



So...podcast – Episode 29

Mary Mallet, Chief Executive Officer, Disability Advocacy Network Australia
Cathy Kezelman, President, Blue Knot Foundation

You're listening to So...podcast with John McKenna

John: Greetings. John McKenna, So...podcast. Today, we're talking advocacy and counselling, in particular, for people with disabilities and their families. I've got two amazing guests on my show today, Mary Mallet, Chief Executive Officer of Disability Advocacy Network Australia, and Cathy Kezelman, President of Blue Knot Foundation. Welcome both. I'm going to start with you, Mary, if you'd like to perhaps introduce yourself formally.

Mary: Hi John. Yes, I'm the CEO of DANA, and that's the abbreviation for Disability Advocacy Network Australia, and we're the national peak body in Australia for the Independent Disability Advocacy Organisation. So, those organisations are all over the country and DANA is the peak that is the national voice for the issues that come up through those advocacy organisations.

John: Cathy?

Cathy: Thanks, John. My name is Cathy Kezelman. I'm President of Blue Knot Foundation with the National Centre of Excellence for Complex Trauma, and we operate the National Counselling Referral Service for people with disability who've experienced violence, abuse, neglect and exploitation, and I'm very grateful to be here, and particularly with Mary, to discuss this really critical topic.

John: It is critical, and I would to remind the audience if there are any parts of this conversation that may trigger a concern emotionally, or a bad trauma, let's remind everybody that some great organisations such as Blue Knot, Lifeline and Beyond Blue, if you felt like you need





to reach out to those people after listening to this episode, that's always important to know of that resource.

I'd like to just remind everybody that we are going to be covering the following issues - it's not going to be a question Q&A, it's going to be a conversation. So, we're going to be talking about the value of counselling and advocacy for people with disabilities and their families. We're going to delve into what is the National Counselling Referral Service and, more importantly, how does it work? What can people with disabilities expect when receiving counselling and also advocacy? And what are some of the benefits from counselling and advocacy?

Mary, I might start with you in relation to, in Australia, we have the Disability Royal Commission and that's basically an inquiry. I might get you to expand on that. But this is, I guess, why we have this conversation where we're talking about the value around advocacy and counselling.

Mary:

Yeah. Thanks, John. Yes, our conversation today, really, is in the context of the Disability Royal Commission that's happening in Australia. And these Royal Commissions are a particular type of inquiry. Royal Commissions happen every now and again, when a Government believes that there's an issue that's so important, that they should have a special inquiry into it, and so they will create a Royal Commission. So, it has its own – Royal Commissions have their own legislation, they are independent of Government, so there are Commissioners that are given the task of doing this.

There are – the Commissioners employ people with legal expertise and then others who are from broadly within the disability sector, including some Commissioners with disability. And those Commissioners are tasked in this case, in this Disability Royal Commission, it's a 3 year Commission, to investigate a really broad list of issues, really. So, the Commissioner has a Terms of





Reference and those – that Terms of Reference includes all of the issues that the Commission is looking into.

So, this Royal Commission is, it's called for short, it's called the Disability Royal Commission, but it's got a longer name and it is the Commission that's looking into violence, abuse, neglect and exploitation of people with disability, and there's quite a long history to the Commission being set up.

So, there's been concerns in Australia by people with disability, and their families and advocates and representative organisations, for many years about the history of the violence and abuse that people with disability have experienced. And so, there's been – there was a Senate inquiry in 2015, which pulled together a whole lot of this information, and then advocacy by organisations and individuals persuaded Government eventually that there should be a Royal Commission.

So, that's how it came about and now – and then there were support services set up, which is what we're talking about today, that the advocacy and counselling that was set up, and is funded by Government, by the Department of Social Services, to support the people with disability, as they deal with work of the Commission.

John:

I might jump in and just mention the Disability Royal Commission, as you said, you've described really well, and it's there to hear complaints. But I'm also aware, with my networks as a person with a disability, you've really got to think hard before going there, as far as what are you trying to achieve? I think – and I say that in a positive way, sometimes people want to share concerns they've got and, at a systemic level, they want the world to be a better place. I think that's great. This is where I believe talking to an advocate or a counsellor, and having that initial conversation beforehand, to really agree on the purpose before going down that journey. Cathy, what are your thoughts on that?





Cathy: Yes, look, I think you're absolutely right. I think it is great that we have a Disability Royal Commission, but I think deciding whether to put in a submission, have a private session, or if you're going to be involved in a public hearing, requires a lot of thought and consideration. Because what it means for people is often revisiting their own experiences, either past or current or ongoing, of various forms of trauma. And obviously, that's incredibly emotionally challenging because, as human beings, we often try and shut away our trauma experiences and not go there and, you know, to some degree, get on with it.

But this Commission is asking people to drill into the detail of what's happened to them, and that's why support through counselling and advocacy is just so critical, because it requires a lot of careful consideration. It takes a lot of careful consideration, it takes a lot of courage to do this and it's not for everyone. Certainly, our National Counselling and Referral Service is there with counsellors, who are experienced Trauma Counsellors. So, they're there to hear, to listen – to deeply listen, to support people to try and make sense of both where they are in the present, what's happening to them, but whether they really do want to go down this path of engaging with the Commission, or what other supports they need, or – and I'll refer onto Mary here – what advocacy service can do in helping to support them through that process of going to provide a submission.

John: Before we to go Mary, the word, "trauma." We know what it is. It's something that's impacted on your life and remembering it could have happened many, many years ago, and all of a sudden there's been something that's saying, that's like, triggered a trauma that happened a long time ago. So if we can, when you respond Mary, [0:08:09.8] reflecting or weaving that into the conversation about whether it be surgery as a person with a disability that's had surgery with a bad doctor, it was an incident in the institution from a carer, there are so many types of trauma. You think you're travelling along well, and then you go and see something on TV, or you meet someone, and something comes up and





goes bang and hits you on the head. “Oh my God, I’m feeling really bad now because I’ve just remembered what happened many years ago.”

So, Mary looking through the advocacy lens, what are your thoughts?

Mary: Yeah. Actually, given what you’ve just mentioned about trauma, I’d love to go take you straight back to Cathy to respond a little bit about the trauma, and then come back for advocacy because I’d like to [0:08:53.3] train of thought about people’s experience of trauma, and [0:08:57.3].

Cathy: Yeah, and certainly the sort of trauma we’re talking about here is what we call “interpersonal trauma.” So, it’s trauma between human beings, and we know that it’s often not just a single incident, it’s often happened over a long period of time. It’s often there are different forms of trauma that people may experience through their lives, and we know that the effects of that can accumulate over time. And we also know that many people have struggled to have their experiences of trauma acknowledged, and especially, the effects of what it’s meant to their lives, acknowledged. And, I mean, that’s why this Royal Commission is so important.

But, you know, I think we need to understand that this sort of trauma is often repeated and is often ongoing, and it often has very serious impacts. But I also am very anxious to say that, with the right support, over time, people can and do heal from the impacts of the trauma. And that’s why, you know, counselling support, emotional support and different strategies to help people manage the effects.

And particularly, you were just asking me a question about trauma coming back to you and yes, we can all have triggers, something that is maybe not even a conscious trigger, but something that is reminiscent from the situation we’ve been in the past. It may be something that stimulates our senses: a smell or a sound, and it can throw us back into a place from before. And when we’re thrown back into a time of trauma, it can often come with very, very strong emotions with the fear of the original trauma,





we can become very agitated and distressed. We can also be shutdown and withdrawn.

And it's very, very important for us all to understand these are biological responses to trauma and, you know, we certainly find that people calling our line when we can start to explain to them, and work with them, to understand what's going on for them, and that these are normal responses to very abnormal experiences that no one should ever have to experience. That can actually start to be you know, an element of the healing process.

Mary:

Thanks, Cathy. I'll bring it back to the advocacy now. So, there's this dual role that the counselling services and the advocates are playing, and you could characterise it, I suppose, fairly simplistically, which that the advocates are doing the – I don't know, the doing work, and the counsellors ... But it's not as simple as that, or as black and white as that. But the way the tasks are sort of divided between what the advocates are funded to do, is that the advocate's job is to – is quite a practical one: helping people to get their submissions into the Royal Commission, or helping people to think about whether they want to put a submission in.

So, people have been coming to the advocacy organisations to talk about things that happened to them in the past, and some people have, some people are quite clear that they definitely want to make a submission, tell their story, really, must be heard by the Royal Commission. They want to, they want to talk about the bad things that have happened to them in the past and as – John, as you mentioned earlier, they want to, their motivation is to make sure that that doesn't happen to somebody else. That's the thing that's driving people, really. But for some people, especially if they've experienced a whole lot of things over many years, that's not necessarily, it's not in their head in a neat, chronological sort of package that they can say, "This happened to me in 1992" and this – but it's not like that. It's sort of a jumble. A tangled, woven jumble of things in their head, and then they have to be able to get all of that out.





And then what the advocates do, is they'll meet with them, and it might be two, three, four, five, a number of times so that the person can find that thread through their story, and the advocates help them do that, and help them frame it, I suppose, in a way that then makes sense to the Royal Commission. Now, the people in the Royal Commission will, of course, everything doesn't have to be perfect when it goes in. They can, of course, work through this, the material as well and help fit it into the categories that the Royal Commission is looking at. But the advocates will help just get things into some practical kind of order. They will then, especially if the person is experiencing that, you know, being triggered in some way from, you know, back to those past experiences, then the advocates will refer them to – either through the Counselling and Referral Service, or to the [0:14:32.6] on the ground counselling services, so that they, people can get that professional counselling support, while the advocates focus on the more practical task.

And the other element that the advocates may also do is, there's another parallel support system, which is called Your Story Legal Service, and that's funded through Attorney-General's Department. And that provides a very specific legal advice for people who are writing those submissions, in case they – sometimes they want to, they might want to name an individual or a person in charge of a system or something, or an organisation, and there may be legal reasons why they should get some advice, take some advice as to whether it's potentially, there's potentially defamation that could happen there. And people just – it's not that they can't name somebody if they want to, it's just that they need to get some legal advice and sometimes people, if they've been through previous processes, they might have signed a non-disclosure agreement previously. So, there are a set of reasons why people might need some legal advice, and the advocates will do that, sort of, intermediary support to help the person connect with the Your Story Legal support, and sit with the person while they hear that.

And all of that sometimes means – Cathy, I think you mentioned this, as well – that there might be quite a lot of work done with someone and





they still might decide actually, no, I'm not going to, I don't want to tell my story, I don't want to have it publicly – I don't want it to be public. So, not everybody will go right through the process and tell their story to the Royal Commission. Lots of people are but some people will still pull back from that actually, even quite a long way into the process. And, of course, they have the right, absolutely, to do that.

Cathy: Yep. Yep.

John: I'd like to explore with both of you, audience listening to us right now, saying this is all sounding good, but I really need to make that decision, the best appropriate person, the best set of ears who is going to work with me. I'm hearing there are counsellors, and I'm hearing there's advocates. When you respond to this, please, I want to also touch interweave the fact both counselling and advocacy has an intake process. And when I say intake, that means that first phone call, that first email, and that's probably the hardest one, because that's where you get that connection about, "Do I go any further?"

So, and I'm making this really hard for both of you, I also want to weave in people without the voice. People who have verbal challenges and how counselling models, social work models, how is advocacy models respecting the fact that these are the anxiousness that goes on before you start to tell your story.

Cathy: I think, well firstly, this comes down to a person's choice, and also the fact that it's not necessarily going to be one or the other. I think, you know, certainly we find that people ringing the National Counsel and Referrals Service, have many, many needs and desires and you know, it's often not a matter of referring on or, you know, making what we call a warm transport for getting another service on the line and connecting the person up. But understanding what the range of different needs are and people exploring them with support over time to find who they feel safe with, who they trust and who can help them with whatever is their particular need in the moment.





So, you know, and we're certainly finding that yes, Mary, I agree totally, you guys are the doers and you do an amazing job and, you know, you are advocacy services are very trusted, you know, and appropriately so in the sector and over time. They've built that trust over a long period of time. And I think that's very critical because, certainly, anyone who has experienced trauma, has been very profoundly betrayed. And, you know, being able to feel and be safe, and to trust, is absolutely bottom line. And so, it's not a question of, you know, necessarily choosing which service but just finding when you find the initial place of trust, and then having someone who can walk alongside you as you explore the other options.

Mary, I'm sure you've got a lot more to add to that.

Mary: Yeah. Thanks Cathy. John, I'll go to your, the issue about people without the voice, I think was the term you used. And so, yes of course, there are people who literally may not be able to speak in any way, but that doesn't mean they can't communicate, but they may not have a literal voice to talk about what's happened to them, they may be able to communicate through other means, and the advocate's role will be to make sure that that person is given every communication support that they need, whether it's devices that they normally use or whatever supports can be found, so that person's story can be told.

Now, that might be that is a person who can only indicate with their eyes, a yes or no. And that that story can be elicited, in a way, by framing questions with 'yes' or 'no' answers. And advocates do that kind of work anyway at other times around advocacy issues. So, it is possible to do that, and that is what advocates will be doing. One of the difficulties will be, is that whether those people, that particular cohort of people whose communication – who have complex communication needs – is whether that many of those people live in quite constrained surroundings. They live in residential support, sort of support, sort of surrounded in the service system. So, one of the problems will be whether they are actually being told and hearing about the Royal Commission and that they have got this





opportunity. So, advocates are working to try and get to those people in the first place to make sure they understand that the Royal Commission is on. That's one of the critical parts.

One of the other things, though, that you've prompted me to think about when you asked that question is, you know, this Royal Commission is a combination of years and years of advocacy, for people to have this opportunity to tell about the violence, abuse, neglect and exploitation that they've experienced. Some people have died before their story, before they themselves have the opportunity to tell their story. That includes quite a lot of people who lived for years and years in the big institutions in Australia. Australia is one of the countries in the world that has done a lot to shutting down most of the big institutions, where people with disability were placed, some of them as children. Most of them have now shut down in Australia and people are living in smaller settings, some of which still are quite institutionalised, but they're not in the big, in the big settings that people think of as institutions.

So, some of those people – and especially people I'm thinking of who were part of the self-advocacy movement that grew up as part of the Disability Rights Movement – some of those people were very active, and there are some film clips, some recordings, some written stories that those people told as they took those steps out of institutions, and so those stories will be told through advocacy and representative organisations, who will write in submissions to the Royal Commission about that history of what happened to people, and using, telling those stories in the form of examples and case studies, so that that history isn't forgotten and those people's voices still are heard.

John: Wow. I'm just going go to 'wow.' Both lovely pieces of commentary from both of you and I hope our audience is enjoying the So...podcast episode on this really important topic. Mary, you've prompted, once again, for me, yes, those people who are no longer with us and, but however, it's those memories that has brought this to attention now, and we all know the





things that weren't working well, but they now have a stage where this conversation can be heard.

So, we're talking counselling, we're talking advocacy and the benefits of families and people disabilities. It's amazing. I'd like to perhaps close this very shortly and hoping that each of you can give me your thoughts on, after listening to this episode, what are their next steps, they might even be a witness, by the way. There may not be something that's affected them, but they know of another family that's got some things going on. It's really a, putting the Disability Royal Commission aside because that, in itself, is a stigma because it sounds big and scary. What I'm hearing right now is, when we've got counselling and advocacy working together and professionals who are really good at listening to stories, I think that's the piece of gold for me, anyway, as a person with disabilities, that we're hearing now. It's okay to talk.

So, a quick question to both of you, for people listening, how do they basically approach this topic? How do they, you know, if you want to go and help someone and tell them, you may not talk about the Royal Commission. You may just talk about, are there any issues? Did you know that you have advocacy and you have counselling that's out there to help. I'll go to you first, Cathy.

Cathy: Look, I think, you know, something I did want to say is that the National Counselling and Referral Service also supports people who, you know, are deciding that they're not going to engage with the Royal Commission, but that they have experiences of trauma and living with disability. And so, I think it's very important to know that there is help and there is support and you know, to know that there are places where you will be heard and listened to and believed, and that if you reach out, there is someone there to support you and to walk alongside you. And that, you know, there are possibilities for a better future with that support. I think it's very important to hold on the hope.





This is not to negate the barriers that people experience, but to say that, you know, we know that people can do better with the right support. And I think when services are working together and, you know, what we are seeing in Australia now is that, you know, we're finally talking about issues that have long been buried and long been stooped in stigma and discrimination and secrecy. Not saying it's magically all going to go away but, you know, we are making steps towards some real change.

John: Thank you, Cathy. And Mary, closing comments?

Mary: Yes. One thing that I think is very important about the support that's being provided around this Disability Royal Commission, is that there's, up until now, there's been almost no counselling available for people with significant disabilities. There just hasn't been. It hasn't been funded by Government, it just hasn't been available and, perhaps, even the expertise in the counselling services hasn't been there because they haven't been working with people with disability.

So, because there's now some funding available through this process of this support system, advocates are able to refer the people who are coming through for this type of advocacy support, they can refer them to counsellors to help them work through that, sort of, backlog of the trauma they've experienced and that's a novelty, to be honest. It's a new thing, it's going to be really interesting as these few years happen to see that there will be people who – Cathy's described it in a beautiful way – about people feeling supported and someone walking alongside them, and that there's hope for healing. Because [0:28:01.9] [audio cuts out] happen in the past is the other way of dealing with things, which is squashing them. Putting them to one side, avoiding thinking about them, not dealing with them. That's how most people with disability that advocates work with, they are incredibly resilient, very strong people, but who deal with the bad things by just putting them in a box and leaving them there.

And this new funded opportunity to have people able to try and come to grips with and deal properly with some of the past trauma, is new and





exciting, and we're really looking forward to being able to see and find out from people, and from the counsellors about the benefits of that. And the advocates will keep doing their job of working away and getting things done for people, and, and as well as, you know, getting the submissions into the Royal Commission. The advocates are also able to do some of the other practical advocacy tasks that are required at the same time, where they have capacity to do it, they are doing some of that, as well. But yeah, we're really pleased that the Government responded to not just funding the Royal Commission, but funding this support that sits around people and yeah, it's a pleasure to be part of that.

John: Very good. We are going to call this a wrap. It's been a lovely conversation. My name is John McKenna from So...podcast. We've been talking to Mary Mallet, Chief Executive Officer of Disability Advocacy Network, and Cathy I think I might have not pronounced your surname properly at the start, I apologise for that. Help me, please?

Cathy: That's all right. Kezelman, and any variation is fine.

John: Very good. And Cathy you're from, of course, the Blue Knot Foundation. I'd like to remind everybody that this episode is available on my website, johnmckenna.com.au. Soon it will be available in transcript. I want to once again remind people, if there's any topics that have triggered concern for people, there are some great supports out there. Of course, we have the Blue Knot Foundation, we have Lifeline and Beyond Blue. My name is John McKenna and thank you, Cathy and Mary, for coming onto the So...podcast.

Cathy: Thanks very much, John. Bye.

Thanks for listening to the So...podcast. I do hope you subscribe for further podcasts. For more information about So...podcast go to our: website

<https://www.johnmckenna.com.au/>



