



# Advocates Discuss: disability rights education and awareness-raising

From June 2022, Disability Advocacy Network Australia ran the "Advocates Discuss" series of fortnightly hour-long discussions via Microsoft Teams - creating an opportunity for interested advocates to take a closer look at and speak about a number of key topics emerging in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission or DRC) and its examination of abuse, violence, exploitation and neglect. Participants were encouraged to share their insights, observations, stories and case studies, and the discussion questions each week included opportunities to share perspectives on what recommendations advocates would like to see being made by the DRC, in relation to the topic in focus.

Identifying details have been removed from the edited transcript below. Participants in each session are identified as advocates from their state or territory, and are also numbered, where multiple advocates from that jurisdiction took part. Participants were informed that sessions would be recorded to capture their insights and observations. Care has been taken but errors may exist in the transcription.

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

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

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## Transcript from discussion – 7 June 2022

Mary Mallett:

...I will just start the meeting and then we will move on to the discussion quickly, but I'd like to welcome you all to this forum today and for the series that we will be doing. I'm on the lands of the Ngunnawal people in Canberra today and I would like to extend our respects to the elders past and present and the custodians of the land where you're from today and welcome any Aboriginal people who are joining us today for the meeting.

Siobhan, did you want to explain about what we're doing in this series and what topic we will pick up today?

Siobhan Clair:

Sure. Yes, we're starting this series similar to one that we did in late 2020. We just think it's great to bring advocates together to sort of pick their brains, get their insights and input about different topics that are coming up in the Royal Commission and you will see that we de-identify transcripts and there is really rich insights and case studies and examples that advocates can provide on different topics and we're just really keen because we know advocates and the advocacy sector is busy, but trying to harness some of that expertise and making sure that the Disability Royal Commission is hearing what we have to say on those topics.

The one we thought we would start today, because we know it is quite late notice, but a theme that's coming up a lot in terms of things that people are proposing and want to see the Royal Commission effect is increased rights awareness, increased understanding of disability rights, so, yeah, broadly we've talked about disability rights, education and awareness raising. So this is coming up in one of the research reports they published recently, which is about - it was looking at examining different methods of changing attitudes and different examples of that.

There's also under the promoting inclusion issues paper, which I know that a lot of advocacy organisations contributed to because it was a cross-domain issues paper compared to some of the others that are more specifically focused on one area of life, that proposals that come up are often about increased investment in rights awareness, and so making sure that people with disabilities themselves know about their rights, but also people across different sectors and across the community understand rights.

So I suppose we know advocacy organisations do this kind of activity and awareness raising and education and engagement, so much work is done on the ground by



advocacy organisations, but we also know that that work is often inadequately or not funded or is funded in very inconsistent ways through projects, so what I guess we want to talk about is your ideas and insights about the best ways to increase awareness of human rights of people with disability and what recommendations you'd like to see the Royal Commission making to ensure that we actually achieve this. Mary, anything else in particular to add?

Mary Mallett:

Yeah. One of the other things that I'm interested in is this sense from the advocacy organisations that at least some of the organisations used to do more of this, more disability rights awareness raising and training, and it's dropped off in the last few years, in the last number of years, as the pressure of NDIS issues, in particular, has sort of taken over the patch, so that's something I'm interested in as any of you comment, I'm interested in knowing whether you used to do it and you don't have time any more. We want to work out what we want to be arguing for in the Royal Commission, for the future, what kind of funding would all of you want to access so that you could train people in disability, in human rights broadly, specifically in disability human rights? But it's over to you whoever wants to lead off on what you have done recently or what you used to do in the past. [NSW Advocate 1]?

[NSW Advocate 1]:

First up, when it comes to putting in a submission, I always make sure that I make reference to the UNCRPD because the client will be discussing whatever matter with so many kind of abuse allegations and so on, and I like to say and always make reference to the UNCRPD and say, well, you know, it appears to be a violation of these articles, we refer to those articles. It's maybe relatively small thing, but I raise the UNCRPD every single time so its profile is raised a bit more, and I know my previous employer [NSW Advocacy Organisation], they were very keen on promoting the UNCRPD, and I assume still do so, but I was just talking about my, I guess, personal experience as a DRC advocate that when I get a request that comes across my desk to put in a submission, I always go to the UNCRPD website, have a look at the various articles and make sure that the Disability Royal Commission knows about this because Australia is a signatory to it. We've got every right to make sure that people know about potential violations.

Mary Mallett:

Thanks, [NSW Advocate 1], and the work of the UNCRPD is essential.

[AUS Advocate 1]:

Building on [NSW Advocate 1]'s comments, what I found over the years is educating people with disability, particularly people with intellectual and other cognitive



disabilities, from that CRPD perspective it is really empowering, and people get excited by it, like "Oh, wow, this thing actually exists?", and then it is easier to relate it to domestic policies and strategies and stuff like that. I think there are two elements of it, like, the kind of objectives and underpinning principles of the CRPD and then, obviously, the specific articles, so if we're talking about employment or living or all those things.

I think probably [NSW Advocate 1]'s experience is quite different to mine in that he has worked in the coal face of when people are in crisis or they are sharing their history of abuse, so it's very much about rights violations, whereas from mine it's probably been more capacity building around the promotion of rights, so knowing about them before you're actually in crisis or before you're calling an advocacy service, so I guess that kind of balance, rights awareness and education needs to bring.

I saw 'education' in this invite and thought we were talking about schools and education, so I'm more excited that it's a rights-based awareness one because that's more my thing.

Mary Mallett:

You could be forgiven for that, [AUS Advocate 1], given that the Royal Commission this week is about education, so that would have made sense.

A question that I'm interested in is for those of you who have been to, present or develop material about human rights awareness raising and training - do you have to start from scratch every time you develop your own sources, go hunting on the UNCRPD sites, is there anything that could be done or would help organisations if you had access to resources and material that you could easily grab and put together and contextualise it for your cohort? Is it a barrier for doing this work or is it a barrier of the time? Leap in, anybody, who wants to speak, otherwise I will start picking on you. [QLD Advocate 1] and someone else has their hand up, and sorry, I'm doing this on my phone.

[QLD Advocate 1]:

Thanks. It's [QLD Advocate 1]. How are you?

Mary Mallett:

Yeah, good, thanks. Just let people know which organisation you're from.

[QLD Advocate 1]:

I'm [QLD Advocate 1], I'm from [QLD Advocacy Organisation]. I'm an assistant advocate and information referral officer there. The biggest thing we found is time.



It's not actually developing the resources per se because a lot of people who are delivering the workshops and the training, they already know a lot of this stuff back-to-back, and they can pump out resources pretty quickly and we have stuff that we build on from previous work. It's the actual time of setting aside and presenting and then also depending on which stream of funding that's coming from, how that's then being reported.

Mary Mallett:

Thanks, [QLD Advocate 1]. I can see that people are putting comments in the chat. There is a comment about at the beginning of COVID in 2020 there was service providers were facilitating remote access to rights education, but that's dropped off again and, yes, so developing their human rights education materials in accessible formats is prohibitively costly in relation to time and costs. Also connecting with remote people is an issue. That point about DARU did. There was funding available in Victoria. The Victorian Government did fund training for people with disability to use technology that provided some internet dongles and other devices. I think the Victorian Government was the only one that did that, though.

[SA Advocate 1:]

I'm [SA Advocate 1] from the [SA Advocacy Organisation]. The biggest barrier is that we're not funded to do the work. All of our staff have great knowledge in this area and we would easily be able to develop resources and training for people, but the funding isn't there. We recently did a submission on the Disability Inclusion Act in South Australia and that's currently being reviewed.

In part of our submission we recommended that education about rights and educating people with disability about their rights should be part of that Act because how can they know how to overcome some of the barriers to being included if they're not even aware of what their rights are, so we've had some positive feedback from that submission and so we're hopeful that that kind of recommendation might go in there, that it really is the role for government to be providing some education. We're not sure if that will translate into any kind of support to do that, but, yeah, we just think that it's something that the government should be doing.

I might send you a copy of the submission because there's a range of comments in there from people with disability about inclusion and disability awareness for the wider community and that was really probably the strongest thing from the submission is that there needs to be better disability awareness in the community and governments need to play a role in that as well.



Mary Mallett:

Thanks. ...I know that in some of the conversations we've been having recently about how, you know, DANA but also like, I guess, DSS and what recommendations we want to be seeing in terms of advocacy, the development of the advocacy sector and other kind of supports that can be sort of brought in more on a larger scale, we have some organisations suggesting that they would love more access to things like the pictures that they used in easy English documents.

I'm not sure of the practicalities of arranging access for that, for smaller organisations, but I know some of the people here would have been involved in developing Easy English documents and might have some insights on that front. Does anybody want to speak to that? [AUS Advocate 1]?

[QLD Advocate 1]:

It's [QLD Advocate 1]. I did an easy English course last week and got a whole list of free resources for the pictures for easy English, so I can email through all those free pictures. Some of them are up to 40,000 images that are free.

Mary Mallett:

We did briefly look into some of these issues some time ago. There were licensing issues that have to be resolved properly if DANA was to try and get a licence for some of the materials that can be used, but we will look into it again for those and it may be that it's not all organisations anyway that need to or want to access the Easy English materials, but for those that need it, they really need it.

I just want to step back a second because I realised we kind of didn't separate out clearly, well, I didn't, the two different things we were talking about. One of which was disability rights training or human rights training for people with disability, and with the purpose being that they then understand their rights and the assumption that that's the ground work for people learning how to advocate for themselves as best they can. And then the other area is disability awareness training for the rest of the community, so that they understand about the rights of people with disability, so we realised that they're not the same thing and that they're different target audiences, there are different ways of presenting, and so you can speak to either or both of those, and a particular thing that I'm interested in is where you have been doing either or both of those trainings is whether you consciously try and make sure that you have people with disability presenting or co-presenting, and if you do, covering the cost of paying people and all of that.



So does anybody want to make a comment on work you've done or tried to do? [SA Advocate 1]?

[SA Advocate 1]:

Yeah, I can talk to that. We have a disability awareness and inclusion workshop that we run for professionals or general community members. We have a version tailored for health professionals as well, and we run those as a fee for service activity, so I think that we charge around \$1300 for a workshop for up to 30 people. We codesigned and co-delivered that with a person with intellectual disability because we think that's the most important thing, is to have that lived experience perspective, talking about intellectual disability, so our inclusion worker [...] usually delivers the workshops and we do pay the person with a disability to do that and include in the costs like travel and travel time and that kind of thing as well.

Mary Mallett:

Thanks. [NSW Advocate 1]?

[NSW Advocate 1]:

As I mentioned, I currently work for [NSW Advocacy Organisation], and we have a range of community development events, workshops, forums for people of various non-English speaking backgrounds or CALD communities. For instance, I was speaking to people yesterday from the Nepalese community and I was called in to just talk about the work that I do with DRC advocacy and how people might like to put in a submission, but also to explain some of the, perhaps, more basic stuff that people don't necessarily sort of pick up on about what is a Royal Commission, what specifically is a Disability Royal Commission about and how you have a right to approach the Royal Commission or to get our assistance in making a submission. That is, obviously, relating specifically to my work, but the organisation more generally, I guess, has a lot of rights-based training for these various communities for whom English is not necessarily their first language.

Mary Mallett:

Does your organisation have the funding or resources to produce those materials, for instance, when you were talking to the Nepalese community, did you have resources in their language and/or were you using interpreters?

[NSW Advocate 1]:

Well, we had another staff member there who is originally from Nepal, and she translated what I had to say and there were some people who did have an understanding of the Nepalese language at any rate, but, yes, in terms of the resources, I think that's something that we can do in terms of translation, sort of on a



case-by-case basis if you like. I mean, yeah, we've had success recently in terms of sort of funding, but, yeah, sorry, I can't be terribly more sort of specific about that.

Mary Mallett:

That's fine. Thanks. [AUS Advocate 1] ... Over to you.

[AUS Advocate 1]:

I have so many things to comment on, but I will try and keep it brief. I think in regards to the different kind of groups or categories of people, so people with disability and then kind of other, I guess the other, we have to also be aware that there's many subgroups in that, so families and supporters, professionals, like health, and then the service provider group, which is kind of a unique group. While it is part of the general community, it, obviously, has a specific role, and [NSW Organisation] and [SA Organisation] piloted a project, and this is in response to the Disability Royal Commission chat I'm not sure who it is online but, yeah, so funded by NDIS Quality and Safeguards Commission to run rights awareness training, particularly around complaints and the role of the Commission, and that's now being led by [Systemic Advocacy Organisation] and rolled out further afield, so something for people to be aware of and keep their eye out for.

Yeah, I mean, there's so many ILC [Information Linkages and Capacity Building] grants and activities out there that is rights awareness training for mainstream and employers and health. There needs to be some better way of, I guess, sharing those resources and not doubling up or tripling up or however many, you know, things have been produced in the same space, so maybe kind of our recommendation to the Royal Commission, you know, is around the ILC, and I know they're reviewing it and it has to be done by 2024 or something, but in the meantime, even just some kind of community of practice or some space where that stuff can be shared and managed makes it sound so easy.

In regards to the easy read and easy English comments, again coming from a background where I was leading some of that work and training, just be really careful with you know, there's a range of, I guess, opinions on what is easy read, what is easy English, what is good quality, the use of images. Some organisations and companies use a lot of animated cartoons and while sometimes sketches and drawings can be okay, from our experience at [NSW Advocacy Organisation] it was very frowned upon by a lot of adults with intellectual disability. The licensing and fake people with disability being used in photos that are free but are actually fake.

I guess the other point which might be really obvious, but I think linking any kind of suggestions in this space to the disability strategy, that community awareness is now





one of the outcome areas or something like that, awareness raising, but it doesn't just stand alone. It is the basis of the other six outcome areas, so, yeah, so that I don't know, whoever is implementing the strategy doesn't go "Well, that's DSS's responsibility to do awareness raising", you know, it's everyone's responsibility. I could keep talking, but I won't.

Mary Mallett:

Thanks very much, [AUS Advocate 1]. I will just see if there's anyone else who wants to dive in on any aspect of this, work that you've done, work that you would like to do more of or you would like to see other organisations doing it so you can get on with your advocacy work? [NSW Advocate 2], you go, tell us from your perspective, I know your organisation does quite a lot--

[Audio issues]

[NSW Advocate 2]:

At [NSW Advocacy Organisation] we have been, you know, what we've been doing for 30 years is talking to families when children are young to teach them about rights, but beyond rights as well, really making sure that they focus on understanding the importance of the child with a disability being seen as a valued citizen in those really important roles in life, which is being a regular student in a class, having a job, living independently.

The things that we value as good things in life, I guess. So not being seen as a service recipient only because I guess whilst rights are really important for people with a disability to understand, when we're actually teaching the rest of the community about rights and we can see that with our situation with how we handle refugees in this country, it's the person applying the right that makes the difference, that the person has to believe that there's value in that right for it to actually have, I guess, function, for it to actually be a right, so whilst it is important that we have this rightsbased philosophy and teachings, it's really attitudes that makes the difference, as we all know.

If somebody actually believes that a person is valued in society, then they will treat them differently. We only have to hear right now this week in the education space, this morning I was just listening to a young student who is now an ex-student, but made a comment that we have the UNCRPD and that's wonderful to have that, but it is one document that applies to the whole world and there's so much intersectionality around those types of issues that we need to really bring it home to our country here and our local community here where we are able to bring it to light, and the way we do that is through having those valued roles, so it is really important that we don't continue



to have the situation where, you know, kids are segregated in schools. I know [AUS Advocate 1] you said you didn't want to talk about education, but this is really important and we need to get it right when kids are young because they're going to be the adults of our future, the people making decisions, and if they are exposed and having experiences with people that have disability, then they will value the rights that are written on these pieces of paper, they will actually give it meaning, so we do that through our different programs like the one of the kids' program which is about inclusive education, we have a program ...at the moment, which is about trying to get kids into work early to start that process early, and then My home, My way, which is another ILC project, which is about individualised housing.

Mary Mallett:

Thanks, [NSW Advocate 2]. I'm in Canberra yesterday and today at the Australia Progress Summit but I have meetings with the DSS and I will be having a meeting with the branch manager and one of the things I'm interested in, a few advocacy organisations have had or have ILC project funding, and I think it was [ACT Advocate 1] there, somebody on the chat made a comment about the resources that they're currently developing through an ILC project, or maybe it was [NSW Advocacy Organisation].

[ACT Advocate 1]:

It was me, [ACT Advocate 1].

Mary Mallett:

Okay. I will get you to speak to it in a second, but the thing that I wanted to check for those people who are using ILC project funding, does it work for this kind of work? I know it sort of excludes advocacy in every way it can, but it does allow self-advocacy outcomes. Have you been able to wrangle the projects to make you do this civil rights or education?

[ACT Advocate 1]:

It is an awkward thing because we're funded to develop online resources. The reporting structure doesn't actually fit with the work that we are doing, so there's a lot of kind of having to stretch ourselves to meet the reporting criteria, so that's a little bit of an awkward in itself. The funding has been adequate, I think, for the resource development that we're doing, but, obviously, it only has value and worth as much as it connects with the community, and we're starting to get a bit of feedback and connection to get people's insights and to change and develop it so that it actually meets community needs, but, yeah, there's a kind of awkwardness. It's like the ILC process has this very limited sort of set of criteria that you have to speak to and when



you're doing work that's kind of fuzzy and outside of that, that's when it gets a little bit awkward.

Mary Mallett:

The ILC framework is due to be reviewed during the next year and that's one thing that we could all try and influence, really, so that advocacy organisations can access that funding to do work without having to sort of pretend you've been doing something else.

[ACT Advocate 1]:

The other bit of rights works that we were doing was in the context of supported decision making workshops. It kind of petered out after a week, in 2019, in terms of people coming to the workshops and engaging. It was generally designed for people with disability but also the wider community, so supporters and service providers and those sorts you know, a very large group of people.

So we did a little bit of a repackage and put it out as a podcast which included the material on rights and it was kind of fortunate because then COVID came and people were looking for online resources and that sort of thing. So it's been reasonably popular, the material delivered that way, and that led us into the kind of online resource avenue for a bit, but we're kind of also aware that it's limited and it doesn't meet that educational need that comes through face-to-face work, so we're kind of negotiating that kind of area a little bit.

Mary Mallett:

Thanks, [ACT Advocate 1]. [NSW Advocate 3]?

[NSW Advocate 3]:

We're doing an ILC project which is a research based project looking at the inclusion of people with intellectual disability at a board level. I wanted to raise the idea that from a rights base, people with intellectual disability have a right to be involved in the decision making, but there has to be more education for the organisations and for the individuals themselves to make sure that it's effective from both sides. But also, awareness of the importance of it and what it will bring to an organisation and recognising that it is quite resource heavy, it takes a lot of commitment and people have to really believe in it and follow it through and provide the supports there for it to actually work and not be a tokenistic activity.

We're not just looking at inclusion as being at a board level but looking at organisations being inclusive throughout their organisation so that there's a natural progression that people have a say in lots of different levels and ultimately be able to have a say at the



board level, but we are ILC funded. Just a little bit on the reporting. The reporting process is very strange, but, yeah, it's going well, so I thought we would just say that.

Mary Mallett:

Thanks, [NSW Advocate 3]. I missed the name of your colleague?

[NSW Advocate 4]:

I'm [NSW Advocate 4] and I joined a few weeks ago.

Mary Mallett:

Hello. Nice to meet you and good that you can join us today.

[NSW Advocate 4]:

Thank you.

Mary Mallett:

I'm interested in those who have ILC projects, my understanding is most organisations with current ILC funding, you've been offered that you can extend the project with or without additional funding if you want it and people are waiting until July to find out, I think, that's what is going to happen. Is that the case with yours as well?

[NSW Advocate 3]:

Yes. We still have the opportunity and July is when they're saying decisions will be made.

Mary Mallett:

Yeah. I'm slightly torn between, I think that's great for organisations that are doing good work currently, but I also know plenty of organisations who weren't successful in the last round of funding, or the last couple of rounds, therefore, they don't have a project that can be extended, so there's pros and cons for what they're doing currently.

I will just open it up again. Who else wants to speak to any of the aspects of this issue about doing human rights education? Siobhan, is there anything that's come up in the chat?

[AUS Advocate]:

[AUS Advocate 1] again. I was just typing away just in response to [NSW Advocate 2] from [systemic advocacy organisation] and it is quicker to say than type. Education, both using the school system to educate people and in the broader community of their rights, absolutely, you know, bang on, 100% agree. I had it down in my notes. The rights of education is a priority for [National representative organisation]. I was thinking



about inclusive education, kids going to mainstream schools, but I think the human rights and rights-based education in specific curriculum or as its own curriculum is a really great ....and it doesn't have to be just disability rights specific, but, yeah, having that as one of the areas of education in schools would be really cool. How good would that have been, being in primary school and learning cool stuff like that.

Mary Mallett:

... if you're not speaking, could you keep your microphone off. [QLD Advocate 2]?

[QLD Advocate 2]:

Thanks. I'm from [QLD Advocacy Organisation]. I just had a comment to make about creating resources and I think it has already been mentioned, a challenge that I know we find with making resources is the duplication of resources that are already out there. I mean, there's so much great work happening across the country with advocacy organisations, but it's a real challenge to know who is doing what, when, and how you can tap into that so you're not spending time on something that is just recreating a resource that someone else is spending time on. I think that's a real challenge of the sector and as well as also once the resource has been made, then continuing to sort of utilise it and give life to it after it's been created, I think that's a bit of a challenge as well, ensuring that they have ongoing relevance and they're not forgotten about. I wonder if people have any thoughts about that.

Siobhan Clair:

Yeah. I think that's something, that's a bit of a symptom of how the funding has been working in terms of it being project based. I mean, I hate to think of how many great websites and resources there are that then don't have that ongoing [funding].

Mary Mallett:

The problem is, of course, if an organisation... you're less likely to get funded for something if you say you're going to use an existing set of resources and just deliver it. Usually you get the funding by making the case for co-designing something with the cohort that you want to work with, so it is an issue.

I just want to mention something that we haven't been talking to the sector about yet because all this happened during the elections period but some will have received an email from DSS about it, but DANA is about to receive funding to develop something called the National Centre for Advocacy, the funding starts on 1 July and we will be doing meetings with the sector over the next few months about what the department is funding us to do and what the sector will find useful, but some of this will come back to this kind of discussion, I think, about a whole range of areas about communities of practice, which I think [AUS Advocate 1] mentioned earlier, or somebody did, and also



about the resources, about being able to map what has been done, what is being done at present, where people can share sometimes depending on what you're doing and why you're doing it, then it's just for your organisation, but sometimes organisations can and are willing to share with the rest of the sector, so as much as possible we're trying to explore what is available that people can share and/or work with others to jointly develop material.

So there will be more opportunity to do this sort of collective work maybe and avoid some of the duplication that some people are seeing, although I do completely understand that if you're working with a group of young people with intellectual disability, for instance, then working with them to develop the materials is a learning process anyway that is particularly helpful.

There is a particular question I want to ask which is about gate keeping. People talked about the various sectors and target groups for this sort of awareness raising and training, disability service providers being one group I want to know about ... do you experience 'gatekeeping' by the service providers, if you are trying to or wanting to deliver rights education, either to the people with disability who they provide services to and support, or to the workers. Does anybody want to comment on that? Or do the service providers all welcome you with open arms? [NSW Advocate 2].

[NSW Advocate 2]:

Surprisingly, with the school to work project we have had support from the Department of Ed because it is aimed at kids 7 to 12 and their family, counsellors and educators, so trying to raise expectations about a person with disability to work and start at a young age, and following the pathways such as getting a job and when you're at school. So we've got that going in three different states at the moment. We have partnered up with [QLD Organisation] and the [ACT Organisation]. So far they have been supportive of that project, but it is only a short term project, so I think it is a three-year project. So I can say, yes, cooperation at this point.

Mary Mallett:

That's very good. Thanks. [NSW Advocate 1].

[NSW Advocate 1]:

With one organisation, an ADE, when I have tried to tee up a sort of forum or discussion whereby we could talk to employees about the Disability Royal Commission and about our advocacy role, yes, the member of staff I was communicating with was rather sort of sensitive and he said, you know, "We have had experience in the past of people sort of coming in and essentially, you know, bad mouthing the idea of ADEs". So, yes, that's just one of the examples I guess, but perhaps people who run ADEs



might be a little bit sort of sensitive about the issues there, but I was going to say, yeah, there are ways of, I guess, getting one sort of message across without, you know, without sort of getting on the wrong side of a particular organisation. The other thing too, the reality is that so many people with disability have had bad experiences with disability organisations, the ones that are, in fact, supposed to support them, provide accommodation, provide day programs and a whole range of things, so, yeah, I mean, I've found there's no sort of easy answer except that I just tried my best to set up meetings with various service providers and trying was all I could possibly do.

Mary Mallett:

Thanks, [NSW Advocate 1]. I will go to [SA Advocate 1] and then [TAS Advocate 1].

[SA Advocate 1]:

I think [AUS Advocate 1] put what I was going to say into the chat that we do have a similar experience. I think we find, for example, the 'Your Service Your rights' project that [AUS Advocate 1] mentioned earlier, where we're going in and teaching people about their rights as a user of NDIS registered services, we found that the organisations that said yes to us coming to deliver those workshops are the ones that know we do good work, so it's the ones that don't really need the training as much but are accepting of it, and the ones that really do need the training are much more difficult to get into.

Mary Mallett:

Thanks. [TAS Advocate 1]?

[TAS Advocate 1]:

I think what we find is that there's a really great difference between policy and practice, especially since the NDIS. So we're really great at talking about rights nationally and having lots of conventions and standards, there's policies in schools, there's some great examples of it, but in terms of practice in Tasmania, there's massive divide, and the NDIS has seen that gap widen. We've got a lot of service providers that are new and incredibly immature and they're not welcoming, many of them, of an advocate being involved, and I'm talking professional advocates, that are going in from that rights base to ensure that a person is just heard and so going back to that the gate keeping, Mary, we experience that in advocacy all the time across mainstream and across the disability specialist areas.

The other day we had an advocate go to a meeting with a health professional because the family member has really low literacy and wanted some assistance to be able to understand what the information was coming from the health professional, and the



health professional in the waiting room told the advocate that they couldn't come in. So that's where we're at and I just see it as a fluctuating thing.

So it can be in a private school that an advocate won't even get in the door, and they will just say "Yeah, just let us know when you're coming and we'll bring our lawyer". So we have experiences like that. Then we have really welcoming and inclusive experiences, but usually where the attitude is very good anyway. I think we've got a lot of work to do in Tasmania and it's interesting to me after being around for so long because the State Government did a lot of work in rights education and so I feel like 20 years ago we were probably in a better space when we had our institution closing down and people moving into the community and we had training in social role valorisation.

We had a lot of really great training across the community as well as the disability workforce. I think now that there's a fragmentation, there's nothing consistent about the training that people are receiving and the messages they're receiving, so often we meet workforce that they haven't had any training, and they don't even know what an advocate actually is. So a lot of work to do.

Mary Mallett:

Thanks, [TAS Advocate 1]. How depressing is that to say that, in your experience, things were better in this area 20 years ago. That's kind of horrifying, isn't it. Just all the more reason why this Royal Commission has to have an impact.

[TAS Advocate 2] raised this in another meeting, which was having advocates having a legislated right of entry, so that that gate keeping can't happen. That's a particular thing. What pieces of legislation need to be changed to allow that and getting a strong recommendation into the Royal Commission about that particular aspect of advocates' work is not particularly what we're talking about today, but given the degree of gate keeping that people are saying, that absolutely needs serious attention and we will have further discussions on that.

Do any of you remember some years ago, like quite a few years ago, I have a memory that the Attorney General's department had on offer funding for human rights education that organisations can apply for. Can anybody else remember it or did it only ever happen once? I know it was available but maybe it was a one-off and it is not something I have seen since. You've given examples of ILC projects where you've found ways to try and create a project that you can do that work in, but there isn't specific funding available for it, so that's, perhaps, another thing that we could be advocating for. We haven't got many minutes left.





Does anybody want to dive in and make a comment? Feel free if you do. Otherwise, anything anybody wants to say about what you would like to see in terms of what might come out of this particular aspect of advocacy work about rights disability training...and I can see people putting things in the chat. We will pull this together afterwards, the comments in the chat plus the transcript, and it will actually go in as a submission to the Royal Commission, but we will circulate it back out so you can all see what was said today, and for the people who couldn't join today as well. Does anybody want to add anything else? ... [NSW Advocate 2] and [AUS Advocate 1].

[NSW Advocate 1]:

I really appreciate your words, [TAS Advocate 1]. Lots more work to do. One thing I have come across just looking at the early education sector, which is where rights sort of begin, is that the real need for pressing the awareness of medical professions because when I'm hearing good stories, it's when the paediatrician, who is the first person that the family...it's a touch point for the family at the beginning of their child's life, when they have a really positive attitude about the child's future and then it makes a huge difference to their life trajectory and whether they end up on a segregated path or living alongside the rest of society, or whether they become included from the very start. And that sort of extends, I guess, broadly, to that allied health professional area, nurses, the general sort of health sector because they are coming across different OTs, speechies, and those people are really influential in how the parent views the trajectory that the child will go on, from the very beginning, whether they go to an inclusive setting for their early childhood care and then school or whether they go to an early intervention place which flows into segregated settings and then into a segregated life, generally speaking.

So I feel that's a big space that we could try to get some recommendations for and funding for, and not to pick on the medical profession because it is a broad society issue, but I feel that's a real touch point that we could focus on.

Mary Mallett:

That's great. Thanks very much. [AUS Advocate 1]?

[AUS Advocate 1]:

Yeah. My final point is just I guess an agency and role that hasn't been mentioned is the Australian Human Rights Commission. So the role of the commissioner and his team, but also the investigations team. So I guess one of their priority areas is disability awareness raising, but, you know, I've just come from six months working there and it doesn't happen. It's very minimal. The team is tiny. Like, you know, the commissioner has one policy officer. It's not like there's lots of necessary time and



money to go around and do this, but they could be involved in the school stuff or certain parts of it. So just make sure we include them.

Mary Mallett:

Yeah, good point, thanks, [AUS Advocate 1]. I think we're all aware that the Human Rights Commission has had its funding downgraded, really, through the governments of the last few years and let's hope that's one of the things that the new government, that the Human Rights Commission will be better funded and have some more respect, I think. [TAS Advocate 1], do you want to make a last comment?

[TAS Advocate 1]:

I was just going to go back to what [NSW Advocate 2] was saying before about people with disability and their families and that the social change, we believe, is going to happen there and it will continue with those people knowing and understanding their rights and educating the people that are around them. And, obviously, those are the people that will have the most motivation to understand what those rights are and then they will use those. So I believe that it's really important to educate the community and the workforce and that that's an ongoing thing, but I think that for us our focus is really the families themselves and the young people with disability, so that they can make that change.

Mary Mallett:

Thanks very much. Thanks, everyone. It's been a really rich discussion. There's never enough time, but there's some great contributions. We will gather up the transcript and the comments that people have made and we will send that, circulate it back around. Siobhan, do you want to speak about the series of workshops and forums and the topic of the next one?

Siobhan Clair:

Yeah. The next one is ... sorry, you put me on the spot.

Mary Mallett:

Sorry. I can't remember either. We do have a series and they're going to be fortnightly on Tuesdays at the same time and I think the list has gone around, but we can recirculate it, so that people can join in the ones that they can. Thank you, everyone, or your contributions.

Siobhan Clair:

Guardianship and substitute decision making will be the next one, so a nice controversial area.



# ADVOCATES DISCUSS



Mary Mallett:

Thanks. Any who can join in a fortnight's time and tell any colleagues or anyone you know who might be interested about guardianship and substituted decision making. Thank you for your contributions today and we will see you next time. Okay. Thanks. Bye.

Siobhan Clair:

Thank you, bye.

END OF MEETING



## Comments In Chat

[QLD Advocate 1]:

I'm just finishing my lunch so camera off and mic off

[TAS Advocate 2]:

Our org has still ostensibly been doing rights education, but the major barrier during covid has been connecting with clients to do that remotely.

Resourcing for work like DARU did during 2020 lockdowns (training clients in using video calling tech, providing personal internet dongles & some devices for PWD without access to those things) in all states feels like it would go a long way.

We've found that providers were willing to facilitate remote access initially during 2020 where facilities allowed, but since then there's been no incentive for service providers to take the time/effort to help their clients connect to rights education remotely

Yes, we've developed all of our own human rights education materials, and doing so in disability accessible formats has been very (at times prohibitively) costly in terms of both time and \$\$

[VIC Advocate 1]:

Staying off mic and camera cause of a full office and multiple meetings today: Gaining access to service providers, eg. being granted a time to come and speak to participants at a certain org/service has been a major barrier, particularly during covid. I agree with [SA Advocate 1], in that centring a human right approach in policy and practice guidelines so that knowledge and education about disability rights is being distributed BEFORE the person is accessing advocacy. We find that if people aren't aware of their rights in the first place, the less likely they are to reach out to advocacy services. This means we need to do a lot more assertive community outreach, which requires, as others have mentioned, time and resources we often don't have.

[SA Advocate 1]:

Another recommendation from that submission was that disability awareness and disability rights training needs to be delivered by people with disability.

[VIC Advocate 1]:

Here here!



[ACT Advocate 1]:

We are currently working on a suite of online resources focused on self-advocacy on a foundation of rights education and self-awareness. The resource will be 5 workbooks with links to some videos we have been working on. It's based on ILC funding. The work has been at times put on the backburner due to Covid related accessible information work.

Siobhan Clair:

I think training being delivered with the involvement of people with disability is a vitally important principle - and needs to be properly resourced so people can be remunerated for their time and expertise

ACT Advocate 2:

More 'mainstream' orgs are willing to create EE [Easy English] documents but are not getting it right or it's not clear if it has been tested by people with disability.

Siobhan Clair

Good point [AUS Advocate 1] about there being a Target Action Plan under Australia's Disability Strategy: [Community attitudes Targeted Action Plan | Disability Gateway](#) - efforts obviously need to cut across all areas of gov't policy

[NSW Advocate 3 & 4]:

[NSW Advocate 3] and [NSW Advocate 4] here from [NSW Advocacy Organisation] - we are undertaking a research project focused on increasing the involvement of people with intellectual disability in the decision-making and governance of community organisations. This is based on the right of inclusion at this level, but also recognises the benefits to organisational planning that is responsive to the needs and preferences of people with intellectual disability

Siobhan Clair:

That sounds awesome [NSW Advocate 3] and [NSW Advocate 4] - really impressed by some of the work in this area by Special Rapporteur [OHCHR | Report on the rights of persons with disabilities to participate in decision-making](#) and VIC gov funded resources and training: [Voice at the Table - State Government funded training with resources for Government and Peer Advisors](#)



[SA Advocate 1]:

Re ILC [Information, Linkages and Capacity Building] - through our ILC projects we try to link in rights where it's relevant in our capacity building workshops for people with intellectual disability and their families. We've also been able to establish a reference group as part of our organisational capacity building funding from ILC which does some speaking up on topical issues, so a bit of rights awareness but on a very small scale.

Siobhan

Clair:

Podcast [ACT Advocate 1] mentioned [Staying Connected Podcast](#)

[AUS Advocate 1]:

Interesting research in the employment space around employer confidence is showing many employers want to increase their awareness and inclusion but are scared to do it and mess it up, shows barriers. This may be similar in other areas like health professionals. Good to keep in mind when providing awareness training and activities in community and help break down this fear. Other evidence in this space is that training activities are only one element of awareness raising.

New National Centre for Advocacy sounds great Mary Mallett well done DANA

[WA Advocate 1]:

I'm off to another meeting. Thank you

[VIC Advocate 1]:

[VIC Advocate 1] from [VIC Advocacy Organisation]. Yes, absolutely. Particularly given that my role is specifically to help people to engage with the DRC and help people understand their rights in that context. I have experienced service providers literally freeze up when they hear the term "royal commission", so my approach to organising information sessions has been a lot more...strategic!

[AUS Advocate 1]:

A real mix of experiences with disability service providers as gate keepers and welcoming us with open arms/doors. Sometimes barriers are timing, staffing issues, no access to online and devices, maybe more systemic issues of the provider rather than managers/staff not wanting us there. And some services will go the extra mile to make sure advocacy groups can get in and train people and staff. [SA Advocate 1] was this similar in SA?



[VIC Advocate 1]:

Framing DRC info sessions and rights-based info as being useful for them as an org and for their staff too. Framing it as useful for professional development etc

[NSW Advocate 3]:

The Inclusive Governance Project will be developing resources to support organisations to become more inclusive in regard to including people with intellectual disability in organisational decision-making and governance. These resources will be freely available on the [NSW Advocacy Organisation] website once developed as an outcome of the research being currently undertaken. We expect to include resources based on developing pathways to the Board, accessible Board processes and individualised support provision. These will start to be uploaded later this year.

[TAS Advocate 2]:

Absolutely agree [TAS Advocate 1] - seriously vast gulf between what's on paper as policy/procedure and what happens in reality

Agree again- health professionals particularly ignorant of disability rights & right to advocacy, and particularly difficult to get to attend any sort of training!

[QLD Advocate 2]:

Some advocates in Queensland have experienced gatekeeping practices by the Public Guardian, including gatekeeping around whether the advocate can talk to a person's support coordinator

[SA Advocate 1]:

Yes agree, time for health professionals to join a training session is difficult. [Our organisation] are working on an e-learning training on intellectual disability awareness and inclusion that can be completed independently at a time that suits them. Hope to have that available later in the year.

[VIC Advocate 2]:

Agree wholeheartedly, [NSW Advocate 2].

[AUS Advocate 1]:

Thanks everyone for a great discussion and DANA for leading, recording and sharing our collective opinions, issues and ideas.

[TAS Advocate 2]:

Leaving for another meeting now, thanks all for the discussion!



Siobhan Clair:

Yes, [...] did a great project on this at ACTCOSS, lots of potential to educate health professionals and Rebus did an awesome theatre project [Access all Areas – HEALTH – Rebus Theatre](#) - hopefully good work is continuing at ACT Gov level. See [Imagining Better - Reflections on access, choice and control in ACT health services for people with disability | ACT Council of Social Service Inc. \(actcoss.org.au\)](#)

[NSW Advocate 2]:

it needs to be made compulsory that All principals and teachers have rights-based awareness training

[QLD Advocate 3]:

I agree, [NSW Advocate 2]