



Advocates Discuss: supported decision making

From June to October 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 for more information.

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Transcript from discussion – 27 September 2022

Mary Mallett:

Welcome to today's meeting. I work from Hobart. I acknowledge the traditional owners here and acknowledge their elders and acknowledge we're all working on Aboriginal lands. I welcome any Aboriginal or Torres Strait Islander people who are joining us today. This is part of a series of meetings. Some of you will have attended the past ones.

Today's one is about supported decision making. We usually use the same sort of fairly loose, unstructured format where you will have an opportunity to put your hand up and dive in and have your say on the topic.

We will switch on to today's topic. Today it's about supported decision making, for you all to tell us whatever you want to from your organisation's perspective, and the people that you work with. The perspectives and insights that we're interested in are the barriers and problems on the ground about ensuring that people with disability have the right to make their own decisions, and whether or not they can access decision making support when it's needed. So, probably that issue first, and then maybe potential solutions to any of that, but what are the potential solutions and good practice and how should we be billing better practice.

What is the role of advocates and the independent advocacy sector as there is, you know, notionally anyway transition to supported decision making models, and there is a small number of advocacy organisations that are funded by DSS for a particular program on decision support, but it's only a small number of the organisations, but lots of other advocates, of course, are involved in, informally at least, in supporting people to make decisions.

Let's start with what you see on the ground. Are there places in the country, areas, organisations, are there things happening that are positive in this area where people are being well supported? And that it's recognised that people have the right to make their own decisions and they're being provided with decision-making support. Or is that not happening at all? Put your hand up if you want to and you can tell us whatever you want from your organisation or what you see.

If you remember, let everyone know what organisation you're coming from when you speak.



[QLD Advocate 1]:

Thanks. It's [QLD Advocate 1] from [Advocacy Organisation] in Queensland. I would like to be able to talk about positives, but in supporting people, we put a lot of effort into getting NDIS access for people, particularly with acquired brain injury and mental illness. The local area coordinator here has been referring people to [QLD service provider] for some reason when there are other service providers that are supporting people very appropriately with psychiatric illness.

It's just because the clients have told me, so-and-so, or my support coordinator has contacted me, they want to come in and sign some documents. So I come in with them and suddenly they're signing forms to have to pay for a cleaner to come in every week for \$100 when their unit is only about four by four metres and already spotless. So we're going to keep an eye on that.

It's also in the more supports service providers. One client just wanted to join a certain service provider because they have ten pin bowling and other things. [QLD service provider] had forms for him to sign, and I think the plan management is external, but they go to a speech therapist, etc, and he can speak fine.

Anyway, the reason I'm bringing that up is that is very subtle. I'm fearful for someone who is non-verbal and more vulnerable being at the hands of this sort of practice. Where you could tell by the look on the face she didn't really like the advocate, even though [she had] a very friendly smile and was quite generous with her time, and it was interesting to observe. It was the same with people with cerebral palsy and non-verbal, [who] have been defrauded, workers taking money out for cigarettes and saying they will pay it back on payday.

And that just doesn't seem to alarm people. So I'm just trying to put things in a nutshell so, but it makes me extremely fearful for very vulnerable people having very complex medical needs being met when these seem to be the blatant practices that we just see first-hand.

Mary Mallett:

A sobering opening, I must say. Thank you. Next person is [WA Advocate 1] from [City].

[WA Advocate 1]:

I suppose I'm wanting to talk about people with complex communication needs, ie non-verbal. We're very concerned that a lot of people, when we go in as part of an ILC project, going into group homes teaching people about their rights and how to stand up for themselves, it is consistent that people who use a communication device who



need that in order to make decisions and to generally communicate, often don't have access to it and it just seems to be there's no kind of - it doesn't seem to be recognised as an abuse if you take away someone's communication system, so if you took away someone's wheelchair or someone's hearing aids or guide dog, it would be considered to be abuse.

It seems to be quite accepted practice that support workers, they forget to use a communication device, they forget to charge them, they don't bother to try and interact with the person who is trying to communicate. So how are they going to have any opportunity to be supported in their decision making if they don't have access to a communication system on a 24-hour basis? That's my major concern. That's quite across the board in many group homes.

Mary Mallett:

Yes, thanks. If other people see the same thing, you can tell us as well. The next person is [QLD Advocate 2] from Queensland.

[QLD Advocate 2]:

Hello, everyone. Thanks, Mary. I'm a decision support advocate working for [Disability advocacy organisation], so I'm one of those agencies. I've worked for one of those agencies of which there's only one in each State or Territory providing the pilot. I've been attending the regular catch-ups of all the providers and one of the interesting things that I heard from another provider, and I will not disclose who that was, is something that alarmed me, but I've come to realise it's probably, in all honesty, happening everywhere we look.

The situation that was raised was one whereby professionals such as therapists, indeed occupational and/or speech therapists, are avoiding the whole domain of supported decision making, and going from someone who is quite capable of expressing let alone making their decision and having that accepted and believed by others, to one where the only other alternative is substituted decision making, and I find that alarming if we've got a range of people who have professional obligation to update their own knowledge and skill set who are denying that supported decision making is a thing.

To the point when I say, I believe it probably is happening more than we realise. I know that the notion is very much harboured by many families, particularly families who themselves have been done over, or are otherwise vulnerable for other reasons, and it is just too easy and people are too tired and too ill equipped.



To enter into the whole notion of learning - what is this mysterious thing called supported decision making? And let's get someone else to do that. It seems to me that there is still a big chasm.

Going back to the first speaker who mentioned that it is common for support workers to forget to put on communication devices or actually use them. I think that's really indicative of poor training, poor attitudes and a very inadequate quality system that's where supported decision making really doesn't get a significant enough gig to be recognised as ordinary decent common practice.

Mary Mallett:

Thanks very much. You're making me think that, I don't know off the top of my head, but maybe somebody here does, is it in the NDIS practice standards. Are there adequate practice standards that cover that area? If somebody else may know. I saw that [Systemic Advocacy Worker 1], I think you just put a comment in the chat. [Systemic Advocacy Worker 1], is from [Advocacy Organisation]. Do you want to introduce yourself and the peer workers that you've got that are on with you today from the making the decision real project?

[Systemic Advocacy Worker 1]:

I will just quickly introduce the peer workers. We have [Systemic Advocacy Worker 2], and [Systemic Advocacy Worker 3], who are both peer workers with [Advocacy Organisation]. They are working on the Make Decisions Real project, which is an ILC project around supported decision making, and, yeah, the aim of the project is to help people with ID [intellectual disability] and their supporters learn about how to do supported decision making and it has been completely co-designed, facilitated, presented by [Systemic Advocacy Worker 2] and [Systemic Advocacy Worker 3] as peer workers.

Please bear with us because we're trying to keep up with the language that everyone is using today, but we have had a big talk about that SDM isn't as hard or as scary as it appears to be. Do you want to talk about your project and what you've been doing? You guys evaluated a bunch of SDM resources that already existed, and from that created the resource directory - so whittled it down to the ones that you thought were best, created a resource directory for people, and then ran pilot workshops. And now you're making a train-the-trainer package?

Yup. So other people with ID can teach SDM, and also we're about to release some videos that go through the steps of doing SDM. They've all been included, you guys, as well as other people with ID in every step of the process.



Mary Mallett:

Thank you. We would love to hear more about the project and what you've been doing. So if you do a report about the project, or I don't know, whether you're going to make videos about the work that you've been doing, but we would be really interested to see them and to share them out with the rest of the advocacy sector, or to have you come back on and talk particularly and tell us about your project. So, thank you for joining us today and we are racing through things, so apologies, we're running a bit fast, but we're very happy for you being able to join us today.

[SA Advocate 1] is next.

[SA Advocate 1]:

I just wanted to mention some stuff around guardianship. We recently had the Office of the Public Advocate and Public Trustee come and speak to our reference group made up of people with intellectual disability, and from that presentation it became really clear to the group that the processes that the OPA and SACAT have in place are not at all accessible, and even just the experience of one of the people in the group, who has recently had a guardianship order put in place that they really don't want, that the process was just really an awful experience for her.

They don't send any accessible communications about the hearing. It's just a letter that you can't understand unless you've got support. We have heard of people missing their hearing date because they didn't know that there was going to be a hearing. People are not automatically provided with an advocate either, and one of the people that we spoke to really needed an advocate, and we connected them with one, but they decided not to bring an advocate to the hearing because they were afraid it would make SACAT and the public advocate angry, and so they didn't have any way of really representing what they wanted to happen.

There's probably a whole lot more, but we wrote a letter about it to SACAT and the OPA which I'm sure the group would be happy to share with you, so I'll send that through, but it lists barriers that people are faced with in that process, and they don't feel like they're listened to at all and their rights aren't respected when that guardianship order is in place.

Just one more thing, they also try and get the order revoked. The system in South Australia is that they have to do that through an online application. So again it is totally inaccessible for a person with intellectual disability to do that.

Mary Mallett:

Thank you. As other people are coming on to speak, if you happen to know about whether any of the public advocates or guardianship processes in other states,



whether any are doing better than that, it would be interesting to know, but we would be interested if you could share that with us under the circumstances.

[Vic Advocate 1] from [Advocacy Organisation] in Victoria.

[Vic Advocate 1]:

We're also one of the agencies doing the supported decision-making pilot. I guess the thing we're concerned about, [and] what we're seeing, is there's a lot more demand from this service than is actually available. And not to undercut the idea of it not being a scary thing, it can be conflicted and requires a lot of skill and education about what the principles are to handle it, and to make sure it's being done properly.

There is no one approach that works the same for everyone. You need to customise it to the client you're working with. We certainly come across situations where it's been seen as an alternative substitute to decision making. Can you make this decision? Help us make this decision for the person rather than engaging with a proper principle of getting the preference understood properly, and giving that person the opportunity. To the extent that the Victorian Office of the Public Advocate has taken on the philosophy -I think they're certainly engaged – The legislation now recognises it is about supported decision making, not substitute decision making, but to the extent that is filtered through all of the practitioners is another question.

We're concerned just to make sure that people understand what supported decision making actually means, because lots of the risk is that things like the NDIA think that they can provide that service without any conflict of interest and without any issues. We think that's not the case and there needs to be more support for people doing supported decision making across the whole sector because there are a lot of people who don't have the opportunity to get the support that they need.

Mary Mallett:

[Vic Advocate 2] did you want to chime in?

[Vic Advocate 2]:

Only that, with the pilot program we work with people who do not have informal supports and there really is no knowledge. And I point out support coordinators because they are quite often very key to the role of supported decision making in regards to the NDIS.

There is a big emphasis that someone needs or has to have informal support to be supported to make decisions, and when we do, particularly for myself and my colleague when we do supported decision making.



50 to 60 percent of our time is spent educating the formal supports around them on how to do supported decision making, and we certainly get push back, significant push back, but most of the time formal supports do end up adopting supported decision making, and that really is good to see because that is how we end up being able to close the file - that the supports around them take on the role of supported decision makers.

And our point of difference is that we found that there's no frameworks or literature out there that can be given to people that doesn't rely, or heavily rely on informal supports, and therefore I find that the formal and paid supports then default. Where there's no informal supports to do supported decision making, we're going to look at guardianship, and so there's kind of this gap in being able to provide people with information on what supported decision making is, and it's just not known.

Mary Mallett:

Thank you. The next person with their hand up is [QLD Advocate 3] from [QLD Advocacy organisation].

[QLD Advocate 3]:

Hello. I've got a couple of things I wanted to touch on. The first thing is the OPG - so we have the same issue here with OPG. It may even be a little bit worse from a Queensland wide perspective. OPG has been choosing what type of engagement the advocate can have. So, with the person with disability, they're barring the advocate from coming to meetings with, say, the support coordinator and the public guardian who is appointed, even though the person has requested that they be there.

As a state we've tried to talk to the public guardian about an MOU and they've completely rejected that saying that that's not their space to be in. So even though they say they have a say how they make their decisions and that it is through a supported decision-making framework, they don't actually allow that to occur. Even when the person is able to access advocacy to provide supported decision-making framework.

I find it interesting that they say they do a supported decision-making framework, but their policy is actually called 'structured decision-making frameworks', and so they use structured and supported interchangeably which are two very different things.

So, we have a lot of advocates in Queensland trying to do supported decision making being blocked by the OPG. The second issue we probably have as well is that children and young people, especially those in care who have disability, there's the automatic assumption that because they've been in care that they are now required to be under



the public guardian as they age out of the system. So, we've had applications come in before QCAT for kids and young people who have disability, and thankfully, with appropriate supports, they've been able to ensure that those guardians are not appointed, but it is happening. As a rule of thumb, it's like, 'You've been in care. Now you move over to have someone else make your decisions as a guardian.'

I'm pretty sure Mary is all over it, but the Queensland disability advocacy sector is really, really struggling, and all the advocacy orgs are having to take on the most vulnerable. And that means people are not able to access that because there is no capacity to do that.

There is also some work being done by our Office of the Public Advocate, [name redacted], and he will be focusing on supported decision making and he thinks advocates are best placed to provide that support and is supporting advocacy to make it happen. That's Queensland.

Mary Mallett:

Thank you very much. [SA Advocate 1] and then [NSW Advocate 1].

[SA Advocate 1]:

We also have information sessions for families about guardianship. They were totally unaware of the process, and that informal supports could be in place, and they didn't need an order. So, if they're not even aware of the basics of guardianship, we feel it is unlikely that they're aware of supported decision making.

We feel that there needs to be an education piece there for family members, and similarly with people with intellectual disability, they are often not aware of their right to make a decision and haven't had an opportunity to do much decision-making. The positives are that organisations like [Advocacy Organisation], they get decisions through and SACID have had funding recently to provide some of that education, but it's not ongoing funding.

Our SDM project ends at the end of November. There is only a small group of people that we have been able to educate in that time and it is really more of an ongoing thing that needs to be funded rather than project based.

Mary Mallett:

Thanks. Was that an ILC [Information, Linkages and Capacity Building] project?

[SA Advocate 1]:

Yeah, it was.



Mary Mallett:

Thanks. [NSW Advocate 1] from [Advocacy Organisation]?

[NSW Advocate 1]:

I wanted to raise some concerns for children out-of-home care, care for carers of children with disability, and the guardianship processes being dragged out for over two years, for the carers to jump through hoops for contact when actually they've tried to do all the contact, and contact the families, and the families aren't responding.

One mother is incarcerated now, so [is in] the process of going from out-of-home care, being case managed in out-of-home care to guardianship. There's been no casework or limited casework once they went into the guardianship phase of the process, and it's been ongoing for two years with no real outcome.

Waiting for the families to make decisions for contact and just touching base every couple of months, to now going to a family group conferencing two years down the track where so much more has happened, and they're still at the same stages as they were two years ago, so the hoops that they've got to jump through and these children are actually getting older and their disabilities are ongoing, so the family's frustration of the department's lack of response and seeming like it is just a tick and a flick.

Mary Mallett:

Thanks. These are Aboriginal families?

[NSW Advocate 1]:

Yes, Aboriginal families in out-of-home care. So the process is no contact from the caseworker for a good eight months, and then they will ring up and ask how contact is going. So, it's no duty of care for the child, even though they're in guardianship, wasn't provided a caseworker, and then just constantly getting phone calls every couple of months. You need to do contact where there's actually issues going on in that community, wanting the carers and child to be put in unsafe places without them responding to and maintain their connection on the department side. The impacts on the families, having to go and do contact when they know it's not safe and requesting a worker [to] go out to that community or to that family, and touch base to see how things are going prior to them doing contact. So that never happens.

Mary Mallett:

We might get in touch separately about that because all of those out-of-home care issues are a bit off to the side, or it's a whole separate set of complicated issues that I think would be good if we had another conversation with you about to pick that up



because there should be things happening there and that's, obviously, sounding like they're not. We will come back to you separately.

[NSW Advocate 1]:

Yes. Some are starting to happen now but it's been ongoing.

Mary Mallett:

Thanks. We have no more hands up at the moment, but put your hand up and dive in as soon as you want to. [QLD Advocate 4] from [Advocacy Organisation].

[QLD Advocate 4]:

I was just going to add that I think in addition to the poor community understanding about supported decision making and what that entails, I think there are some issues with the legal framework that make it easy or too easy for people to resort to formal guardianship or administration applications. Things like no threshold test for appointment before it is accepted by the tribunal. The tribunal are bound by the rules of evidence, so people are making applications with reports that don't really relate to the person's decision-making capacity.

It could be reports that were used for the person's NDIS application or it's outdated, from many years ago. We know people struggle to get legal representation in QCAT hearings as well, and then in addition to issues with the legal framework, there's practices starting to take place, like people from the OPG beginning to be embedded into institutions like hospital services, and I feel like there's things with the legal framework that could be a lot - could be putting in place a firmer boundary in a way, in terms of preventing unnecessary applications.

It's just a bit too easy for people who in the context of having poor understanding of what supported decision making is, it is too easy to resort to formal guardianship-type arrangements.

Mary Mallett:

There's a queue of people waiting. Just a couple of things that have popped into my head in the meantime. Have any of your organisations already written submissions into the Royal Commission on these topics, on the guardianship, supported decision making and substitute decision making? [QLD Advocate 4]?

[QLD Advocate 4]:

We did one, a lengthy submission, and endorsed by a number of advocacy organisations in Queensland.



Mary Mallett:
Is that public now?

[QLD Advocate 4]:
Yeah. I can put a link to it in the chat if you would like.

Mary Mallett:
Yeah, that would be good. If anybody else has submissions that your organisation have done on this topic and you're happy to share them, then please do the same thing, put up a link or send them to us. We might already have them on our website.
[Vic Advocate 3]?

[Vic Advocate 3]:
I'm from the [Advocacy Organisation] in Melbourne. We find that there's great variability in the SDAs about how they do supported decision making. It's really hard to know, even within the one organisation, it seems to be up to how well the house supervisor can explain things to the person. So, I see the variability coming into the different organisations. Also, with access to people's money, the workers say they follow the organisation's policies and procedures, so each organisation could make up what their own things are, there is no consistency across the board as a safeguard.

Sometimes our citizen advocates are not invited to NDIS reviews or not informed about them, even though the support coordinator and NDIS know they are listed. Sometimes people are waiting for the person to be asking for their advocate to be there, and they don't always know to ask or that they can ask. So that's not being done when it could be done.

I've had advocates saying "I wanted to be there, I didn't know it was happening" and that's hindering the supported decision-making process.

We've also had - something was mentioned before - about support coordinators having services from their own organisations. We've seen that happen. There is a house at the moment where we have some difficulties within the house, and they were wanting to get behaviour support practitioners who were internal, and yet there were lots of signs that there was something going on in the house.

We had two people who all-of-a-sudden started acting out who wouldn't normally act out, that it felt like there was being something covered up also in that house.

Also in that house, before one of the people had a citizen advocate, he was asked, will you move into the unit that had the very violent person and he just said, yes, and



then we found one other person who had a citizen advocate, that person moved interstate and he was asked, will you move into there and we can move the other one out? We've seen instances where people, if they don't have a citizen advocate, they're vulnerable.

It would be lovely to have more citizen advocates, more funding for that to have more of them around, because you can see in that house all the other people in the residence had informal supports and it was the ones that didn't have the informal supports that were being asked to do something, and not really knowing what their rights are, and what the consequences of saying yes and they're in a vulnerable position - that's their providers.

There aren't many organisations who are able to provide citizen advocates for people, so it's good to see that it is still happening in some places but it's not that common now.

Mary Mallett:

Yes, but when you see the difference between those that have it and don't, and even with the ones that lose it, straightaway, they're being asked to do things and sort of having to do what they're asked and it's not in their best interest.

The next person is [Systemic Advocacy Worker 4] from [Advocacy Organisation].

[Systemic Advocacy Worker 4]:

Thanks for having us here today. I've put some documents that are relevant to the DRC into the chat. I have to head off, and so I wanted to say it was great to see people with lived experience in this meeting represented and present. That's just me saying that also I'm low capacity myself as a person with disability, so my point was we will be there at the DRC in December, so we will be making sure that if anybody is not around or working over the period, we will be live tweeting and supporting.

Do feel free to connect with us at [Advocacy Organisation]. We love having people who are also looking at this issue, so I just want to say thank you for having me and I've got to run off now but thank you.

Mary Mallett:

Thanks, [Systemic Advocacy Worker 4]. Live tweeting the hearings is fantastic, helping people who can't watch to keep up to date with them.

[WA Advocate 1] and then [NSW Advocate 2] after you.



[WA Advocate 1]:

I'm from [Advocacy Organisation]. Something that has been working is we've actually been developing a communication profile that we've sent into the state administrative tribunal for guardianship hearings and that profile is given to the member and that's the main document they read to get a current picture of the way the person before them communicates and understands and responds, particularly responds in stressful situations.

I'm thinking it might be a useful too, to suggest that other advocacy organisations may wish to use these, because quite a few of the judges or members, depending on what state you are and what you're calling them, have said it's been really helpful because sometimes they don't know the communication skills of the person before them until the time they start communicating. And then they realise that this person is struggling to understand what I'm saying, so I think there's a lot more work about for the communication profile supports the member to better understand the person before them, and I suppose hold the hearing in a way that is paced the way the person with disability can understand, not at their own pace. It's just a suggestion. I'm happy to provide a copy of examples.

Mary Mallett:

Thank you. That would be useful. I think a lot of people would find that useful. [NSW Advocate 2] from [Advocacy Organisation] New South Wales.

[NSW Advocate 2]:

Thanks. I guess from our perspective, we, obviously, try to build the capacity of family members to walk alongside their person with a disability. So what we're hearing a lot on the ground is that it's being made very difficult with Centrelink and hospital scenarios where families are being treated in a bad way, as if they are all conspiring to harm the person or written the person off or whatever, and especially when there is a person that might be non-verbal, being accused by Centrelink of trying to take their money and records

And I'm talking about the transition when they turn 18, so I guess from our perspective, it is the importance of highlighting the family is the natural authority in the first instance, and the majority of the time has the best interests of their person at heart, and that needs to be invested in, in terms of building the capacity of that family, the family members, to support the person, so they can be building their supported decision making, their decision-making abilities.

So, I guess just finding that right balance between - we talk about the power and safety of having those personal relationships - and those informal supports, which a lot of



people have talked about. When a person is taken over by the service sector, we need to have proper supports in place so that we can balance out, I guess, put a safeguard in.

As we've heard from some of the examples already, if the supporter of the person isn't au fait with how to provide the dignity of risk and promote autonomy but in a really respectful way, and also being mindful of the dangers of being thrown into choice-land when you've never had real choices before, or informed choices because that can be dangerous to not - if you haven't had that incremental build-up of learning how to make decisions and understanding consequence and, perhaps, you may never - you might not learn consequence. It might be a process of understanding what something might lead to, but I think there are traps in that, in only valuing autonomy as the panacea because sometimes those choices are not real choices.

They might be a person agreeing with the last suggestion or wanting to make another person happy or not knowing anything different and just choosing the same choice every time for safety reasons. I'll share a submission about those kinds of concerns we have around just focusing only on choice, but we need to value interdependence over individualisation

And not in every case, but we just need to see that there's value in that as well. Justify weighing up the dignity of risk versus choice argument and I guess really focusing on that we need opportunity and capacity to have the informed choice and we need to support that.

Mary Mallett:

Thanks very much. [Advocacy Organisation] and [Advocacy Organisation] are organisations who are working with families whereas the rest, most of the rest of the advocacy organisations online today, primarily always work with a person with disability and they may work with the family as well. But the family isn't the major focus and so for the other advocacy organisations, I think sometimes when they are dealing with the family some of the time it is because there is a problem with the family, and so they're supporting the person to advocate against the family, and so it is really good to hear your perspective because you have the opportunity to work with the families who are wanting to understand better how to do those processes. I wish we had ten hours to do this topic but we've only got a few minutes left. [Vic Advocate 4]?

[Vic Advocate 4]:

Hello, everybody. I'm from {Advocacy Organisation} in Victoria, working with people 12 to 25. We have a specific age range. [NSW Advocate 2], it was interesting to hear your perspective and your thoughts about working with the family. We always want to



be working with the people in the context of their own lives, but obviously there can be issues with family that do occur.

I think that like everybody else, the issues that we find when with supported decision making, is coming against other systems and the biggest one would be the department of child protection and also particularly for us at the moment the Administrative Appeals Tribunal, for people dealing with taking the NDIA NDIS issues to the AAT and the complete kind of just no real room in that process for supported decision making insofar as they have set it up.

There is a lot of legal speak that occurs that is very difficult to navigate, and that's an area where we do support young people where maybe others aren't able to do that and we're kind of grappling with what that means for us as well, you know, in terms of being advocacy and being in the legal space with supported decision making as well. I guess what I'm trying to say is, it's interesting with children and young people because there's obviously [a family's] perspective of [children and young people]. We work with children under 18 and they have people in their lives who are their guardians who will be traditionally, in some circumstances, making decisions for the young person. We know that young people with disabilities are very able to make decisions for themselves.

We are often trying to convince families of that and trying to convince other workers, like, support coordinators, support workers, SDA providers, as people have said, that it is like really important to be working directly with that young person and allow them to make the decision and I think that there's even a higher level of sometimes, like, risk, and people don't want to put the young person at risk because - simply because they are a young person but, obviously, we want - I think I'm rambling.

I just wanted to highlight that perspective of young people and it can sometimes be difficult as well trying to identify - balancing our organisational values working with the young person, and also the legal stuff, if the person is under 18, they might need X, Y, Z specifically rather than what an adult needs. I wanted to highlight that. Thank you.

Mary Mallett:

Thanks very much. You cover an age group that many of the advocacy organisations don't, so it is useful to hear that perspective. [QLD Advocate 2]? We only have five minutes left.

[QLD Advocate 2]:

[Vic Advocate 4], I just wanted to endorse what you mentioned. I think one of the things we're talking about today is supporting others to help individuals to make decisions. I



think the other aspect we often forget is actually being very conscious about helping to build individuals' capacity to make decisions right from birth.

You know, it is something that parents do ordinarily as part of raising their children. It's something that we do with our partners, we figure out which ways are best for each other in this relationship to make decisions, but I think many children with disabilities just don't have that opportunity at all to learn how to make good sound decisions for themselves, so thank you for raising it. I think it's the proverbial elephant in the room, really.

[Vic Advocate 4]:

I just wanted to tag on the back of what [QLD Advocate 2] was saying, in regards to building capacity. It's certainly something that we see at any age as well. I work with a gentleman in his 60s who I have worked with for over a year now who says, 'I am no longer a yes man'. So that's a really easy and clear example of supported decision making, in the sense that that person is now able to recognise that they were previously not given choices and options, and now 'I am not a yes man'. It works.

We use the rational model of decision making and that has been helpful in realising that lots of people can do supported decision making, but it's also not straightforward or easy as well. It requires a lot of self-reflection if you're assisting in a professional capacity, which I am as a decision supporter. I am assisting through a service. A significant amount of self-reflection goes into it, and it's not something that you learn and that's it. You continue learning and up continue developing yourself, and working and learning something new from every person that you work with. It is not something that stops. It doesn't remain stagnant. You continue to learn, and you have to continue to learn, otherwise you won't be building anyone's capacity.

Mary Mallett:

"I'm no longer a yes man", would be a fantastic title for an educational resource about this kind of work. DANA has put in recommendations to the DRC. This topic is significant, and it may be one that we think we will try and pick up and do some more on because I think that there's so much knowledge and expertise in this group and so I think we will go through what's come out of today.

I can see [Vic Advocate 4] has a quick question in the chat there if anyone knows of any training appropriate for advocates about supported decision making that she is looking for. She has found some online modules.



ADVOCATES DISCUSS



If anybody else knows of any training that you're using or you have accessed, if you could share it, send it to Siobhan and we can share it with [Vic Advocate 4]. We have just come to the end. [QLD Advocate 2] is saying the Latrobe stuff is good.

Thanks, everyone. Not everyone got a chance to have their say today, but some people did, and I think we will come back and have a think about this topic and what else do we need to cover on it.

Thanks for joining today.

END OF MEETING



Comments In Chat

Systemic Advocacy Worker 1:

Hi all, Make Decisions Real team here from [systemic disability advocacy organisation]

Systemic Advocacy Worker 1:

From MDR Peer Workers: SDM isn't as hard or as scary as people make it out to be!

QLD Advocate 2:

Fantastic Stuff, can't wait!

Systemic Advocacy Worker 4:

Really happy to hear about meaningful codesign is happening.

Siobhan Clair:

SACAT = South Australia Civil and Administrative Tribunal

QLD Advocate 2:

Well said, [Vic Advocate 1]!

Systemic Advocacy Worker 1:

Sorry we are going to jump off as the Peer Workers are struggling to keep up with the speed and language of the conversations. We will send around info once the project's SDM videos are released. Thanks for having us today.

Siobhan Clair:

If you'd like to know more about the [Make Decisions Real Project](#)... That includes a link to the SDM Resource Directory

QLD Advocate 2:

That is scary isn't it!!!

QLD Advocate 1:

The application to QCAT is made by Child Safety some 6 months prior to the person turning 18.

QLD Advocate 3:

<https://www.publicguardian.qld.gov.au/guardianship-and-decision-making/supported-decision-making>

How we make decisions



QLD Advocate 3:

https://www.publicguardian.qld.gov.au/_data/assets/pdf_file/0008/574721/Structure_d_Decision_Making-Nov-2019.pdf

Siobhan Clair:

Yes, so important that resourcing extends beyond short term projects!

(Let me know if I've missed any)

NSW Advocate 3:

[Disability advocacy organisation] has made some preliminary points to DRC in a letter

QLD Advocate 4:

<https://qai.org.au/2022/08/24/guardianship-substituted-and-supported-decision-making/> - [Disability advocacy organisation's] submission to the DRC which was endorsed by [6 advocacy organisations]

Systemic Advocacy Worker 4:

We have a few relevant on the [systemic advocacy organisation] Website under 'Publications' - the search function is useful. <https://wwda.org.au/publication/disability-royal-commission-wwdas-response-to-promoting-inclusion-issues-paper/>

Systemic Advocacy Worker 4:

<https://wwda.org.au/publication/supported-decision-making-and-guardianship-proposals-for-reform/>

Systemic Advocacy Worker 4:

I would love that tool Mary. I have to leave but please email me at [email address]

QLD Advocate 2:

Yes please Mary.

QLD Advocate 2:

Totally agree.

QLD Advocate 5:

there is an existing Resource and online course (no cost) that is relevant to this topic perhaps www.supportforddecisionmakingresource.com.au



ADVOCATES DISCUSS



QLD Advocate 3:

I need to jump off to prep for another meeting but thank you all!

Siobhan Clair

This legal concept recognises that young people gradually develop the competence to make decisions [Gillick competence](#)

QLD Advocate 4

apologies, I need to leave as well, thanks Mary and everyone else for today

QLD Advocate 2

I love it!!!!

SA Advocate 1

I need to leave as well, apologies. Thank you!

NSW Advocate 4

Thank you so much. This has been a great discussion. I am very concerned about some of the proactive choices being made by providers to make applications to NCAT for guardianship orders to be put in place for individuals they are providing support for.

QLD Advocate 2

Absolutely, there are many generic aspects to SDM, but it must be relevant and often tailored to each individual.

QLD Advocate 2

I agree - it's a fabulous statement.

VIC Advocate 4

I forgot to ask when I was speaking - if anyone knows of any training appropriate for advocates about supported decision making we would love to hear about it at [advocacy organisations]. I have found some online modules but thought I would ask the brains trust

QLD Advocate 2

The La Trobe stuff is good

VIC Advocate 4

Thank you!