SARA GINGOLD: Hello, everyone, and welcome. My name is Sara Gingold. Just to describe myself quickly, I am a white woman with a short brown bob, and I'm wearing a red dress and a green cardigan. I'm the editor-in-chief of DSC's NDIS newsletter, and I'm co-hosting this event along with Todd, and we would like to welcome you back for another Open Dialogue.

I want to begin by acknowledging the Traditional Custodians of the land on which we gather. For me, I'm on the land of the Wurundjeri people, and I recognise their continued connection to the land and waters of this beautiful place, and acknowledge that sovereignty was never ceded. I also want to pay respect to all Elders and ancestors, and any First Nations people here today.

TODD WINTHER: Hi, everyone. My name is Todd Winther. I work with Sara, and I'm a subject matter specialist in home and living and a policy expert. Just to give a very brief description of myself, I'm sitting in my motorised wheelchair in my home office. I'm wearing a maroon shirt and slightly salt-and-peppered hair. I'm joining you today from Brisbane, which is on the lands of the Turrbal and Jagera people. For those of us who haven't been to this type of event before, think of it as a live show where you 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. Throughout today, we will be collecting all your comments and questions in the chat throughout the event, so we may even ask you for participation in this conversation, if you would like to join.

SARA GINGOLD: Yes, so please do participate. A little background about us. The Disability Dialogue is a project to promote inclusive, collaborative and disability-led conversations. Before we start, I just want to give a quick shout-out to our partners. They include DANA, Inclusion Australia, Alliance20, the Melbourne Disability Institute, and we are funded from an Information, Linkages and Capacity Building grant from the Department of Social Services. Also a shout-out to Powerd, Community Broadcasting Association of Australia, and Vision Australia.

TODD WINTHER: We're going to have a very important conversation today and we're going to try and avoid using jargon that is commonly associated with this topic. It's around the idea that we're all going to hear about over the coming months, and that you may have heard of before - General Foundational Supports. These are the basic supports that everyone should have to allow them to navigate the disability system, whether or not they're accessing the NDIS. Now, I've read a lot of reports in my time, and all the reports I've read about the NDIS were only part of making sure that everyone with a disability has the same opportunities to other people in the Australian community.

SARA GINGOLD: Yes, so in the spirit of having less jargon, I think we can think about General Foundational Supports as the supports you need to help you access the other supports you need. So, this term - Foundational Supports - it's really just a new word for an old idea. And it describes all the supports that people with disability need that sit outside the NDIS. At its heart, it's really about a simple idea, which is that a one-size-fits-all approach doesn't work, and it's about making a connected system where people can get the supports that match their actual needs.

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

SARA GINGOLD: And now the second bucket is the NDIS. I imagine you've all heard of it. It's a big bucket, not as big as the mainstream bucket, though, and to use these services you need to be eligible and meet eligibility criteria. And we also know that not everyone with a disability is eligible for the NDIS, but also that not everyone needs it. And then, finally, there is this teeny-weeny bucket stuck between the middle of those big buckets, but it should be growing. In this bucket are the services that are for people with disabilities, and their families, but which are not funded by the NDIS. And these are what we call Foundational Supports. Some people with disability will use these services a lot and some will never use them, but the point is that they should always be there for the people who need them, when they need them. And in that bucket, we have things like peer support, self-advocacy, independent information - and that is what sits under the umbrella term "General Foundational Supports". These are the things that most people with disability will use at some point in their lives. Sometimes a little, sometimes a lot. But you do really notice them when they're not there and when you need them. They have the potential to make an incredible difference in people's lives.

TODD WINTHER: Finally, in the last bucket should be some services for people with disability, who need some help in their everyday lives but aren't necessarily eligible for the

NDIS. These are Targeted Foundational Supports. We say that there should be lots of stuff in this bucket, but it basically doesn't exist yet, and that is why the bucket is so tiny. We've described these different categories like buckets because the NDIS Review, which was published at the end of 2023, talked about it in the same way. They just described what these terms mean slightly differently. If you went to one of the Town Halls, like I did in Brisbane, you would have seen this diagram shown as a triangle, with the NDIS at the top. But what we want to focus on today is what the review called General Foundational Supports - those things that almost all people with disabilities need at some point in their life. In our next Open Dialogue, we are gonna talk about Targeted Foundational Supports, so watch out for that one in August.

Anyway, that's what we're gonna talk about today - all the good stuff, like information and peer support, and self-advocacy. So, why we are here is because we want to understand how these supports work and how they can help us live better lives, and we encourage all of you in the chat to add your own ideas and thoughts as we go. Because, after all, this is a dialogue, a conversation with everybody here today.

SARA GINGOLD: And speaking of dialogue, we asked all of you to fill out a survey before this event - and thank you for everyone who did. It really helped inform how we ran this event and what we wanted to speak about, and we want to highlight a few responses. I would like to note that 68% of people who filled out the survey identified as a person with disability, and the rest were family, friends, and people who work with us.

The first question we asked was, "Have you ever heard of the term General Foundational Supports?" And over 60% said yes, as you can see in the pie chart. And for those who said yes, we asked, "What do you know about General Foundational Supports?" And it seems that a lot of you are very well-informed, but there is still some confusion and doubt, of course, which is why we're here.

There were some good responses, such as, "General services not NDIS-supported," and, "Mainstream services for people with disability who do and don't have access to the NDIS." And also just a reminder, as Todd said, to keep active in the chat and post any questions here. We'll try to get to as many of them as possible. We're very excited to.

TODD WINTHER: So, what would it look like if everyone who filled in that survey had told us if they had accessed General Foundational Supports? We're gonna have a conversation now, and I'd like to introduce Catherine McAlpine and Sonia to talk about what that world might look like. Catherine is the chief executive officer of Inclusion Australia, the national representative organisation for people with intellectual disability and their families. She is a respected leader in the disability community, with previous senior roles in state and national advocacy, and not-for-profit disability organisations. She brings personal experience to her role at Inclusion Australia, where she has led the organisation through a period of growth and collaborative change through such things as the Disability Royal Commission and the recent NDIS Review.

Sonia here is the members' president of Speak Out and is the Tasmanian member for Inclusion Australia's Our Voice Committee. Sonia has worked on multiple projects at Speak Out and she's advocated for the rights of people with intellectual disability and has taught people about their rights. In 2019, Sonia was part of the Civil Society delegation that travelled to Geneva to present to the United Nations Committee on the Convention on the Rights of Persons with Disabilities. Sonia loves birds and has a pet cockatiel called Pippy, and Sonia is passionate about standing up for herself and others. Thank you to you both for joining us. Over to you, Catherine.

CATHERINE MCALPINE: Thank you very much, Todd. And a big welcome to my colleague, Sonia.

SONIA HUME: And I have a support person here today, Sophie.

CATHERINE MCALPINE: And a big welcome to Sophie as well. Hi, Sophie. So, we just heard, Sonia, your very, very impressive resume of things that you've done. But what we really wanted to explore today was your journey from when you first came into contact with an organisation, with Speak Out, with an organisation that provides the sorts of supports that we are talking about when we talk about General Foundational Supports. And we wanted to think about all the ways that you built your skills and experience through the relationships that you developed with that organisation. So, if I start at the beginning, about how long ago did you come into contact with Speak Out? When did you first become aware of them and go to something?

SONIA HUME: Over 20-odd years ago.

CATHERINE MCALPINE: And what was your first experience? What was the first thing that you did when you came to Speak Out, when you learnt about them?

SONIA HUME: I had to go to court on a legal thing and someone had told me about Speak Out, how they can represent you in court.

CATHERINE MCALPINE: And so they helped you with individual advocacy to start off with?

SONIA HUME: Yep.

CATHERINE MCALPINE: So you got your help with your problem. Then what happened next? What did you do that wasn't related to your problem, but was the next step with your relationship with Speak Out?

SONIA HUME: I started going to the Speak Out Conferences, the first-ever conference that I went to was in a little town called Orford, which is down Hobart way. So, that was only a small conference to begin with.

CATHERINE MCALPINE: And when you went to that conference, how did you feel about yourself? Like, how did you feel about yourself as a person with disability? And did you know anything about having - did you know anything about rights? Had you ever heard anything about rights? I'm asking about how you felt about it when you first came in, and what you knew about rights when you first went to one of those - you know, when you got helped in court and then when you went to the conferences?

SONIA HUME: Hmm, I'll have to think about that one. I felt a little bit shy and didn't know what to expect.
Because it was my first conference and, you know, I didn't know what to expect, and that. Yeah.

CATHERINE MCALPINE: And did you ever, at that stage of your life, had you ever felt confident speaking up for your rights?

SONIA HUME: No.

CATHERINE MCALPINE: Had you ever heard about rights?

SONIA HUME: No, I didn't even know about rights.

CATHERINE MCALPINE: So, 20 years ago, you didn't know about rights and you needed some help, and you came to an organisation like Speak Out and they had conferences that looked pretty interesting.

SONIA HUME: Yep.

CATHERINE MCALPINE: So, what happened over the next few years? What happened over the next few years in terms of you going from a person who didn't know anything about rights to someone that felt confident about speaking about rights? What sort of things did you do with Speak Out in, let's say, the next 10 years?

SONIA HUME: I heard from people that went to conferences about their stories and stuff like that, and then I thought to myself, "I can do this." So, yeah, I started to get my confidence about that time. But I still didn't have a voice yet.

CATHERINE MCALPINE: And so... And how did you meet those people? Was that all at conferences or did you meet them at other places as well, the other people with disability that did feel confident?

SONIA HUME: I met them at conferences and Speak Out. Self-advocacy groups, so, yeah.

CATHERINE MCALPINE: So, by then you started going to self-advocacy groups, because Speak Out support self-advocacy groups all through Tasmania, is that right?

SONIA HUME: Yep.

CATHERINE MCALPINE: And so then you had started to speak up for yourself. What happened...? So, you had been to self-advocacy groups. Had you gone to - was there any training that Speak Out ran that you went to? Or did that not really happen back then?

SONIA HUME: Not that I know of.

CATHERINE MCALPINE: But then, gradually when you got more confident, and then Speak Out got a big grant right at the beginning of the ILC, of the Information, Linkages and Capacity Building funding program, Speak Out got a grant. Do you want to talk about that grant, the Mainstream and Me grant?

SONIA HUME: Yeah, Speak Out got a grant for a project called Mainstream and Me, and it was to do with parents with an intellectual disability. And we had parent and children camp a couple of times, and we learned from other parents about what they have issues with, with the child safety services, yeah.

CATHERINE MCALPINE: And then something else changed in your relationship with Speak Out about then, 'cause I asked before about workshops, and I think because Speak Out actually got some funding - because they'd always believed in self-advocacy but they'd never been funded to do it, and they were doing the self-advocacy without any funding - so, the difference that funding made to the organisation is they were able to develop workshops. And what changed with your relationship with Speak Out at that point?

SONIA HUME: Yeah, I started getting employed by Speak Out. Because, before I started working with Speak Out, I was working in an ADE, which wasn't very much money. But I felt like, because it was a job, I had to do it, so... But then, yeah, Speak Out offered me a job with Mainstream and Me, and we did a lot of workshops to people like dentists, child health nurses. And I think one of the workshops, there was a person from Child Safety Services.

CATHERINE MCALPINE: And so you talked to them about the experiences of being a parent with an intellectual disability and about all the problems that you have with the different systems, and helped them to get better at their jobs?

SONIA HUME: Yep.

CATHERINE MCALPINE: And for them, was that the first time that they'd had a person with disability actually leading the conversation? Was that a new experience for them, actually hearing a person with a disability running the workshops?

SONIA HUME: Yeah.

CATHERINE MCALPINE: Did you get any feedback on that?

SONIA HUME: We got a lot of feedback, but can't remember all of the feedback that we got. But, yeah, we got heaps.

CATHERINE MCALPINE: And then because of all of that work, you had really good skills and confidence around speaking up for yourself and understanding about rights, and then the Australian Government funded you to go to Geneva. And what did you do there?

SONIA HUME: I went to Geneva as part of the Australian delegation and I spoke on behalf of parents with an intellectual disability, how they are more likely to get their children removed out of their care.

CATHERINE MCALPINE: And that was a really important thing for the UN to hear, wasn't it?

SONIA HUME: Yeah.

CATHERINE MCALPINE: Were you the only person that was a parent with an intellectual disability that spoke at that conference?

SONIA HUME: Yes.

CATHERINE MCALPINE: Yeah, so it just shows how important that work was. So, since then, as well as being employed by Speak Out and having the opportunity to earn more money, you've been involved more in the governance of Speak Out, in terms of how the organisation runs. Can you talk about that experience a bit, how that started and what your position is now?

SONIA HUME: Yeah. Now, because I'm the Members' President of Speak Out, I'm actually on the Speak Out Board at the moment. And I represent our members. So, if our members have any issues with anything to do with people with intellectual disability, I take that to members and then we talk about that, and then I take it to the Board.

CATHERINE MCALPINE: And so if members are having particular problems with government systems - like the NDIS or like transport or anything - does that mean Speak Out does its work based on the feedback from members, and talks about the things that the members think are the most important?

SONIA HUME: Yep.

CATHERINE MCALPINE: And how have you found that experience?

SONIA HUME: Yeah, good.

SOPHIE: Did you want to talk, Sonia, about what you recently did with Members' Executive with transport, with the buses?

SONIA HUME: Oh, yeah. One of our members has just been accepted on the Board for

Buses, because there's a lot of bullying and stuff like that on the bus. And it's helping to make accessible information, because the bus timetables in Tassie are just so hard to read.

SOPHIE: And what did Members' Executive do as a group to address that issue in Tasmania? You wrote a letter?

SONIA HUME: Oh, yeah, we wrote a letter to - what was it?

SOPHIE: The Police Commissioner.

SONIA HUME: Oh, the Police Commissioner.

SOPHIE: And what did you talk about?

SONIA HUME: We spoke about the bullying and stuff like that. On the bus.

CATHERINE MCALPINE: It's so important. 'Cause I know that Speak Out also - a person from Speak Out appeared at the Disability Royal Commission, talking about that same issue, about the nastiness that happens on public transport towards people with an intellectual disability. So, it's so great to have your voices. So, when you think back, if you think back to when you started with Speak Out to where you are now, what sort of...how important has Speak Out been? How important has it been for you to learn about your rights and to meet all the people that you've met in terms of becoming confident to speak up for yourself?

SONIA HUME: Well, my journey with Speak Out has just been wonderful. Like, I've gone from a person that got told that I couldn't do anything and I wouldn't get anywhere in life, but I've proved them all wrong. And I really love what I do at the moment. I'm very passionate about standing up for people's rights, and my rights as well. Yeah.

CATHERINE MCALPINE: And do you think... Sorry, keep going.

SONIA HUME: Speak Out has been wonderful.

CATHERINE MCALPINE: And do you think if you'd never gone to that first conference and heard people speaking about things differently from what you'd heard before, that you would have the same confidence and skill now?

SONIA HUME: No.

CATHERINE MCALPINE: And also, the other thing that's interesting, is this didn't happen in five minutes, you didn't just go to three training sessions and go, "Hey! I feel really confident now!" You've just described a journey that's taken 20 years for you to be in this leadership position now.

SONIA HUME: Yep.

CATHERINE MCALPINE: Is that what you see with other people, that it takes time?

SONIA HUME: Yeah, it does take time.

CATHERINE MCALPINE: Why do you think that might be?

SONIA HUME: Um, I'm not sure.

CATHERINE MCALPINE: Do you think when you have people in your life saying negative things to you, or if you don't know about rights, it takes a long time to sort of really understand it and, you know, I think it's scary, the first time you ever speak out and you say something different to everyone else in the room and you have your own opinion. Did that feel scary the first time?

SONIA HUME: Yeah, it did. Because when you get told stuff all your life, when it comes to doing something good, you really come out of your comfort zone.

CATHERINE MCALPINE: And the other piece of information... So, we've talked about things like the Government calls Peer Support - so, that's when you meet people, you know, that are similar to yourself, have a similar life experience and you learn from their experiences as well as your own - so, you've talked to me before about how the people that you met were so important to you?

SONIA HUME: Yeah, my peers, and I've made friendships, and most of my friends are a part of Speak Out.

CATHERINE MCALPINE: Oh, that's interesting. That's really important. And we've talked about self-advocacy. And the thing that the Government calls capacity building, which is about building new skills, you've talked about building new skills. The last two things are about accessible information and about how you get that information, and whether Speak Out helps you get that information, and then I'm gonna talk about decision-making in a minute. But if you could talk a bit about what Speak Out does with accessible information and how you get information that you need about the NDIS and transport, or, you know, you just talked about the bus timetables - what work does Speak Out do there?

SONIA HUME: They do a lot of Easy Read, so then it's easier for people with a disability to read.

CATHERINE MCALPINE: And do you use that Easy Read yourself?

SONIA HUME: Yes.

CATHERINE MCALPINE: And when you do it, do you do that by yourself or do people still support you in understanding what the Easy Read means?

SONIA HUME: No, I'm pretty good with understanding Easy Read. But if there's some words in there that I don't understand, I will ask what they are.

CATHERINE MCALPINE: And when you first started using Easy Read, were you able to do that by yourself?

SONIA HUME: No!

CATHERINE MCALPINE: I think... Because that's part of the learning - the first time that you see information, you're not used to looking at the... You know, in your experience, did you have much experience at looking and reading information for yourself before then?

SONIA HUME: No.

CATHERINE MCALPINE: No. And you were an adult by then and you really had not been given information in a way you could access it. And the last thing I wanted to talk about was building your decision-making skills. Did you learn more about your rights about decision-making and also where to get help with decision-making? What sort of things did Speak Out teach you about making decisions in your own life? Not so much... Sorry. Not so much teach you. What things did you learn from other people and from being around Speak

Out about making decisions? Sorry, rather than speak yourself.

SOPHIE: Did you learn about your rights? Like, your right to make your own decisions?

SONIA HUME: Yeah, I learnt about my rights and stuff. And I also, like, I listened to people at conferences and stuff, and seeing their journey, and then, yeah, listening to their stories, I actually was able to tell my story. So, I think it's to do with peers and mentors and stuff.

CATHERINE MCALPINE: That's great. And so just to... Sorry. You go.

SOPHIE: What about the, like, NDIS decisions? Remember when you've talked about going to your own plan meeting. How did Speak Out help you to get to that point?

SONIA HUME: I'm not sure. But, yeah, I do my own NDIS plan now.

CATHERINE MCALPINE: And so does Speak Out do some pre-planning with you to help you think about what you want to say in that planning meeting?

SONIA HUME: Used to.

CATHERINE MCALPINE: Yep. But now you do it yourself?

SONIA HUME: I do it all on my own now, yeah. And I get what I want.

CATHERINE MCALPINE: That's great. And so Speak Out helped you get the skills and confidence to be able to do it by yourself.

SONIA HUME: Yep.

CATHERINE MCALPINE: That's so great. So, just to finish off with, Sonia - it's just been so wonderful hearing about how you've developed and about how your leadership has developed over all these years - would you have any advice to younger self-advocates? Is there one thing that you would like them to know about organisations like Speak Out or about their own selves? Would you have a piece of advice for them that you'd like to talk about now?

SONIA HUME: I reckon one of the rights that I would like to say to younger people, that no matter if you've got a disability or not, everybody has rights.

CATHERINE MCALPINE: That's just such a great place to finish, Sonia. Thanks so much for your leadership and your courage in talking about your own journey today. And you're gonna hang around and help with answering any questions as well?

SONIA HUME: Yep. Thank you, Catherine.

CATHERINE MCALPINE: Thank you.

SARA GINGOLD: Thank you so much, Catherine and Sonia. I really enjoyed that interview. It's so powerful to show how you can go from being unaware of rights to then being a leader in the space of rights, speaking at the UN! And it shows how powerful some of these events can be. And it did make me wonder - 'cause I think a lot of people with, like, disability, or on their disability or advocacy journey, have this moment where they're like, "Oh!" And things click into place and they realise what they're meant to do or they understand themselves better. And I thought, if anyone has any stories like that, that they can share in chat - it could be a conversation you had with someone, an event you attended, something you read, literally anything - we'd love to hear it.

And before we go on, I want to acknowledge that we have a couple of viewing parties watching today, which I absolutely love. So, a big shout-out to VALID and any other viewing groups joined. There's so much love for you in the chat, Sonia - it's not hard to know why. So great to hear your stories. I wanted to ask you, Catherine, if you could reflect on the role of General Foundational Supports in this context?

CATHERINE MCALPINE: One of the really interesting things about Sonia's journey is the support from an organisation and the difference that some funding made to that organisation as well. So, all the way along, having access to information and advice for people with disability that's based on facts and real-life experience, that over the journey, getting that information for yourself. Because not only has Sonia been a great leader, but in her own life - you heard that story about how she's become more independent in dealing with the NDIS and in speaking up, like, for her story and not needing so much support - so, that's the idea, that people are more included in the community with these sort of supports. But also that building confidence and skill takes time. It's not something that you deliver in three workshops. I'd also like, in particular, to give a shout-out to Minda and VALID, who are another Inclusion Australia member and who also have spent a long time. One of the things we have a problem with at the moment is that, for people with an intellectual disability, they tell us how much face-to-face conferences and seeing other people speak, how much that impacts them, and that's something that's not funded. It's not funded in plans because people think that going to a conference is for a different purpose, and they don't understand that for people with an intellectual disability it is about peer support, it is about learning about rights - which is self-advocacy - and it's getting the confidence to speak up for yourself. But having all the friendships and other people to talk to, that's peer support, having confidence in learning about your rights and being able to speak up for yourself, that's self-advocacy. And increasingly, helping families. So, that's not so much a feature of Sonia's experience, but for me as a family member, like, someone's had to teach me to start with. What does supported decision-making look like? And they had to teach me about, "What is dignity of risk?" People with disability, if we're trying to be good parents, sometimes we try to make sure everyone does things that are good for them, but we all make our own decisions and we all take risks, and sometimes we make decisions that are not that great for us, but we make them anyway, and we've got the right to do that. And so helping families learn about that, and helping them support their person to become more independent as well, means that, hopefully, there won't be so many people with disability - like Sonia - who only first learn about their rights when they're already an adult, but they can learn about their rights when they are children and growing up as well. So, having supports for both families and people directly is really important.

SARA GINGOLD: Yeah. And I did pull that out of the interview as well, because it takes time you need that continual support at different processes throughout the thing. I just wanted to pull out one of the comments from chat. So, Sarah or Sara, said, "More self-advocacy organisations and peer support programs for people with intellectual disability in the Sydney metro area, as well as other areas."

CATHERINE MCALPINE: That's right. So, what we don't have... One of the reasons that Sonia got access to Speak Out to start with is that Speak Out is also funded under the National Disability Advocacy Program, which is the individualised advocacy program, and the Government funds that to make sure that everyone in the country - no matter where you live - should have access to an independent advocate. There's no funding at the moment to make sure there's a national network of self-advocacy groups, and so you can only be part of self-advocacy if you're in contact with an organisation that does that, and mostly those organisations are not funded to do it.

So, an organisation like Speak Out has got the occasional grant for self-advocacy, but the rest of the time they make it happen around the other work that they're funded to do. And so that's the same problem for other organisations. And so if you're lucky - like Sonia is - you live in an area where self-advocacy is available, or if you live in the Melbourne area there's more than one organisation, but one of them is VALID, and in Victoria we have the Self Advocacy Resource Unit, known as SARU, which has a whole lot of self-advocacy. We are the only state where that happens. One of the things we really want in General Foundational Supports is to see the building of a National Self Advocacy Network. I could not agree more with that comment.

SARA GINGOLD: And we had another question for Sonia, from Tee. And the question is, "How does knowing your rights help you in your own life?"

SONIA HUME: I think knowing about my rights makes me more confident and... I can't remember the other word I was... I just feel more confident in standing up for my rights.

CATHERINE MCALPINE: How about even things...? Sonia, one of the things you do now is we mentioned you're on Our Voice for Inclusion Australia, so one of the things you do do is travel independently to get to conferences. You travel by yourself sometimes.

SONIA HUME: Yep.

CATHERINE MCALPINE: And how does feeling confident help you do that? Does it mean that you're confident asking for help if you need it? Or asking for directions?

SONIA HUME: Yeah, yeah. Yeah. I would be confident in asking for directions and stuff.

CATHERINE MCALPINE: And would you have done that when you were much younger? Would you have travelled interstate by yourself when you were much younger?

SONIA HUME: Definitely not, because I never knew that I was going to do that. Like, I'd never dreamed of it!

SARA GINGOLD: Yeah, I think sometimes just even knowing that you have the right to be in a place and take up space and get the support you need, can be really helpful. So, thank you so much, Sonia, for that. And thank you, Catherine, as well.

SONIA HUME: Thank you.

TODD WINTHER: Sonia's example is really powerful there because we get stuck in this notion, particularly with the debate over the last 12 months, that General Foundational Supports is this really complicated policy-laden process. But it's all about getting information, and that's what I want to focus on now. Where do we get the information? I'm keen for anyone who is able to use the chat right now to post - when you want information about support related to your disability, where do you go? Sara, we have very different background stories. I have acquired a disability from birth because I was born with cerebral palsy. If you can indulge me for a minute, can I ask you about your personal experience, about how you found out information about your disability? Because unlike me, you were diagnosed later on.

SARA GINGOLD: Yeah, thanks, Todd. We were talking about this the other day. I was diagnosed at 21 - technically an adult, but looking back at it, I'm not sure I see it that way. But when I first heard about General Foundational Supports, I have to say I thought I would never use them. But then, through learning more about them and going to forums like this, I realised, "Sara, you silly goose! Of course you've used them!" And I think sometimes when you're at a certain point of your disability journey, it can be hard to remember what helped you right at the beginning. So, in 2013, when I was diagnosed, I was diagnosed with ME/CFS, and it's one of those disabilities where even doctors can't give you any solid information, which is literally the worst for me because I'm a person who needs a lot of information. Like, it's borderline a problem, how much I need to know about something!

So I attended this small information session run by Emerge, which is the representative body for people with ME/CFS, and my parents came with me, which was really helpful. And what I learned was what is known about the disability, what is unknown, and what I can do next. And then I started attending other events. I met other people with the same disability as me, who were the same age as me. I'm still in contact with many of those people. And I also joined social media groups. But I would say that one thing I didn't have, which I think would have been really helpful, is peer support. And just to be clear, it's no-one's fault that wasn't available, the resources just weren't there, but I think learning from someone who had, like, who was further along the journey from me, and getting that guidance would have just been invaluable for me at the time.

TODD WINTHER: That's really interesting, Sara, because having been diagnosed with my disability at a very early age, only months' old, it was more about, "How can I become less of a disabled person? More of your average person?" in a way to hide my impairment or reduce the impact of my impairment, and less about, "How do I interact with my disability and the world around me?" So, that's quite an interesting contrast there.

SARA GINGOLD: Yeah. And I think it's interesting that we do need different pieces of information and different supports at different life stages. And at different transition points.

TODD WINTHER: Absolutely. And that's what we want to focus on when we talk about these Foundational Supports, because we want to focus on living an ordinary life and living the life we need to have as individual citizens that go through the same transition points as anybody else does.

SARA GINGOLD: And so we did ask in the survey where you go for information, and some of the most common responses were government websites, disability organisation websites, or family or friends - which all make sense. But please keep those comments coming and give us a sense of where you go for information, because it's a very interesting thing to think about as well. Like, where you've gone for information now, where you've gone for information in the past, and where you would like to go for information in the future, what gaps you're seeing when you're looking for answers.

TODD WINTHER: So, we want to bring Catherine in for any final thoughts about what we've discussed? Any takeaway points for our audience here today?

CATHERINE MCALPINE: Sonia, did you want to go first?

SONIA HUME: No.

CATHERINE MCALPINE: I think that understanding that having peers and learning about your rights, and being able to go to workshops and learn new things explicitly about your own disability, and about how to make decisions, are just critical for everyone with a disability. But they're really important for people who have a disability that involves decision support needs and who a lot of other people make decisions for them. And so really understanding your own rights and that you're able to speak up for yourself. We've seen mention of peer support and self-advocacy keep coming up in the chat about how important they are. And they're just vital. I can't say how vital they are. So, having a proper funding system so that people can get those supports, that it does matter which disability you have - you know, one thing that I learned from a blind friend years ago is they said, "You go to Vision Australia to get a cane, or you go to Guide Dogs to get a dog guide," to the service providers. But it's going to Blind Citizens Australia where you learn the confidence to have a go. That thing about getting confidence, confidence to speak up for yourself or be by yourself and do things by yourself, is just critical. And so General Foundational Supports is a hard concept but, actually, having people, you know, meeting people with similar life experiences, getting tips and tricks on how to live a more inclusive life, being able to get information for yourself - these are all fundamental to an inclusive life.

SONIA HUME: And I think, Catherine, that advocacy is very important, and also peer support is really important as well. So people with a disability can know that there's help there for them if they need it.

CATHERINE MCALPINE: Absolutely. Well said.

TODD WINTHER: That's really powerful, Sonia and Catherine. I want to thank you for your time today. And, Sonia, I found your story particularly powerful and I must admit I'm a little jealous that you got to go and had the chance to speak your mind in that forum. A tremendous opportunity, and you're a terrific advocate. Before we go to the break, I just want to share this comment in the chat from Dariane that really resonated with me. She said, "As a parent of someone with disabilities, I have learned everything I need to know to support my son in having his choices heard, and helping him feel confident to express them through using an advocacy service and attending conferences that share other stories about strengthening choice and control for people with disabilities." And that's what we heard from Sonia and Catherine too. So, when we talk about sharing information, it's about what type of information, but it's also about giving people with disabilities the opportunity to express themselves and use that information so they can be in the driver's seat of their own lives.

So, we're now gonna take a 10-minute break to give everybody time to digest what they've listened to, because there's such a lot of content that we've heard today so far. We've got lots more to talk about after the break and a very special guest, so I hope you stick around. Enjoy your break.

(BREAK)

SARA GINGOLD: Hello. We'll be back on shortly, everyone. 19 seconds, to be exact. And we're back! I have to say, I love it when events have breaks. It just speaks to me personally. Welcome back, and thank you for all the great comments and questions you're posting in chat. Please keep those coming. And if you're gonna be keen later to turn on your camera and your mic and make some comments, just let us know and we'll try to get through some of your thoughts and opinions and questions shortly.

But, first, we're going to be hearing from Katrina. Katrina has been working with VALID. VALID is the Victorian Advocacy League for Individuals with Disability, for adults with intellectual disability. Katrina has been doing various programs on interviewing residents about how service providers can help them speak up in their homes. She is an active member of the local drama group and is passionate about helping others through self-advocacy and empowerment.

TODD WINTHER: So, to begin with, Katrina, we're gonna be talking about how we build a good life. Hi, Katrina.

KATRINA: Hi!

TODD WINTHER: Can you talk briefly about what friendships and community mean to you?

KATRINA: I, um... Yeah, they mean a lot to me. Particularly nowadays, because when I was younger, I was living in Emerald, where it's a no, no-go area. Only one road in and nowhere else to go. So, I was a bit isolated. But now I'm living in Montrose, I now have NDIS, all my support workers, my parents, and they've been supporting me. And now that they're elderly now, all my support workers have taken over in helping me and explaining to me, and they've been showing me how to do things, like internet banking. And now having this VALID job has also really supported me in so many ways. Communication is a big one.

TODD WINTHER: What do you like doing for fun, Katrina? Do you like hanging out with your friends?

KATRINA: Yeah, I do. Yeah, I love going out with my friends. They're a bit too far away, but eventually I'm hoping to move closer, like, Wantirna, spend more time with them and keep up my supports.

TODD WINTHER: So, you've spoken previously about helping other people, and you have been working with VALID, so you have been recently helping at the Advocacy in Action Conference. Can you tell us about that and also what lessons that you have learned from working at the conference?

KATRINA: In a big way, I've never worked at a conference before, I've always been watching the conference. I've never been working at it. This was my first time. And that was a huge eye-opener for me 'cause I didn't know what to expect until I was actually there. My coworkers helped me all the way through, which was really lovely. And I got a lot of communication from them, not only my workers but also my peer supports and everything else. And I've also got great, big knowledge of ins and outs.

TODD WINTHER: And what sort of thing did you talk about at the conference?

KATRINA: I was mainly the interviewer, where I interviewed people, like from the NDIS, the NDIA, the Disability Commissioner. And one aspect of it was also working on the VALID table as well.

TODD WINTHER: Oh, wow. It sounds like you got to talk to lots of powerful people. I'm sure lots of people would have enjoyed those discussions. I want to move away from your work a bit. And I recently heard about the fact that you're living independently. Can you tell us how you made that decision and how that is going for you?

KATRINA: Well, Mum and Dad were in respite. My brother was in South America. And my dad was recently diagnosed with a tiny bit of dementia, and my mum has got Alzheimer's. And so he thought, to keep them safe so Dad doesn't fall over, to put them in residential care. And I have been living on my own just as a trial to see how it all fits in the future.

TODD WINTHER: And how do you think that's going, Katrina?

KATRINA: That went really, really well, now that they're back. I enjoyed their company but I enjoyed living on my own more.

TODD WINTHER: I feel the same way. Definitely. It's good to live with your parents but it's even better to live by yourself.

KATRINA: It is.

TODD WINTHER: Is there anything else that you want to talk about that we haven't covered?

KATRINA: The fact that how I got to VALID.

TODD WINTHER: Yeah, go on.

KATRINA: Very, very important for me. I had trouble with my brother trying to understand the whole family situation, and also me in general, because it's never dealt with before until now. And so then we were going around and around in circles, I was trying to explain to him that Mum and Dad didn't need aged care two years ago, now that they need it. And he was trying to put them into a home two years ago, and I'd be better off in a supported living unit - which I don't need. And so we were going around and around in circles. He couldn't understand it. So, we brought in... I wrote a letter to Bill Shorten and Bill Shorten and my support coordinator back then - my older support coordinator, who's not now - they both thought I would be better off having a self-advocate for my situation. So, we brought in a lovely lady that works with VALID, and she helped him to make sense of our issues. And I wrote her a letter saying how people with disabilities respect - need to be respected, need to be heard, and so forth, because I'm rather passionate about it, and she said, "This is a very good letter. I have a coworker that you can be very well suited to." So, that's how I got into VALID now. And now I work with my ex-self-advocate.

TODD WINTHER: Thanks for sharing your story, Katrina. It was really powerful and it sounds like you're doing some great work.

KATRINA: Thank you.

TODD WINTHER: Thanks for your involvement today.

KATRINA: Thank you. That's my pleasure.

SARA GINGOLD: Yes, thank you, Katrina. I really love the story about how you came to be involved in VALID. And we also had a lot of love coming through on the chat, particularly people love that you stood up for yourself and the strength that you showed. One of the comments from our watch party is, "I have skills to advocate for myself and use my iPad to get new information. I can catch public transport and get around and know where to get new information," which is amazing. We had a number of shout-outs in the chat for self-advocacy organisations, and peer support programs, and particularly lots of people want there to be a lot more of them, and also programs for people with disability to have their voice heard, including those not eligible for the NDIS. We also heard from Grace, who said, "I would personally benefit from community-led supports that move away from institutional responses to distress. For example, peer supports and implementation of local community-led alternative first responders for people with psychosocial disability." And like the recommendation in the National Justice Project. That's a really interesting idea.

And also we heard from Tee, who noted the importance of self-advocacy for people who don't have speech, and highlighted that it's a gap. Tee also noted that they have joined the Complex Needs Reference Group and looking forward to contributing.

TODD WINTHER: One of the things that Katrina talked about was making the decision to live independently, which was a pivotal one for me too. So, Sara, when you're looking at making big decisions, who do you talk to and what helps you the most?

SARA GINGOLD: I think, like a lot of people, I talk to family and friends.

TODD WINTHER: Yeah?

SARA GINGOLD: Depending on the decision, I might talk to a professional as well, so I might talk to my doctors or a therapist, or someone. But I think the most helpful thing for me is always talking to someone who's had the same experience as me.

TODD WINTHER: Yeah, people with disabilities can be a really good sounding board. Often, we're confronted with challenges that people without disabilities haven't confronted before, or can't even imagine, and we're really good problem-solvers, people with disabilities. I know in the place that I live, I live in an apartment block with some accessible buildings, and between all us residents, we have a Facebook chat going if we run into any difficulties, and try and solve any problems. So, that's quite useful as well.

SARA GINGOLD: Yeah, I love that. And sometimes also talking to other people who have the same, or similar, experiences can really help you put words around your own experience, in a way that you haven't before.

TODD WINTHER: Yeah. It's always good to get new and different perspectives to look at issues or problems in different ways.

SARA GINGOLD: And so we asked you in the survey who you go to when you want to make a big life decision, and here are some of the results. So, 63% of you said family, 58% said friends, and 52% said support workers. We also asked, "What helps when you're making big decisions?" And there were a number of great responses. To highlight just a few of them, we had, "Talking things through over and over, lots of ruminating and reflecting alone and/or with a trusted person." I can really relate to that one! And I'm someone who really likes to think things through. Journalling is one I would add.

"Having all the information I need to make an informed decision." So important. "Access to a strong peer network." "Writing down all my options." And, "My heart," which, honestly, love that one, 'cause sometimes you just know, and you don't know why you know. And I also love the little emoji with that one as well.

We had a question come through from Tee. "How do you stay connected with your friend? Do you rely on supports to keep you connected?" I think that's a good one for you, Todd.

TODD WINTHER: Well, it can happen in various different ways. We've got to use technology. Technology is a really big one for people with disabilities, particularly social media. Sara, you talked about connecting with others that share your diagnosis or disability, and it's a way that we can contribute, but also not only feel part of the disability community but the mainstream community as well. Because some of us may not be able to get out and about as much as we want to and see the people that we care about on a regular basis.

SARA GINGOLD: And I think, if you're able to, also communicating with your friends what you need, and how you communicate. So, maybe, like, saying, "It takes me a few days to reply if I don't have enough energy or if I'm not in a state to reply." Or, "Can we have a phone call instead? Or can we talk on Messenger instead?" Or whatever it is. Sometimes just speaking up for how best to communicate.

TODD WINTHER: Yeah. That's a really good one, Sara.

SARA GINGOLD: And we also want to build a better life, and we talk a lot about inclusive communities, and I was wondering, Todd, what this looks like for you?

TODD WINTHER: Well, building inclusive communities, people immediately go to physical access, but it's also allowing us the opportunity to think about different ways we can be active participants in community discussions, whether it's more events online, like this, or other ways that we can contribute, or more support to get around our community. We recently had a Disability Dialogue on the troubles that the disability community has with access to public transport. The footpaths around my community aren't the best, and that really inhibits me from going out and exploring my local community. So, we've got to look at infrastructure, but we've also got to look at different ways of opportunities for connecting for people with disabilities too.

SARA GINGOLD: Yeah. And the one thing I would add to that as well is we've got to work on community attitudes and stigma as well.

TODD WINTHER: Definitely, yeah, for sure.

SARA GINGOLD: Yeah. So that, like, everyone understands that when people with disability are advocating for their rights, they're doing exactly what - we're doing exactly what we're supposed to. We're supposed to stand up for ourselves and we have the right to access these services.

We also had an anonymous question from the survey and I found it really interesting. It's, "How will General Foundational Supports be made available and accessible to people in regional and remote areas? Will there be user-focused and education-based support systems? I believe it's important to involve more disabled voices in creating these programs." And, like, one thing I would say in answer to that is we don't know yet how these will be made accessible to people in regional or remote, and we don't know exactly what it will look like, but that is the importance of getting involved now, so that we can help shape it.

TODD WINTHER: It's one thing the NDIS Review and the Independent Review Panel identified as a real challenge. And during the consultations with the Department of Social Services, a number of people from regional and remote areas contributed to that discussion. So, hopefully, those in power and those creating the policies took note of those suggestions and are going to implement them going forward when the rollout of the Foundational Supports continues.

SARA GINGOLD: And we're gonna keep reminding them as well.

TODD WINTHER: We sure are.

SARA GINGOLD: Now is the time to help shape what Foundational Supports look like.

TODD WINTHER: One of the questions in the survey was, "What new supports or services do you wish were available to help you?" And we've got a couple of responses here. One says, "More Foundational Supports. Therapeutic support, such as OTs, help at home for personal and domestic care, as well as carers." We've already talked about mentoring and advocacy and social support groups for people with disabilities, parents and carers, organisations have to stop or reduce these sometimes due to funding restraints. And we've seen that recently, particularly in my area we've had a major organisation have to reduce the community funding that they do to support these groups. We've also got, "Easier access to seeking a diagnosis. More advocates and advocacy training. Peer support, mental health, wellbeing and transport."

SARA GINGOLD: Yeah. And I think it's an important point about, like, the access to seeking a diagnosis as well. So, information about where people can go early in their disability journey. Like, who can they ask for help? How can they get these services funded? All these sorts of information is really valuable.

TODD WINTHER: What is really resonating with me today is, if given the opportunity, people with disabilities can clearly articulate through whatever method possible what they want from their lives and what they want from their community. They just have to be - they just have to create and be a part of new opportunities, and perhaps that's what Foundational Supports are all about. As I said before, we get stuck in this complicated language about, "What is General Foundational Supports and what is Targeted Foundational Supports?" and how the Government is going to implement them. But it's really about giving people with disabilities the opportunity to have their voices heard, like other members of the community. Sara, do you have any thoughts on that?

SARA GINGOLD: No, but I really love what you're saying. It's tempting to feel a bit, like, pessimistic at this point because we don't know what's happening and, like, sometimes we kind of assume the worst because we've had a lot of bad experiences in the past. But I think it's also important to think positively and that we do actually have an opportunity at the moment and we have a really strong sense from this chat what people want, and it's about peer support, it's about self-advocacy, and it's about, like, opportunities to connect with one another. And I find that amazing.

TODD WINTHER: It's really a fine balance, isn't it? Because the history of disability advocacy and the history of disability rights has been one where we have been constantly marginalised, segregated and ostracised from the rest of the community, and now the Government is asking us to trust them to say, "We know what you want, we are listening to the right people, and can we get this across the line?" And until we see some detail, the jury is out. We've got some interesting comments from the chat. Tee has really contributed enormously to the discussion today, and they want to talk about learning to run their own business, especially for people who can't access mainstream employment, as well as the ability for mainstream employment and the ability to access further education. It's really about knowledge is power.

Allan Hunter, I believe, wants to speak. Allan, if you want to take yourself off mute, but we've only got about a minute, so if you can keep your comments as brief as possible.

ALLAN HUNTER: Sure. My understanding - can you hear me?

TODD WINTHER: Yes.

ALLAN HUNTER: My understanding of what really happened when the NDIS came in was a lot of state and local government functions just died. This whole thing about Foundational Supports should be about getting the state governments involved, the local governments involved, getting those connections, those functions that are better off done at the local level back at the local level. Housing offices and community housing, for example. That's what my understanding of a lot of this stuff is all about.

SARA GINGOLD: I think you're absolutely right, Allan. Like, it's about getting all levels of government and all levels of community involved. It can't just belong to one government agency or one level of government.

ALLAN HUNTER: ..cannot do it all.

SARA GINGOLD: Yes, exactly. We've also got Sarah Butler. And, again, Sarah, just, like, 60 seconds or less. You'll want to take yourself off mute. I think you're off mute now.

SARAH BUTLER: I've struggled to find any self-advocacy organisations in NSW, despite being a person with an intellectual disability on a Disability Pension. I can get no services in NSW. The only services I can access for self-advocacy and peer support is based in Melbourne, Queensland, South Australia, WA, anywhere outside of NSW, but nothing in Sydney Metro area, and it's been an absolute struggle for me. So, I've had to gain my self-advocacy skills with Reinforce Self Advocacy, fantastic, by doing the majority of it online, very occasionally going down there, met them, lovely people. But I can't understand, as a person living in NSW, why is it that I can get accepted for services elsewhere when I don't live in the area, I'm not a Victorian resident, and I'm in NSW, and yet every advocacy one I've called for self-advocacy, they can't help me, I can't get services, and my life has just gone without having to be able to fly out of Sydney to get my services, my disability groups to feel safe and participate and have that voice and be heard.

SARA GINGOLD: Yeah.

TODD WINTHER: That's really a valuable contribution and speaks to a comment that Lindsay has made in the chat, that says, "The system cannot operate in silos. They absolutely need to work together." And that was the whole political philosophy about the NDIS, about nationalising the services across the country, so no matter where you lived, you'd get access to the same type of support. And yet we're stuck in this negotiation between the Federal Government and the states. So, it's really time for them to put their heads together and start working on a cooperative solution.

SARA GINGOLD: Very true. Today has been a really awesome discussion and the good news is it's just the start. We have talked a lot this afternoon about what Foundational Supports should look like, who could use them, who should provide them, how they're funded, but we also don't need to, or particularly want to, wait for government because, let's face it, we know that the best ideas come from people with disabilities, their families, their supporters, the people in this webinar today. So, over the next few months, we're going to create different ways for you to have your say about Foundational Supports. We want to create safe, inclusive spaces where people with disability can come together and talk about the stuff that matters to them. And, most importantly, not just talk about what the problems are but what good solutions look like. And then we can talk about how we can bring those good ideas to life - the fun part.

We are going to hold these discussions regularly as part of Disability Dialogue and we're going to take a topic and find a different way for people to have their say. Once we have solutions, we will get back together and talk about how we can make these changes real. And this process, we're gonna be calling Feature Dialogue. So, the work on Foundational Supports is really just getting started and we will hold more of these Feature Dialogues in the future. If you're interested in being part of this, please keep an eye on your inbox - we will be sending out emails when it's under way, and you can decide if you want to get involved.

In the meantime, next month's Dialogue event will be called: Unlocking Potential - Support for Children with Disability. We'll be talking about what good support outside the NDIS looks like for children, and we'll put a link to that event in the chat now so you can register, or you can find it on The Disability Dialogue website, or we'll send an email with a link in a couple of months - a couple of days, sorry! These Open Dialogue events are monthly, so we hope you'll join us next month and every month after that for more debate and discussion. We will be taking these ideas on board and letting you know when we know what future months' subjects will be. And we will also be sending out a feedback form after this event, or you can also click on the link through chat, so please let us know what your experience of the event is and give us ideas for how we can make it better and more inclusive in the future.

Thank you for everyone engaging in such a lovely event. We look forward to seeing you all next month.

TODD WINTHER: Thanks, everyone. Bye!

SARA GINGOLD: Bye.

(End of Transcript)