Bernadette McGoldrick
Stenocaptioner, RPR, CRC
0405 350 799
bernadette@accesscaptions.com.au
www.accesscaptions.com.au

Live Transcript

Essential Media

The Disability Dialogue

Unlocking Potential: Support for Children with Disability

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Captioned by Bernadette McGoldrick and Kasey Allen

>> Recording in progress.

SARA GINGOLD: Hello, everyone. We're just waiting for everyone to join. Thank you for everyone who's coming. Alright. Shall we kick it off? Hello, everyone. My name is Sara Gingold and I'm the editor-in-chief of DSC's Resource Hub. And just to describe myself, I'm a white woman with a short brown bob wearing a very colourful jacket. And I'm co-hosting this event along with Todd, and we would like to welcome you back for another Open Dialogue. And I want to begin by acknowledging the Traditional Custodians of the land on which we gather. For me, I'm on Wurundjeri land, and I want to recognise the continued connection to the lands and the waters of this beautiful place, and acknowledge that sovereignty was never ceded, and also to pay respect to all Elders and ancestors, and any First Nations people joining us today.

TODD WINTHER: Hi, everyone. I'm Todd Winther. I am currently sitting in a motorised wheelchair. I have short hair with a green shirt on. For those of us who haven't been to one of our events before, think of it as a live show, where you can control the conversation. It's designed to be inclusive, accessible, collaborative, respectful, and - most importantly - fun. We encourage you to have your camera on if you're comfortable with that. We will also be collecting all your comments and questions in the chat throughout the event, and may even ask for your participation if you want to join.

SARA GINGOLD: . Yes. And just a little bit of background about us. The Disability Dialogue is a project to promote inclusive, collaborative, disability-led conversations. And before we start, I want to shout-out our partners, including: The Disability Advocacy Network Australia, Inclusion Australia, Alliance20, and the Melbourne Disability Institute. We are funded through an Information, Linkages and Capacity Building grant from the Department of Social Services. Also, a shout-out to our media partners Powerd and Vision Australia Radio.

So, shall we get started on today's topic? It's a big one. We are gonna look at what good support looks like outside of the NDIS for children and their families. Now, we like to try to be as jargon-free as possible in these events, which is very hard when talking about the NDIS, but I think it's important that we define this category called Targeted Foundational Supports. Because it's an important term to get across, where we're seeing it used a lot lately by politicians, in the news, and different organisations who work in this space. So, what are Targeted Foundational Supports? So, they're a targeted support for people with disability who need some help with their everyday lives but aren't eligible for the NDIS. And it's about making sure, even if you're not on the NDIS, you still get the support you need and get the same opportunities as everyone else in the Australian community. And it might be helpful to go back to the explanations we used in last month's event, which some of you might have attended and some of you might have missed, but it's a good refresher.

TODD WINTHER: So, one way to think about - which we have talked about last month - is it's like having three buckets, which we can see on the diagram. In the first bucket is mainstream services, which is at the bottom of our diagram. Everyone in Australia needs and has the right to use mainstream services, like health, education, or transport. And these services have a responsibility to be inclusive and accessible for everyone. Now, we all know that they often spectacularly fail at this, but that's a conversation for another day. The point is that everybody has the right to use these services, and everyone needs all of these services, so this bucket has to be a pretty big bucket.

SARA GINGOLD: It does, indeed. And, now, the second bucket - the one at the top of the diagram - is the NDIS. I joked last time that you might have heard of it! I imagine you've still heard of it! It's a big bucket, but it's not as big as mainstream services. And you have to be eligible to use services in this bucket. And as everyone here knows, not everyone with a disability is eligible for the NDIS, but also not everyone needs it. And, finally, there's a teeny-weeny bucket stuck in the middle of those two buckets, but it's a bucket that we think should be growing. And this bucket is for people with disability and their families, for disability supports, but not funded by the NDIS. And that is what we call Foundational Supports.

So, some people with disabilities might use these services a lot, some might never use them, but the point is that they should always be there for people when they need them. And in that bucket are things like peer supports and self-advocacy and independent information - and that's what we call General Foundational Supports, and these are things that we think most people with disabilities will use at some point in their lives.

Sometimes a little, sometimes a lot. But when you need that information or advice and it's not there, you really notice it.

TODD WINTHER: In this bucket, there should be some services for people with disability who need some help in their everyday lives for the NDIS. These are Targeted Foundational Supports. We say these should be in this bucket because these services basically don't exist at the moment, and it's why the bucket is so tiny. We have described it here today like buckets, but the NDIS Review talked about the same thing - they just described it slightly differently. If you went to one of the Town Halls last year about the NDIS Review, you would have seen this shown as the triangle with the NDIS shown at the top. That's what we want to focus today - what the review called Targeted Foundational Supports, and we're specifically gonna be talking about the ones that are for children and their families. Many of you would have seen the speech made by the Minister for Disability and the National Disability Insurance Scheme, Mark Butler, actually made a pretty big announcement about this last week. It's relative for this event, and, Sara, I know working with you at DSC, you've written a really comprehensive article about this, so can you tell us a bit more about the announcement, please?

SARA GINGOLD: Yeah. Thank you, Todd. Also, because we were watching the announcement together, so your contribution really helped me get across it. I want to be clear first off that there is a lot that we don't know, and we're basing this largely on Mark Butler's - the Minister for NDIS's - speech at The Press Club last Wednesday, and subsequent media events. But there's still very limited information. So, here is what we do know. The Federal Government is talking about introducing a new system called Thriving Kids. And the minister suggested that Thriving Kids will be particularly targeted at children with - and these are his words - mild to moderate developmental delay and autism. And what we don't know - and what I imagine is still to be designed - is what Thriving Kids will look like, and what services it will include, but Mark Butler in his Press Club address did mention some initiatives the government is thinking of, including: Universal checks for children, more training for GPs , an allied health item in Medicare for children, online information and services, and also community drop-in centres. He also said that health services and early education centres and schools will have a bigger role to play in delivering Thriving Kids. And the minister said he wants to get this program launched by mid-2026, so about a year from now.

TODD WINTHER: I know, like me, Sara, that you have been frustrated about the confusion in the mainstream media, so let's clear some context up a bit and talk about this in slightly more detail. What everyone wants to know is, "Is Thriving Kids replacing Foundational Supports?"

SARA GINGOLD: No. So, Thriving Kids is a way of talking about Targeted Foundational Supports for children, but the other day the minister did say they are still looking at other Foundational Supports systems for other people to use.

TODD WINTHER: So, what does that mean for kids who are receiving NDIS support at the moment?

SARA GINGOLD: So, again, this is just going off what the minister said last week, but he said that children currently on the NDIS, or who join the NDIS before Thriving Kids rolls out, they won't be automatically kicked off the NDIS and onto Thriving Kids. But the minister did say they will still be subject to eligibility assessments like they are now. So, which basically means their access and eligibility for the scheme might be reviewed regularly. I want to make it, like, very clear, we understand there's a lot of mixed feelings about this in the community, and a lot of people are really nervous, and it's particularly difficult when we don't have a lot of information to go on and, like, particularly when you're depending on these supports and they make such a big difference in your life. I just want to really acknowledge the anxiety out there.

TODD WINTHER: So, according to the government, what's gonna happen next?

SARA GINGOLD: It looks like there's gonna be a consultation period, where the government will be talking to a lot of different people about how Thriving Kids should work, which actually makes today's discussion even more important because we're here to talk about what good support for children and families looks like, and those are the kind of stories and ideas that we really want the government to hear, to help them shape our Thriving Kids will work, so that basically children and families continue to receive support that helps them thrive.

TODD WINTHER: So, we're gonna share some links throughout today in the chat, including Sara's wonderful article that she wrote on Wednesday.

SARA GINGOLD: Rush-wrote! (LAUGHS)

TODD WINTHER: We're going to shift the discussion a little bit. Before I introduce our first guests, I want to encourage you in the chat to share your own thoughts and ideas as we go. We'll also be taking questions from the chat throughout the event. Now I want to move on to our next section. I want to introduce our first guests - Stella and Sarah Barton. Stella is a disability rights advocate and Paralympian. She attended Shelford Girls Grammar and has a Bachelor of Arts from Swinburne University. In 2024, she competed at the Paris Paralympics in the Grade 1Para Dressage, scoring over 70% in all her events and coming seventh from a field of 22 riders in her grade. Stella has been involved in activism and accessible public transport, and has also presented in community radio programs for SYN FM and 3CR.

And Sarah is also joining us - she's Stella's mum. Sarah is a 2010 Churchill Fellow with 30 years of filmmaking experience. Her first film, Untold Desires, talked about sexuality and disability, and she won her first Logie Award for SBS Television, and an AFI Award.

Sarah is currently making a feature documentary about comedian and disability activist, and my friend, Stella Young. Thank you, Sarah and Stella, for joining us today.

SARAH BARTON: Thanks for having us here.

TODD WINTHER: No worries.

STELLA BARTON: Great to be here.

TODD WINTHER: Sarah, firstly, can you talk about the kind of support that was available for Stella when she was young, Sarah?

SARAH BARTON: Sure. Well, the NDIS was really just a twinkle in a few people's eye back when Stella was, you know, before she was at school age. So, she was born in 1999, and a lot of us thought that something like an NDIS would be a brilliant idea but it was absolutely not even on the radar back then. And so what we had was actually incredibly inadequate early intervention support. It was confusing and hard to figure out where we should go, and all of that sort of thing. But if you could find your way through the maze, you could find certain kinds of, you know, group support and group activities, but it was really up to us to go and find the therapy that Stella needed, and also at a level that was going to make any kind of change to her cerebral palsy. We knew that, you know, the concept of brain plasticity, you have a child who's born with a brain injury, and you have got a window of opportunity to improve that child's outcome. You know, we know the differences that happen with good early intervention compared to the bad old days, when kids were put in institutions and they just didn't thrive at all. So, we know that it's really important to have a lot of good-quality early intervention. And, look, that was really very limited in what you could get back when Stella was at that age where she desperately needed it.

TODD WINTHER: Stella, I know it might be hard for you to remember 'cause you were a young girl at that time, but is there anything you want to add to that?

SARAH BARTON: I think at this stage of things, yeah, she hasn't got anything to say at this point. She would probably barely remember it, except we've still got friends that we met back then!

TODD WINTHER: So, you did a lot of programs through an organisation called Noah's Ark, Stella. Were there any particular challenges or things that could have been done differently?

And, Sarah, feel free to jump in.

SARAH BARTON: Yeah. So, look, one of the things we had talked about in the lead-up to this event was that what was on offer through, kind of, funded supports, so we didn't receive any individual funding for Stella's therapy. But we tried to find what might be, you know, like, when you enter the world of disability, you just assume that there's all of this infrastructure to deal with it. And there kind of wasn't. But we did find an early intervention play group that we went to, and it was, in some ways that don't happen so much now, it was wonderful 'cause we got to meet some other families. We got to exchange ideas, we got that sense of community. But, of course, on the other hand, therapeutically, it was almost completely inadequate because it was once a fortnight, and, you know, for an hour and a half, or maybe an hour - I don't actually remember - so, it was really, like, it was very minimal and piecemeal. But what we did get was the opportunity to ask other families what they'd found, and the opportunity to tell them what we'd found. So, sharing ideas and information was fantastic, but really that was because the system was so fragmented. And there were places that offered more comprehensive support, but you couldn't get in. Like, they were just full. So, I think, in the context of what's happening now, I think there's some positive things that actually are inherent in doing things with other people in developing community, and that sort of thing, and doing things within mainstream services. But the fundamental thing is that there has to be enough to actually make a real difference to people's lives, and it also has to service not just us that live in the inner city at the time - you know, we had the best access to things - but we have to think as a nation that a lot of people live in rural and regional areas, and even remote areas. So, we really do have to create a new framework that offers adequate... Multiple times a week. You can't just be going once a fortnight to see some specialist teacher in a school. It has to be, you know, a lot of intervention. And the other thing - sorry, I'm just jumping ahead a little bit.

TODD WINTHER: Sure. Sure.

SARAH BARTON: You were talking about services being offered in schools. And one of the things that - this is what Stella would remember - is that throughout her childhood, many afternoons a week after school were spent driving, often across town, you know, for 45 minutes or so, to see the physiotherapist one day, the speech therapist, the OT. The osteopath. You know, like, all of these specialists that were helped, they were great, but we basically spent just about every afternoon after school with Stella and her brother - killing each other in the back seat of the car! - driving to these different therapies. And it was incredibly inefficient and it also took away from Stella's childhood, you know, her ability to do other fun... Although, you did go to ballet and horse riding and stuff as well, so, you know, yeah.

STELLA BARTON: For example, we drove hours and hours.

SARAH BARTON: Yeah, so we would be driving for hours and hours. And by the time you'd get home, it would be 6:00 and the kids would be starving. They'd spend a lot of time wanting to kill each other, because one of them didn't want to be there but he had to come because you can't just leave a 5-year-old at home after school.

TODD WINTHER: I'm sure my brother has very similar stories, and he wanted to kill me in the back of the car too! If you have just joined us, everybody, I'm talking with Stella and Sarah Barton. I want to remind people who need extra access that there is Auslan available and captioning available.

But I want to throw it to you now, Stella. Can you remember about the different types of supports you received and whether you had a preference between group and one-on-one support?

STELLA BARTON: Well, I remember doing a lot of one-on-one support. I remember a lot of it. But really a lot of one-on-one support. One-on-one appointments, it varied. And, yeah, when I look back now, even though it was helpful and helped me get where I am now, it was very...

SARAH BARTON: Yeah, so just to recap, she had a lot of one-on-one appointments with physio, speech, OT. And although it did have an impact on her function and physical wellbeing, it sort of took away from your, sort of, ordinary childhood somewhat. And I think also there was a, kind of, very much a, sort of, medical-model focus on, you know, medically we've got to get you well, and it didn't really include anything that sort of developed into community and...

STELLA BARTON: No.

SARAH BARTON: And just a sense that you were part of, you know, something...something bigger. And there was a tendency to feel like we were the only ones going through this, you know?

TODD WINTHER: I went through a very similar experience. Lots of early intervention, the practitioners were really focused on getting me walking and up and moving, about. And I remember as a child that that's not really what I wanted to do, I just wanted to really focus on the stuff that I was good at, rather than what the practitioners really wanted me to do. And I can hear that sort of a similar theme coming through in your response there, Stella.

STELLA BARTON: Yeah. And it was mostly about walking.

SARAH BARTON: There was a sort of obsession with walking. But I just thought of something else that happened, like, in amongst all of this, because, yes, we did physio and speech therapy and that, but one of the things I very...sort of quickly figured out was that we also needed to make things fun. And so we were incredibly fortunate - we were actually at swimming lessons, Stella was learning to swim, and the swimming teacher suggested that, you know, maybe Stella could do ballet. And she knew of a ballet school that Stella could go to, and the teacher turned out to be incredibly inclusive. Like, really inclusive. So, Stella started doing ballet when she was four. And she just reminded me - when she was four. And I remember the ballet teacher was the first person who ever said to me, "You can leave her here and come back in an hour. Like, it's fine, don't worry about it."

STELLA BARTON: And I remember and wanted to help me.

SARAH BARTON: She had organised one of the older students to help Stella in the class. And, you know, she really, really got it. And she used to yell at you the same as she yelled at everybody else, which was amazing!

TODD WINTHER: That's true inclusion, isn't it?!

SARAH BARTON: It sure is. Yeah, but Stella was part of that ballet school from the age of four to the age of 16. She did every concert, suffered through hours of rehearsals. You know? And, look, not every moment of it was accessible. Backstage at the concerts was a nightmare. There were lots of things that were, like, yeah, not perfect, but that mainstream ballet school, and being part of it, not only did it give Stella fantastic skills with her poise and, you know, ability to kind of move her...

STELLA BARTON: Balance.

SARAH BARTON: Balance and all of that. But it was social and inclusive and the teacher was amazing. And then, of course, she did Riding for the Disabled, which she really took to.

Not every child wants to be on horses but it worked for you. So, there were lovely group activities. And one of the things that frustrates me so much about the NDIS is that it's completely lost that focus on how do we support a ballet school to include somebody like Stella, if the teacher doesn't have the confidence or the skills to do that well? How does the NDIS engage with the mainstream world to say, "Here's... You know, disabled people want to be a part of your school or your group or your activity, or whatever, here's the support to include them better." And maybe even... It's just... I just think that was lost way too early on, when all of the service providers swooped in and took all the money. You know, it was lost, that idea that mainstream services could support people to do things without feeling like they had to have a support worker to do it. You know?

TODD WINTHER: And that kind of leads me to my next question, Sarah. And I want to talk about your journey as a parent - it could have been overwhelming early on, especially not knowing much about disability services. So, trying to make sure you got the best support for Stella and navigating a very complex system was like encountering a whole new world. So what kind of support was there for you as a parent?

SARAH BARTON: We were very lucky that we had some close family friends, Stella's - we thought it was kind of possible that she was going to have cerebral palsy from the day she was born because there was a major - it was a difficult birth and we actually just happened to have family friends who had a 5-year-old daughter who also had cerebral palsy. They had a difficult birth as well. Different but similar. When we were in hospital with Stella as a little one in intensive care, they were the first people who came in and took us out to lunch. They didn't overload us and we just had a new baby and we weren't fully receptive but to just have friends that we knew we could turn to when we were ready. It took a while for us to be ready to say, "I think we need some help here." That was incredibly fortuitous, having - just knowing other people who were five years ahead of us down the track. The fact that they generously - they just said, "We're here when you're ready. If you need something come and see us." The mother was a nurse so she had a pretty good idea of what was going to happen. Probably knew before I did. I had made films with the disability community as well. I was not uncomfortable in the disability world. I had time and contacts and all of that sort of thing. Having those friends was a real game changer and just having what you might call peer support but it was informal. That was great. Then once we had accepted the likelihood that she was going to have cerebral palsy, then finding our way through all the services, that was a lot. Pretty much a full-time job.

TODD WINTHER: It is. I had a friend that described it last week as 10 full-time jobs because you're always on the go. I can see a lot of parallels between your story and mine, both Sarah and Stella. I wanted to ask you what it was like for you, Stella, when you were younger. I can remember as I was growing up, doctors were increasingly asking me and my parents to have surgeries when I was younger and I had three or four operations when I was a kid and that sort of balance between wanting to do as a child and that sort of balance between what you wanted and what was medically feasible, or available. How did you feel about that, Stella?

STELLA BARTON: Yeah, well...

SARAH BARTON: Can I recap so people can understand you? There was a lot of medical staff and when Stella was about 14, the doctors and the surgeons…

STELLA BARTON: I want to back track a little.

SARAH BARTON: She had three or four rounds of Botox with the surgery. So they were designed to relax her muscles and it did work a bit. It worked for a while.

STELLA BARTON: But eventually, it would wear off.

TODD WINTHER: Sarah, it must have been quite a balance between what the doctors were recommending and what Stella was telling you that she wanted - it must have been a really difficult balance to sort of navigate?

SARAH BARTON: At the Botox point it wasn't too bad. It was when they started suggesting multilevel leg surgery that it got tricky. Stella, do you want to talk about that?

STELLA BARTON: Yes. I was about 14 when the doctors told me and my parents about having -

SARAH BARTON: The doctors started talking about having multilevel surgery on her legs.

STELLA BARTON: And it was a big thing for all of us. I was really adamant that I didn't want to have it. I remember that and someone like me, the result would be -

SARAH BARTON: Stella was adamant she didn't want to have the surgery and they also said the results were variable and they weren't going to guarantee any results.

STELLA BARTON: If I had the surgery and it went well, I would be able to walk everywhere.

SARAH BARTON: They said if the surgery went well, she would be able to walk down the street and walk wherever she wanted to go.

STELLA BARTON: At that point in my life, my goal was to be able to walk.

SARAH BARTON: At that stage her goal was to walk around the house and maybe carry something.

STELLA BARTON: I didn't want to be able to walk long distances, that's why I had an electric wheelchair.

SARAH BARTON: It wasn't a goal to walk long distances and she had her electric wheelchair.

STELLA BARTON: I didn't want the surgery to -

SARAH BARTON: Stella was instantly like, "I'm not having this surgery." She was terrified of it. Stella was 14 or 13 and we as her parents felt like - doctors are well educated, they have got a lot of experience and all of that sort of thing, so we felt that it was our responsibility to make sure that we were making the right decision and that if there was a compelling argument why she really needed to have the surgery, then maybe it was something that we needed to kind of try and bring her over the line. But one day, the doctor said something about, "The surgery will make her legs look straighter." That was the moment when I just went, "I don't think this is…" They were talking about 12 months of rehab but it was more like two years. My husband was much quicker to say, "No, if she doesn't want it, we are not having it." I was a little more impressed by the doctors, which I am ashamed to say, because it would have been the wrong decision. There is a real risk in society that we look to doctors as being wiser than they are. Surgeons will always recommend surgery nearly always. Surgeons often recommend surgery and also we had seen our friends who were five years ahead of us. They had done the surgery and it had been very unsuccessful and we saw that as kind of something that we didn't want to do. In the end, we just said, "No, we're not doing it." And it was the best decision we ever made but it was really led by Stella. It was a very hard time in our lives to kind of really feel like we were making the best decision. There is lots of other details that we won't go into here, but it's just an important message for families to understand that you're the ones that have to do those year or two of rehab, the surgeon won't be there to do all the exercises that need to be done and deal with the pain and all of that.

TODD WINTHER: Cut first, ask questions later type thing, hey?

SARAH BARTON: Yes.

STELLA BARTON: I was overpowered by the doctors…

SARAH BARTON: They had the power. We are educated and privilege and we felt the doctors had the power. I would hate to think that the families that have less confidence to speak out and perhaps not so well educated. There would be people who would be much less able to say no than we were.

TODD WINTHER: We have got a couple of questions in the chat but before we address those, I would like to thank you both, especially Stella, for sharing her lived experience and yours too, Sarah, for sharing your experience and telling some stories and hopefully educating our audience. Sara has got the first question in the chat. Over to Sara.

SARA GINGOLD: Thank you. That was so interesting to hear. I love the story about the ballet school, it just shows there is a place for mainstream services, there is a place for specialist services.

SARAH BARTON: Absolutely.

SARA GINGOLD: We had some great questions coming through. The first one is from Jax and it is for Stella. It is, "Were there things you found hard or even damaging about early intervention?"

STELLA BARTON: When I was really young, but what I had to do - and I think now…

SARAH BARTON: Walking. I guess just to summarise it, sometimes because you're an athlete, sometimes people will suggest Stella physically could walk around the block and it would be a good form of exercise for her, but in her mind, walking is about therapy and torture and it is like, "No, I'm not walking, I'm not doing that."

SARA GINGOLD: That's fair.

TODD WINTHER: Physio for me is like - I associate that with pain as well, which is why I don't want to have a bar of physiotherapy as an adult. One final question for Stella. Somebody asked, "Are you still friends with the people that you interacted with at Noah's Ark and how about the people in the ballet class that you mentioned?"

STELLA BARTON: They are pretty much my oldest friends to this day.

SARAH BARTON: They were in Paris, yes.

STELLA BARTON: It was really great having them there as friends.

SARAH BARTON: We have got other friends from the early intervention group that we're still in contact with and you also still have a friend that you actually - we didn't realise that, as 4-year-olds they were at ballet together and then they met at school and they are still friends.

TODD WINTHER: Awesome.

SARA GINGOLD: That is lovely.

TODD WINTHER: Thank you, Sarah and Stella, for sharing your stories and lived experience. I hope I speak for the audience when I say I got a huge amount out of that. Thank you so much.

SARAH BARTON: It was an absolute pleasure. We enjoyed it. Thank you.

TODD WINTHER: Bye.

STELLA BARTON: Bye.

SARA GINGOLD: Before we go to the break, we sent out a survey to everyone before this event and thank you so much to everyone who filled it out. One of the questions we asked was, "What are your memories of early intervention? How did it make you feel?" I just want to clarify some terminology. When we are talking about early intervention, we are talking about support when children are younger earlier in life. This slide shows some of the responses that we got. We haven't been able to include them all, of course. But they were all really helpful.

Here is a couple. I loved the first one, "For me, early intervention was not a small thing. It was a lifeline. It changed my story from one of fear and exclusion to one of hope and possibility." And someone else said, "I felt included." And another person said, "Extremely grateful and thankful, to them and to my amazing mum, the force behind it all, because if it was not for her, I will not be the person I am today." I really related to that last one. I am dyslexic and the teachers at school didn't believe I was dyslexic but my mum knew and she fought for me to get a diagnosis. The early intervention really helped me. Now I am a writer, so it helped me quite a lot. It was something that we had to source privately which I think is sad, because it makes it less accessible for other people. There was also another response that said, "There wasn't any…" early intervention, which shows how different some of the experiences can be.

TODD WINTHER: They are different for everyone. Like you, Sara, I resonate with those earlier responses, particularly in regards to my parents did an awful amount of work taking me to all sorts of appointments and things. Those appointments were only available because the government actually gave enough funding to actually have those available to kids in my generation. We have gone through a lot of content here at this point. We are going to take a 10 minute break now for everybody to digest what we have listened to and learnt and we've got two terrific guests after the break, Gretchen Young, from SNAICC, and award-winning disability inclusion and gender activist Akii Ngo. We hope you can stick around for more conversations. Enjoy your break, everyone.

(BREAK)

SARA GINGOLD: Welcome back, everyone. Thank you for the great comments you have been posting in the chat and the questions. Please keep those coming. If you are keen to jump on camera later on and turn on your mic and make a comment, that would be wonderful. This event is all about trying to hear from you as well and we will try and get through some thoughts and opinions later on. Maybe have a think now about what you want to say. Get yourself ready.

First up, we have Gretchen Young, and Gretchen is a Gadigal Eora descendant from Redfern, NSW, and before relocating to Melbourne, lived in northern NSW country for many years. Gretchen is the executive director of programs at SNAICC, the national voice for Aboriginal and Torres Strait Islander children. Welcome, Gretchen. Thanks for joining us today.

GRETCHEN YOUNG: Thank you so much, Sara. Thanks for having me here.

SARA GINGOLD: We are so glad. Gretchen, the first question I have for you is how do you think the experiences of Aboriginal and Torres Strait Islander children and families accessing supports is different from the experiences of non-Indigenous families? If I could make it a double question. What do you think this new system Mark Butler has announced Thriving Kids needs to consider in order to ensure it also meets the needs of Aboriginal and Torres Strait Islander children?

GRETCHEN YOUNG: Yeah, great questions. Thanks, Sara. I would like to start by acknowledging that I am coming to you today from unceded Wurundjeri country and to acknowledge traditional custodians and elders from all of the countries that you are joining from and also acknowledge any of my Aboriginal and Torres Strait Islander brothers and sisters on the line today.

In terms of the first question of experience of Aboriginal and Torres Strait Islander children, just some framing is that the NDIS review found that Aboriginal and Torres Strait Islander children were almost 2.5 times more likely to have a disability, compared with the general population of children. Despite this, Aboriginal and Torres Strait Islander children and their families regularly miss out on services put in place to support early assessments, identification and delivery of developmental supports for children who need them.

The experience of Aboriginal and Torres Strait Islander children accessing support as much with difficulties navigating the complexity of the current NDIS and we're talking current at the moment, and the general service system. While this challenge isn't unique to Aboriginal and Torres Strait Islander families or children, there are added barriers, including the lack of safety - the cultural safety in services and geographical barriers for remote communities.

When Aboriginal children and families are looking to access services, they bring along the whole family. Aunties, grandparents and extended family. For families that do manage to get NDIS plans or are seeking support outside of the NDIS, the next barriers are finding appropriate programs and services in their communities and for many this is impossible, as often they don't exist, or they are just not accessible. This might be due to geographical isolation. One of the things that is very common in our communities is fear of the child protection system, or a lack of cultural safety. Assessment tools used are often not culturally appropriate and don't consider Aboriginal ways of knowing, being and doing. SNAICC is working alongside the University of Melbourne to roll out an assessment tool that is culturally responsive for our communities.

In consultation with communities, Aboriginal Community Controlled Organisations, ACCOs, that SNAICC held in 2024, were consistently heard early childhood services report challenges finding available allied health practitioners to visit their communities, or to refer their families to particularly for remote communities. Even if families get through all of those barriers to access supports, the way the health system understands disability is very different from how Aboriginal and Torres Strait Islander communities understand it. In many Aboriginal languages, there is no word for disability. The Aboriginal culture is one of inclusion and disability is just part of the diversity of people in the community. What a wonderful way to be, right?

SARA GINGOLD: Exactly.

GRETCHEN YOUNG: There is the strength to Aboriginal communities, where no-one is left behind and everyone belongs and is accepted as they are. But it can also create barriers in understanding what the child support needs are in SNAICC's conversations with families, we often hear about the shame that can come with the label of disability. The experience of Aboriginal and Torres Strait Islander families and children with developmental delays and disability is often one of dealing with intersecting barriers as a result of both disability and being an Aboriginal and Torres Strait Islander person. All of these barriers and challenges often result in Aboriginal and Torres Strait Islander children not being assessed or being assessed later in life and not accessing the supports they need to thrive in their communities.

So the second question that you raised was about some of the lessons that we have from our Aboriginal Community Controlled Organisations and how that can be applied to Thriving Kids or the sector more broadly. The way we often think about ACCOs, Aboriginal Community Controlled Organisations are they are holistic. They are not siloed. They are sustainable, so they are always thinking long-term and long-term funding cycles. They are inclusive. They centre relationships and voices that are not always heard and the healing about restoring balance.

ACCOs take a strength-based child and family-centred approach to service delivery and this results in services that are holistic, tailored, relationship-based and responsive to need. These services often have an open door policy, staffed by local community members that have knowledge and insight into families' lives. We all know families are the experts, right?

With place-based community had centred approaches ACCOs bring multiple services to the child and family in one location, rather than the family having to attend multiple locations. ACCOs, or Aboriginal Community Controlled Organisations create an open and welcoming space that the community are welcome to come to any time and have a voice in. This has great benefits for the community in reducing barriers to access. It means ACCOs really understand the needs of community and they are present in and can develop solutions collectively that will work for them. We know in the context of early year services, many Aboriginal Community Controlled-led early integrated services provide offerings beyond the traditional early childhood education centre or settings. Families access these broader services after entering the ACCO for early childhood services, providing such avenues for entry is important for families to determine their needs at their own pace.

SARA GINGOLD: That is wonderful, Gretchen. When we were speaking earlier in the week, we were talking about how a lot of the learnings that you have had working with Aboriginal and Torres Strait Islander children and including some of the strengths that are coming from it and also some of the barriers that you have faced can really help inform what Thriving Kids looks like for the broader community and I guess what would you like - what are the lessons you would like to see?

GRETCHEN YOUNG: One of the things we would like to see is - I guess those experiences of ACCOs that they are both a reflection and representation of community. Whether or not that's boards of governance, cultural governance being at the core of those centres, whether or not it is reflected of community being involved, whether it's volunteering or parental engagement but they are reflective and representative. ACCOs have such strong relationships with the communities where they're present. They understand the needs of the whole community, including children and families because children are just at the centre of all of that work, the ripple is that it's whole of community involved. The connection and accountability that ACCOs have to community makes them uniquely placed to identify the services, the supports that are most needed and will have the greatest impact.

The diversity of that Aboriginal Community Controlled sector is overlooked or misunderstood and at SNAICC we often hear about the lack of capacity of the Aboriginal Community Controlled sector, so we flipped this because at SNAICC we are always trying to look at strength-based approaches and solutions, so we flipped it to have a focus on the capability. We talk about place-based organisations that often have 50 years of experience in governance, financial management and managing multiple funding streams as well as being reflective of community.

ACCOs go well beyond the mainstream scope of child care and early education to provide holistic wrap-around support for children and extended families. ACCOs have been the leaders of holistic early childhood supports for decades, long before terms like integrated hubs were coined in the mainstream.

SARA GINGOLD: I was just going to say I love that it sounds like they are very much part of the community, not separate to the community, it is like a natural embedded thing which I imagine it feels safer to go and seek support from an ACCO compared to an organisation you have never heard of before?

GRETCHEN YOUNG: Yes, I will give you a funny yarn. Somebody asked me, "How do ACCOs promote the services in community? How do community know where to go?" And we were like, "Because they are community". Do you know what I mean? You wouldn't need to have a formal referral or you wouldn't need to Google their web site, people just know where they are. As I said, ACCOs play a crucial role in Aboriginal and Torres Strait Islander communities providing culturally safe services, including disability services. They also support communities to navigate government and non-Indigenous service systems, including but not limited to the NDIS, justice, health, social and community services and on the new landscape as Thriving Kids.

SARA GINGOLD: Yeah. I imagine another important concept is cultural safety and what does cultural safety and support mean and why is it so important?

GRETCHEN YOUNG: I am going to give you a word wall around definitions but one of the things, before I do that, is I really want to emphasise that cultural safety is about the people that are going to be impacted by unsafe behaviour defining it. For Aboriginal and Torres Strait Islander people, they would define what cultural safety is as opposed to a mainstream service or government telling them, "We are culturally safe." People feel it. Cultural safety is the positive recognition and separation of cultures. It is more than just the absence of racism or discrimination and more about cultural awareness and cultural sensitivity. It empowers people and enables them to contribute and feel safe to be themselves. SNAICC defines cultural safety for Aboriginal and Torres Strait Islander children as the child being provided with a safe, nurturing and positive environment, where they're comfortable with being themselves, expressing their culture, their spiritual and belief systems and they are supported by the carer who respects their Aboriginality and therefore encouraging their sense of self and identity.

I have had lots of conversations in the last couple of weeks about how that applies to not just Aboriginal and Torres Strait Islander families and children but to wider marginalised and vulnerable groups and how we can use that feeling of cultural safety in multiple settings. So it is important to note that for many Aboriginal and Torres Strait Islander families, the painful legacies of the Stolen Generation are very much present and experienced in the present day. This creates fear of child protection interventions when Aboriginal and Torres Strait Islander families navigate government systems, access services or interact with mainstream organisations. Cultural safety is about creating an environment where families and children do not experience fear and they feel like they belong.

Cultural safety is essential for Aboriginal and Torres Strait Islander children's wellbeing and development and it is really up to the people engaged to define their cultural safety. As I said, not service providers or government. Aboriginal and Torres Strait Islander children and young people, families and communities are more likely to access services that are culturally safe and experience better outcomes in those services. It is critical that disability services and supports are culturally safe for Aboriginal and Torres Strait Islander children and families. As I said, we also engage with the applicability of cultural safety in multiple settings. I am really happy to take any questions, Sara.

SARA GINGOLD: That was so interesting. I guess something that stood out to me is a lot of it is about how you feel - do you feel safe accessing the service? Maybe sometimes a person might not know what cultural safety means to them until they are in an experience where they're not experiencing cultural safety?

GRETCHEN YOUNG: Yeah, and we talk in terms of intersectionality of alliances of those feelings that people have, that have been marginalised or discriminated against and that there are similarities. Often it does come down to a gut feeling or a gut response, right?

SARA GINGOLD: Yeah, because we pick up so many signals and sometimes we just know when something doesn't feel right. Gretchen, this has been a fabulous conversation. I really wish we could keep going but I think we are running a little bit short of time at the moment. Thank you so much. I think Todd is joining us again.

TODD WINTHER: Yes. Thanks, Gretchen. That was a really important conversation for us to hear about. We are running a little behind time. Since there aren't any questions in the chat, we are going to move onto our next fantastic speaker, Akii Ngo. I will give you a few moments to come on screen and gather your thoughts. Sara and you are about to have a really interesting conversation. I know when we did the pre-interview the other day, I learnt so much from you. I am looking forward to hearing about it.

SARA GINGOLD: Welcome, Akii, and thank you, Gretchen. Akii is our final guest today and Akii is an international and multi-award-winning disability inclusion, gender equality advocate - activist. They are a proud young disabled, transgender, nonbinary and LGBTIQ+

queer person of colour. Thanks for joining us today. I think you are still on mute. One moment, sorry, everyone. I wonder if we can…

TODD WINTHER: Akii, you should be able to turn your own mic on. They are shaking their head. Could we get a bit of help with the tech support, please? Sorry, everyone. Just got a message from the backstage crew. Bear with us a second. Apologies.

SARA GINGOLD: You can't run an online event without having one tech issue. It is almost tech bingo that we haven't had one yet.

TODD WINTHER: Akii, you should be able to get a request to turn your mic on now. Do you have one?

AKII NGO: I apologise. So sorry. As soon as I was about to share, the screen went blank and I couldn't touch any buttons. Thank you, I apologise for that.

TODD WINTHER: Over to you, Sara.

SARA GINGOLD: Thanks, Akii. That is stressful. Akii, can you tell us a little bit about what your experience was like as a child getting support? I know from talking to you previously that it was quite challenging for you. Can you tell us a bit about what made it hard?

AKII NGO: I didn't get any support, so I think not having support made it really hard. Not knowing that I was - it was possible to get support made it hard. Not knowing that a world in which I coexist as I am, just as I am made it hard. Growing up as a child of refugees, my parents were refugees, they lived in refugee camps prior to coming to Australia and we were sent to - people don't know, you are often sent to regional towns. I was born in Geraldton, WA and because I was so unwell, I was flown almost immediately to the hospital. My parents don't have much education - their education level is quite low, their English levels are quite low. There is so much stigma there, but also the contrast between surviving a war and living in refugee camps without any support, or considerations. Having or getting support is a privilege. A full stop, end of story, like having a roof over my head and food on the table, or education - like going to school in Australia is a privilege. Anything beyond that was more than I could ever ask for, and if I dare ask for it - or if I knew to ask for it, I would have been a very ungrateful child.

I moved out of home at 15 as a result of intimate partner - sorry, family violence, intergenerational trauma, a lot of that but also the embedded stigma within a non-Western - if we think that the stigma that exists around Western culture is overwhelming, you cannot imagine how truly disabling and heartbreaking it is within non-Western cultures. Your existence is determined to be useless or worthless, or non-contributory to society because of your illness. I was born very unwell. I didn't know or identify with disability. I was just always the sick kid in and out of hospital, like surgery, back and forth, all of that, without really an understanding or consideration for my own quality of life, but also because my parents didn't have the knowledge or understanding I was my own parent.

I was also an advocate. I didn't have a childhood. When you are taking care of yourself and I was the youngest out of three children. Unfortunately, my siblings didn't take care of me or understand any of those challenges that I had. Getting support or receiving support or any of that, it was essentially not a thing that happens. The lack of language and the lack of knowledge - so yeah, what made it hard was I didn't understand disability pride, I didn't understand the social model of disability. A lot of communities presently in - let's just say in so-called Australia at this present moment that are in non-Western cultures don't have an understanding of the social model of disability, don't have an understanding of disability pride. There is so many of us - many of those communities that are forgotten about, falling through the cracks and left behind. Especially with the lack of language and understanding and knowledge and the contrast been - sorry, my brain just, with the previous speaker, I have forgotten your name…

SARA GINGOLD: Gretchen.

AKII NGO: Yes, Gretchen, and the First Nations language and the massive contrast is the opposite of that. You are essentially useless and worthless and the language is equivalent to the R word in disability.

SARA GINGOLD: That is awful.

AKII NGO: Japanese, Cambodian, Chinese and Vietnamese. I don't know every single Asian language, nor do I non-Western language, but it is pretty common. How can you have pride in something that describes you as essentially a useless…

SARA GINGOLD: That you don't have a word for.

AKII NGO: Learning disability but also learning that I am autistic, neurodivergent, all of those things were missed because I was a high-achieving student. I guess I am intelligent in the sense of that but because I came from that cultural background, it was drilled into me that if I wasn't a high-achieving student, I was useless and I was worthless. I guess I had to keep fighting to be worthy in their eyes, in my own parents' eyes. I think that is the challenge. Parenting yourself but also having to prove your own worth to your own parents, when it is not your fault - like it is not your fault you have a disability. It is a natural part of the human experience but I didn't have the pride that I have today and I don't have the fight that I have today when I was a child because why would you expect that from a child that's going in and out of hospital, all of that?

The worst thing was, like I am a '90s child, I was in high school about 20 years ago, even my teachers - I was in Year 12 and like so many of them told me, "You should repeat. You're going to fail." And I lived in hospital for the first - I was only 15, so I was in hospital in year 12 for half of the year and I still got the 90-plus ATAR because that was embedded into me, to be not worthless to my parents essentially, to be worth something to them. Without it, not surprisingly I moved out of home. I am completely estranged from my family. I have had no contact with siblings and the whole shebang. It is not a fun existence but I have community through the work that I do in advocacy.

SARA GINGOLD: I wanted to ask you about that. Also just firstly, thank you so much for sharing all of that. I know it's not always an easy thing to reflect on and it is not an easy thing to experience. So many people will be listening and relate to your story and feel like a little bit more seen because of it.

AKII NGO: Hopefully learn from it.

SARA GINGOLD: Thank you, so much. I wanted to ask you, because Akii, I know from talking to you that you have found community now and I wanted to talk to you about how you went from where you were to where you are now and also about your journey if you have time to talk about that?

AKII NGO: If I have time? I know we are on a time crunch.

SARA GINGOLD: If there is time.

AKII NGO: If people are happy to be here and let me - yeah. That was all hard childhood. What would have helped? I am going through all of the questions, what would have helped is having that support and understanding, that language early on. I mentioned my teachers quickly, because they failed me, in the sense of because I was the high achieving Asian student and that is a racist micro-aggression, assuming all Asian kids are smart. I was literally told, "You must be good at maths because you're Asian." And I remember once I got diagnosed with Autism, my whole world spun around and I remembered thinking that's why I was so overwhelmed and banging my head against the wall, against the concrete wall in the library as a child when I was overwhelmed. Teachers saw that and they didn't pick it up. All of this is triggering. I was self-harming. I wasn't OK. I was very not OK as a child. If I didn't move out of home, I didn't think I would be alive today. I had to do what I - and no child should ever have to do this, but I had to do what I needed to do and that was to keep myself alive, so moving away from the people that were supposed to protect and love me. Sorry if that is a lot for a lot of people. What I wish would have been different is all of that.

Unfortunately, so this relates to community later on, is I experienced a lot of intimate partner violence because I accepted the love that I thought I deserved and I sought love from people that weren't loving, or that weren't caring or supportive or inclusive and they were physically, emotionally, all the things, forms of violence and abuse that I am still presently going through actually. That spinal injury is the direct result of intimate partner violence. It leads back to my community, my background is public policy and health promotion and the work that I did in that space wasn't as invigorating, public health nutrition was great and all but I wanted to create change, so I used my transferrable skills within public health and public wellbeing and health promotion within the violence prevention space and I got my first job doing a women's empowerment and violence prevention program which is where I kind of - I knew I was doing it because of my own experience but then I got to a point where I felt safe enough. Ironically in the relationship I am currently fighting from and safe enough where I am now in my autonomy as a person to have shared my experience on Our Site, it is a WWDA iteration, and I was the safety from violence expert advisory person and I put my hand up to share my story and my lived experience and that was the first time I had ever done that publicly.

SARA GINGOLD: It must have taken a lot of bravery?

AKII NGO: Yeah. I felt personally how could I - which I know some people will never have this ability to do this and that is fine. If I felt that I could share this experience and help others, then I will because how could I encourage and work and do the work I am doing if I don't feel trust and safety within the work that I am doing? It is almost kind of a - which is a lot of them in my life. Being the representation that I never experienced growing up and that includes within modelling and fashion and everything that I do and in my existence as a person with so many different identities that overlap and cause so much different types of marginalisation or oppression. The way in which I found community was slowly sharing my lived experience and slowly finding power within my story and slowly recognising that I have power within my story and I have a professional - numerous qualifications but I truly believe that lived experience often can trump most of that lived experience - most of the professional qualifications. I was able to thankfully link that altogether and use my lived experience, expertise as well as my professional expertise to carve out the world in which I have, where I know my experiences matter but I can uplift other marginalised people that exist and may have felt any of the emotions that I have probably taken you all on in this very short 10 minute conversation.

SARA GINGOLD: It has been amazing.

AKII NGO: Ultimately, how I found them was putting myself out there, scary as that has been, but I also found people in certain organisations that made me feel safe and some of which I have been texting just like throughout the day. Including The Disability Dialogue and DANA and many organisations and the people here today, on the Australian Disability Council. There is Jane and plenty of people on this webinar that are and have been safe people. Finding people is not always easy because it can mean putting yourself out there but there are people that have been in your position, or in some form of your position and I hope that you know there is that community that can be found if you don't have family, if you don't have such supports. That's my little nutshell because we are running out of time.

SARA GINGOLD: Thank you, Akii. I feel like people can - you have faced a lot of challenges but there is a lot of hope in your story and there is a lot of hope in who you are. I think you've done a brilliant job to become an activist who is making a huge difference in peoples' lives. I know it is scary to share your life experience and thank you so much for sharing it with everyone today because I think people can really relate and get a lot out of it. Thank you. We are unfortunately running out of time, which is - I think we could talk - I could talk to Akii for at least another couple of hours, but unfortunately, we can't do that today.

TODD WINTHER: I want to jump in and say thank you for having such an important conversation to you both. Thank you to Akii, in particular, for being so emotionally vulnerable. We really appreciate it. The team are putting links in the chat in case that was a difficult conversation for you, or if it brought up some thoughts and feelings that you need to digest. Today has been a really important discussion. Thank you to all our speakers for being here. It came at a really important time, when support for kids and families is in the news a lot.

As we said at the start of today, the government is going to be talking to a lot of people about how Targeted Foundational Supports are going to work and how Thriving Kids should operate. We don't need to wait for the government to get started on coming up with ideas for this. We know that people with disability, their families and their supporters have the best ideas about what it should look like. Over the next few months, we are going to create a different way for you to have more conversations about foundational supports and we will have more to say on this soon. Keep an eye out in your email inboxes over the next coming months.

SARA GINGOLD: In the meantime, the next Open Dialogue event is called Facing the Storm Together: How We Can Plan and Respond to Weather-Related Disasters. It is going to be an interesting event. I am super looking forward to attending that one. We will put the link in the chat and you can register for that or you can find it on The Disability Dialogue website under Events. I know we are running quite late, but we want to hear from you about how today's events are going. If you have a moment to complete the survey, we would really love that. When this event finishes the survey will pop onto the screen and it is also available in the chat. Please tell us what you thought.

TODD WINTHER: Thanks for being with us today and being engaged and lively. We look forward to seeing you at next month's event. Bye for now.

SARA GINGOLD: Thanks to all our speakers. Bye.

(End of Transcript)