Episode 1

0:09

Emilia Bell [EB]: We'd like to acknowledge the traditional Owners of the unceded lands this podcast is recorded on, and pay our respects to Elders past and present.

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EB: Hi, and welcome to GLAMR Disability in Dialogue, the podcast that delves into the intersection of disability and neurodiversity in galleries, libraries, archives, museums, and records professions.

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EB: We're all about inclusivity, challenging the norm, and creating positive change, impact, and community.

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EB: Today, as we jump into our first episode, we celebrate the launch of ANDPA - the Association of Neurodivergent and Disabled GLAMR Professionals Australia. We explore ANDPA's values and vision, how it came about, and the challenges along the way.

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EB: Hello and welcome to GLAMR Disability in Dialogue's very first episode. I'm Emilia Bell and I'm incredibly excited to be co-hosting with my co-founder, co-chair, and wonderful colleague Nikki Andersen.

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EB: Nikki and I are our own guests for this episode as co-founders of the *Association of Neurodivergent and Disabled GLAMR Professionals Australia* (or ANDPA). And GLAMR refers to galleries, libraries, archives, museums, and records. If you're not already a member of ANDPA, we'd absolutely love to have you on board, whether you identify as disabled, neurodivergent, or an ally, you are welcome to be a part of this community. We're excited, and we really hope you are too.

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EB: So a good place for us to start is probably going to be actually just introducing ourselves. So Nikki, I might pass to you to start and you can give us an introduction of who you are and why you care about disability inclusion and advocacy.

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Nikki Andersen [NA]: Thanks Emilia.

1:58

NA: I'm a librarian in Queensland so I live on the lands of the Jagera and Giabal peoples in the Darling Downs region. So I'm an academic librarian. I specialise in open education and I also do a lot of freelance work in diversity, inclusion, and that involves, you know, freelance writing, consultancy, and freelance speaking.

2:19

NA: And so the reason that I'm passionate about disability inclusion is because I was born with a rare connective tissue disorder called Stickler Syndrome, which affects my vision, hearing, spine, and joints. So I'm hearing impaired and have worn hearing aids since I was a teenager. I'm also significantly visually impaired and have lost a lot of my vision from retinal detachment over the years. And I also experienced a lot of mobility issues and chronic pain and have spent time in a wheelchair as a child.

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NA: And so since my condition is extremely rare and no doctor has ever heard of it except for the doctor that diagnosed me, so I've had to do a lot of advocacy in my whole life, you know, advocating medical professionals and mostly advocating for myself.

NA: And eventually that advocacy turned into broader advocacy for others, not to experience the same barriers I have - in the medical profession, in education, and now these days in the library and information profession where I work.

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NA: So that's where a lot of my advocacy started. But when I entered the library and information profession in 2015, I just didn't see myself represented at all. Disability was hardly ever spoken about, and if it was, it was kind of done in whispers and, you know, done very quietly. There was a lot of shame attached to it. And to me that was sad as someone who has multiple disabilities and someone who has been open from a very young age. And so that's something I've been hoping to change my whole career. And this is why the establishment of ANDPA is really exciting to me.

4:08

NA: And that's me. So Emilia, would you like to introduce yourself and tell everyone why you do disability advocacy?

4:16

EB: Absolutely. Thanks Nikki. So I live in Queensland, Australia with my wife. We have a few pets, most recently a grey tabby cat and like Nikki I work as a librarian, I'm working across academic services and also evidence based practice and I'm also a PhD candidate researching open scholarship and knowledge diplomacy.

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EB: And I've been working with Nikki for the last couple of years and that's honestly been one of the highlights of my career so far, she's absolutely wonderful, and all of that though is coupled with my lived experience of disability.

EB: So I care about disability advocacy for a number of reasons, fundamentally because I care about people and disability rights are human rights, but also because I don't want people to have the same barriers that I've had. So that's really important to me, to be able to kind of reflect back on where I'm at now, realise some of the barriers and challenges along the way, also some of the strengths that I've brought to them. But just recognising that I don't want other people to have to experience those.

EB: And if there's any way that I can make a difference or support someone in not having to face those barriers or being able to find ways around them, then that's something that I'd like to be able to do. Another reason is that we do need professional representation and allyship for disability and neurodiversity across GLAMR sectors. I think that at least in libraries, when we have initiatives that are focused on library users around disability, or really any other marginalised or underrepresented group as well, we need to make sure that we're supporting professionals in those spaces and also in leadership. And that really contributes to the authenticity of those initiatives and makes sure that they're not coming across as disingenuous. And finally, I care because I do want to see change happen where it's needed, and that's something that's become quite clear with ANDPA - that there was a need for it. But I never really expected to be speaking about disability in professional spaces at all. It's been really unexpected and honestly sometimes a little bit terrifying and exhausting to be navigating - especially because I went into a career in libraries thinking that it would be a really great field for me to just quietly fly under the radar in.

6:18

EB: And Nikki we've both talked about before about the energy that's actually required to navigate any kind of advocacy or disclosure, and you've talked quite a bit about the emotional labour that's involved. I think that's something that we've kind of shared across both of our experiences in this work.

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NA: I think there's strategy involved in disability advocacy and strategy, but not always recognised. I think there's a delicate dance between advocacy and adaptability, and that's sometimes quite hard to navigate in professional contexts.

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NA: And it's also the emotional labour of living with a disability. And for me, my disability is predominantly invisible. So you know, it's a term in the disability profession called passing. You know, whether you disclose your disability or whether you hide it from someone. And I don't think people realise that passing is a choice that happens every day, often multiple times a day, depending on the person you're interacting with. So even though I'm quite open about my disability, quite publicly in the profession, there are still times where I must choose whether I pass or not in certain contexts.

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NA: And that might be even unintentional. You know, someone might forget my disability and I have to reassert my needs or, yeah, reassert, you know, the support I need. Yeah. So that's a challenge, and it's also a challenge to determine who you should disclose to and who you shouldn't.

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NA: And, you know, I've got mistakes I've made where I've, you know, wish I had disclosed to someone and wish I hadn’t disclosed to someone. And these all take emotional tolls and they all require energy that I didn't really expect.

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EB: It's that risk management aspect that you've spoken about a few times, isn't it?

NA: Absolutely. It is a risk management decision and even though I'm open about my disability, I don't really encourage or expect other people to be. It's an individual choice and it's an individual choice because there is such a risk involved not just in the library and information sector, but I think in all sectors in Australia. You know, the research is showing us that disability discrimination in employment is a reality. Yeah. So what about you Emilia? Have you experienced emotional labour too, in the advocacy work you've been doing?

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EB: It's definitely something that I felt as well, and perhaps should have expected more. And just like you said, it does take a toll. You end up learning to navigate that risk and make decisions in a new way. You're engaging with both the personal and professional, and navigating how they're entwined to probably a greater extent than other people might have to. It can be equally as exhausting to just be hiding. Interestingly, I was quite open about being, or much quicker, I suppose, to come out about being queer and shifting to using language from partner to wife in workplaces than I was to actually mention anything about disability.

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EB: And that was an interesting experience because that was something that I'd hidden in previous workplaces and then stepping into libraries, I just wasn't sure, you know, again, who I should disclose anything to and what that kind of looks like. So when I was able to come out as queer, that was only because I had seen a senior leader within my own workplace actually just share something, might have been for Wear Purple Day, and seeing that just gave me the courage to go, oh, this is, this might be okay.There's a number of safe people who I can disclose to, and this can just be part of normal conversation within the workplace. But I was much more reluctant to do that disability, and I think that's where some of the values that we're going to get to later come in, with things like pride, I can have a sense of pride for things like my queer identity, but that same visibility and sense of pride - a lot of the time we're not quite there with disability and neurodiversity in workplaces, we barely have a level of acceptance, I think.

EB: So, there is that emotional label of navigating that process of disclosure. Just like you Nikki, I think I've had times where I've just gone - I don't know if that was the right decision to disclose. I've had people who I have disclosed to, and people I haven't. A lot of the time when I do choose to disclose and be more open, it's because someone else has approached me after hearing me speak and gone, oh that really resonated with me or I've had a similar experience.

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EB: And it's times like that when you just go, there's a relational element, where you also want to share, and recognise that being open about disability and neurodiversity does actually lend support a lot of the time to someone else who might not feel like they can be open. And I know that the more open, like during this process, me and the emotional labour that's being involved in it, I've been continually looking for people who I can kind of look up to. And to be honest I probably wouldn't actually be having these kind of conversations or speaking out about this if I hadn't seen you be open about this in the workplace and hadn't had that opportunity to work with you.

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EB: And that's made me just realise the value of, again, it's a personal choice, but having people who are kind of willing to step forward and be a little bit more bold and open about their own experiences.

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NA: And that really highlights the importance of why representation matters. And thank you for your nice words about me but you've made such a difference to my career too. So as I said quite earlier that you know I had a sense of isolation because I didn't see other people like me. And when you came into the workplace, I was really grateful because I connected to you straight away, and you know, you got my experiences. Like even though we have different experiences, there was a sense of understanding and a sense of empathy. And someone who just understood me at a deeper level and I really appreciated that. And that's why that sense of community and leadership is so important.

12:28

EB: And that's something that has been really beneficial in co-chairing and co-convening anything that relates to lived experience, because there is more likely to be that understanding - it’s not always the case, but I know that in the work that we've done together there's just been that this person gets this kind of, this person is going to understand why this actually matters to me or why this might be a problem when other people aren't recognising it as such. I think it's really important just to have people who can identify with, who share elements of those lived experiences, and also be able to recognise where they differ and learn from each other as well.

13:03

EB: And so we've also encouraged everyone who's become a member of ANDPA over the last few weeks to be asking questions. And we've had a whole bunch of wonderful messages, emails, conversations that have happened over the last few weeks. But one of the things that we did was we set up a Slido for people to ask some questions anonymously about ANDPA. And so it's probably a good idea for us to work our way through those questions and actually answer them. But also just to chat more broadly about how ANDPA actually came about, we've got a little bit of a background about our own experiences, some of the challenges which are kind of hinted out that there as well around emotional labour, disclosure, what that actually looks like on a personal level, but also why we’re excited about this and what change we’d actually like to see. So I think the first question that we had is a really good one to kick us off and that was: What led us to start ANDPA? Nikki, did you want to give this one a shot?

13:56

NA: Absolutely. So for me, I guess the main motivator was establishing a community, you know, having people that we can relate to and learn from, and bringing people together.

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NA: I think that there are a lot of disabled and neurodivergent people in the GLAMR sector, but you know, the conversations don't happen. So just encouraging those conversations and collectively making change. You know, as I said before about the emotional labour, it can't just fall on several people, it needs to be a whole community sort of thing. So I'm really excited about ANDPA and the potential of working with other people with lived experience. But for those of you who are listening, ANDPA wasn't originally my idea, it was actually Emilia's idea. And Emilia came to me with this fantastic proposal to establish ANDPA. So Emilia, what motivated you to come to me with this proposal and say, let's just boldly do this?

15:00

EB: Thanks Nikki. It absolutely wouldn't exist without you though.

EB: I didn't feel very bold at the time. I mean, I guess it was a little bit bold, but I was really nervous to actually put that idea out there. It was one thing then to share it with you, we already worked quite closely together, but then to know at some point we're going to just put this out into the world and see how other people kind of responded to it. And we had a few opportunities to test the waters along the way. But it was still a bit of a, you know, nerve wracking experience to see what those kind of responses were and if we had really captured the need that people had identified and that was where it was really important, I think, to be looking back on those motivators and why we were actually doing this in the first place.

EB: For me, it was definitely a whole bunch of different experiences. Some of them would probably over the past 10 years, You know, you kind of look back and see where you are now, what barriers you have had, what challenges you've had, what strengths you kind of brought to that and how you've overcome them and gotten to where you are. And when I say overcoming challenges, I'm not talking about overcoming disability. So I'm talking about the societal and attitudinal barriers that exist for people with disabilities. And while they're certainly not the only barriers, often it is that deficit lens, stereotypes, and some of the misconceptions and stigma that are brought, which are what need to be overcome instead of disability or neurodiversity itself.

16:26

EB: But over that time, I'd really had a few different experiences that had made me think if I want to be part of anything professionally, whether that's projects, building professional relationships, whatever, whatever that happens to look like, I've got to hide my disability. And there's one in particular that just left me absolutely feeling absolutely devastated around that - I just went - I don't want to have to completely hide this aspect of me, that's really challenging to do - it puts a lot of extra …it's honestly exhausting. It's exhausting to have to hide part of yourself. But I just kind of … It took me a few months to kind of work out how I wanted to approach that, what I wanted to do with that experience, how I wanted to respond to it, if I wanted to talk through it with someone and I didn't end up really doing that for a long time. I just kind of pushed through, decided that I was going to be persistent and just take the time to reflect and respond to it in my own way.

17:24

EB: But it was really, it was definitely a really defining point for me and I had a whole series of those that then led up to thankfully some more positive experiences. And I was able to kind of go if I can't have been the only one who's had those negative experiences. And imagine if more people could have these positive experiences because I recognised the positive impact that it had on me professionally. And it was such a contrast to some of the experiences that have been from a few years back. And at that point the idea for ANDPA was not fully formed. It was just a case of, this is kind of what I'd like to see and what I'd like other people to experience.

18:00

EB: But I had no idea what kind of form it was going to take. I certainly - I didn't have anything I think like what we have now actually in my mind. And it was only, I think it probably took a few months, for that proposal to develop. It changed a number of times and even the original one that I sent to you, I think it's ended up in quite a different form from that original document and we still have that and I think there's a lot that we're going to continue to draw from as we continue to progress ANDPA. But it's yeah, it's definitely interesting to kind of look back at how these experiences are …

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EB: prompts to kind of set something like this in place. And they're certainly not experiences that I'd necessarily want anyone else to ever have. But that's part of the reason why ANDPA exists, to actually be able to start conversations around disability and neurodiversity and bring together a sense of community so that people don't have to feel quite as alone with their own experiences, whether negative or positive, and just to bring that sense of belonging. And that's exactly what you were talking about before where you kind of look around and you are looking for people who've shared - who can share - experiences with you and you can actually talk to and relate to professionally. And I'm really hoping that that is something ANDPA can bring to its members.

19:22

NA: That's an excellent answer. And you've just touched on two of our values, community and belonging. And so we established ANDPA on four values and the other two are pride and leadership. And pride is an unusual one, Emilia, you don't see that very often in organisations? What led you to include pride as one of our values?

19:46

EB: It was actually something that, it might have been you, Nikki, you might have spoken about it a few times. We've both talked about the need to move towards disability acceptance from disability awareness, and I think eventually we'd hope eventually that was disability and neurodiversity pride.

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EB: And it's a challenging value in some ways because we've had to be clear about what we actually mean by Pride. People do have challenges. I've spoken about them, my own challenges, just a little bit there. And we had to be clear that it wasn't about ignoring those challenges, it wasn't about ignoring any kind of discrimination, but about celebrating that inherent worth of people within these communities and just the inherent worth of people and the diversity that our experiences bring. So I think we've got here, “Pride embraces disability and neurodiversity as part of human diversity.” And you've spoken a lot about that: disability is just part of diversity. It's the natural course of our experiences.

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NA: That's right. Like disability is the only minority group that everyone at some point in their life is going to become a part of. And so to me, I don't understand why there's so much shame attached to disability and why it's viewed through such a deficit lens. Because, yeah, it is part of human diversity and you know, it happens to people or they're born with it or it comes - chronically or naturally - and it's beyond our control. So, you know, shame should not never be attached to disability. And so I'm really proud that we've included pride as one of our values.

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EB: And I think that touches on what you're just talking about with moving beyond like deficit lens and deficit language and the, I guess, the sense of shame that has often been attached with disability and neurodiversity. I think that touches really well on our leadership value because we've mentioned inclusive and authentic leadership. And I think part of that is actually recognising where we need to make change in the language that we're using, how we're leading people, and recognising where those needs lie. And I think a lot of the time that gets missed as part of the conversation.

22:02

NA: I think there's a narrative that people with disabilities are made for technical positions and not considered for strategic or leadership opportunities. Then that's something we're hoping to change with ANDPA. Like we want to focus on careers, not just getting disabled people into the workforce. So we're going to look at things like mentoring and coaching, but it's also about having allyship. And I think I've said before in one of my other speeches that I think disability lacks allyship compared to other diversity initiatives. And I'm hoping that’s something that is going to change. And I feel like there is a shift towards that, so that’s really exciting.

22:43

NA: Our next question is for you Emilia. So what was the Australian Institute of Company Directors training you did before founding an organisation like this and did you look at other training providers?

EB: Yes, this one was definitely for me. It's an interesting question because the AICD training and ANDPA overlap in time, but it certainly wasn't a planned occurrence, just happened that way. There are certainly things that they did take away from the Foundations of Directorship course that I'd apply in my approach to ANDPA. But it also just gave me a new perspective and different approaches when it comes to a lot of things professionally, in ways that I just did not expect it to. But it certainly has guided and provided some input for, I guess, our approach to this and some of the questions and considerations that have gone into it.

23:35

EB: But again, did I look at other training providers? No, because it was a scholarship opportunity. It wasn't something I ever expected to be doing. I never expected to be doing any kind of board or governance training. So there just wasn't that, at the time, that motivation to actually consider other training providers. It was something that happened quite quickly when I realised I wanted to put myself forward for it, that I wanted to be doing it. And I have a number of people to probably thank for, you know, just leading me in that direction. But it certainly, it was completely new to me, just wasn't something I had pictured myself doing at all.

EB: But it was a really positive experience. I did it all online, got sent a wonderful binder of reading which I was very excited about. There's nothing like getting a box of paper to read, box of reading on a Friday evening. I was very happy.

24:26

EB: There was a heap of case studies, some great discussion around them and the different sessions and in my experience as well really terrific support for accessibility. So overall a really positive experience. But yeah, I feel like a lot of people might have picked up on that overlap between the training and the starting time for ANDPA and it really was not a planned occurrence. It was just something that happened and worked out quite well, I think.

We did have one last question come through as well. I think this is a good one and something I'm interested in because it relates to a lot of the partnership conversations that we've been having lately and that's something that I've been really excited about and really appreciated about, just as an experience starting ANDPA.

25:05

EB: So the question was are you interested in collaborating with ALIA, the Australian Society of Archivists, Australian Museum and Galleries Association, CAVAL, unions, other related groups. It's with - this is a question that we've kind of had some thoughts around ourselves, you know what kind of industry collaborations and partnerships do we actually want to have? And that led us to the second question which was asked, which was how important is it to maintain independence from them? So we might take a shot at answering this together. Nikki, did you want to make a start on that one?

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NA: Partnerships is one of our objectives, and partnerships is really important because we don't want to duplicate the amazing work that's already happened. Like there's wonderful people and wonderful groups doing just sensational stuff. And we've already started having conversations with some of these groups, like the ALIA disability group. And you know we've been sharing their resources on our websites already and we look forward to working with them further.

26:06

EB: Yep, exactly what you've been saying Nikki. I think we're both really excited about that collaborative potential and I guess what we're seeing is a way to strengthen and reach their shared objectives and extend the conversation further. But we did also want to recognise the importance of agency and some kind of independence in our governance. So part of that was making sure that we had lived experience leadership. So that's something that we think pretty upfront about. And while there's still a lot of conversations around what governance for ANDPA actually looks like, we do know that lived experience leadership is part of it. We do want this to be a community lead initiative and that's something that we've tried to do

26:45

EB: We had surveys that we asked people who were potential members to actually respond to and identify those needs and we wanted to make sure that that lived experience element was there from the start. And so that's something that we've factored into. And that's not to say that you can't have lived experience leadership in any other kind of arrangements. There were a lot of ways that we could do this. So we could have come under another industry body in an auspice agreement and had that sponsorship and infrastructure already there and still maintained that lived experience leadership. But there was a few factors that we considered there.

27:23

EB: So firstly, we aspire to be bigger than just one GLAMR sector, so not just libraries, and that limits just a little bit who we might come under. So we were also then mindful about wanting to take ownership and have some agency over the policies and procedures that are going to influence how we operate and conduct projects. So we were weighing up those pros and cons around our ambitions in the manner that we actually wanted to be conducting this work in. For me personally, there's definitely a sense of authenticity in actually being able to define our organisations values and also reflecting on how those values are going to lead us forward. And we want to make sure that we're clear and upfront about what principles, what values, what our objectives are, and to be able to take ownership of them and use them to guide our projects and the way that we're heading.

EB: I think, again, speaking back to values, something that I've always been, I've always asked is whose values, perspectives and voices are reflected in the work that we do and in our profession. And so it's those kind of questions that we're asking that are actually factoring into our governance structures and the decisions that we're making across this work. And it’s challenging. And it's also incredibly rewarding though to see something like this come to be and to be able to bring other people alongside it.

28:36

EB: And even though we're maintaining that independence, to still be creating collaborative initiatives and to start to start to see some emerging partnerships come out of this as well. That's why I was so excited to have actually seen so many people come on board and associate members as well who see themselves as allies just come on board and say, yeah, I'm willing to volunteer, I want to be part of this community. And so we're really hopeful that those partnerships are going to exist within ANDPA as we actually start to see us be more community led and to be able to see the direction that the community that we exist in wants to take this.

29:16

EB: But also there's external partnerships where we can strengthen and highlight the work that's already happening and hopefully contribute and come alongside it as well.

29:25

NA: Absolutely. I just want to thank everyone who's reached out to us and who, you know, given us positive thoughts or written us emails already volunteering their time and your support means a lot to us.

29:37

EB: And I think on that topic of partnership and collaboration, we're also really excited for the guests that we have lined up for future episodes of this podcast. So, it's really continuing that conversation and bringing acceptance for disability and neurodiversity and that's such an important part of what we're hoping to achieve.

NA: So thank you so much for joining us in the launch of ANDPA and our first Disability in Dialogue podcast episode. We're really excited for the guests we have lined up for future episodes and of course welcome you to become a member of ANDPA to stay up to date with future events and projects. So thank you and until next time.