'm interested... so, whether it's zero tolerance or something else, has anybody got anything in particular about if you... especially pushing towards solutions, that issue about the skill, education and training that is required for the disability support workforce in particular? Has anybody got any solutions that should be being put in place to improve that?

[NSW ADVOCATE 4]: I have one suggestion. Hi, it's [NSW Advocate 4] again. As far as the quality of support workers that are being employed by service providers, it's quite questionable and a lot of them have got no experience whatsoever. And then they will pair them up with someone with really high needs and intellectual disability and expect that person to be able to cope with the person with high needs, and of course it's going to fail. Then that poor person with the disability is left with no supports. And that's a common theme in this area. There's a shortage of support workers, so I'm finding that they're employing people who really shouldn't be working with people with disabilities. Who's there to speak up for that poor person with disabilities?

So, I think better training and sometimes these organisations can be proactive. There is one I know of up here who actually... because I've spoken to them and told them about this situation and it was sort of a cultural thing in their organisation, and also the staff, their admin staff weren't very nice to people with disabilities either and... told them they can't choose the workers they want to work with, et cetera. Those people have been dismissed, which is good.

So, there was a bit of a cultural thing in that particular organisation, but the CEO has... there's been a new CEO employed and she's looked and gone "no, there's a bit of toxic admin staff here or people that are not respecting the choices of people with disability," So, she's actually got rid of them, which I thought was really good. So, these services can make changes, but it has to be brought to the attention of the person at the top, the CEO or the managers or whatever, to make changes. They need to make sure they hire quality staff, [or] at least train their staff before they put them with someone with the high needs so they're not put at risk.

There was one incident up here last year and this one lady ended up naked and in the river. It's just ridiculous. So, they need to be more accountable, but also putting better safeguards for people with disability. And there needs to be more choice and control because when I'm hearing people have come to us for advocacy and said, "This provider is not listening to me," I've said, "I want to work with this key worker so many days" and they've told me "no, sorry,

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you can't have them." It's like they're not available, but they are. The person with disability knows that they are. So, there's that sort of discrimination as well.

MARY MALLETT: Thanks, [NSW Advocate 4], and I can see people are putting some comments in the chat about some of the solutions. So [VIC Advocate 2] has put in a point about the standards of training, training by proven providers only, not the generic RTOs that are just in it to make money, minimum qualifications, Cert IV... [VIC Advocate 2] is suggesting and they must have supervised placement, et cetera.

Can I ask about... as the NDIS came in, this was an area of heated debate about the qualifications of staff and the people who wanted to, people with disability who wanted to self-manage and wanted to be able to recruit staff... whoever, whoever they wanted, whether or not they had qualifications. I'm just interested, does anybody have a view as to... was that a mistake? Has that played out well? Has it caused a problem? Should it be revisited?... just if anybody has a view on that, and feel free to put it in the chat if you want, but you can dive in quickly if you want to respond. Okay. We'll put it in the chat.

[VIC ADVOCATE 5]: I'll dive in.

MARY MALLETT: Thanks, [VIC Advocate 5].

[VIC ADVOCATE 5]: That's an option for people with funds. They have more flexibility around who they use for support, but we're still seeing a great deal of these issues for the registered providers and the participants who have their funding managed by the agency and those registered providers that have to jump through the hoops and do whatever else, there are still those workforce issues. So, I'd say that's not the key causal... it might be playing a role, but it's bigger than that I suppose, yes.

MARY MALLETT: Yes, it's about the whole workforce, yes. Thanks, [VIC Advocate 5]. [NSW Advocate 5] and [QLD Advocate 4] have joined us as well since and I can see people are putting some comments. There were some people who were still waiting with their hands up, which I think was [SA Advocate 4] I think and then [WA Advocate 4], I'm not sure if your hand is still up or you've put it back up.

[SA ADVOCATE 4]: I just had something going back to the lack of service providers and the lack of choice. We've been doing a bit of outreach, and I've been on Kangaroo Island fairly recently, and there isn't much choice there with the service providers. And, what I'm seeing a lot of is, people going to their GP and the GP suggesting perhaps they should look into NDIS and they have quite serious disabilities that they've just been managing on their own on their farms and things like that. And also people having strokes and injuries later in life and then trying to access NDIS. But there's nothing there that assists them to help, so we're coming in and trying to do as much as we can., But there's also really low literacy because there's few jobs so people leave school early. So, they can't really just be given forms to fill out. We've got to go... it's a big time commitment to read through with them, to make sure that they know what they're going into and even if they do get NDIS, they have such a slim choice of providers and if they don't... a lot of people know everyone... if they don't want to go with that provider, they choose not to engage and then they're just not getting any services or support.

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So, perhaps something linked in with the GPs, advocates, social workers, that they could be directly referred to as a third party that can help them with those processes and encourage them to stay engaged, because I'm finding people are becoming engaged and then can't contact them again. It's too hard.

MARY MALLETT: Thanks... lots of interesting points raised there, that issue, that sort of last one about common... not the GP one but the one before that, about an issue that's common to regional areas where people tend to know each other, and they are therefore wary of all their business being known by other people. If anybody has seen a good solution or response in a regional area, the Royal Commission I'm sure would be interested if you have a good example.

I want to move on to another specific question, but it picks up on some of the issues that people have already talked about. Do you have examples you can share of when you've seen service providers take serious steps to make positive cultural change and implement that practice across their organisation, and what barriers have they faced in doing that? I suppose where it flows from is when you've worked with providing individual advocacy with a person who's got a problem with a service provider, have you seen the provider resolve the situation for that one person but then bring in changes across organisation. Do they just fix the issue for that one person, or have you ever seen a good example of where a provider or a service has then picked up the good practice they've put in for one person and implemented it across the organisation? Has anybody ever... do you ever see that happen?

[VIC ADVOCATE 7]: Can I jump in there, Mary? It's [VIC Advocate 7] from [VIC advocacy organisation]. I've seen both. I've seen a situation where they've just changed the processes for that one particular person because we were working with the participant and we work with people with intellectual disabilities. But I've also seen just recently where a provider has gone out of their way for one incident that happened and changed their policies and procedures and even their training.

I think the barrier there is just the willingness to do it. So, one provider wasn't really willing to dedicate resources to ensuring that their processes are adequate for their participants, whereas another one just was able to do that.

MARY MALLETT: [VIC Advocate 7], do you want to tell us the name of the provider who did make that change?

[VIC ADVOCATE 7]: Yes, am I allowed to say that?

MARY MALLETT: Yes, please do.

[VIC ADVOCATE 7]: [VIC provider] so they're a nursing provider that there was a big medication mishap which ended up with the person with disability needing hospitalisation and quite serious hospitalisation and they... yeah, they just identified, you know... they basically confirmed what we found in our investigation as well, but they also found out that initially it was definitely an issue with their policies and procedures and also particularly their policies and procedures didn't really... it was very difficult for a new person to come on board, like a new employee to come on board and follow those procedures. So, they went back to the drawing board, from what we can tell, to realign, yeah, their procedures, to make

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it more accessible to everyone in the organisation. They even went to the point where they allocated for each person... allocated a manager that needs to do at least two shifts with the participant in the week.

MARY MALLETT: Mmmhmm-. Thanks, [VIC Advocate 7]. What's interesting about that example is that it's a nursing service and it just makes me wonder whether there's something in that sort of medication issue thing. --

[VIC ADVOCATE 7]: I'm not sure because that was the second nursing provider that that person had. The previous one actually walked away from this person because it was a little bit... this person had complex needs and was probably a little bit too difficult for that other nursing provider to deal with. So yeah, it probably depends on the provider.

MARY MALLETT: Yes, thanks, [VIC Advocate 7]. We might come back to you about that. That particular one might be interesting as a case study, I think. There are other people waiting. [VIC Advocate 3], [TAS Advocate 2] and [VIC Advocate 8], I think, are all waiting to speak. [QLD Advocate 4], you had yourself, I'm not sure if you wanted to speak or not. Maybe.

We'll do [VIC Advocate 3], [TAS Advocate 2] and [VIC Advocate 8] and then [QLD Advocate 4]. Thanks.

[VIC ADVOCATE 3]: I just wanted to go quickly back to the safeguarding issue. So, I was thinking advocacy is part of that nexus of the Quality and Safeguards Commission and lawyers who provide... have this safeguarding role. But one of the things that's really apparent, I suppose, in most legislation around Australia - although I guess I'm speaking more specifically about Victoria - is that people's rights don't travel with them across sectors and across legislation and so safeguarding doesn't either. So, we have these pockets of people who are not able to... they don't have rights because they happen to be subject to legislation that is stronger than disability legislation and so, we have these kind of dark forgotten corners, like people in prison and people involved with child protection, for example, which are two really big areas for us at [VIC Advocacy organisation].

So, we actually need to have some legislative change around strengthening disability rights within legislation so that people's rights can travel with them because, at the moment, we basically have a system where you can only have rights in a disability system, you cannot have rights in any other system because the legislation in other systems is stronger.

So, one of the things that we find in advocacy, particularly around child protection and people involved in the justice system, is that talking about disability rights, talking about the UNCRPD [United Nations Convention on the Rights of Persons with Disabilities] is fairly useless because it isn't... it's not enshrined [or] it's only in disability-specific legislation. So, we have to rely on say, for example, the Equal Opportunity Act in Victoria, which we know is not strong. We also know that the human rights charter is not strong and has to be tied to other legislation.

So, in advocacy, we can do what we want in terms of the NDIS Act [and], in Victoria, the Disability Act, but once we have people who are trapped in other systems, we have absolutely no power. So, we only ever serve people in disability systems... People with

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intellectual disability in particular, I guess, only have rights when they're in disability systems, which they're captured in, and when they go into other systems, they lose those rights. So, then one of the things that happens is they bounce between systems, but it's usually a mess and there is no safeguarding for people when they're bouncing between different systems.

MARY MALLETT: Thanks very much, [VIC Advocate 3]. That's a really useful way to think about it and frame it, yes. So, I think [TAS Advocate 2] next.

[TAS ADVOCATE 2]: Yes, I just put in the chat that I'll write up some examples and send them off, but I think there's... we need to lift the bar in terms of expectations because the support worker... it seems that they've got more sense of responsibility to their employee than they do to their clients. So, we need to somehow shift that and, in fact, to the community as well. Because when I witnessed this issue of abuse, the local inspector who lives three doors up walked past, witnessed the same thing and did nothing. So there really is a need to lift the bar in terms of expectations and everybody's responsibility to protect the rights and prevent abuse.

MARY MALLETT: Mmm, thanks very much, [TAS Advocate 2]. [VIC Advocate 8]?

[VIC ADVOCATE 8]: Hi, thanks. I'm relatively new to the role, specifically as an advocate, but I'm just drawing on some of my experience. When I worked for a service provider, I was doing facilitation of like circles of support, that kind of thing, in terms of positive organisational change. We had this model that got rolled out based on trialling it with one individual who was experiencing what we came to reframe as, like, nonverbal expressions of distress, but a lot of their support workers were reporting them as behaviours of concern and this kind of thing. This person was acting sometimes in what was interpreted as an aggressive manner, they were sort of lashing out with some... yeah, just moving around a lot I guess in that way and getting very frustrated. It was causing them a lot of distress and sort of not allowing them to go about their day-to-day lives.

And what we devised talking with that person and their family was this idea of getting everybody who works with that person together on a semi regular basis, with that person present if they want to be, and their family and, in this case a behavioural specialist as well, to devise like a positive behaviour support plan that was driven entirely by the individual, because another challenge we were having was that everyone who worked with this person wasn't really in regular contact, they were all trying different approaches to assist this person and there was no, like, consistency.

That was really, really successful. We started to put that positive behaviour support plan into play with this person and their anxiety was easing and people were able to, yeah, stay in contact about that and the person's voice was really central to that process. Then that model was rolled out and trialled with a number of other families too - not necessarily around the same issue, but just it was seen to be really effective getting everyone in communication with one another.

MARY MALLETT: Yes, thanks, [VIC Advocate 8]. What's the name of that provider?

[VIC ADVOCATE 8]: That's [VIC provider] in Brunswick.

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MARY MALLET: As a matter of interest, we want the Royal Commission to hear and know about some providers that are doing some innovative things and trying, you know, doing versions of some good practice. So, people can feel free to name some of the good ones, or you can name... --

[NSW ADVOCATE 4]: Can I name a good one? The one I spoke about before that they're making cultural changes and the new CEO, it's [NSW provider] up on the north coast in Ballina. They've been very proactive. They've gone as far as hiring a behaviour support person, like a specialist. They've hired this person for this young man who's 17 because he had... was having behaviours at school and they actually hired this person to assist with the teaching staff and the caring staff there to work with this boy [because] he was getting a bit anxious and heightened at school and biting himself and stuff, not so much lashing out but throwing things around. So, they've actually been proactive and hired a behaviour specialist, and they're going to train all the staff and support workers to work with this lad.

I thought that was really positive, a good cultural change for that organisation, and they're being very proactive and it's good business. They see him as a person, not as a burden, or they're treating him with respect, which I think is really good, and talking to the family and involving the family and all the care workers and teachers, et cetera, to manage him and keep him happy, keep him at school as long as he can. So it's good.

MARY MALLET: Thanks, [NSW Advocate 4]. [QLD Advocate 4], I think I muted you, but you can unmute yourself. Hang on, take yourself off silent.

[QLD ADVOCATE 4]: With regards to good cultural change, I'm sorry, but I can't think of anyone. Unfortunately, when advocates get involved, it's usually because of problems and we're talking NDIS systems with service providers that are not doing the protege, person who needs an advocate [is] stuck in a bad situation, so the advocate is trying to deal with providers... not good examples of service provision and good culture. And so it's hard for advocates, and even our program as a coordinator, to be able to see changes at individual settings, let alone across an organisation.

It's just like oh, I'd love to see that happen, but my impression is it's smaller niche-type providers that are more interested in doing what the NDIS is aimed to set up to do, which is provide that high level of service, which is really trying to improve the lives of people rather than fit them into the organisation's way of doing things. If there's a big provider out there that can change after an advocate has been involved, I'd love to see it. I'm more and more convinced it's going to take a systemic change through the Royal Commission where, for example, advocacy is given credence and given recognition, rather than just the Act say that, that the actual providers have got systems in place to listen to advocates.

An example of where it's not happening up here at Rockhampton is - one provider has just contacted me again this morning and the NDIS fragments services so you've got service providers, you've got disability support coordinators, and so on, and different entities - So, the actual staff in this residence are telling... one of the residents has got an advocate, a new advocate has come in for another resident, so they've gone to the first resident and said to that advocate, "Can you look after the interests of the other person too because his advocate is not showing up?" trying to co-opt the advocate to help them move these two residents out of that house and they both don't want to move.

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I'm just staggered at turning a whole advocacy process around, so the advocate is working for the provider, not for the NDIS participant or, in our case, it's the protege, but they're NDIS participant, just perverting the process. So, they're trying to get an advocate to do their bidding instead of being independent and working in the interests of the person with the disability. They don't think twice about it. I've explained it, that's not going to happen, you can't take on more than one person, it's a one-on-one relationship, and yes, I will ask the advocate who's been called away to work out of town to get up to speed and start dealing with this issue as soon as he can.

And another provider... it's a separate example where the advocate wasn't even given permission to talk to their protege in the house they were in, and this is not a SIL house or it wasn't... the house was not owned by the provider, it was the resident's own house, and they announced to the advocate, "No, we haven't got permission to talk to you because of privacy." So crazy stuff... an independent advocate being denied access to a person who's got a right to an advocate.

So, dealing with that particular service provider at CEO level and national director level, it's been hard because they are a for-profit organisation, not a not-for-profit. They don't have any background in disability support, and they see NDIS as a bit of a cash cow. They don't want any threat to their relationship with a participant with a very high NDIS plan, a high-value one, and they don't want advocates coming in and rocking the boat.

So, to get a cultural change in a big organisation... to name names, it's [NDIS registered provider 1], the first example where they're trying to move residents out without the consent of these advocates, and this other organisation, [NDIS registered provider 2], where it's coming from the top down right down to support worker level. They're saying, "We've been told by the office that we're not to talk to the advocate." When I ring up that office, they deny it. But it's obviously been the case and they're saying, "Well, we can't allow this because of privacy." I'm saying well, you quote the privacy rules that say consent by a protege doesn't allow the advocate to talk on their behalf about their welfare?

So, it's almost like there is no need, no recognition for the role of independent advocates with some of these providers. And I've talked about this with you, Mary, that I think we need almost like a blue card system where there's official endorsement of an advocate, an advocate has official standing, it's not just trying to explain themselves each time and get the goodwill of people at a setting, that there's actually some actual teeth that go with being given the authority or the role of an advocate.

MARY MALLET: Thanks very much, [QLD Advocate 4]. I've already made a note at the beginning of this discussion because this similar topic came up at the beginning and it's been through on the chat thread as well. And I think there's actually a need for a whole separate piece of work, and some of you are welcome to be involved in it, about what are... actually what are the changes that are required, to which pieces of legislation, to give advocates that further standing and right of entry and all the things we think advocates need to have for you all, including citizen advocates, to be able to do their role, play their role properly. We won't pick it up today because it's too big, but I think we will pick it up as a separate piece of work.

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I can see people discussing which Act actually, in the background on the chat, but the Disability Services Act nationally is where the NDAP, the federally funded advocates, that's where they sit, it's where they get their authority, I suppose, and the same in the Disability Services Acts in the different states and territories, but some of those have changed. We'll bring it up as a separate issue.

We might move on from... I can see... I've got [WA Advocate 4] and [SA Advocate 4], you both have your hands up. Do you have particular... other things you wanted to say now before we move on to the next issue?

[WA ADVOCATE 4]: Oh, perhaps just briefly one thing on providers we've had good experience with here in Perth, I'd say [WA provider] is one. You know, we've seen a good transparency around their operations of being supportive of advocates [and], the other advocates' access to information like NDIS plan provisions and plans.

The other thing I wanted to say, in regards to qualifications and training of support workers, is some of the cultural considerations... here, I mean cultural and linguistic background ... some of the feedback I'm getting from experienced advocates is that that's a two-way process sometimes with recently arrived migrants or workers coming in from different cultural backgrounds, that they benefit as well from some additional training about the environment that they're going to be working in, and perhaps more can be done around that area. Thanks.

MARY MALLET: Thanks, [WA Advocate 4]. [SA Advocate 4], did you have a point you wanted to make? I'm not sure. Come back or put it in the chat, [SA Advocate 4]. And [VIC Advocate 5], were you wanting to leap in there?

[VIC ADVOCATE 5]: Just a quick point about I think - part 2 of question 2, about what barriers they face in broadening these positive cultural changes. I think [VIC Advocate 8] raised an example of [VIC provider] I agree is a good service, a small service... pointed out as is often the case later. That seems like the exception to me where there's that more consultive, transparent, multidisciplinary approach because it's an individualised funding scheme and it's about what funding the client has in their plan, so how much time can we devote to them and how many experts can we... how much time do we have to spend on the phone, so on and so forth. That's a barrier why it's often an approach of providers to kind of contain a situation to just address individual as opposed to broadening those practices.

MARY MALLET: Yes. Thanks, [VIC Advocate 5]. I'm going to pass over to [P6] now in the Royal Commission policy team. There's a couple of questions that [P6] wants to lead you through. So, if you want to pick that up now, [P6].

[P6]: Thank you, Mary, happy to. Basically, at the Royal Commission we'd like to ask questions in relation to what we call primary prevention and whole-of-population approaches (inaudible) I realise bringing these terms to the team, already we've had a very rich discussion and some examples actually being used in this space. But I'll explain what we mean by primary prevention, and here we're talking about - we'd like to seek your views on - what we can do to address the underlying deep-seated causes of violence, abuse, neglect and exploitation in order to stop them from happening in the first place.

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So, I think it was - it may have been [VIC Advocate 6] or [TAS Advocate 2] - spoke about the need to lift the bar to talk about this in terms of the golden opportunity that early preventive stage. What can we do in terms of advocacy to ensure that these things don't happen in the first place? For example, if we see one of the deep-seated drivers of violence, abuse, neglect, or exploitation being the lack of rights awareness, both on the part of people with disabilities themselves and the broader community, then advocacy would be a key way, very important way, in which to safeguard the rights of people with disability against that sort of violence.

By whole-of-population, we're speaking here in terms of approaches or solutions that work with people across all sectors, all systems across the broader community, which makes, I think, I think [TAS Advocate 2] referred to earlier - prevention everybody's responsibility. So what can we do and what role can we play in changing the culture, the structures and attitudes that drive violence? And already we've heard very rich comments in that space, not least reimagining forms of decision making arrangements that came up... I think it was [VIC Advocate 6] who put that forward, in terms of guardianship, and Mary just mentioned probably a workshop on that, but what role can advocates play in a formal way to give them the standing they need for example, just a few... We already had a very rich discussion, but I might hand over here with a question. Can you explain to us, for those of us who aren't at the coalface and on-the-ground in this work, so that we can spell it out clearly in our recommendations, the preventive power of advocacy for people with disability? And how does access to independent advocacy assist in prevention of violence, abuse, neglect and exploitation? Thanks, Mary, I'll hand it over.

MARY MALLET: Okay. So the preventive power of advocacy. Does anybody want to dive in on that one?

[NSW ADVOCATE 4]: Hi, Mary, can I? I've just been chatting to [NSW Advocate 6]. We both feel it would be good if every service agreement given... whenever people sign their service agreements, that the service provider informs the participant... it should be basically on the service agreement [that] there is a local advocacy service in their area that can support them if they have any issues of abuse, neglect or exploitation, et cetera... so just to make them aware that there's someone out there, an independent person that can help them.

MARY MALLET: Thanks, [NSW Advocate 4]. That's the first time that's been suggested to me. [VIC Advocate 3], I can see you've got your hand up.

[VIC ADVOCATE 3]: I think one of the things that we find is that one of the biggest roles that we play in advocacy is about reframing issues and reframing behaviours. So, I guess because we work exclusively with people with intellectual disability, one of the things that we see is that a behaviour is interpreted in a particular way, and people respond to it with restriction or in a punitive manner, and one of the things that we constantly do is reframing issues in a kind of rights sense. So, a lot of the time we're not actually busting in and making complaints and doing things, but, actually we're kind of, very subtly, doing a whole lot of education around rights.

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And that's one of the huge absences in the community at large, is that the kind of knowledge of people's rights and inclusion and also the diversity of people with disability is... people with disability are still very much excluded, discriminated against and marginalised. And so, if you have a sector that is very new and with a lot of new people in it, often those people come in with a whole lot of, kind of, community attitudes about how people with disability should be treated and especially people with cognitive disability, and the risks that they pose, and the risks they pose to themselves, and the decisions they're not able to make... all that kind of thing.

So, a lot of the prevention work we do is kind of going in, talking about how you might sort of see an issue differently, and reframing people's understandings of things, which I think is... like that's a huge thing for us. And it's an educative function, but it's also a preventive thing, because what we find is that people then come back to us again and again and say, "Oh, so I've got another client and I was remembering that time you told me blah," and so you can provide them with a whole lot of resources or education around how you can do things and see things differently in a more rights-based way.

MARY MALLET: Thanks, [VIC Advocate 3]. [TAS Advocate 2], yes.

[TAS ADVOCATE 2]: I think the suggestion before about being in service agreements is fine, but if you have someone who has a significant disability or who has communication needs, then they actually rely on their support, or someone to actually contact an advocate. And that's the assumption, that they actually know what abuse is because I had one just a couple of days ago who was thrown in the shower with her... by her support workers fully clothed. She thought they were just having a bit of mischief. So, there's real... understanding around what is abuse, but also there's a dependence on support workers to actually contact an advocate, that doesn't always happen.

There was another point I was going to make and now that's slipped out of my brain. Oh, so the preventive, so it's been really strongly evident... we co-facilitate Self Advocacy meetings monthly around Tasmania with members, and support workers say to us that just the fact that they have that... clients have or members have an invitation to attend a Self Advocacy meeting with [our organisation] on a monthly basis is a prevention. And they say this person in a four-bedroom group home who attends gets better treatment, because the staff are aware that they're connected to us, than the other three people in the group home.

So that's a really absolute stark example of the value of when they know people are connected to advocacy, that they're actually... they're a bit more aware and a bit more conscious and it's unfortunate for the other three people in the home, but it's fairly strong evidence that it actually works and it is a prevention.

MARY MALLET: Thanks, [TAS Advocate 2]. [QLD Advocate 4], did you want... --

[QLD ADVOCATE 4]: Yes, just quickly, it's hard to say something was prevented when it didn't happen because you're saying some intervention stopped something happening and then you're saying it didn't happen because of that. But I agree with [TAS Advocate 2], if you've got a person coming in with fresh eyes who's not paid by that provider... and we're talking SIL settings and the NDIS world of clients and providers here... so, if you've got someone coming in who's not a community visitor but an independent advocate who can

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ask questions and say, "How has your day been? What's going on?" And the value of advocacy in these situations is so much more valuable where people are very vulnerable, because they've got communication problems and they don't have family and friends around them. So, an advocate makes that person more visible - suddenly the staff are aware 'this person has a right to come in, ask questions, talk to us and we are being watched.'

So the example I've got is the house that I mentioned earlier with [NDIS registered provider 2], someone, a support worker, had been buying groceries and those groceries had been disappearing and the advocate noticed why was this big pork roast in the freezer, and it's gone and I know it wasn't cooked up and used for the protege, for the person with disability, she never got to eat any of it. There [were] a few other questions about groceries being bought, using the funds of the person with a disability and being ticked off without anyone, a family member or an advocate, seeing it. I inquired on behalf of the advocate and wrote an email and suddenly things started to happen and they launched an inquiry and that particular support worker was no longer working at that location.

Now, she'd been getting away with it and who knows, it may be just a bit of pilfering, which is not just pilfering, it's a breach of trust and an example of the financial abuse. It could have gone further. She had no-one watching.

This is the sort of thing that advocates can do, they can nip it in the bud. And you can't say random things that didn't happen here because you... they were going to happen definitely, but you can see the way it was going.

MARY MALLET: Thanks, [QLD Advocate 4]. Can I come back to... there's some really great stuff that people have been putting in the chat. [VIC Advocate 2], can I come back to something you put in the chat about suggestions about circles of support or making supported decision making mandatory and human rights and disability rights training. Do you want to just explain about how the supported decision making and the circles of support will help?

[VIC ADVOCATE 2]: So, I did put question marks next to them - I'm not generally into making things mandatory, but in terms of... really concerned about how do we ensure that someone is actually making a decision, that they fully understand what they're making a decision about, and it is something that they want to do if they do not have that support? So, people with cognitive disabilities particularly, there was a comment earlier about having... when you sign a service agreement, having it spelt out that there is an advocacy service they can contact. Great if they can, but yes, not great if they don't know that they are experiencing abuse, or their rights aren't being met, or if they do not have the cognitive and/or communicative capacity to do that without support.

If I could wave a magic wand, I would see that all people with disability were offered that. Obviously, there are people who have no need for that, and have the ability to make decisions without any support - but it actually be offered to individual. Imagine that, hey... folks, imagine that along with that concept of circles of concern, if that was something that was valued in our community... --

MARY MALLET: The NDIA are bringing out, sometime soon, a paper on supported decision making, so let's hope good stuff will come out of that. It will come out for

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consultation. Thanks, [VIC Advocate 2]. Sorry, I'm rushing a bit now because I want to get some other things in in the last 10 minutes or so. [SA Advocate 4], I think you've been waiting to make a point.

[SA ADVOCATE 4]: I wanted to make a point about preventive systemic advocacy. I think probably, looking at my files, if I could put a systemic file for every client I probably would... like, for example, someone comes to me with a communication issue and then we identify they haven't had an aged care assessment. And then when I'm talking to the communication provider, there's just no access for people with disabilities. And then I'm putting a systemic issue to them and trying to get that changed within the provider so that for other people in the future they will never have to use an advocate to resolve this issue, the provider can resolve it themselves.

I think that the role of systemic advocacy is so important in this sort of [prevention] of abuse and neglect, and if we just had more time and more funding for systemic advocates, that would be amazing because we've got all of these clients that have crisis issues. And if I have the time, I can put together these files, but they're really time-consuming... but I think systemic advocacy is just so important.

MARY MALLET: Thanks, [SA Advocate 4]. That's a really good point and, yes, we will take it up further and it's good for the Royal Commission to hear it, that there is more that individual advocates could do if you had more funding and capacity within your organisations or between your organisations to do some systemic work as well.

In the chat there's some really great points - [VIC Advocate 5]'s point about role modelling, that advocates role model respectful treatment of people with disability and empowering people and that that's visible to everybody that you deal with then in meetings and other situations. And that's a point that probably should be written up a little bit more, I think.

Somebody made a point earlier on...[VIC Advocate 4] I think it was... [that] independent advocacy can assist in individuals understanding their rights, and that they take that forward into other places and that all of the work about improving the disability rights landscape is preventive.

I'll just ask one... just quickly, in terms of that primary prevention focus that [P6] talked about, what is there that could be done about that whole-of-population level sort of cultural and attitudinal change towards people with disability? Can you think of examples that have worked in any other area of rights, or anything else that you think could be used as a good model and what... yeah, is there anything you can think of that could be done in terms of just that big picture cultural and attitudinal change? [VIC Advocate 7]?

[VIC ADVOCATE 7]: Hi. Yes, I'll unmute myself. That's better. I guess if I can give a slightly different answer. I'm not sure if I'm answering your question directly, but in the northeast suburbs of Melbourne - it's a very multicultural area, and we come across people with disabilities and their families that are not connected to services, don't even understand, never heard of advocacy. We've met somebody recently who's 45 years old, intellectual disability, not on the NDIS, being cared for by his 95-year-old mother from a CALD background that is no longer able to look after this person.

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So, I think the Government needs to, and even advocacy organisations maybe, have a little bit more funding to go to have more of an impact on people from cultural and linguistic backgrounds in a point of view from providing information, basic information, as to what services are out there and how to access advocacy organisations.

MARY MALLET: Thanks, [VIC Advocate 7]. Yes, very good point. [VIC Advocate 2] wants to compel everyone to be self-aware, open-minded and open-hearted. That's a nice ambition, [VIC Advocate 2]. How do we do that?

Is there... can anybody think of a practice example of positive change that you've seen, that could be replicated across other systems? Has anybody got any example of a success that's happened in one area or a system and you think oh, yes, maybe that could be, the same change could happen in other systems as well?

I can see everybody is madly trying to think of 'God! success, do we ever have success?' ...It's really terrible because you kind of have small wins, don't you? It's the thing that keeps you going, that you do have successes for people, but whether they could be considered big picture successes is another thing.

Sorry, I can see in the chat some other stuff that's coming in. [P5] is suggesting to [VIC Advocate 7] that they'd like a submission into their CALD paper, might talk to you separately about that, [VIC Advocate 7]. [VIC Advocate 3] had a point... and this is a big issue for advocates... that there's an assumption that advocates will do substitute decision making. That's a common assumption and that advocates are often asked to do that. So, I think there is a common misunderstanding, isn't there, in the disability sector about what guardianship means, what... even nominees in terms of the NDIA, but about actually who... yes, who can or should be making decisions for people. So, it's a big gap.

We've only got the last few minutes, so I'll just ask - and we've covered wide areas today - I'll just see if people have any final ideas or thoughts that you want to put forward today about, really across any of these areas, what you think the Royal Commission should be thinking about in terms of their recommendations in their final report? You'll have more opportunities to do this, but just as we close today, just to see if anybody has any other things that you want to make sure the Royal Commission considers?

[VIC ADVOCATE 5]: If I can, Mary, on those bigger population things, I guess these are obvious and I think might have been mentioned, but some of the things my team was saying are just visibility in pop culture, representation, and also early childhood education, and visibility and proper education for teachers in terms of inclusion, representation, staff training. I think those are the kind of broader population initiatives.

Raising the DSP [Disability Support Pension] so people with disability are perhaps in a position to be content creators and more involved in mainstream productions, and so on, might go some way to addressing some of those upstream kind of approaches, or cultural attitudinal changes, I should say.

MARY MALLET: [VIC Advocate 5], the very first point you made there, did you say visibility in popular culture, is that what you said?

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[VIC ADVOCATE 5]: Yes, I think one of the things that was mentioned when I was chatting with colleagues was that rarely are people with disability as actors in mainstream programs represented as fathers, lovers, whatever it might be. It's still often the case that it's about the disability. So, I think that's starting to change and it's not something you can just, kind of, change overnight or with the right policy or whatever. But I think these are the kinds of things that go a long way to progressing the culture.

MARY MALLET: Yes. Whatever that... I can't remember what it is, some music program that was on television late-ish last night [The Set on ABC] and I caught a glimpse of it, that Dylan Alcott is one of the presenters now ... not necessarily my music or stuff, but just the fact that there is a person with disability who's there not because he's a person with disability but because of his presentation ability and his interest in music. So, that's one current example, - actually, that is useful.

I can see [SA Advocate 4] and [QLD Advocate 4] I think have their hands up to make some closing remarks.

[SA ADVOCATE 4]: I think it's been covered.

MARY MALLET: Okay, thanks. [QLD Advocate 4], did you have a final...?

[QLD ADVOCATE 4]: Just a conversation I was having this morning about the funding situation for disability advocacy in Queensland and the Royal Commission is obviously aware that the Aged Care Royal Commission recommended an increase in funding, substantial increase for advocacy for the aged care sector. And I guess all of us are wondering and hoping there will be some recommendations, with input from us with submissions, by the Royal Commission about disability advocacy, the system.

The current systemic limitations are really clear - very poor funding across the board, split funding between the feds and the states, and even in Queensland at the moment, discussion about calling tenders for longstanding small disability advocacy programs... funding from next year is only for two years. And there may be tenders called, which means that no-one is saying yes or no, but it's a lot of uncertainty in this state when the Royal Commission is still taking submissions on issues to do with including advocacy.

So, I would love to see the Royal Commission maybe in a preliminary statement or like they did earlier last year - they released an interim report - start talking about these issues to try to give some direction to the policy makers for advocacy, federal and state. It's in limbo. We're on the edges. The NDIS has got all the funds and advocacy is really quite marginalised. So, it would be good to see some of these systemic issues looked at sooner rather than later.

MARY MALLET: Thanks very much, [QLD Advocate 4]. I think [VIC Advocate 3] is the last person I'm going to call on, but I'm just going to point out that [NT Advocate 2] put some points in about those primary prevention big picture, whole-of-population things and [NT Advocate 2] has pointed out some of the sort of obvious ones that have made a difference at a population level, like the drink driving, smoking, seatbelts, all of those issues, and that they require commitment and resources, of course. [VIC Advocate 3], did you want to make a last point?

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[VIC ADVOCATE 3]: I was just going to say, Mary, this probably sounds like I'm pitching for money or something, but I think one of the benefits of advocacy being an independent service for people with disability is that the power of advocacy is the independence and the attachment... attaching rights to a person. We can't be part of a safeguarding system, you know, we don't want to be attached to government. It's different to lawyers who are bound by legislation and the limitations of their role, but I think the power of independent advocacy is that we can be incredibly agile and put ourselves in all sorts of corners where essentially nobody else can get to. And if we have, kind of, more strength to be able to get into some of those places, then we can be part of the safeguarding landscape more effectively.

MARY MALLETT: Thanks very much, [VIC Advocate 3]. That's a very good point to finish on.

[Closing remarks and wrap up]

MARY MALLETT: Thanks, everyone. And thank you for giving us your time today and we'll hopefully create some more of these opportunities. Okay, thanks, everyone. See you, bye.

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Comments typed in Zoom chat function

[VIC Advocate 2]: Great example [TAS Advocate 2]!

[VIC Advocate 3]: Same for us [TAS Advocate 2]. Most advocacy in Victoria is inaccessible because we're all at capacity.

[SA Advocate 4]: Apologies connection is rubbish but i'll jump in here is I have a q. Thanks

[TAS Advocate 2]: Strongly agree - no whole of life

[VIC Advocate 3]: service capture.

[VIC Advocate 9]: SDA are tendered to the one company within our regional area. if they want to stay in the area they don't have a choice of their SDA providers. i think this is usual practice

[P5 & P6]: Hi, it's [P5] from the DRC. Could you speak more to that cultural change - what does that look like? How do we make that happen?

Siobhan: standing or right of entry/access?

[VIC Advocate 3]: definition of the role of advocacy in the Act? It is mentioned in the act not defined.

[NSW Advocate 5]: What Act are you referring to?

[VIC Advocate 3]: NDIS Act

[P5 & P6]: [P5] again. Has the introduction of 'Zero Tolerance' approaches in workforce training had any impact?

[SA Advocate 4]: haven't heard of it or seen an improvement

[VIC Advocate 6]: The cultural change is extensive but may include involving people with disability in decision making at all levels, including people choosing their own workforce in group homes. The culture around zero tolerance to abuse, restrictive practice. Valuing people with disability and their contribution in our community and society. Also a cultural change around the value and powers of advocates.

[P5 & P6]: So this points to the casualization and lack of support for people in the workforce, as well as training?

[VIC Advocate 9]: organisations need to allow advocacy, sw [support workers] are too scared to reach out to us from group homes. theyre terrified they will lose their jobs

[P5 & P6]: Thanks [VIC Advocate 6]

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[VIC Advocate 5]: Yes [P5], I'd agree that casualization is a key issue

[VIC Advocate 2]: National Standards of Training and Training by proven providers ONLY - not generic RTO's just making money. Minimum of Cert IV, must have supervised placement etc etc.

[VIC Advocate 3]: It has been disastrous for people with intellectual disability mostly, and has led to unauthorised restrictive practices, abuse, neglect and exploitation

[SA Advocate 3]: [Our organization] is aware of some good news stories in this space, but also significant risk for others

[SA Advocate 4]: I think theres an assumption that if the provider is registered, they are qualified and people don't challenge them

[VIC Advocate 6]: We must not forget about the abuse and discrimination occurring at the hands of some family members. Who has oversight or safeguards these people

[VIC Advocate 2]: Good point [VIC Advocate 6]. How can we address this?

[VIC Advocate 9]: [VIC Advocate 6] great point when the only option is a welfare check by the police often people don't want to get the police involved we need a safeguards commission for people being cared for by family members

strengthening the relationship between OPA and the advocates who are frontline?

[VIC Advocate 5]: Addressing instances of abuse/neglect in the home/private setting is perhaps the greatest challenge

[NSW Advocate 5]: have supported several pwd challenge their family members who were being financially abused and controlled and not allowing services into their home to assist the pwd. We have gone as far as NCAT

[VIC Advocate 2]: [NSW Advocate 5] what is NCAT?

Unfortunately no

[VIC Advocate 3]: It often seems to be financial barriers. There is often good will with providers, but they are always constrained by funding.

[VIC Advocate 5]: Agree [VIC Advocate 3]

[NSW Advocate 5]: NCAT is NSW Civil & Admin Tribunal

[VIC Advocate 2]: Thanks [NSW Advocate 5]

[TAS Advocate 2]: Regrettably there are too few examples but are happy to write up and send later

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[VIC Advocate 3]: We find that service providers don't have the resources for good practice, so they just cope as best they can. WE also find that they will take direction from plan nominees due to fear of losing funding - and this can create situations where service providers are clearly colluding with restrictions and abuse, but fear of loss of funding seems to drive the behaviour.

[VIC Advocate 2]: Agreed [VIC Advocate 3].

- Accountabilities from those service providers that have had a complaint against them or several
- Penalties to those that show neglect and abuse but aren't serious enough to charge
- More regular but random audits that include the people who use the service – unannounced
- More protections for those that make a complaint or are whistle-blowers in particular with the employer so people don't feel uncomfortable or don't speak up for fear of losing their job or being targeted as a trouble maker

[VIC Advocate 2]: Brilliantly articulated [VIC Advocate 3]

[VIC Advocate 3]: Thanks [VIC Advocate 2].

[P5] & [P6]: Thank you for that, [VIC Advocate 3]

[VIC Advocate 6]: That is true [VIC Advocate 3] that this could also be viewed with families outside the disability system

[SA Advocate 3]: improved unity between systems is critical to success going forward

[NT Advocate 2]: Here in the NT larger providers and how much, as a percentage of their overall budget/funding, they allocate to their ongoing staff development and support in residential and outreach support (SIL, day program etc) is often more about lip service or severely compromised.

[VIC Advocate 6]: If NDIS supported people to develop circles of support or if this could be offered with paid facilitation this would naturally bring more people to someones life. Anytime I have tried to raise circles of support and funding attached to this NDIA planner was clear in denying this

[NT Advocate 2]: I see these as inextricably linked to minimum qualifications as exists in some jurisdictions of Child Protection, and the issue of safeguarding and access for advocates and/or CVP's.

[VIC Advocate 2]: Yes [SA Advocate 3]. I'm hoping that the DRC team are seeing the absolute importance of this and it will be addressed in the life of the commission via its recommendations

[VIC Advocate 8]: @[VIC Advocate 6] agreed! I should mention one barrier to the example I mentioned was NDIS funding, or rather lack thereof

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[VIC Advocate 3]: [Melbourne provider] are really good with Support Coordination. They have some innovative ways of doing SC that are very holistic. But they are not the standard model of SC in our experience.

[VIC Advocate 6]: Sorry Mary have to leave for another meeting

[SA Advocate 3]: Clarity of roles, responsibilities & best practice principles at every level, in every system, is required to safeguard people, activate supports and opportunities for individuals & remove the onus on people with disability to navigate and access any system or service

[NSW Advocate 5]: I want to mention that Medicare dental rebate scheme act is discriminatory towards children with Dis under 18 as they are not allowed to use this rebate if they have any dental work done in hospital, it has to be done at the dentists rooms to claim the rebate. But when these kids with disabilities can't sit in a dentists chair they have to be anaesthetized, so don't have the option as main stream kids.

[VIC Advocate 3]: Not having any official status also means that we are often locked out of QSC complaints. We have found that if the person is unable to understand the nature of the complaint and can't tell us what is happening, then service providers give disingenuous information that we are not party to (because of privacy).

[P5 & P6]: Thank you [WA Advocate 4]. We would be very interested in any responses to our issues paper on culturally and linguistically diverse communities, which is open until 11 June (but we'll accept input at any point).

[VIC Advocate 2]: Circles of Support? Supported decision making mandatory? Effective advocacy training/awareness of human rights in all communities

[VIC Advocate 3]: Definitely mandatory funding for people with cognitive disability for SDM [Supported decision making] if they require it.

[VIC Advocate 4]: independent advocacy can assist in individuals in understanding their rights as they move forward and enter new workplaces. While it is impossible to fully control or compel employers to respect the values and systems in place, a commitment to improving the disability rights landscape as a whole is, in a sense, preventative.

[VIC Advocate 2]: Yes [VIC Advocate 3]!

[SA Advocate 3]: Well said [VIC Advocate 3]

[VIC Advocate 3]: Yes, that's a great point [VIC Advocate 4].

[VIC Advocate 5]: Agree with all that's been said on this subject. Advocates can role model respectful treatment and provide an experience of empowerment when working with people with disability. The person themselves therefore have an experience of what it's like to be listened to, and supports around them witness this.

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[VIC Advocate 3]: Sorry, I meant that NDIA need to be compelled to provide funding for SDM when the person needs it. At the moment they state that the decision making gap should be filled by guardianship and advocacy.

[TAS Advocate 2]: Rights training needs to be compulsory for support workers and rights need to be tied to duty of care - only advocates make this link

[P5 & P6]: In Victoria, have advocates seen a change to the role of advocates with the introduction of the new Guardianship act?

[VIC Advocate 2]: Not yet @[P5]

[VIC Advocate 3]: Yes, there's now an expectation from NDIA that advocates will make decisions on behalf of people with cognitive disability.

[VIC Advocate 2]: Seriously [VIC Advocate 3]? I haven't yet had that experience. Some days I so wonder....

[VIC Advocate 3]: Knowledge about the new act seems to have filtered through somewhat, but there is a very obvious decision making gap, and service providers and NDIA have expectations that advocates fill the gap. We get lots of angry requests from planners and services demanding we attend planning meetings and make decisions.

[VIC Advocate 2]: Culture change: Compel everyone to be self aware, open minded and open hearted. If only we could!

[VIC Advocate 3]: I think there's often a general attitude that advocates will do substitute decision making without realising the legal framework about it.

[P5 & P6]: [VIC Advocate 7], we'd really welcome submissions in that area - we haven't received much information on this. You could respond to our issues paper on experiences of CALD people with disability

[VIC Advocate 2]: Failing that....concerted effort for ongoing positive media stories/social media campaigns nationally???? Long term commitment to this?

[VIC Advocate 3]: So one of my solutions is around SDM - frameworks, practice guidelines, training. It's also important to define what is a decision and what is an entitlement that doesn't necessarily require a decision.

[VIC Advocate 2]: I am thinking past national campaigns re changing behaviours and cultures. Time and finances required.

[SA Advocate 3]: The impact of conflict of interest on safeguarding

[TAS Advocate 2]: Example of primary prevention activities include schools-based programs (*Respectful relationships education program looks good) to create gender-equitable environments and build students' relationships skills

<https://education.ourwatch.org.au/>

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[VIC Advocate 8]: And the infantilisation of pwd in these roles!

[VIC Advocate 3]: I think also supporting disability activism is really important.

[VIC Advocate 4]: Good point [TAS Advocate 2],

That's what I was thinking.

[NT Advocate 2]: Past national campaigns around drink driving, smoking, slip, slop, slap, exercise, seat belts etc. and yes they take a fair amount of commitment and resources

[VIC Advocate 2]: Thanks Mary, DRC and colleagues. I appreciated being a part of the constructive conversation today. Good to focus on solutions!

[QLD Advocate 4]: The DRC needs to review independent advocacy systems throughout Australia

[VIC Advocate 3]: It is also really important to give access to advocacy for people who are unable to consent - advocacy needs to have a defined status so we can advocate for people who can't consent or tell us what the problem is.

Thank you!