

**REPORT ON PROCEEDINGS BEFORE**

**PORTFOLIO COMMITTEE NO. 3 – EDUCATION**

**CHILDREN AND YOUNG PEOPLE WITH DISABILITY IN NEW  
SOUTH WALES EDUCATIONAL SETTINGS**

**At Macquarie Room, Parliament House, Sydney, on Monday 22 April 2024**

**The Committee met at 11:00.**

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**PRESENT**

Ms Abigail Boyd (Chair)

The Hon. Mark Buttigieg

The Hon. Anthony D'Adam

The Hon. Natasha Maclaren-Jones

The Hon. Tania Mihailuk

The Hon. Sarah Mitchell (Deputy Chair)

The Hon. Emily Suvaal



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**The CHAIR:** Welcome to the second hearing of Portfolio Committee No. 3 – Education inquiry into children and young people with disability in New South Wales educational settings. I acknowledge the Gadigal people of the Eora nation, the traditional custodians of the lands on which we are meeting today. I pay my respects to Elders past and present, and celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and waters of New South Wales. I also acknowledge and pay my respects to any Aboriginal and Torres Strait Islander people who are joining us today or who may be watching the broadcast.

My name is Abigail Boyd and I am Chair of this Committee. I ask everyone in the room to turn their mobile phones to silent. Parliamentary privilege applies to witnesses in relation to the evidence that they give today. However, it does not apply to what witnesses say outside of the hearing. I urge witnesses to be careful about making comments to the media or to others after completing their evidence. In addition, the Legislative Council has adopted rules to provide procedural fairness for inquiry participants. I encourage Committee members and witnesses to be mindful of these procedures. Please also note that Auslan interpreters will be interpreting at this hearing for some witnesses and also for the gallery and live broadcast. I ask members and witnesses to please make sure they speak clearly into the microphone and wait until the previous speaker has finished talking.

I note that a number of witnesses will be participating via videoconference today. A few notes on virtual hearing etiquette to minimise disruptions and to assist our Hansard reporters—firstly, if the participant loses their internet connection and is disconnected from the virtual hearing, they're asked to rejoin the hearing by using the same link provided to them by the Committee secretariat. Secondly, I ask Committee members to clearly identify who their questions are directed to, and I ask everyone to please state their name when they begin speaking.

I ask witnesses on videoconference to mute their microphones when not speaking and to please remember to turn your microphone back on—there is always somebody who doesn't, so don't worry if it's you—when you're getting ready to speak. If you start speaking while muted, please start your answer again so that it can be recorded in the transcript. Members and witnesses should avoid speaking over each other so we can all be heard clearly. Also to assist Hansard, I remind members and witnesses to speak directly into the microphone and avoid making comments when your head is turned away.

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**Ms RHONDA RYDE**, Auslan Interpreter, affirmed

**Ms NICOLE CLARK**, Auslan Interpreter, sworn

**Ms KYLIE CLEAR**, Auslan Interpreter, affirmed

**Mrs KAREN TIPPETT**, Advocacy and Inclusion, Senior Manager, Family Advocacy, affirmed and examined

**Ms CECILE SULLIVAN ELDER**, Executive Officer, Family Advocacy, affirmed and examined

**Ms LIBBY GUNN**, National and New South Wales Coordinator, Square Peg Round Whole, affirmed and examined

**Dr MARIKA FRANKLIN**, Member Advocate, Square Peg Round Whole, affirmed and examined

**Mr ANDREW WILSON**, Chair, Australian Alliance for Inclusive Education (All Means All), sworn and examined

**Mrs SUE TAPE**, Project Coordinator, Inclusive Education, Children and Young People with Disability Australia, before the Committee via videoconference, affirmed and examined

**The CHAIR:** I welcome our interpreters first. Thank you very much for interpreting today's hearing. I turn to our first panel of witnesses. Thank you so much for taking the time to give evidence today. I now invite each of you to make a short opening statement. I will start with Family Advocacy.

**CECILE SULLIVAN ELDER:** I would like to acknowledge the traditional custodians of the land and recognise their rich culture and what it brings to all Australians. Family Advocacy is a State and federally-funded disability advocacy organisation with over 33 years' experience supporting people with disabilities and families to advocate for change at the individual and systemic level. The change sought isn't complicated or over-expectant; it's really about everyday opportunities. Advocacy at both levels is required, as this population group has been systemically removed—completely through segregation or partially through integration—as highlighted in the DRC report. Being seen as one of the kids, one of your colleagues, another person in your social group, your neighbour or committee member, won't occur without decisive and coordinated action.

Inclusive education has been a long-term strategic focus of Family Advocacy, both on the ground—equipping families on rights and actions—and across our education system. Education-related inquiries made up 78 per cent of our advocacy inquiries in the last six months. This number is constantly climbing. Our extensive experience has equipped us to be very decisive around the steps required for change. Our decisiveness isn't by accident, nor has it come at a moment's notice, in having to strategise the best way forward whilst considering this complex system. You aren't the first inquiry to grapple with this social issue; there have been many. Addressing the issues in isolation will not be effective unless it's seen as a whole. We have witnessed hundreds, if not thousands, of good examples of inclusive practice, either driven by well-informed family advocates or with the will and skill held at the school.

This education system holds many circuit breakers across it. These circuit breakers trip the flow-on impact of a good education. It's not built to accept and support students with disability in the mainstream. It's built to decide where someone belongs. As one parent told me, "It's like my daughter is swimming through the ocean. The water opened up right in front of her and then closed right behind her. She was seen as one of the kids at school. The advocacy was constant. The next child with disability came along and they were met with all the same barriers, but most parents can't fight that. Families are then faced with difficult decisions. They call this informed choice."

I would like to finish by saying to the Committee you have, for the first time, decisive direction from the DRC recommendation 7.1 through to 7.14. This squarely sets the tone for what is required and provides guidance to insightfully reform the system over time. The lived experience of disability was stamped all over recommendation 7.14. Evidence has shown that all students can learn, thrive and grow together. They just need a system to support this, also a system that supports their futures into post-school life.

**LIBBY GUNN:** Thank you, Chair, and the Committee for inviting us to give evidence to this inquiry. We would also, at Square Peg Round Whole, like to acknowledge the Gadigal people of the Eora nation and recognise that sovereignty was never ceded. We're here as representatives of the community grassroots national advocacy group Square Peg Round Whole. Broadly speaking, we advocate for inclusive education. Our community members are pretty much all parents and carers of neurodivergent and disabled children, and we are also teachers, researchers, doctors, lawyers et cetera. Many of us are neurodivergent and disabled ourselves. We are a neurodivergent-led group and we are committed to amplifying the voices of the neurodivergent community.

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The Square Peg Round Whole community was established by the late Louise Kuchel, who some of you knew, around three years ago, and we now have around 2,000 member advocates. There is also a Facebook page that's public and an amazing archive of podcasts which Louise left us, and I strongly urge everyone to listen to some of those when you get time. We're all volunteers. We operate with no funding. We have no material or vested interests. We have, however, recently incorporated in WA, and we were a finalist in the Australian Human Rights Commission's Human Rights Awards last year in the community category, so we're still churning along without Louise.

Our guiding principles are, firstly, we believe in a fully inclusive education system where disabled children learn alongside their non-disabled peers in the same schools and the same classrooms following the same curriculum with appropriate accommodations and supports for those who need them. This form of inclusive education is a human right guaranteed by the Convention on the Rights of Persons with Disabilities, which I'm sure I don't need to say to this room. We note that if our mainstream schools were truly inclusive, there would be no need for a choice or segregated settings to be available. Everything positive about those settings would be included in mainstream schools. Secondly, the current system of behaviourism-based approaches to behaviour management should be replaced with neuro-affirming, trauma-sensitive, culturally responsive and neuroscience-informed approaches, such as Dr Ross Greene's Collaborative and Proactive Solutions.

Thirdly, nothing about us without us. Neurodivergent and disabled people should be a central part of all decision-making and design that affects neurodivergent and disabled children in the education system. We note here that the intersections between First Nations identity and disability are critical, and First Nations people with disability must be at the centre of ensuring that our education systems are fully inclusive, including culturally safe and responsive. Until our education system is universally inclusive, we will be letting vulnerable individuals slip through the cracks and we will be requiring constant differentiation by teachers, and this is not actually necessary. A universally inclusive approach would make life much easier for our teachers and therefore improve outcomes for all children.

We particularly thank the Committee for this invitation to give evidence because, as you know, we did not make a written submission to this inquiry; although we are a member of the Australian Coalition for Inclusive Education. We have been struggling to keep up with the number of inquiries requiring submissions over the last year to 18 months. We've made a number of other submissions to related consultations and inquiries at the Federal and State levels, and we've expressed relevant experiences and opinions in those. We're very happy to provide those, although a lot of them are public anyway.

A couple of final points, our main value-add is that we bring the lived experience of our members, and our core role is to elevate those voices. We also want to recognise the efforts of school administrators, leaders and educators to support our neurodivergent and disabled students, our children. Our interests are aligned with the interests of teachers. Teacher conditions, particularly resourcing and the culture of schools and departments of education, directly impact our children. Lastly, we want to say how important this inquiry is. The previous New South Wales Government made some really significant progress towards inclusive education, and at Square Peg Round Whole we know that progress was hard-fought for. We hope that this critical issue can become one which illustrates how a collaborative approach to problem solving can bring about huge, positive and sustainable change.

**The CHAIR:** Thank you for coming. I understand what you're saying about the pressures that many in the disability advocacy sector are feeling at the moment with all of the great inquiries—but very time consuming. Could I also pay my respects to Louise; we miss her and she was a critical advocate for many of us in leading us to having this inquiry today.

**ANDREW WILSON:** My name's Andrew Wilson. I'm the chair of All Means All. I would also like to acknowledge the traditional custodians of this land, the Gadigal people, pay my respects to their Elders past and present and extend my respects to all Aboriginal people who may be joining us today. I hope that in the conversation later we may have time to reflect on some of the Aboriginal wisdom about how they dealt with people with differing abilities, simple but profound wisdom that we could learn from. I thank the Committee for the opportunity to appear.

All Means All is also known as the Australian Alliance for Inclusive Education. It's a nationwide multi-stakeholder alliance that brings together people with disabilities and their families, educators and academics. We work together for the implementation of an inclusive education system across all of the States in Australia. This includes advocating for the removal of legal, structural and attitudinal barriers that limit the rights of some students to a full inclusive education. The board of All Means All has a majority of members who are persons with disabilities or family members of persons with a disability. I am the chair and I'm also the parent of my

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daughter with an intellectual disability, Grace. I live in Pennant Hills, Sydney. Grace is now 19 years old and she attended our local primary and secondary schools.

All Means All started in 2017. It's a not-for-profit and has a range of networks to foster stakeholder connections. The three main networks are families, academics and teachers, educators or support workers in the education system. We currently have a total membership of over 9,500 people. All Means All is also a member of Inclusion International, the international peak body working for the human rights of people with disabilities. Our work is guided by two main principles: a human rights framework that includes the principles embodied in international conventions that Australia has ratified and been implemented in the disability standards of education that are often neglected at the State level, the human rights recognised under the United Nations Convention on the Rights of Persons with Disabilities—we reduce that to CRPD—and specifically the right to inclusive education, which is set out under article 24 and is also explained and clarified in what's known as general comment number four, the right to inclusive education.

Sometimes in New South Wales we pretend that segregation is inclusive education or we pretend that you can do inclusive education in a classroom of only people with a disability. That is not the case and it's very clear in all these international conventions and the interpretation of them in Australian law. The second main tenet of what we do is we try to achieve what is in the best interest of the person with a disability in terms of what will give them—in my case, my daughter—the very best quality of life—given that she has a disability. There is overwhelming evidence of the positive benefits of inclusive education for the student with a disability, for the other students in the same classroom doing the same course without a disability and for the educators, and for all of us in the rest of the community because education should be a microcosm of the real world where we have people who are black, people who are Jewish, people who are Christian, people who are Muslim, people who have disabilities all mixed together. Why do we change it in the education setting?

All Means All can see that there are many significant barriers to students with a disability getting a quality and inclusive education in New South Wales. Sadly, New South Wales is probably the most backward State in Australia in this regard, despite having significant funding. It's just that that funding is directed to inefficient and ineffective programs. What I mean by inefficient is that a lot of money is wasted in special schools that would be more efficiently—you'd get better bang for your buck if you put it in an inclusive setting. To make that ineffective, they're doing the wrong things. Teaching someone how to be herded around a shopping centre is not the same as teaching someone how to go shopping. We have direct experience in New South Wales of poor outcomes, exclusion, lack of resourcing, inadequate expertise, gatekeeping—that is the bullying of parents and kids into segregated settings—limited availability for professional development for teachers, problematic and inadequate complaint mechanisms and, sometimes, restrictive practices and abuse.

It's important, at the very outset, to say that when All Means All talks about inclusive education, we do not mean segregated, separate or self-contained programs or separate classes where kids with a disability are learning in a different setting. I will table 10 copies of this dotted diagram. I'm not sure if you've seen it before. My daughter is very much a visual learner and I have learnt how to put lots of things into visuals rather than words. It just describes the difference between proper inclusion and other things that may be considered close to it. We note specifically and it is evident that the New South Wales Government policy on inclusive education for kids with a disability is at odds with the definition under human rights law. It leads to policies and practices that harm students with disabilities, perpetuates poor education outcomes, leads to a lesser quality of life for people with a disability and also undermines public trust in the Government because human rights are being ignored.

I love the role of being the parent of my daughter with an intellectual disability. Some people think that this role should be pitied. Let me reassure you—it has struggles, including with the education system—it has joys that the parents of kids who don't have a disability miss out on. I have a daughter with a disability and a son 18 months younger who you would call gifted and talented. I celebrate them both in different ways though, sadly, the New South Wales education system strongly favours my son and not my daughter. It's from this conversation that I would like to have a real conversation with you later about parent choice, because what the NSW Department of Education defends—its segregated policies—under the name of parent choice is just bollocks. I mean that in the legal sense of the word. Parents being bullied into a 1950s framework of special education is not choice. It may be something our grandparents would have been proud of, but no-one in New South Wales should be proud of it now.

Mainstream school with Grace's peers is the goal, but it's quite a torment for parents who have to bash their heads against the wall that is the education system. It would be great to convert what we are currently experiencing as parent choice into the reality of a truly informed education choice. We need to change the world view that the education system and our society has that kids with a disability are sick and need a medical model so that we can help fix them. We need to change that to a view of diversity. We have kids of different religions, we have kids of

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different colour, we have kids of different mental and physical ability, and they form a wonderful spectrum that gives our society difference, nourishment and diversity.

The royal commission agreed on the need to invest in mainstream schools for educating kids with a disability. We note in particular the words of commissioners Galbally, McEwin and Bennett, who were the three royal commissioners who had a lived experience of disability. In their final report, they said:

We understand that parents want the best for their child with disability and we want all children with disability to have the best lives an inclusive society can provide. However, the structure of education systems influences the choices families make about where to enrol their children. The Royal Commission received evidence and information that parental choice to enrol a child in a special/segregated school or unit is often not a 'free choice'. ... This has been described as 'coercive choice'.

Further, one of my main concerns is that the Department of Education says one thing and does another. They describe inclusive education but actually put it in a segregated setting, which is not inclusive education. A recent example would be the announcement by the New South Wales Government in February 2024 of its intention to open 243 new support classes. That's a train headed in the wrong direction. It takes a lot of funding and, despite being funding constrained, there is a clear commitment towards segregation. This will significantly increase the amount of segregation of students with a disability in New South Wales schools and is in contravention of their human rights and in contravention of what would be in the best interests of the children. I note that All Means All didn't make a written submission for the reasons described by other people, but we did make a very extensive submission to the disability royal commission that covers some of these same areas. Thank you very much for the opportunity to appear, and I very much look forward to the discussion.

**The CHAIR:** Thank you. Last but not least, Mrs Tape.

**SUE TAPE:** Thank you to the Committee for inviting us to be part of this panel of very experienced and vocal advocates from New South Wales. CYDA is a national organisation and I have the privilege of coming today from the lands of the Jagera and the Turrbal people in Queensland. Like Andrew, I'm a very passionate parent-advocate as well. I just wanted to make a few comments that go a little bit further than what has been said by the others this morning. The Disability Standards for Education, the DSE, have been in place for 18 years, and the Disability Discrimination Act, the DDA, since 1992, and neither the DDA, the DSE nor any State- or Territory-based policies ensure an equitable and quality education for students with disability. CYDA is committed to ensuring that children and young people with disability are afforded equitable opportunities to succeed, and we advocate that this cannot be achieved until they are fully included and feel fully included across all systems and community life.

The voices and experience of students with disability are paramount. As a CYDA staff member, I acknowledge my privilege in this role, which stems from the invaluable feedback and dedication of CYDA members. Many people have contributed significantly, whether as family, staff or young advocates sharing their stories and insights. My contribution is built upon their collective work and experiences. It is also crucial to recognise the efforts of teachers and school leaders striving for inclusive education. Unfortunately, they often face inadequate support from the systems they work within. While students have the right to education, it's equally important to support those facilitating this right. Many challenges arise from the lack of support for educators and teachers. In examining the experience of students in Australia, CYDA would encourage the Committee to reflect on the following from the Productivity Commission study report on their review of the National School Reform Agreement. It stated:

**What has been happening to student outcomes?**

...

**Persistent gaps in education outcomes for some cohorts of students point to systemic barriers.**

...

- Gaps cannot be measured for students with disability, despite the agreement naming them as a priority equity cohort, as there is no consistent data tracking their educational outcomes.

The inequalities that drive the exclusion of children and young people from accessing quality education and, ultimately, an inclusive life are complex and multidimensional. Thank you for having us as part of this panel.

**The CHAIR:** Thank you so much. They were all excellent opening statements. I will kick us off with a question and then throw to my colleagues. I will start with you, Family Advocacy. I know that you talk a lot about a road map to inclusive education, and we often hear people are worried that suddenly the special schools will get shut down tomorrow. Can you talk a little bit about what that transition looks like and how long you're envisaging it would take?

**CECILE SULLIVAN ELDER:** Yes, definitely. So the road map here—I haven't got 10 copies, apology—was developed through the Australian Coalition for Inclusive Education. It was really an opportunity—



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I believe it was developed about four years ago—to really sit down with all the relevant people in the room, which would be academics, teachers, advocates and family members, just to be able to understand what it would take for us to reform our system. With that, there were certain steps that were taken, and each step then required the insight to be built into the education and system reform.

The Government, in adopting this, could step through and change all the aspects that were required over a 10-year period. We absolutely realise—I know one of the DSE recommendations was a lot longer than that, and we wouldn't support that, but we certainly would strongly support a conversation of a middle ground with that around what our Government here could actually do in working towards that road map. It starts with a plan. And this initiative was really to assist the Government and decision-makers to understand what that plan could look like.

**The CHAIR:** Once you have a plan in place and you know it's 10 years, say, and that's where you're going, then that helps to bring everybody on board to start moving in that direction. What would you see as being the first steps?

**CECILE SULLIVAN ELDER:** The position that Family Advocacy would take in that is that we absolutely understand there are a lot of conversations around people having to be on board, everybody has to agree, we have to wait for that point to arrive. However, there are really strong indications that that's not going to happen. What's often needed in that change strategy perspective is for the Government to make a really firm decision. "This is where we're going. This is what this looks like. We need to bring everybody along with that." And so if local schools, school principals, district officers—whatever the role may be across this mammoth education system—are clear that this is where the Government wants to go, and then the process is designed to bring people along to be part of that solution-based focus about what that could look like, the decisions being made, then that would absolutely be the first step. Any kind of change strategist requires people who are involved in that change to be brought along, and so we would absolutely see that special schools, support units, educators, Department of Education staff, families, advocates—everybody should be involved in that, and that's where the engine starts.

**The Hon. SARAH MITCHELL:** Thank you for all for being here, and for the continued advocacy of your organisations. I have known and worked with many of you—I acknowledge that. I also acknowledge Lo and send our condolences to her family. I think it is appropriate to put on record what a strong and fierce advocate she was. It was a pleasure to know her and work with her, as I'm sure others on the Committee would agree. I will start with some questions to Family Advocacy. Thank you for your very extensive submission. It's very helpful when we get those from organisations such as yours. I acknowledge Leanne, who I see in the gallery. I go to the point around the independent complaints process for appeals on expulsions in Victoria that you call out in your submission. Obviously, again, it's something that the Committee has discussed. We've discussed the over-representation of young people with disability in suspensions and expulsions. Can you tell us a bit more about how the Victorian model works, as far as you're aware, in terms of that process for families?

**CECILE SULLIVAN ELDER:** That was in the submission.

**The Hon. SARAH MITCHELL:** I'm happy for you to take it on notice, if you want to.

**CECILE SULLIVAN ELDER:** Absolutely. I would like to call my colleague Leanne, but I know I can't formally do that.

**The Hon. SARAH MITCHELL:** That's okay.

**CECILE SULLIVAN ELDER:** That particular process, I'm not aware of. I'm aware of the process, but some of the nuances around that, absolutely not.

**The Hon. SARAH MITCHELL:** If you want to come back on notice, that would be fine.

**CECILE SULLIVAN ELDER:** Yes.

**The Hon. SARAH MITCHELL:** Following on from that, in the same section of the submission you also talk about the project that commenced with the department. Obviously, I'm aware of that from my former role in terms of the parental engagement and the student and parent exchange directorate, which is no longer operating. What has been the involvement or the view of Family Advocacy around that no longer happening? You seem to indicate in your submission that it's not really clear in terms of what is going to replace that or how it's going to work, particularly in terms of families having that support. Are there any insights into that process you could give?

**CECILE SULLIVAN ELDER:** I've been a part of that group, as well as the reference group, since the Disability Strategy launched both pieces. I think, standing back, the observation is that there is such a dramatic changeover of staff within the department who come in with ideas around "this is going to fix it; this is what we



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need", and it's lost almost every six months to 12 months, I'd say. I really would applaud in some ways some of the things that those groups were looking at. I think what I certainly wouldn't support is that as a member of the reference group and the other group, your ability to feed in in any meaningful way is shot right down. In many respects, you're given a five-minute window to discuss something and come up with a solution that quite frankly is already decided.

They're both examples of what's going on in that respect. It's not good collaboration. It's not a good way to bring people along. It's actually not an opportunity to talk about some real issues happening for people on the ground. As an example, how many inquiries did we have in the last six months? It was 278. We hear every day what's happening for people as they're intersecting with that education system. Those groups do not enable a platform to actually get the Department of Education to understand that. The reference group—there are a couple of members, at least, that have stepped out of that because they didn't feel there was any value. They are trying their best—we will certainly take our hat off to that—but it's not good enough.

**The Hon. SARAH MITCHELL:** I have a question for Square Peg Round Whole. Libby, you talked about being the advocates for parents and the lived experience of your members, but also, in terms of school leadership, the culture within a school when it comes to inclusive education. We've had a lot of families write in to this inquiry. Unfortunately, some haven't had what we would say are positive experiences at all in their mainstream schools. From your perspective, what are some of the things that actually make it work in terms of that culture and that school leadership that other schools or all schools should be emulating to get the best outcomes?

**LIBBY GUNN:** We certainly hear good experiences at times from our members. Not everything is dire, although obviously a lot is. The good experiences tend to be when the stars align: where you've got a sort of lighthouse teacher or two—often it needs to be more than one—where you've got a receptive executive, principal or assistant principal, and parents with the privilege and capacity to advocate and form those partnerships. Like conversations for collaboration—that sort of side of things. The school culture is really—even the best schools. I can probably pass to Marika to talk from personal experience about what is actually a really good school that still operates within the bigger system and struggles. The best cultures are where there's a "know better, do better" culture—where there's no arse-covering, for want of a better word, and that culture where people are feeling like they're going to be blamed and teachers in particular feel like they're going to be blamed.

The negative stories that we hear from our teacher members, actually, and from new teachers in our schools who are desperate for the other skills that they know they don't have—they know there's something wrong with what they're being told to do. They often come out of university, they've been told about the most recent evidence-based approaches, and they are immediately told, "No, you will use the traffic-light system. Here we use PVL, and it looks like this." They don't have any capacity to do anything different. And, worse, there's sometimes what almost feels like an army induction culture, where new teachers are made to take every shift on the playground. They don't get a chance to even go to the toilet. There are bizarre stories that really do make you question how any teacher would then be able to provide proper care and education for a child in their care. I will pass to Marika for some stories that might elucidate.

**MARIKA FRANKLIN:** If I could take a moment just to introduce myself and share some of our story, which does point to many of these issues? Thank you to the Chair for this opportunity. I am a parent and member advocate with Square Peg Round Whole. I am a parent of two neurodivergent children who are both in mainstream school. I would say we have had many positive experiences and opportunities for inclusion to work well, but the lack of consistency is—it's just not consistent. From the get-go, if I go back to preschool, trying to find a preschool and having a child who is not toilet trained and told we'd be best placed to keep our child in day care until they start school. Inclusion at that point would have been having support workers who can meet children's self-care needs and healthcare needs. So it's a lack of an interface between the disability sector, the health sector and the education sector that really structurally impacts on inclusion, in our experience. We have had wonderful relationships with teachers passionate about inclusion and doing what they can, but the structures are just not there and supporting them.

What we've found really helps is when there's flexibility, like Libby just talked about the rigidity of systems. To be able to support inclusion, we need creativity, adaptability, flexibility and understanding of the nuances of disability. It's not a one-size-fits-all approach for people with an intellectual disability, for children who are neurodivergent and for children who have a physical disability. We're dealing with the very complex and nuanced experience of individuals. Also, what works against inclusion is the language that is reflective of culture. We have had teachers use words such as "handicap". We've had parents tell us they don't want their children in the same class as someone who's autistic. It's not only systemic within education and the way the structures are in place, but it extends throughout the whole school-wide community, which works against inclusion. If I could take a moment, I'd be happy to share some real-world examples, if I may.

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**The CHAIR:** Please, go ahead.

**MARIKA FRANKLIN:** I'm here today as a rep and sharing some of my own experiences, but I acknowledge that this is representative of many of the experiences that we hear on a day-to-day basis. Although I have two children who are neurodivergent, I'd like to share and draw on my eldest son's experience, who is a funny, passionate young boy about movies and music. He's a lover of history and he's also very creative, and he has a love for learning. He's autistic, with ADHD, generalised anxiety disorder, hypertonia, sensory processing disorder and learning difficulties. He has an individualised education plan, receives funding through the integration funding scheme and has been receiving support for literacy, numeracy and social skills since kindergarten. He is now 15 and in year 9, and on a partial attendance plan, and has not attended a full day of school in over 2½ years.

Although we are in a school which supports inclusive education, there are many policy-to-practice gaps that work against this happening on the ground. I'd like to draw attention to issues around safety, inclusiveness and also the issue of quality education. I would firstly like to share an example of safety. I'm sharing an example of a time I was called at work to say a school could not locate my son, and would I like the police to be called? Absolutely. My son was eventually located hiding in a storeroom—and why was he hiding in the storeroom? Because he was extremely stressed and was trying to calm himself down.

Contributing to this stress was that our son's teacher was away, which was scheduled leave, and due processes were not followed. The due process was for a one-page information sheet to be shared with the teacher and that he go to a classroom with an executive staff member. However, the one-page handover notes and allocation of our son to a class with an executive teacher did not occur when a change in staff was foreseeable, resulting in the teacher not following Leo's medication schedule, not supporting him to eat, a lack of support given to him to follow instructions and many of his other needs not being met.

Unfortunately, this is not a one-off situation. We have been advocating on these issues since he started school in preschool, but he is doing the same thing and he is now in year 9. Our goal on his IEP at the moment is around safety and belonging. We are still not there and he is in year 9. As I mentioned, he attends now on a partial attendance plan. Why? Because his needs aren't being met, and not because the teachers aren't wanting to meet his needs; they're not able to meet his needs.

Due to this lack of support within the education system, Leo at times has not felt safe. He feels he doesn't belong in school. A sign of him not belonging, externalising behaviour, is refusing to wear the school uniform, which in some schools results in disciplinary behaviour. But he is saying, "I don't belong. Why should I wear it?" This is a sign, through his behaviour, which is often met with—he has been suspended—punitive disciplinary behaviour, rather than addressing the underlying issues. He's experienced bullying; he's felt lonely; he's been let down. His mental health has suffered terribly, as have his education and social connections. The behaviourist approaches, including suspension, have been incredibly ineffective and detrimental. We are advocating for a relational approach—a trauma-informed practice—which would be far more beneficial and attentive to our child's needs. I'm happy to provide contrasting examples of when these have worked well.

**The CHAIR:** Can I just interrupt you there, just because I am worried about the time. We might come back to the other examples, because it's very useful.

**MARIKA FRANKLIN:** That's the end. I wasn't going to give any others; I was just going to finish up by listing out points of concern that point to the issues with inclusive practice on the ground. Inconsistencies within and across schools in supports provided to autistic children—one school might have permanent support workers which are in every single class, whereas another school might not have that option. Support for children is too often linked to parents' capacity and privilege for a diagnosis and to advocate, navigate and fill the gaps. There's a lack of transparency in what support is available and what is considered a reasonable adjustment, and I would really like to table that issue and have better transparency and understanding around reasonable adjustments.

There's a lack of independent support for parents through the Department of Education, which we have talked around, and a poor appeals process. There are significant impacts to our children, as well as parents, who are picking up the burden and dealing with economic, mental health and social implications. Significant cultural reforms are needed, including values and attitudinal change, improvements in infrastructure that are fit for purpose, adequate training for staff, decasualisation of support staff, and greater transparency and consistency in processes and accountability. I could go on but I'll stop here. Thank you for the opportunity.

**The Hon. NATASHA MACLAREN-JONES:** I'm happy if you need to take this on notice, but one of the things that came out of the disability royal commission was in relation to data collection, recommending that more data needed to be collected but also to be released and reported. I'm keen to get an understanding of your

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understanding of what data is currently available and what should be reported when it comes to barriers to accessing inclusive education, particularly in mainstream schools.

**CECILE SULLIVAN ELDER:** Sue, do you want to take that? I know CYDA—

**SUE TAPE:** I was waiting to be invited, thank you, Cecile. This is covered in detail in CYDA's submission to the "better and fairer" review that was done at the Federal level, but ultimately, in each State and Territory, at a public level. What we're able to marry up with the experience that we have as organisations is information about attendance and some information about enrolment, so we will know where children with disability are enrolled if they're in a fully segregated setting. Often the information about whether they're in segregated classes or rooms or times of the day—we don't have that information. You've got attendance and enrolment, but what we don't have is information about how adjustments are made.

The NCCD, or the Nationally Consistent Collection of Data, is reported nationally. There are various State and Territory reports about the numbers or the percentages of students, their ages and what level of adjustment the school says that they provide. We have no way to compare that to outcomes. We have no way to compare that with student experience and student engagement. We also have no way to compare that with how money is spent and how effective that money may or may not be with those particular adjustments.

The other thing that's missing is achievement. Whether it be the A to E achievement in some States and Territories or whether it be things around NAPLAN, there is no clear information about what students with disability are achieving in their current settings, in their current experience. But we know all the organisations across that table, and CYDA—we know that families leave primary schools wondering whether their children can read or write, wondering what level of literacy and numeracy they have, and there are very few outward measures to actually explain that. Obviously, there's quite a variation in the level of adjustment and therefore the level of the curriculum that they're accessing, but we have no oversight of that either.

The other thing that is sorely missing at a State and national level is student voice. What do students with disability in mainstream settings and segregated settings think about their experience? How do they feel about going to school? How do they feel about the experience they have at school? There is very little consistent public data around student voice.

**The CHAIR:** Thank you. Just to bring Mr Wilson in, I guess when some people are hearing about experiences with mainstream schools with kids with disability, the response might be, "Wouldn't they be better in a special school?" It was notable that in the disability royal commission, those commissioners who, as you say, were in favour of ending the segregation between schools were themselves people with disability. Did that surprise you?

**ANDREW WILSON:** No, not at all. Our grandparents thought it was completely useful if you have a daughter with Down syndrome to take them away. It's the lost generation of people with disability. We talk about the Aboriginal experience, but there's also the disability experience. In about 1977 Australia decided that wasn't the right thing to do. If so, it's better to have your daughter live with you. Those grandparents who gave their children away to an institution, they weren't bad people. That was just what happened in that day. The same thing here: We've been used to segregated education; therefore, we think it's probably a good thing. But the evidence is completely to the contrary. The evidence is you get a much better education in a mainstream setting. Even though we do it really badly in New South Wales, you still get a better education in a mainstream setting than in a special school, so it's not surprising. It's sad, but it's not surprising and it's not surprising that we need a road map to bridge the gap between what is and what could be.

**The Hon. ANTHONY D'ADAM:** Thank you all for your appearance. I listened to Dr Franklin's account and it struck me that a lot of what was described didn't appear to be the result of maliciousness but an outcome of an underfunded, under-supported mass system. I am a sceptic about the question around segregation. I want to be persuaded, right? I know the evidence is integration gets better outcomes when all the supports are there, but we're dealing with an imperfect system, and I don't believe the system's going to be perfect at any time in the foreseeable future.

I want to pose this question about specialisation and the system trying to deal with the resource constraints in the best way it can, and that's why there's reluctance around the integration versus segregation question. We've got specialists developed with special education skills and they're in short supply, and you probably want to use them in the best way you can in the most efficient way you can. That often means bringing kids together who those teachers can work with in smaller groups. I just want to open that up for discussion because I think the question—around the system trying to deal with an imperfect situation in the best way it can, not in a malicious way—is: How do we move forward?

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**MARIKA FRANKLIN:** If I could share some examples of that working well: To overcome the lack of specialised staff, there are many champions within our local public schools who are in a position to develop positive relationships with our young people with disability which fosters a sense of safety in the school. Having a strong sense of safety is fundamental. Some of the other things stem from that. Also, when we talk about class sizes, why do we need to have a smaller class size, just with people with a disability? Why can't we have smaller class sizes which include people with a disability and people without a disability? We can still have large class sizes and small. That's what I'm talking about.

It's about flexibility and creativity, not thinking of rigidity and trying to have one model here and one model there. How do these approaches work together? How do we find the middle ground, which is true inclusion? Yes, we've got a long way to go. I think the disability royal commission talked about in 10 years, 20 or 50, we're going to have another generation of children, like Mr Wilson was talking about, not having access to this inclusivity. Yes, there is this risk of harm. We are experiencing the distress because of the failings. However, the outcomes are still more positive for us to go through this experience in the mainstream school than if we moved into segregated schooling, and the evidence shows that.

**CECILE SULLIVAN ELDER:** I'd like to add to that. I think it's a really important point that you raise because this inquiry is looking at the issues across the whole system and it's almost doing so with the intention of solving all those issues. I absolutely agree: They can never be completely solved, but we're also looking at the wrong problem because, when we're talking about genuine inclusion and whole of community, it starts with school. Grappling with issues in an inclusive education system is certainly going to feel a lot better than grappling with an education system and all its issues when segregation is the prevailing piece.

I also wanted to mention that there was a piece of work done by the disability research team around the data post school. If we think about what's the intention of school, there are all of these lovely things that happen in our education; but, primarily, it's actually around post school and what happens for people in employment. It is woefully low for people with disabilities—woefully low. The findings from this particular piece of work looked at young students who were on the NDIS who were in segregated settings, both special school and support units, and what that looked like post school and significantly lower than students that were in mainstream. The New South Wales Government, like every government across this country, is facing the predicament of what do we do around this.

The starting point is our education system, effective transitioning, and expectations around employment for everybody with disability. They're all problems that need solving. More than likely there'll be tensions years to come. If government is going to take a position on this, that will need addressing then, but at least we're grappling with a good foundation versus we're starting right back.

**The Hon. ANTHONY D'ADAM:** Can I just ask one more question?

**ANDREW WILSON:** Could I give some good examples?

**The Hon. ANTHONY D'ADAM:** Just in terms of the recommendations, is that only to be applied to the public sector? Is it the intention that segregated schools will be phased out across the board, in the public and private sector?

**ANDREW WILSON:** That is the recommendation.

**The Hon. ANTHONY D'ADAM:** That is the recommendation, and so the intention is that, effectively, you'll prohibit parents from creating private schools that are solely dedicated to special education?

**LIBBY GUNN:** Eventually.

**ANDREW WILSON:** But there are other ways of infringing people's human rights that are also not allowed in Australia. That's one of them.

**The Hon. NATASHA MACLAREN-JONES:** Just to follow on from Sue Tape's comments earlier in relation to measuring outcomes, I note that in the Government's plan for education that was released last year, it doesn't specify disability and the reason they gave was that it is about inclusiveness more broadly. But one of the things they do say is that they intend to measure success by reducing the gaps in student outcomes. I'm interested to know what specific outcomes should be measured. The reason for that is we also have the department appearing, so it would be good things to put to them, such as: Are these the things that are being measured, based on the expertise from witnesses?

**LIBBY GUNN:** If I could just make very general comments about that. The term "wellbeing" is used a lot in our schools now, but it is fairly clear to most of our members that there's not a very comprehensive understanding of that in terms of the way it's implemented across the whole system. There is an increasing



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understanding that wellbeing is important, but it's close surface-level understanding: It doesn't pervade. But I would say that what we should be looking at—and this is actually a point more generally that I would like to make—is the term "evidence based", which is also used quite broadly in the education sector. It really needs to be scrutinised carefully because we need to know what it's evidence of, exactly, and then how strong the evidence is, separately. But the question of what it's actually evidence of is really important because, particularly in the behaviour management area, when people talk about evidence-based programs, not only is the evidence quite weak but it's often, if you delve into it, evidence of compliance.

So, yes, it's successful—the evidence shows it's successful—but successful means "sit down and shut up now", essentially, when, in fact, what we want to measure is access to education, engagement, happiness at school, long-term wellbeing and mental health outcomes. I don't believe that individuals are only valuable members of our society just because of what they can produce, but it does result in economically productive citizens. The better the education and the more included in society people feel, the less aggravated and aggravating they are more generally. That would be my general comment from our members' experience: They want wellbeing to be at the centre.

**The CHAIR:** We've heard a lot about different schools being quite different in terms of the experience: whether they're private or not, whether you have a special school or a mainstream or satellite class. There are some people who will come and say that their child had the best education possible in a special school and they find the idea of closing them quite shocking. What would you say to them in an effort to convince them as to why it's necessary?

**CECILE SULLIVAN ELDER:** When the Disability Strategy, which came out of the 2017 inquiry, was launched, there was a consultation process that went for a good nine months and had everybody at the table, including parents. When we stripped back everything, including all the things that weren't working in the education system for every single child with a disability—well, for most children with a disability—when you got to the heart of do parents actually want their child to belong, do they want their child to be welcomed, do they want their child to be accommodated, those of us in the room that are actually parents know the answer to that. For many of these parents, they had either been forced and coerced quite strongly by many or they had been very subtly. If we think about how emotional we are about our kids—we want the best, we want everybody to love our kids and to see our kids in a certain way—when parents are then sitting in front of a school or professional authority that says, "If you love your child and want to do the best by your child, this is where they belong", it's certainly more subtle but it has a real impact.

So I think what family advocacy would say to that is that really needs to be challenged on a deeper level because our need to belong is a human instinct. Nobody misses out on that. So more often than not, and I think we talked about this in the submission, if a child is currently being educated in a support unit and a special school, it is usually because the mainstream system has let them down. That, we would absolutely say, needs to be challenged alongside that notion of choice—and really deeply.

**ANDREW WILSON:** I'm feeling what Mr D'Adam is saying in terms of surely there's some greater efficiency in a specialised model where you can have the OT and the speechie there. The evidence doesn't show that. I can give some good examples of my daughter in Pennant Hills Public School. She was the one person in the class who had a disability and the other 24 kids didn't. Brilliant educators like John Hattie will tell us that—kids and parents know this—kids learn more from other kids than they do from their parents or their teachers. It's what the other kids bring to Grace that is missing in the special school. It's the other kids who invited Grace to join the local soccer team. It's the other kids who invited Grace to join a dance group so that by the time Grace was going to high school she had four friends from her primary school that went to the same high school. She had three friends from soccer who went to the same high school. She had one friend from dancing who went to the same high school. She already had a group of friends. She was already belonging and being there.

Who's going to find her a job? It's probably her friends at school. Because that's what everyone does. Everyone in my local community works for either the Chemist Warehouse or Harris Farm or the IGA. It's friends working along friends—that's how we want our whole society to work in the bigger picture and so that's how we want our school system to work. It sounds inefficient because we're used to specialisation but it's actually more efficient to do it in that way. What doesn't work is when you put six kids with a disability in that one classroom because that is too much of a burden for the teacher.

Someone asked the question at the very beginning about where we have some good examples of good inclusive education. The first principal of Grace's primary school was absolutely fantastic. Grace went to school spec. She was in the choir. She's performed in the Sydney Opera House. She's performed in the Sydney Town Hall. She's performed in Chatswood Concourse. She's had some of the most amazing school experiences. It's not actually about how well she did in maths; it's that my kid was one of 10,000 kids on stage at one time that broke

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a Guinness book of records for the most people attending on a stage. That was a buzz. I don't care how well she did in the maths test the next day; I care about the experience she had.

I've got some photos of Grace in the pre-party to her school formal last October just glowing with a group of friends and it's those friends that are going to help her accommodate. Now, if we push Grace into a special school, then she's only going to have other friends who are people with disability. She's not going to get invited to the local soccer team. She's not going to be invited to the local dance group. So you've got a snowballing effect. We want a positive snowballing effect, not a negative one.

I would say the first principal was really good. Grace was in about year 4 when that principal retired. The second one was a complete dud. I'm aware of friends with kids a little younger than Grace who have, you might say, a lesser disability that were basically punted down the road: "You don't belong here. We think the special school at Clarke Road would be better for you." The real problem with having a choice is parents are allowed to make bad choices, whereas if you force them to the better model you get better outcomes.

**The CHAIR:** I could talk to all of you for a very long time. Unfortunately, we are seven minutes over time, so I will have to stop there. Apologies to you, Sue. I would have loved to have heard more from you as well. There may well be questions on notice, and supplementary questions that we will give to you later, but the Committee secretariat will be in touch. Thank you all so much for all of your advocacy and for the time that you've spent with this Committee today. That concludes our session.

**(The witnesses withdrew.)**

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Ms NICOLE ROGERSON, Director, Autism Awareness Australia, affirmed and examined

**The CHAIR:** We now welcome our next witness. Just before you read your opening statement—do you have an opening statement?

**NICOLE ROGERSON:** No, I was just going to get straight into the chat.

**The CHAIR:** Even better. I will disclose for the Committee's benefit that you and I have met before, about 11 or 12 years ago. You were a lifesaver for my family when we brought my daughter to you just after she had been diagnosed with autism. She came to the Lizard Centre, and also my second daughter came to the Lizard Centre, and both benefited from the work that you did there, so thank you very much.

**The Hon. SARAH MITCHELL:** We'll allow that conflict. We think it's a good one to have.

**NICOLE ROGERSON:** I'd really like to hear how the kids are going, but I know that we've got limited time.

**The CHAIR:** They're great.

**The Hon. SARAH MITCHELL:** Thank you for being here, Ms Rogerson. I have a couple of questions about your submission. You talk a little bit about the most recent survey, and one of the things that you speak about is school refusal and the percentages around what that data is showing you. I was wondering if you could share some of the reasons why families and students are experiencing that school refusal, and whether you think that those statistics and trends have increased over time and perhaps the reasons why.

**NICOLE ROGERSON:** I should just qualify, as an important thing to say, that specifically when we talk about disability today I'm probably going to stay in my lane, which is autism. Also, it's important to say that I am not somebody with autism; I am the mother of a son with autism. It's important that probably the perspective that I give today is that of parents and parents' experiences with the school system. That's probably what I am most comfortable speaking about, but I know you've got so many other wonderful speakers that are going to be able to give you more direct lived experience—although, I did feel like I was living for a lot of those years when my child was at school. But he's 28, so I've put the trauma behind me, I think it's fair to say. What's interesting is that at the same time we were putting this submission together, Autism Awareness Australia had produced and was in the middle of doing a national parent autism-in-education survey, which was going out to our parents nationally—we have a database of about 175,000 families—and getting their firsthand experiences of what was happening in schools.

Fundamentally, the interest for us in schools has always obviously been there but the recent interest is some of the upcoming changes or suggestions in the NDIS Review I feel are going to have a direct impact on the New South Wales education department. Rather than just complaining about that in the national press, I decided to go and visit with education Ministers around Australia and have a talk to them about the problem I saw coming and still do see coming. And I was very welcome to get an invite to meet Prue Car, so that was really effective. I don't remember the actual dates, but we released the report on 1 April—and I will make sure it's sent around to you all. What I think is interesting about school refusal came in another way. We found that 35 per cent of families told us that they had either been discouraged or unable to enrol their child at their local school. Of that particular 35 per cent, 50 per cent of that cohort had experienced that in the public education system—and that's just absolutely not on.

So what we know, and what families are telling us, is that right from the get-go, when Johnny's five and we turn up at the school gate and the school is kind of cross-armed and "Johnny's probably a bit too hard; he'd be better down the road in that school", that's kind of the introduction of where children can then go on to refuse to be in that school. Something so unwelcoming, a school so unready to assist that child, ultimately is not going to be a very welcoming place for that child or family. Imagine the impact that has on the child's mental health and the siblings' mental health who may go to that school. It's an absolute punch in the gut to the parent who feels like "your child is different" and hence "different is not welcome here". So that particular piece of information out of that survey was really critical to me. The survey was covered by *The Australian*, who did a front-page story on it and went through some of the results of the survey. I made what I now understand is the rookie error of reading the comments section of *The Australian* underneath that story.

**The Hon. SARAH MITCHELL:** Never do that.

**NICOLE ROGERSON:** Never read the comments. Wow, it was just amazing. The prevailing view of some of the broader community, or at least those who read *The Australian*, was "Why are these kids even in our schools? They shouldn't be here; they should be in separate schools. They should be moved away from our kids." I heard all of the wonderful speakers that you just had—they were great—so I don't want to go over things that



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they talked to you about, because so much of it was really important. They did a great job, so I'm not going to jump in on that. But I will throw one other perspective that came out of our survey. When we asked parents whether or not they believed that all schooling should be inclusive and that schools should be made to have children with autism enrolled in those schools, or whether they would like the choice of having a separate or segregated schooling option, 89 per cent of parents reported that they would like the choice. There is not an appetite, I believe, in the parent community at the moment that says we want to shut these options down. I think, to everything that everybody just said in the 15 minutes I heard before, sitting up the back, all of those points were absolutely relevant.

Are our schools, our communities, better if they're inclusive? Absolutely. How far away are we from that? I don't know—I'm touchy; I'm turning 50 in a couple of weeks—but I always say in my lifetime it would be great if we could get that done, because we have known inclusive education for people with a disability and inclusive societies work better. We know the outcomes are better for the child; we know they're better for the family. Have we done much in the last 25 years I've been in autism? Not a lot. Not a lot's changed. We're all still talking about the same things we used to talk about when my son was enrolling in the local public school, which, ironically, way back then, weren't terribly welcoming, so we did move to another area and rent a house in order to be in that school catchment to get a school that would accept my son. That's not on. I'll just throw in the last bit on that one. I think New South Wales education for a very long time has been committed to the concept of local principals, local choices—what is it, local decisions?

**The Hon. ANTHONY D'ADAM:** Local schools, local decisions.

**NICOLE ROGERSON:** That's a nonsense. Stop that. There's got to be rules that say that the leadership of public schools in particular have an obligation to be welcoming and accommodating of children with additional needs, and to genuinely sit down and try and work out what that looks like. We know what strategies work. We know how to manage children with behavioural difficulties and learning difficulties in the public education system. Do we do it well everywhere? No, we do a terrible job. But are there pockets of great? Absolutely there are, in both the public- and private-sector schools. It's disingenuous to say that we don't know what works well. What we know is that it's leadership led: If the school principal is on board, you will find there will be a team of people that will be on board as well. I would like to see the legislation changed that means, sure, local decisions and local principals make your choices but there's got to be some rules around what is okay because that leads to expulsion and suspension. Suspensions are absolutely shocking.

For a child with a sensory issue or for a child with a learning difficulty, being made to sit down on the spot and listen for half an hour might be very difficult for them. They might need to move. They might need to have certain accommodations that are made possible for them. In order to say to a child, "That's not available to you"—you wouldn't say to a child in a wheelchair, "It's time to line up with everybody else at the door. Come on, these are the rules—line up." You wouldn't say that. If we don't make accommodations—let's face it, the kinds of accommodations we know and the strategies that work for children with autism in schools actually work very well for other children with different learning profiles as well. So we're talking about great strategies to help kids who learn differently. And that's the thing about society: We are all different. If we reject children who have a disability or who think differently, from when they're five, what outcomes do we expect for them and their families when they're adults? We're just starting off on the wrong foot.

**The Hon. SARAH MITCHELL:** I have one quick one and then I'll hand to someone else. I was interested that in your submissions you talked about the lack of before- and after-school care for children with autism. Obviously, as a Committee, we're looking at all educational provisions. What are some of the experiences or feedback you've had from those families you work with around accessing before- and after-school care? Is it something that they can do readily? Are there challenges with that? What could we suggest to improve that for families as well?

**NICOLE ROGERSON:** The challenges typically are that before- and after-school care providers tend to hire young, pretty inexperienced people to watch the children, and children with autism can have a higher likelihood to abscond or have difficulties during that time. Again, it's a suggestion. No parent wants to start off a conversation with, "Do you think your child would be safe here?" "Oh, no, probably not." "All right. We'll enrol them anyway." I mean, that's a nonsense, but, again, the system allows it. There have to be rules around what the system will accept because, of course, if you limit access to before- and after-school care, what does that do? It just limits access to one parent's ability to go back into the workforce in any meaningful way, and that's usually mum.

I think we can be honest about where all the problems are, and we've known them for a very long time. I think people like me feel frustrated—again, just because we're old and cranky—but the frustration is that these problems have been around for a very long time. Lots of groups, not just my own, have long been telling

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governments of both colours that this experience has been the way it is for a long time and still New South Wales education seems very unwilling to have a good look at the sort of systemic change we would need in order to get to the ultimate goal, which is what the people that were just here on this panel were talking about: true inclusive communities and schools that accept all kids with a disability. I absolutely think that's the outcome, but I'm practical enough to understand that there are about 10,000 steps between now and then on how to get there. I'm honestly not one of those people that screams, "Inclusion or nothing!" I'm one of those people that says, "We need to get to a better place, so how do we start doing that from today?"

**The CHAIR:** I'm sure I was not alone when the NDIS Review was handed down in feeling a sense of alarm that schools that were already failing kids with disability were going to be expected to somehow pick up more of that. Can you talk from a New South Wales perspective, or from this Committee's perspective? What should we be trying to make sure is in place before seeing those changes coming down the line?

**NICOLE ROGERSON:** I'm so glad you asked me that question because I think that's my most useful contribution to this Committee, because you've got too many other really smart people coming to talk to you and they're smarter than me. My contribution would be that what I think is going to happen to the NDIS Review. And when I say "think", it's a massive "think" here. I don't know, but this is what worries me—enough to be talking about it at the moment. It's fair to say that we understand that State governments around the country stepped away from a lot of disability services when the NDIS came into being. We well understand that, at the moment—to use Bill Shorten's much-overused phrase—"the NDIS is the only lifeboat in the ocean." He's not wrong, and I have a huge amount of sympathy with him on that point.

The statistic of the amount of people with autism in the scheme—namely, the amount of children diagnosed with autism currently in the NDIS scheme—would indicate that Australia has the highest percentage of children diagnosed with autism than anywhere else in the world. Is that percentage incorrect? I think it is, yes. I think that there are a lot of children with developmental delays that are presenting for diagnoses. The clinical community in Australia wants to help those children—it comes from absolutely the best place—but the response has been, "Let's get those children in the NDIS to get the help that they need." As a result, the numbers have blown out and the headlines ensue—cue *The Australian*.

Moving on from that, I think the changes to the NDIS that are being discussed, reading between the lines, of maybe the best place for these kids isn't the NDIS—okay, fair enough. I'll accept that for a second, but where would be the second-best place? Back in the States, because States have something called foundational supports. The States don't have anything at the moment called foundational supports. They might, but they don't exist at the moment. Could it be better? Yes, possibly. I don't disagree with the Federal Minister on this one. I think States should step up. I think there is a role for foundational supports. I think there are overblown numbers of children with autism on the scheme. I think all of those things are true, but then what I think is actually going to happen is they'll say, "Okay, let's determine who actually gets in the scheme," and diagnosis alone won't be it.

That's fair enough. I don't disagree with that either. A child has autism, but what's the level of disability that comes with that autism? As we know, it's a very, very broad spectrum. There are some children who will have moderate to profound autism. Those kids are always going to be accepted and supported within the NDIS. It's the children at the other end who present with more milder forms of autism. It doesn't mean they have less challenges; it just means how they present.

If we take those kids out of the NDIS, that will come back to being the States' problem. I personally see that that will land at the door of the New South Wales Department of Education. You will have a significant portion of children that are now getting some support through the NDIS that will be in your schools receiving no support. That will hit particularly hardest on families in rural, regional and remote Australia. Not only were those kids not getting many supports under the NDIS, in a way, because of the thin markets and the services were just not there, now it really will just be up to families to be able to support those kids. That's fine, but not all families are going to have the skills or the resources to be able to do that.

My message to education Ministers around the country is gird your loins, because if you think it's difficult and you're not doing well now, it's about to get horrendous for you. Sadly, not only are the unintended consequences obviously these children but outside of that, get ready for the headlines. It's going to be a disaster. Then what do we do? Then do we turn around and say, "We went too far with the NDIS Review?" These are the issues that I think States need to be thinking about really seriously: all the things that the people that were here before talking about the kinds of resources you need in schools, what we know about SLSOs and what we know about the level of skill. I won't bother going through all that again. You've heard it and you'll hear it, no doubt, many times more.

**The CHAIR:** There are quite a few things to unpack in that. I don't want to hog all the time. The first one is when we talk about the increased rates of diagnosis because people are going, "This kid needs extra support or

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needs some extra support. They might not meet the diagnosis but I'm going to put them in there so that they get that support". Is part of that because our schools have become perhaps—you look at the class sizes increasing and you look at the teacher workload increasing. Is it because our schools were under-resourced in the first place that then we're seeing people being pushed into NDIS? Is that part of the cycle?

**NICOLE ROGERSON:** I think that is part of it. I should also say that I have huge sympathy with the New South Wales education sector as well, because we've got a lack of teacher retention. That's real. Finding the right support services for kids with disability—it's not like there's an army of people out there waiting to work in this field. There are some structural and workplace issues that can't be solved overnight with just funding, but they do need to be on the road map. I don't have any actual data on that. Is it a deep suspicion? Yes, it is. What we often hear anecdotally is families will come to us and say, "I don't know that my child is autistic, but is the label a bad thing to have, because the label will apparently get me some help?" These are not parents doctor shopping. These are parents with children with genuine developmental delays and learning difficulties. Those kids have every right to be helped and supported as much as a child with disability, but they won't get any help if they aren't coming into the NDIS under an autism diagnosis.

**The Hon. NATASHA MACLAREN-JONES:** Can I jump in there? I take on board everything you're saying, particularly the concern of it becoming an education problem. To what extent is the department of health, across all jurisdictions, responsible? Do they need to take some of that responsibility to step up and say, "Right, we need to have a whole-of-government approach in how we ensure that a young person is properly assessed and given those supports, even before they get into the early childhood system?"

**NICOLE ROGERSON:** That's a really excellent question, and the answer is NSW Health are missing completely diagnostic services. The waitlists are ridiculous.

**The Hon. NATASHA MACLAREN-JONES:** Are there proper waitlists? Can you actually obtain that to say, "This is how many young people are waiting to be assessed or referred to services"? Does that data actually exist?

**NICOLE ROGERSON:** It does within NSW Health, yes. They know absolutely how long the waitlist is at the children's hospital in Westmead and Randwick. If you're on that waitlist, your child is not getting any services for anything, and they're getting older, so they're losing the important early intervention gap.

**The Hon. NATASHA MACLAREN-JONES:** And that's when a parent or parents may choose to then say, "Let's look at another avenue," which is a diagnosis to get them—

**NICOLE ROGERSON:** Private, yes. Again, that just causes other socioeconomic issues. Obviously for a lot of families those private services just aren't accessible for them because of the cost.

**The CHAIR:** You either wait six months for public or you pay \$1,000 for Aspect.

**NICOLE ROGERSON:** No, it would be more like \$3,000 now.

**The Hon. ANTHONY D'ADAM:** The department in their submission referred to moving to a functional assessment. I'm a little sceptical because practitioners that I'm in contact with seem to suggest that that's not actually being rolled out in the department at all. Is that the solution, that we move away from a diagnosis-based model for support?

**NICOLE ROGERSON:** I think there's merit to thinking about it. I think the problem is that the last Federal Government did roll out a pilot program around functional assessments and it was poorly organised. I don't think anyone thought the idea in and of itself—I will give you an example. I hate to use a personal example, but it's a good one. My 28-year-old son with autism was given a functional assessment by a physiotherapist. Part of the assessment was checking if he could take the bins out and how he managed the stairs out the front of our house. I don't know if you know much about kids with autism, but managing stairs is often not a big problem. It was badly done and then, quite rightly, everybody in the disability community said, "Come on, that's just a nonsense."

If you want to sit down seriously and say, "Let's have a look at each individual with autism and decide what that individual needs"—because autism affects people differently. What is true for this end of the spectrum may be very true for the other end of the spectrum and everybody in between. Should there be individual functional assessments of individuals in the NDIS? I think yes, but that's going to take time and it's going to take resources. But coming back to the NSW Health part, apart from the fact that yes, they have a responsibility here, I also throw a little bit of that responsibility back to the clinical community as well. By all means, you have to give a diagnosis that is true and accurate using assessment tools that are internationally recognised as best practice to be able to determine whether a child is on the autism spectrum or not. If they're not, that does not negate that child's need for supports and services, but the State Government have to have a think about how you want to do that.

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I think it's absolutely pointless for the State Government to be doing that unless they are in discussion with the Federal Government. I've said this to the education, autism and disability Ministers in South Australia. I'm really pleased South Australia are leading the country on this, and they are. If you haven't looked at some of the work by Minister Emily Bourke down there, I encourage you to do so, but I think they're doing so on an island, by themselves. I think this is a wonderful opportunity for all State governments to work with the Federal Government, to sit down and say, "Absolutely, hand on heart, the community are telling us we're doing this badly." But organisations like mine are actually keen to also say, "We'd like to contribute to helping you do it better." We're not here to catch you out, to tell you how badly governments do things. We're actually here as parents to say, "It is vitally important that our children have a successful time through their schooling years."

My family is extremely lucky and my son did have that success. He was yesterday at the pub with his friends from school, and that's what you would expect for a 28-year-old young man. But that's not guaranteed for everybody. Of course, there are always going to be equity issues, but until we have a system where we honestly say, "There are some rules around how schools behave with students with a disability," and a national approach to how we are going to manage these children more broadly, both in and outside of our education departments, we're just going to keep fumbling the ball.

**The CHAIR:** You've touched on early intervention. I know from experience, but also from friends with kids with autism as well, the difference in—prognosis is a bad word for this. But for someone at four, who can present in a way where you believe that that child might never actually become independent—move out of home and that kind of thing—who gets early intervention to an extent where they are able to go into mainstream, how important is it that we fund early intervention better in order to then have children that perhaps are more prepared for school once they go into school?

**NICOLE ROGERSON:** It's absolutely critical; it's absolutely everything. We've been doing it badly for years. When we were doing it badly, I guess we would say the reason was that pre-2014 there was very limited support. Pre-2008 there was no funding support whatever for any child with a disability. The only children getting access to early intervention and early supports were those whose families could afford it. A little bit of funding came in through the Federal Government in between that and before the NDIS started, and of course the NDIS is here now. But just because there is funding it doesn't necessarily mean those early intervention services are good quality.

The Government is still big on rolling out packages. I 100 per cent believe in the choice and control of parents being able to use the early intervention funding towards the services that they think will help their child—they should be able to make that choice for their family. But what we do know is that if a child is delayed in their development, doing nothing and then popping them into the school system at five is just going to make it so much harder for that child to be able to navigate that system. The more unsuccessful they are in that system, the more unsuccessful—they kick down the can to the next school and the next school, and then there is school refusal and then they're staying at home, and so on and so forth. How are we going to build great adults out of that?

**The CHAIR:** And there are huge waitlists for the intervention services too.

**NICOLE ROGERSON:** Huge waitlists for good quality early intervention, absolutely.

**The CHAIR:** We might end it there. I could keep talking. I have now gone back in my head to my early days with my children. It's quite distracting.

**The Hon. TANIA MIHAILUK:** Ms Rogerson, thank you for what you've said today. It's really a huge eye-opener. I certainly agree with the concerns that you relayed around NDIS and the reality of what potentially will be announced down the track, and that will be that some functional services will be redirected back to the States. I do have concerns because I think New South Wales probably will be suffering the most when these changes happen, because I think the decision that New South Wales made a number of years ago to completely remove itself from the disability space will essentially leave it in a position where it will struggle to be able to provide the necessary supports.

I am intrigued as to what you were saying earlier in relation to the work that's being done in South Australia, and that's perhaps something that, as part of this inquiry, we should look further into. I raised this earlier. We were listening to some of the parents speaking in camera earlier and they certainly provided some harrowing experiences that they have had with the school system, particularly the public school system. They're saying the solution is unlikely to be made within the Department of Education itself. They would rather see, perhaps, an alternative department, or the Department of Communities and Justice was suggested, or a separate third party playing a bigger role in that regard. Would you agree with that?

**NICOLE ROGERSON:** I don't disagree with it. I would say the more brains in the brains trust, the better. People with autism live and traverse all departments, whether it be Community Services, whether it be Education,

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whether it be Health. We live in all of those places. Having an intergovernmental approach—and I think that's what South Australia can be commended on—the Premier decided to put the money aside to work out a strategy of how they could do better as an all-of-government approach. I'm shamelessly a Sydney girl and I would like my State to do better. I'm here to say that we can. There are lots of people who know what better looks like.

Let us help you work across departments to make sure all of the worlds that people with autism and their families live in understand them, accept them and are set up to support them. It can't just be left on Education's front door. I'm just saying that I think that's going to be the front door that's going to be the biggest pain point to begin with, but are they the only answer? Not at all. Absolutely, this has got to be a cross-government approach and it has to be from the Premier down—not that I'm telling him how to do his job, but I just did.

**The Hon. TANIA MIHAILUK:** Why not? Someone has to.

**The CHAIR:** I love it. That is all we have time for unfortunately. Thank you so much.

**NICOLE ROGERSON:** As an aside, I would like to hear how the kids are going on another day, but thank you very much for having me.

**(The witness withdrew.)**



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**Ms GRACE FAVA, OAM**, Founder and Chief Executive Officer, Autism and Advisory Support Services, sworn and examined

**Ms SARAH LANGSTON**, Policy Co-Lead, Australian Neurodivergent Parents Association, before the Committee via videoconference, affirmed and examined

**Ms EMILY McCANN**, Board Member, Executive Committee, Australian Neurodivergent Parents Association, and Parent to an Autistic Child, before the Committee via videoconference, affirmed and examined

**The CHAIR:** We now welcome our next witnesses. Ms Fava, do you have an opening statement you'd like to read?

**GRACE FAVA:** I don't. However, what I can say is in my 18-plus years of being involved with the education system, be it on a personal level with my children or through advocating and supporting families and other children going through the education system, I have seen how it can be done fantastically well but I've also seen the huge gaps in supports, services, understanding and culture within a school. It's my dream to see that change because every individual with additional needs has the right and has the potential to have a meaningful life, and that starts with our education department.

**The CHAIR:** Ms Langston and Ms McCann, do you have an opening statement that you'd like to read?

**SARAH LANGSTON:** Yes. The Australian Neurodivergent Parents Association is an incorporated association and disabled peoples representative organisation, DPRO, for New South Wales. In this process, we assert our right to primacy under international law in shaping decisions that impact our community, in line with the guidance given by general comment No. 7 of the UN CRPD committee 2018. We assert that, in advising government, our voice is legally paramount as disabled people and should be considered above private interests, industry courses, non-representative and carer-led organisations according to international law. Our comments in this document apply only to the New South Wales public education system and the NSW Department of Education, and are based on the lived experience of our members and community—nothing about us without us.

We're an autonomous organisation comprised entirely of neurodivergent families where intergenerational neurodivergence is present. This means parents and children in these families are both neurodivergent. We do not receive any funding from private providers, government or the community sector. We are entirely volunteer run. We are politically non-aligned. Our constitution and our function are aligned with all principles, acts and conventions of the United Nations, in particular the UN CRPD 2008. The ANPA uses the word neurodivergent as an umbrella term to include all people with learning disabilities such as dyscalculia and dyslexia, all the dyses; psychosocial disabilities, schizophrenia, bipolar disorder, anxiety, depression, PTSD et cetera; and all forms of neurodivergence commonly understood to be ADHD and autism et cetera.

**The CHAIR:** I might start off with you, Ms Fava. You mentioned before that you can think of situations where inclusive education has been done very well and cases where it hasn't. Could you maybe tease out a little bit more about what makes something a good application of inclusive education and what doesn't?

**GRACE FAVA:** Absolutely. A lot of this is in my discussion paper that I submitted. I've seen situations where, again, it's all around culture, it's around understanding and it's around willingness to look outside the school for supports because it really does take a village. I hate that term but it does take a village in order to support a child with additional needs. Schools who do it right have a collaborative approach. They will have meetings with the parents. They will include parents in individual learning plans, in setting up the classroom. They will take into account what each therapist says. They do it very well.

However, where it has not looked good is the exact opposite and, sadly, I see that every day. I actually had a phone call on my way here about an early childhood setting that were doing that quite poorly and so the family have to look for a new setting. It's all about having those flexible needs met—"reasonable adjustments" I think policy says in the Department of Education. Reasonable adjustments need to be addressed by having understanding of what the child's needs are. Sadly, we lack experienced educators; we lack trained educators. I have in here a whole heap of suggestions on how to make that right. They're just suggestions but we need to utilise our university students because it all starts from uni. They only get one unit, generalised, on disability. That's not enough. We need to have broad experience across different settings for university students so they understand what they're getting into, not just for special ed teaching but for teaching in general.

Teaching isn't what it was 20 years ago or even 10 years ago. A teacher in mainstream has to be something different to every child in that classroom. One of my sons went through a support unit for all of his school life and I have another son who had two years in a support unit and the rest of his school life in mainstream, and it was hit and miss and it depended on that teacher. I remember one teacher. I said to her, "At work we've got this really

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great workshop on autism. Would you like to come?" And her reply was to me was non-verbal; it was actually eye-rolling, and I was mortified. And then the therapist that went into that room actually said to me, "Grace, did you know that your son is sitting at the back of the class with his back to the class, with a teacher's aide next to him, looking back at what the rest of the class are doing."

These are the sorts of things that we need to have teachers understand that are not okay. We can do it well. Where it's done well, we have that inclusive model. We have visuals out for all the students. I don't know any child that doesn't suffer from some form of anxiety or any sort of additional need, especially because of COVID but because also there are those needs out there. How can we, as a school or as a class, include all of these children and not have anyone stand out? Support for one child is a support for every child, and that's what teachers could and should be doing, in my humble opinion. And it's done well, and when you've got a principal who backs up that teacher, then you've got an amazing school.

I have seen principals shut down parents and shut me down in discussions when we go for return-to-school suspension meetings. I follow the policy and I say to the parent, "Would you like to mention to the principal about this, this and this?" So they won't let me talk; that's okay. It happens very rarely, but when it does happen we utilise those policies to try and open up a discussion, because a principal won't allow that discussion to happen. Without that two-way communication and without that collaboration, very poor outcomes happen.

**The CHAIR:** On that, turning now to the ANPA, we know that a lot of neurodivergent children have neurodivergent parents. What are the additional obstacles that neurodivergent parents face when advocating for the kids?

**SARAH LANGSTON:** It's a piece of string. They are enormous. I had all these notes; that's probably easiest to—for context, I am autistic and have ADHD, and Em has ADHD and is probably autistic too, but diagnosis is too expensive. All of our members pretty much have AuDHD, which is the double diagnosis. Quite a lot of them are undiagnosed but highly aware that they are neurodivergent. There are so many barriers for neurodivergent students that directly arise from the complexity of intergenerational neurodivergence. I would say that the biggest barriers to access for our children are the complete and total inaccessibility of the system for our families. At the very start, when you look at enrolment, we know that a key feature of neurodivergence is often difficulties with executive functioning. Executive functioning can include things like being able to read and comprehend, to listen, to make decisions, to task order and to remember things. This affects enrolment forms, being on time to a school meeting and being aware of when the first day of school is. All of these things that might seem easy to other parents are greatly difficult for neurodivergent parents.

It also affects social and communication differences. A great number of our members have experienced very high levels of hostility towards them, which affects their children's enrolment and school experience on the basis of their communication and social differences as parents. It is almost inevitable that if a child is neurodivergent, when they engage with the school system, they will have difficulty. Very few neurodivergent children enter the New South Wales public school system and it all goes smoothly. There are a lot of neurodivergent children who are in mainstream classes. There are some in support units as well. Regardless, they all have a really hard time, and it is when they have that hard time that parents then begin to advocate.

Advocating in the New South Wales public school system as a neurodivergent parent is fundamentally unsafe. The things that make it unsafe are—essentially, we are what I would call hyper-vulnerable to victimisation on the basis of complaint. What I mean by that is, when we advocate for our children, very often the ways in which we advocate for our children—our presentation, parents who send long emails, parents who might be abrupt, which is—being abrupt, being blunt, being bolshie and being direct is a very common aspect of communication difference, particularly for disagreement.

It is when you get this interfacing between a system that is fundamentally quite hostile to neurodivergent ways of being and neurodivergent parents that we see conflicts happen. We have decades of this pattern. What this often triggers—it is the experience of our membership and our community. Very commonly, conflicts between the education system and neurodivergent parents very often is a trigger point for child protection reports. There is a very large uptake of parents from our community and their children and their families into the child protection system on the basis of mandatory reporting within the education system, particularly the public education system. This is a massive problem and, as I said, there are very significant patterns of this over time, and they're not isolated experiences. I would say, in fact, it's so common that it is something that's very openly and broadly discussed within the neurodivergent community, to the point where there's sharing amongst the community around problem schools, problem teachers and problem principals who tend to be surrounded by clusters of reporting because they take particular exception to neurodivergent women and how we communicate.

That affects kids, because what we see is there is a really significant problem with families withdrawing children from the public education system. That is a problem on many levels, the biggest and most systemic of



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which is it furthers the cycle of inaccessibility. The cycle of inaccessibility—I don't know if you're familiar. It is the idea that—and I think it may have been an assisted disability advocate came up with this theory—when disabled people experience access barriers, they very often end up withdrawing from that system, which means they're not in the system. Therefore, the system says, "We don't have any disabled people in our system, so we don't need to provide for them," and so it goes around and around. So every time a neurodivergent child is withdrawn from the New South Wales public education system and is homeschooled or put into alternative schooling, what happens is we have fewer and fewer neurodivergent people and children in the system, which means it then looks like we don't need to cater for the needs of these children because they're not in the system.

I personally, as a parent, have experienced all of the things that I just talked about. Emily and I have made really different choices as parents, but that's because we have really different children. I have made the choice, despite my experiences of discrimination and hostility, to stay put. I refuse to leave our public school on principle, because I know that those of us who can stay must stay and take the system back, because if we don't nothing will ever change. That said, there are children whose needs are so unsupported by the system that they don't have a choice to stay because their mental health is at risk. My child can mostly cope, and Emily's—

**EMILY McCANN:** My child is now eight, but from kindergarten he was getting suspensions, and we've ended up in a second school. We've chosen—I say "chosen", but I don't really feel like it is a choice—to homeschool. It feels like the only safe option for my son. Homeschooling in itself is a great thing that a lot of families choose to do, and that's wonderful, but when you've got multiple children with extra needs, I would like to make that as a choice rather something that I feel like is my only alternative. It impacts on whether I can earn money and have a job outside of parenting as well. It isn't good for intergenerational vulnerability, when it comes to poverty, to not even know when you might be able to go back to a schooling system.

**SARAH LANGSTON:** Even after the kids were born, Emily is a very skilled child protection worker so she was a very valuable addition to our community but can no longer work now because of having to homeschool. At the moment that is the safer—even as I'm a very strong, passionate advocate for public education. I personally believe all public money should be in public schools, because it is public money. I don't believe private schools should receive any government funding whatsoever. If you want to send your kid to a private school, you pay for it. But, by the same token, when Emily told me that she needed to, for his mental wellbeing and learning, withdraw Alfie, I fully supported her choice because he's pretty much like a nephew to me and I could see that he just could not cope. And also the economic impact of that.

**EMILY McCANN:** I would love to see the level of flexibility I can give Alfie at home, because with his autism and his vulnerable nervous system, he needs a very low-demand environment—very, very highly flexible. There's not really any reason why a school couldn't provide that. It's really down to funding and attitudes. It's an attitude change as well, that a child can lead what their needs are—so that they're able to lead when they've had enough and they need a break and they need to do this other thing to regulate. Whereas, really, if schools are generally—it's about trying to get everyone doing the same thing, ultimately. Without both the funding and the attitude change, then I think that's really hard.

**The CHAIR:** I will interrupt because I need to let one of the other Committee members ask a question. Bear with us.

**The Hon. SARAH MITCHELL:** Thank you both for those insights. They'll be very useful for us in our deliberation. We appreciate that lived experience as parents. My question is to Ms Fava. In your submission—I love submissions that have recommendations; they are very handy for committees and politicians to consider—one of the things you talk about is the long waitlist for assessments. This has come up in other submissions and in other evidence we've heard today. You call out the potential of maybe using school counsellors in the assessment process, particularly for students who may have autism or ADHD et cetera. Can you talk us through why you think the school counsellor would be best placed to do that, and any barriers you see to that becoming a reality?

**GRACE FAVA:** Absolutely. Right now there are huge waitlists across the community. I work in south-west Sydney, and most of the community that I serve is south-west Sydney—the most vulnerable that we have. You've got a two-year waitlist at Campbelltown Hospital. You've got about the same at Fairfield and at Liverpool for access to getting free assessment. Our organisation does—I think it's \$1,700 for an assessment. However, everywhere else you're looking at the \$3,000, \$3,500 mark. It is out of reach for most families to get that funding and put it together. It's terrible.

School counsellors are usually one of the first ones to earmark there's something going on here or they have discussions with the teachers. They're the ones that do the psychometric assessments every two years, which are mandatory in a support unit. Why can't we have them trained to do ADOS as well? Why can't we have them trained to do all these other assessments as well? They are there, actually on the ground. They can see. No, there

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are not enough psychologists. We just don't have enough allied health therapists across the board, full stop. We can put the cart before the horse and get more university students into that—get more supervision, because that's what's preventing more coming through university. And then we can have a much better system where nobody needs to wait or fall under the radar for an assessment.

We've got kids waiting two, three years. We've got multiple children. When my kids were diagnosed, it was unusual to have more than one child in a family with an autism diagnosis. Today, it is quite common. One of the things I do suggest now to families is get a genetic test done, because that way we can see what the underlying causes are. Because with our cohort of refugees, we have a lot of genetic issues that do have autism as one of the traits. In the community, again, you've got long waitlists and it's very expensive and out of reach for most of the people who we serve. Having it in the schools, it is on the spot. You can offer that collaboration with the family because families drop their kids off to school. It is ideal. It should be able to happen relatively soon, as opposed to—like, I know it is three months before we can get the next person on the appointment with our work. Let's make it in schools. Let's make it happen. Every school counsellor is now a psychologist. They should be able to do those tests.

**The CHAIR:** We are, unfortunately, out of time. Thank you so much for coming to—

**GRACE FAVA:** Am I able to just bring up one quick point? I'm so sorry.

**The CHAIR:** Yes, go ahead.

**GRACE FAVA:** The lovely ladies here spoke about suspensions. Unfortunately, suspensions are used so that schools can get more evidence on their access requests in order to get children into support units. We have a situation at the moment: not enough support units, not enough SSPs. As soon as they're built, they're filled. Therefore, the hundreds of kids who have their access requests sent into panel—it's based on evidence. It's based on need, and the one who has the most suspension generally wins that one spot. We need to address that. Getting rid of Local Schools, Local Decisions and having the Government say, "No, every school is going to have support units," will help fix that as well.

Early intervention—there have not been any new early intervention classes formed in the last 20 years. We have got about half a dozen early intervention units to serve thousands of kids, and you don't get in. It's very difficult. You've got like six kids who can get in twice a day, a few times a week, or you can have resource support, but we have hundreds who do not get accepted into the public early intervention system. They rely heavily on preschool. Preschools are suspending our kids. They are putting them on shorter days, so parents can't work. We need to fix that. We need to get around that. It would be really great if we could do that through this Committee, please.

**SARAH LANGSTON:** Because there are limits on time we will send on some more material we've put together. But something that I would really like to say is that the greatest solution recommendation from the ANPA is that there should be, absolutely, without a doubt and in line with the UNCRPD, disabled oversight of the education system as it applies to disabled children. We need a disability oversight council that is not made up of experts, clinicians, providers and carers, but is made up of disabled people—in particular, people with disabilities who have psychosocial disabilities and are neurodivergent, because we are the key group who are excluded from education in New South Wales. Until we have disabled people guiding the decisions being made for disabled people in New South Wales schools, we will not actually see, I think, significant progress towards disability justice in New South Wales schools.

And the last thing which we need to do—all of the discussions had here are kind of moot without this—is funding. We have to fund public education. The ANPA, we're very pro-union. We stand with the AEU and we stand with the NSW Teachers Federation in demanding that public schools are funded above the level of the SRS. Until we do that, we can't implement any change. And when we try, we end up with situations like what has happened with the disability standards for education mandated training rollout, where we have a new policy supposed to create access and equity but all that it does, because it was unfunded, is drive conflict between the union and families. In New South Wales, if you don't have the union, you have nothing. We need to address that. We need to address the funding issues and we need to let people with disability lead.

**The CHAIR:** That's a great note to end on. I'm sorry that we don't have more hours to chat because I think we could use them but, unfortunately, we're running late. Thank you very much for your collective time today. To the extent that there are follow-up questions, the Committee secretariat will be in touch with you about that. If there is anything that you just want to give us, feel free to send it in as well. That concludes our session for now. We'll be back at 2.00 p.m.

**(The witnesses withdrew.)**

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**(Luncheon adjournment)**

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**Mr JULIAN LAURENS**, Senior Policy Officer, People with Disability Australia, sworn and examined

**Ms JOANNE YATES**, Acting Deputy Chief Executive Officer, People with Disability Australia, affirmed and examined

**Ms CHARLOTTE SANGSTER**, Chief Executive Officer, Muscular Dystrophy NSW, affirmed and examined

**Ms LAURA HOWARD**, Senior Community Support Specialist, Muscular Dystrophy NSW, affirmed and examined

**The CHAIR:** We now welcome our next panel of witnesses. Thank you very much for coming along. Would you like to commence by making a short opening statement? We can start with Muscular Dystrophy NSW.

**CHARLOTTE SANGSTER:** Thank you, everybody. I would like to start by acknowledging the traditional custodians of the land, the Gadigal people, and pay my respects to Elders past, present and emerging, and extend those respects to all First Nations people joining us today. I also thank the Committee for the opportunity to appear today on behalf of Muscular Dystrophy NSW. My name is Charlotte Sangster and I've been the CEO of this organisation for seven years. With me today is my colleague Laura Howard, who is a senior community support specialist working closely with children and families at MDNSW.

We are honoured to shed light on the work of Muscular Dystrophy NSW in supporting children living with neuromuscular conditions and their families. Muscular dystrophy, for those who don't know, is an umbrella term that refers to a group of rare, complex genetic conditions, with a wider group of 75 conditions sitting under that umbrella. These are collectively referred to as neuromuscular conditions, and these commonly cause progressive deterioration of muscle strength and function, resulting in profound physical disability in a lot of cases.

Our organisation has over 65 years experience supporting over 13,000 individuals and their families in New South Wales. At MDNSW, our mission is to empower, connect and support people with neuromuscular conditions and be an effective advocate for our community. We achieve this by providing information and support coordination, running community events and peer support groups that bring people together to share, learn and support each other. We also have a strong commitment to research into neuromuscular conditions.

Central to these efforts is the provision of children's camps and capacity-building retreats for young adults, which serve as a core component of our service offering. These programs are tailored specifically for those living with neuromuscular conditions, particularly those who rely on a power wheelchair for mobility. With anywhere from 20 to 40 children attending each camp, they provide a conducive environment to gain independent living skills and have experiences in a connected, safe and supportive environment. Unfortunately, mainstream school camps remain inaccessible to many children due to their specialised support needs, leaving them out of these activities or completely forcing them to sit on the sideline and watch their classmates as they participate. This further underscores the significance of our inclusive initiatives for children.

I would like to highlight to the Committee that there is an absence in New South Wales of suitable venues, which exacerbates the limitations and exclusion faced by children, hindering their access to equitable and essential development experiences. Moreover, one accessible venue that we access, Narrabeen sports and rec centre, imposes escalating costs and significant logistical complexities, which involve removing all motel accommodation furniture and bumping in hospital equipment that we can use to run these camps. This impedes our ability to provide vital services and has resulted in MDNSW being the only provider left delivering large-scale capacity-building camps for children with severe physical disabilities as a result of their degenerative muscle-wasting conditions.

There is a real need in New South Wales for a fit-for-purpose secular venue that is accessible to community organisations and mainstream schools, which responds to the needs of the community and the goals of the New South Wales Government. As we face increasing costs and logistical challenges, a fit-for-purpose facility would benefit all and significantly reduce overhead costs, not just for our organisation but for all organisations and education institutions working with children with high physical support needs. This will allow for increased provision of camps, sport and recreation programs that mainstream schools just do not have the capacity or the specialised disability knowledge to provide.

As we know, there are many intersecting factors impacting inclusion and equality for children living in New South Wales. It is a complex and nuanced issue which requires knowledge and expertise which are currently not within the broader community and mainstream services, so we would like to support bringing these issues to your attention. The UN Convention on the Rights of Persons with Disabilities, article 30 part 5, states that parties should take appropriate measures "To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school

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system". MDNSW have witnessed firsthand the exclusion from these activities in mainstream schools, which leads to low self-esteem, mental health issues and bullying from school peers.

Considering these challenges, we believe that the New South Wales Government has a unique opportunity to lead by example in fostering inclusivity and support for children with disabilities, while supporting the New South Wales Government commitment to upholding the Disability Inclusion Act and the disability inclusion goals. My colleague Laura and I have collected examples of lived experience, as well as our own experience in running these programs, and are happy to provide you with examples during this inquiry. As the inquiry does unfold, I implore this Committee to recognise the urgency of this issue and champion the rights and wellbeing of children in New South Wales. Together, we would like to support New South Wales to lead a more inclusive and equitable education landscape for all. Thank you.

**The CHAIR:** Thank you. Would you like to make a short opening statement as well?

**JOANNE YATES:** I would, thank you, Chair. Thank you, too, for the opportunity to address the Committee today. I'm Joanne Yates, the interim deputy CEO, and with me is Julian Laurens, senior policy officer. We're here representing People with Disability Australia. Our organisation is funded, in part, to undertake individual and systemic advocacy, not only to assist people with disability to negotiate government services but, importantly, to recommend changes to institutional and systemic barriers that create and/or exacerbate the vulnerability of people living with disability. Our work is person centric. We uphold and promote the human rights of people with disability so they can enjoy a full, participatory life.

PWDA members are people with lived experience of disability, who often live with the consequences of denied support, choice and control over their own lives. Our submission to this inquiry highlights how this occurs within educational settings. Our submission addresses the Committee's terms of reference in broad terms, focusing on those issues that have a direct impact on our members. Approximately one-third of all matters our members seek individual advocacy about are matters relating to education. In the six months between July and December 2023, PWDA advocates oversaw 183 cases. That's the equivalent of seven a week just for education.

Our team of individual advocates support students with disability to exercise their right to access an inclusive and whole education within a New South Wales government primary or secondary public school. We begin by addressing the inquiry's final terms of reference and suggest that very little, if anything, has changed since the Committee's 2017 inquiry. We note that there are approximately 200,000 students with disability in the New South Wales education system—equivalent to 20 per cent of students in public education. We contend that the New South Wales education system is not inclusive, as segregated learning settings for students with disability still exist and practices, attitudes and structural barriers that restrict students with disability from full participation in learning environments stubbornly persist.

We recommend that segregated education settings must be phased out, and within 10 years. We often hear the argument that placing a student in a segregated learning environment, referred to as a school for special purpose or a support class, is about the exercise of choice: The continued existence of schools for special purpose and support classes in mainstream schools are part of a range of options to provide choice and cater for diverse needs, including for students with intellectual disability, mental health issues or autism, students with physical disability or sensory impairment, and students with learning difficulties or behaviour disorder. However, we contend that the active choice is made because there is little other.

Because students with disability are not fully integrated into mainstream classes, they are less likely to be with other students without disability. Being excised from the main school body or from the community itself leads to students and their parents unsupported and without collegiate connection. Neither the disabled nor the abled community experience each other. Segregation becomes a self-fulfilling need, and because fully inclusive, unsegregated schools do not exist, it is incredibly hard to imagine their reality. Segregation itself stifles and impedes the transition to inclusive education. It negates any opportunity for parents and students to envisage a fully integrated learning environment.

Education plays a critical role in shaping attitudes towards people with disability. Segregation also underpins the ongoing negative attitudes towards people with disability that predisposes them to lifelong disadvantage, poverty, abuse, neglect and exploitation so highlighted by the disability royal commission. Ableist attitudes that underpin the stubborn and immovable low expectations about the learning ability or interest of students with disability to learn further contribute to segregation's entrenchment. Restrictive practices are a substitute for proper early intervention and individual class support. PWDA calls for an end to all restrictive practices that deny students the experience of inclusive education.

We understand that the education system is under significant pressures. Teachers are leaving or not joining the profession and there is a paucity of available, well-trained learning support officers for the students who



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require them. This makes it harder for schools and teachers to respond appropriately to all students, let alone students requiring supported learning. Segregation and the use of restrictive practices, therefore, can seem to be a very simple solution, but neither upholds the dignity or the human rights of a student with disability. The diversion of public funds to private schools has rendered the public sector unable to meet demand so that even those schools, teachers and their principals who want to do the right thing are left unable to fund the necessary and legally entitled reasonable adjustments sought by the students and their parents. Nobody wins.

Private schools are exempt from the Anti-Discrimination Act and are therefore not required to take or attend to the needs of students with disability. We would like the public school system to be appropriately and properly funded to attract and retain the quality teachers all our students deserve and to help our wonderful State school system provide the programs and services that all students deserve. Education is an enabler of all other rights. Education provides the skills and knowledge for all people to participate fully in society and to exercise their autonomy. This same right should be afforded to students with disability. Thank you.

**The CHAIR:** Thank you very much. We hear a lot about reasonable adjustments for kids with disability. The discussion tends to focus on kids with intellectual disability when we're talking about adjustments, and also in the context of exams and assessments as opposed to the overall education environment. Could you give us some examples of the types of adjustments that kids with a physical disability might require and what an inclusive school environment looks like for someone with a physical disability?

**CHARLOTTE SANGSTER:** I can give you an example, if you like. This is a quote from a parent of a young boy who is in year 3: "The morning of George's first athletics carnival we received a panicked call from the deputy principal, asking us how George was going to get to the track. We had completed the necessary paperwork provided by the school, checking the box that George will be catching the bus with the other students. At no point prior to that day did they consider the fact that he was a power wheelchair user and failed to organise suitable transport for him. The deputy principal put it back on us to return to the school and then drive him to the track in our accessible car. Our response was 'We filled out the form like all the other students, so it's up to the school to organise suitable transport.'" I can give you another one, if you would like?

**The CHAIR:** Please.

**CHARLOTTE SANGSTER:** "As my son is in year 3"—this is around testing, though—"he participated in the NAPLAN tests. We received information very late that there were adjustments available for disabilities and that the school could ask for a scribe to help him, which would mean he had to take the tests in a separate room as not to disturb other students. The school incorrectly informed us that the technology was not available as an option for the year 3 tests, even though George had been using his iPad on occasions in class to type responses to questions, rather than providing written responses, which takes him longer to complete as he finds it tiring. Our preference is for George to participate with his peers in these tests, rather than to be excluded and have to take a test in another room by himself. Upon writing to the Department of Education to express our concerns due to the technology not being provided as an option, we discovered that the school was wrong. He could have used technology online or PDF format. It turned out that the school had actually just missed the deadline to apply for the alternative options, including the technology, and didn't want to admit this to us so they told us that a scribe was actually the only option available."

**The CHAIR:** Thank you.

**LAURA HOWARD:** In answer to your question, I would suggest there are a few different aspects. Obviously, one of the main features for a child with a physical disability is accessing the built environment, and that does mean all areas of the school. Sometimes there might be adjustments made to the classroom for them to access the classroom, but the way that they get into the hall is different, or they're in a different section, or they can't access the playground the way that the other kids can. It is about the spaces that are used by the children at the school being accessible to all of the children at the school. One of the challenges with that is that that will change, depending on the children at the school at the time. Given that disability is not a fixed state, it might mean that one year, they can access that way and next year, they can't. But, unfortunately, because of the structures with funding and the time that it takes to meet some of those needs, there can be huge delays and then exclusion as a result of that. But I would say built environment is something that's at least widely understood, if not carried out.

The thing that we're really passionate about is this idea that for a child, their main occupation is play: that interpersonal relationship development that happens through play and that exploration with their peers. That is something that can be very challenging to adapt. Often teachers and support staff might not have the skills or the time or the other resources necessary to do that, whether that be a physical recreation sense. Obviously, we do camps and so we make sure that all of our activities are tailored to children with the physical support requirements that the kids that come have, but usually they talk about when they've been at school and they've just had to watch the other kids do it, or they had to get someone else to just do it for them because they couldn't. Whereas there is

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usually a way to adapt it; it just takes a bit more time or someone's expertise. I think the other key is the additional support required, whether that be a trained support staff. That system does exist in places, but there's often issues in that the training, or the expertise of that person, is not really meeting the need. Either they're not there or they can't quite do it the way that would be ideal. That would be my response.

**The CHAIR:** Thank you. Did you have anything to add?

**JOANNE YATES:** No.

**The Hon. SARAH MITCHELL:** I have two questions for People with Disability Australia. Thank you, both of you, for coming and for your submissions and evidence. I wanted to ask about two of the recommendations specifically. The first is recommendation 1 around establishing a ministerial disability advisory council. We have had evidence from some other witnesses today about having a better voice for people with lived experience, for parents and for advocates. I guess I'm curious as to how you think a body like that could or should operate, and why you called that out as your first recommendation.

**JOANNE YATES:** We've called it out as our first recommendation—noting that sometimes it's governance arrangements that allow a voice to be heard—as one of the most important parts of the work that we do. We're an organisation that provides both individual and systemic advocacy, so for us it kind of makes perfect sense for that voice to be leveraged. There are many ways, of course, that government can receive the information and advice that it wishes to, but it just made sense to us to formalise that as a ministerial council so that the voice was directly heard by the person who's got the decision-making power, the budgetary levers and the administrative tools before them—to hear directly from people who have that lived experience.

**The Hon. SARAH MITCHELL:** Which Minister do you think would be best placed to have oversight? We're looking at educational settings today in this hearing, but we've had health come into it, we've had DCJ and obviously there's a Minister who's responsible for disability. How would you like to see that whole-of-government eye over an organisation or advocacy group such as that?

**JOANNE YATES:** Great question. There are many ways you could do it. One way might be to have an implementation board chaired by the education Minister—that would be its logical place—that is accessible to the community so the voice of the community comes and briefs all Ministers that have an administrative responsibility for the delivery of an education setting to a person with disability.

**The Hon. NATASHA MACLAREN-JONES:** Have you had any dealings with the Minister for Disability Inclusion or the Disability Council NSW, which reports directly to that Minister and does do some of this whole-of-government approach?

**JOANNE YATES:** It does do some of it, but that council provides advice to government on the implementation of the overarching Disability Strategy. It's not education specific. We do have members of our community on that committee.

**The Hon. NATASHA MACLAREN-JONES:** In relation to your recommendation, have you thought about whether or not it's better to look at expanding that council or the role of that and how it reports as an overarching body? Or are you suggesting that each Minister should set up their own advisory body directly to the Minister?

**JOANNE YATES:** Have I thought about it that deeply; and, goodness me, if I had.

**The Hon. SARAH MITCHELL:** That's not an easy question.

**The Hon. NATASHA MACLAREN-JONES:** I suppose it's looking at the existing council. Should that potentially review its operation and expand its role to be more of a whole-of-government approach, or is it better to have standalone advisory councils that report directly to Ministers, whether it's Health or Education?

**JOANNE YATES:** When we were drafting our recommendation, I thought we were thinking just specifically for the Education portfolio with that extension to the possibility of an advisory or implementation board. Disability Council NSW does have a very broad remit and I suppose you could provide a good way of communication between those two fora—that is, you would have some members that sit on both parts—so that there is an overarching concern with the implementation and the redevelopment of the strategy, but for an education-specific setting, to deal with that incredible requirement of a really large organisation. There are, what, a million students just in a public setting? You would want to have something that was specific to an education environment.

**The Hon. SARAH MITCHELL:** In recommendation 9 you talk about improved communication and deeper consultation between schools and families of children with disability. I'd be interested in both



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organisations' views on this. Where do you think some of the shortfalls are in terms of that communication process, based on your experiences? How do you think they could be improved?

**JOANNE YATES:** One of the main topics of conversation that our individual advocacy team reports on is the school's inability—or refusal, sometimes—to communicate well with parents who raise concerns about their children's experience of either not receiving a reasonable adjustment or receiving an inappropriate response. It's oftentimes just they're short of time, they're short of resources, they're untrained—all of those issues come into play in malcommunication. Oftentimes, it's just the willingness to find somebody who's just prepared to meet with the student and the parent at the same time. It's a very broad description but that's often what it comes down to. You have might have some finer comments to make about that.

**JULIAN LAURENS:** The general view for many of our clients is that they are not listened to, there's a poor understanding, and there's not clarity around who is to do what, what the roles are and what the approaches involved are. I think it's important that that's not across the board, and we're very keen to ensure that there are many great examples of schools doing it really well—in fact, I spoke to advocates the other day who said just that. But that's a great example because, in that instance, even though it ended up having a really good resolution, it took one person in that organisation to actually I guess almost get the initiative to take it to the next step and say, "Look, no, we are going to block an hour of time off just for this family to work out what the issue is that has been bugging around."

We see quite a lot of that and it's not a malicious thing going on here at all. I think the genuine desire among many schools is to assist people. I think a number of families and a number of students have very specific needs, and they're not always able to be understood or accommodated. It's as simple as that. The idea of having a renewed effort placed into schools to support them to develop those communication channels, where they can identify them, would be a really beneficial, low-cost, high-win initiative, I would suggest.

**The Hon. SARAH MITCHELL:** We've certainly heard from other witnesses, even this morning, about a lack of consistency in terms of what that communication channel can look like and it depending very much on individual staff. It's not unheard of that we've had that presented to us today. You don't have to, but is there anything from Muscular Dystrophy in relation to that sort of feedback?

**LAURA HOWARD:** We often find we hear from the community about it taking substantial effort on the family's part to get that communication across, to get the meeting. That means that in situations where the parents have either the time or the skills to navigate that they will push—but it's exhausting and they shouldn't have to do it—and get what their child needs. In some situations, it means that they're not aware, because they asked and the school or the teacher said no, that was it, and the child missed out. There are instances where it feels like the school or the teacher has a mindset that they're the experts and they don't need the input from the family, but that isn't all cases. It's often that it's a time or resource issue that they can't provide the thing that the family is asking for—they don't have access to that resource or the funding to meet that need. So there isn't any, as you said, maliciousness in it. It's just that they don't know how to help.

Sometimes too, particularly in that the group of conditions that our community have are rare, the likelihood that the teachers or the school understands those conditions well and how they might manifest or impact the child isn't likely. We have had some great experiences where a family and the school have been in touch with us and we've been able to go out and run some education sessions with both the staff and the teachers, and also sometimes with an assembly of the student's peers, or potential peers if they're moving into the school. We're really lucky to be able to do that within the services that we offer, but that's not a common thing and it's not something that people know to ask for or that all schools would let us do. It very much takes all parties being willing and available. So it can work but it does require either a lot of effort on a couple of people's parts or everyone being on the same page.

**The Hon. SARAH MITCHELL:** And the knowledge that organisations like yours exist.

**LAURA HOWARD:** Yes, that's right. This is our whole thing: We can't offer any expertise on cerebral palsy but if you ask us about neuromuscular, sure, happy to.

**JOANNE YATES:** But I think the common thread is that it really does put the onus of responsibility back on the student and their family to get a resolution to the issues that they're confronting. If they know about our advocacy service and they can call, then we can also provide that expert understanding of the system—which itself is not easy to navigate—and navigate on their behalf. But it's often left up to people to find their own resolution to often really complex questions.

**LAURA HOWARD:** And the emotional cost of that as well.

**JOANNE YATES:** It's exhausting.

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**LAURA HOWARD:** Particularly, a lot of people with disability are also trying to navigate the NDIS, which has its own emotional cost, and so people are exhausted.

**The CHAIR:** There are a lot of submissions talking about ableism. I think when we talk about ableism sometimes people can feel like it's a personal blame on a particular individual as opposed to it often being a lack of understanding, empathy or appreciation. It's not a malicious, deliberate exclusion. And then we also have systemic types of ableism. Can you give us some examples of the way in which ableism really plays out in the school context, particularly with this lack of provision of an inclusive environment?

**LAURA HOWARD:** I think we often get the feedback that kids have this mindset that they're an inconvenience or they're an added burden on the school. And they're aware of it with their families—not that I think that's an intentional thing, but that they just know how much time it takes. I was speaking with a colleague this morning who shared a story from a mother in our community who had had a phone call with the school. They attended a fair day. The parents were there, came and dropped him off and they couldn't find the accessible parking. They spent about half an hour finding somewhere to park and then tried to speak to the administrator of the school about it after it and she said, "You should have asked us about the accessible parking." The parents' response was that the email that had all the information had information about parking. So someone had done the research about where you park your car but just hadn't factored in that not everyone is going to be able to park in that and someone might need this other—so sometimes it's just that it's sort of missed.

But then, when challenged, the administrator had come back to the parent and said, "Oh well, I think the ground wasn't that flat. Maybe it wasn't really a suitable place for your son to attend anyway", suggesting that they should have just stayed home. Sometimes people are quite defensive about that being asked or about being challenged on an access need and then can unfortunately be rude in their response to that. But, yes, lots of examples of the kids feeling like the work required to include them is too hard. That would be the real takeaway for us. For them to have taken that away—that their access requirement is more than is reasonable—is huge. However that has come from, it shouldn't be.

**The CHAIR:** Somehow you're a burden.

**LAURA HOWARD:** Yes.

**CHARLOTTE SANGSTER:** I can give you a quote, if you like, that we got. This is another one from a parent. It's slightly related, but hopefully it will make sense to you. "During an excursion to Luna Park, despite clear instructions and prior arrangements for my son's engagement, a learning support officer failed to follow through. Instead of facilitating my son's participation in activities tailored to his abilities, she neglected his needs and focused on making his wheelchair a place to hang other children's hats and bags from his wheelchair. This disregarded my son's need for inclusion and enjoyment of the outing. It was disheartening, to say the least." I think that's probably an example of very inappropriate conduct.

**The CHAIR:** Yes. Mr Laurens, do you have any examples?

**JULIAN LAURENS:** I was just going to say that ableism can be quite complex. I think about it both in terms of substance and expectations that are placed on people—all people, all of the time. The disability royal commission was quite strong about drawing that aspect out. An example is the assumptions about what somebody can and cannot do, what they will or will not like and expectations as well about what they can and cannot achieve. I pick up the point you said about the structural element of that, or the systemic element. It's actually quite insidious. I was just thinking about that earlier. Ableism can creep into—in both those dimensions—so many aspects of an education system: from the assessments we set, from the playgrounds we design, from the seats we have, from the size of the doorways, from the writing—it literally can creep in anywhere.

Again, there are so many people out there who are doing a wonderful job in calling this stuff out and teachers who are challenging their own beliefs and assumptions. I will suggest that there is a really big need for teachers within New South Wales to become much more reflective practitioners. That's what all this comes back down to, and that's something that is quite well known within the literature—about the need for self-reflective practitioners. It's a huge aspect of what's been happening over in Canada, particularly New Brunswick, and subsequently in Ireland as well, where they've introduced their inclusive education systems to tackle exactly what we're just talking about right now.

**The CHAIR:** So how have they done it? Pointing out ableism is one thing, but how do we actually change it and turn it around?

**JULIAN LAURENS:** Look, we could spend hours talking about that, about how they've done that. But I will say, again, a big thing they've come up with is developing a reflective practitioner process within teachers

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to challenge those assumptions, at their level at least. And hopefully that pervades and hopefully in other places you can do that as well. It's checking as you go, for everybody.

**The CHAIR:** You also say in your submission that SLSOs don't have, necessarily, particular qualifications. Can you talk more about that and whether there is a role for SLSOs to really educate and try and act against some of that ableism within schools?

**JOANNE YATES:** Again, Chair, I wouldn't put the requirement to educate the whole of community on the shoulders of those that are assisting some of our most vulnerable. We need a systems response to it. That's part of the reason why we call for an end to segregation: so that the experiences of students with disability are within a whole-of-education setting, so that students without disability also get exposure to colleagues that do. It would be a bit like suggesting that in a hospital orderlies have the responsibility for changing the behaviour of professors of surgery. There has to be change at the top and an understanding that students with disability deserve to be seen and heard and to experience a full education. Those that assist them in their daily experience aren't necessarily those that are required to emancipate the whole of the education system.

**The CHAIR:** Can you speak, though, to that point about SLSOs? I'm sure it was one of your recommendations.

**JULIAN LAURENS:** In recommendation 8 we talk about support in the classroom. Can I just say, Chair, I just want to make a point that I don't consider SLSOs are uneducated. There is actually a range of backgrounds. Many of them are hired—they're just doing it as a second job. But there is a minimum standard required now for many SLSOs. I think what we were suggesting in that recommendation talking about that is that perhaps the existing training is not sufficient to encompass a very large range of different eventualities, particularly when it comes to things like behaviour management. There's an extremely large range of disability out there, and we still learn things about it all the time. So I think it's more that, number one—and I don't want to detract from the great work many of them already do—we need more of them. We think there should be further ongoing training for them as new trends develop, as new knowledges come about, but just as part of their professional development to ensure that they want to stay in the role as well. And they may well go on to become a teacher themselves later on; it's a wonderful pathway. So we're not saying they're uneducated, and we are saying we need more of them and to train them well.

**The CHAIR:** I guess where I'm coming from is often when we're changing attitudes we talk about having to change the attitude at the top. But the most effective training in areas where people might be initially resistant is by leaving behind a change leader or a change maker who works alongside and is embedded. My question was more about whether SLSOs could be those people if they get better training on disability. But maybe they've got plenty to do as it is.

**JULIAN LAURENS:** Obviously very generally, why not explore all options? Exactly right. Why not see how far we can go with something like that? They need more funding and they need more professionalism—absolutely. I will acknowledge that coming from the top there has been efforts from the current Government to lead that change. Again, we don't want to detract from that either, and you are right.

**The Hon. NATASHA MACLAREN-JONES:** I've just got a couple of questions. One is around reasonable adjustments. We've heard from a number of witnesses and submissions that quite often these adjustments are not being made. I am interested to hear what your clients have been saying to you—maybe some specific examples where adjustments are not being accommodated but also the reasons behind that. Is it resourcing? Is it lack of understanding? Is it deliberate? I'm just interested to know the reasons behind that.

**JOANNE YATES:** There would be instances of all of that. We haven't got a set of case studies that we can provide you with narrative about that at the moment, but very happy to supply them post this meeting.

**The Hon. NATASHA MACLAREN-JONES:** That would be good.

**CHARLOTTE SANGSTER:** I've got a finding from a parent that I can share. Again, it's quoting from them, so hopefully it's relevant for you. This is from an occupational therapist, actually, and then I'll go on to the parent's quote. Education in schools is essential to ensure that the assumption is always inclusion, and not a question about whether or not a kid wants to participate because of their disability.

Then, from one of our parents, we have, "Participation in school camps is always extremely difficult. During the senior years at upper primary, the camp becomes about providing access to physical challenges as a way of providing access to mental growth for the kids. An aspect of life for the mainstream student who plays a load of computer games is not presented with, which is the challenge for attending camp. For a student with physical disabilities, this can be very difficult. I'm seriously not sure how it can be changed without changing the

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entire focus of the camps. Utilising NDIS funding for my son's personal carer and equipment and reporting requirements is particularly something that they're using."

So they're using their NDIS funds to access these instead of it going through the Department of Education. They go on, "This leaves less room in our budgets for other necessary requirements. Dealing with the logistics of securing adequate support services and managing NDIS funding has been emotionally draining. I feel that this should be the school's responsibility, but I have had to use my NDIS funding, otherwise my son would have just missed out."

**The Hon. NATASHA MACLAREN-JONES:** My other question is in relation to adjustments that are made. Is there a requirement that parents are advised or part of that decision-making if changes are going to be made?

**CHARLOTTE SANGSTER:** Yes, there is, and I think that puts a lot of pressure on the parents in their already complex and busy lives. Certainly I can have a look through here to find some quotes around that, but I know there is some feedback in here that, essentially, working with the schools has become almost a second job.

**The Hon. NATASHA MACLAREN-JONES:** That moves to your submission, Ms Yates, about the individualised education plans. You've actually said that some of the statistics show that close to 20 per cent of students with disability don't have a plan in place. Obviously it is a requirement to have one. Why is it that there isn't one for these young people?

**JULIAN LAURENS:** I just want to pick up again on the reasonable adjustments as well. One of the things that came through very strongly from our members and our clients about individual advocacy was that quite often they would go to the school to talk about reasonable adjustments and the school was unable to help them to work out what was actually available, what would be the best thing to pick or what actually works in this environment. What came through on a number of occasions was that they, the parents, were then having to go away and do their own homework and find out all about these reasonable adjustments and about what would work in that environment et cetera and then go back to the school and then see what the school says. They were really upset about this.

So the school was not seen to be a great source of information and help about what reasonable adjustments should actually be put in place, which is a separate issue than not having them available at all, which is another barrier got put in place. So the school was meeting its obligations but, in reality, again, there was a lack of understanding and knowledge. You mentioned before about one person might've been in a job and they've kept track of all these things then lost sight of it or they'd moved on. I just wanted to mention that on the back of Charlotte. Thank you. In terms of, sorry—

**The Hon. NATASHA MACLAREN-JONES:** It's the individualised education.

**JULIAN LAURENS:** Yes. The short answer is we don't know. We've seen incomplete behaviour support plans. Some of the feelings about why this is the case—some of the anecdotal evidence as well as some of the actual evidence—is a lack of understanding of how to put them together and a lack of a centralised person in the school to have oversight of those. They're the kind of issues we're talking about. So a new teacher being told to do this and not actually having the training to do it. I've actually looked at those things. They're difficult to do. You have to actually know the student. You need to know their learning styles and requirements. Giving them to a teacher who's got no background and understanding in disability within a school environment, where they're supportive but have no knowledge, means that this plan gets missed a little bit. Simple as that, I think, at one level.

**The Hon. NATASHA MACLAREN-JONES:** In relation to the plans, does it need to be reported back to the Department of Education to say, "These are the students that don't have plans in place," or, "The plans are no longer being followed"? Is there a centralising of the data and who's monitoring it?

**JULIAN LAURENS:** I would ask the department about that. We only know about what our members tell us about their experience of a particular kind of issue. Again, there are some great plans out there, and then we see ones that come through and people are going, "This is terrible. It tells us nothing." I think in those cases they are literally an example of where people have not had the appropriate training and support to develop these as part of their job. I certainly didn't do them at university.

**The Hon. ANTHONY D'ADAM:** How realistic is it? On the statistics that have been provided, one in five—maybe it's one in four—kids have a disability. They would need to have an individual learning plan. With the extent of our teacher shortage and the increasing pressure on teachers in terms of time, this kind of load is quite a substantial expectation that's being pushed onto teachers. It's not really realistic that we can actually meet that expectation. What do you say to that proposition?

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**JOANNE YATES:** I think there's probably some reasonable evidence in that assertion. We know the education system is really stretched. We know that individual teachers are really stressed. It could be that part of the absence of a plan is the inability for the school to be able to make the kind of adjustment that the student needs to engage fully in their schooling. You reach an impasse in being able to negotiate what your child needs in a school setting. That is part of the reason as well.

**CHARLOTTE SANGSTER:** Can I add to that in terms of what you were mentioning earlier about the support from parents? I have an example here, which I will quote, "The biggest challenge we've faced has been gaining support from moving from a primary school to a high school setting. Gaining access to the high school to evaluate the changes that needed to occur, for instance, was one of these challenges. It took a substantial amount of time and effort on my part to access the school to even let them know what my son needed." So even when the families are willing to support, they're struggling to get access to see what the options are.

**LAURA HOWARD:** I would say to the point about it being realistic is that it can be a bit of a slippery slope, because it can then be one of those things that becomes too hard or not worth it. That does come to that idea of ableism, and giving children with disabilities an equitable access to education to their peers should be just as important. That's not to minimise the struggle that teachers are under, but then there needs to be another solution. We can't just say, "We don't have the resources," or, "It's too hard."

**The Hon. ANTHONY D'ADAM:** PWDA raised the issue around behaviour management systems. I wanted to pose a similar question around the expectations that are being placed on teachers. The submission is opposed to the use of behaviour cards, which I know is quite a common system in mainstream schools. What's the alternative? The other question I would have is behaviour is a big challenge for teachers trying to keep an orderly class. If you don't have some system for managing behaviour then everyone's education is affected. How do we have an inclusive system for managing behaviour, particularly in situations where you might have kids who might have high-functioning autism? Other kids in the class won't necessarily recognise that there's a kid with a disability, and then the teacher has to manage that situation where you are having a different approach to the behaviour of one child and they then follow the pattern, obviously without the underlying issues that need to be considered.

**JOANNE YATES:** It comes down again to the issue of resourcing well-trained support officers and the availability of support officers and a school that wants to take on that culture of service delivery and inclusivity, rather than one that just finds a problem too hard. So it's a willingness to change that culture of, "We'll just pluck them out of the classroom and go and put them somewhere else until everybody calms down and then allow them to come back." If those students were adequately supported by really well-trained staff who knew how to de-escalate, who knew how to keep situations calm, you would find those outcomes really different, in our view.

**The Hon. ANTHONY D'ADAM:** Is there a preferred behaviour management system that you would support?

**JOANNE YATES:** I don't think there is one size that fits all. I think it's a matter of adaptation within a classroom setting. The context within which all of those things happen is really important. I think there are different models for different times and places, and all of those should be available really.

**JULIAN LAURENS:** I just wanted to add that it's actually a very complex area. We're talking about behaviour management here, and a number of these students are going to be on what we call behaviour support plans as well. It becomes another dimension we're talking about, which might be too much scope for us today, and we don't have enough time. Discipline is one thing, but restrictive practice as an actual denying and preventing of a student from participating in learning is completely something else and different altogether. I think everybody would agree that there needs to be some structure and discipline—and I use that term quite generally—within a classroom environment, and teachers should be supported in doing that. With these children who have what we call "behaviours of concern"—it's not a nice term, but the DAC did say we could use it—there are particular children, for example, and they do have particular needs. I don't think they are atypical.

What we are finding, and we'll anecdotally say—well, actually we won't anecdotally say it because the Human Rights Commission has picked up on it—is that a number of children with autism who would otherwise be in classrooms have been removed from these classrooms and now put back into what we call "segregated settings" because this idea of behaviour management is just too much for some people. Absolutely, but simply putting a child back into a secluded environment is not the answer here. We are seeing that with children with autism across the board, which is quite alarming. There is no easy answer to what you are saying in that question. It is recognised as an issue. I think it goes back to looking at what does that teacher need and what does that school actually then need to ensure that we do have an inclusive classroom that all students are able to participate in.



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It could be as simple as that student who is showing a behaviour doesn't actually want to be in that classroom, which is fine as well. They might want to learn outside. We need to ensure that the actual school evolves around the student, not the other way around. I think it happens with behaviour management quite a lot and veers into restrictive practices, which is something we are concerned about.

**The Hon. ANTHONY D'ADAM:** This was one of the key issues around the change to the behaviour policy that was introduced and then withdrawn. We are here to make recommendations. We want to have some concrete proposition to put. If we can't support the existing framework, then we need to be able to identify what should be put in place, and part of the pushback on the change to the behaviour policy was that there was no real answer in terms of what to put in place. Teachers weren't given the tools they need to be able to respond to those situations in a sensitive way. Do you have any further contribution?

**JULIAN LAURENS:** My only suggestion would be that a further deep inquiry in this area would actually be quite warranted. It's a very specific issue and I think it touches on other things. But I think PWDA really does feel for the teachers involved here, and the students. These can be incredibly stressful situations. It's not just about money either sometimes. We need to get that mix right, and what's going on in the classroom. That's potentially the issue: We are not always getting that mix right about training, about structures, about the appropriate methods for supporting a particular kind of behaviour. I do hear you; it's a difficult one.

**The Hon. ANTHONY D'ADAM:** In order to move away from the status quo, we need to know where we are going, I suppose is the point that I'm trying to make.

**JULIAN LAURENS:** I'd like to know more from teachers in a very structured, almost formal way about what it is exactly they would be needing from the classrooms, as well as the families of children involved with behaviours of concern—a really clear understanding of what's going on and what the teachers need.

**The CHAIR:** Unfortunately we are over time, so that will conclude our session for today. Thank you very much. The Committee secretariat will be in touch in relation to questions taken on notice and supplementary questions.

**(The witnesses withdrew.)**

**(Short adjournment)**

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**Mr CHRIS EDWARDS**, Director, Government Relations, Advocacy, NDIS and Aged Care, Vision Australia, sworn and examined

**Ms CATHERINE MILLER**, Policy Officer, Deaf Australia, affirmed and examined through interpreter

**Ms SHIRLEY LIU**, Acting Chief Executive Officer, Deaf Australia, affirmed and examined through interpreter

**Mr BRENT PHILLIPS**, Chief Impact Officer, Deaf Connect, affirmed and examined through interpreter

**Ms MELISSA MARTIN**, Auslan Interpreter, affirmed

**The CHAIR:** Thank you very much to our next panel of witnesses for appearing today. I'd like to invite each organisation to make a short opening statement if they wish. I will start with you, Mr Edwards.

**CHRIS EDWARDS:** I'd like to acknowledge the traditional owners of the lands that we're appearing on today and pay our respects to those past, present and emerging. Vision Australia is the largest national provider of services to people of blind and low vision across Australia. Last financial year we provided services to over 37,000 clients, and 36,000 of those hours were to children and young people. As I said, I am the director of government relations and advocacy, and I'm totally blind and rely 100 per cent on my compensatory skills, some assistive technology and my seeing eye dog, Eva, who's below me. Much of the skills that I use today to be able to do the job that I do were learned—and the foundations—when I was at school. We know that, for children, an inclusive and accessible education experience is critical for when they are adults to be active participants in the economy and in the community. We know this by 75 per cent of people that have completed tertiary studies encouragingly are employed whereas only 24 per cent of our general working population are employed full time.

As you would have read in our submission, a common theme when we are thinking around accessible and inclusive education is a lack of consistency in the adjustments that are being applied and offered to students. There tends to be also a significant difference across schools and educators despite them being governed by the same legislation and standards. The support that we see, or the experience, tends to focus around three things: the school that the student attends, the teacher that the student is allocated to and the extent that the parents are effectively able to advocate for those students.

In our submission, we supported many of the recommendations that were raised in the royal commission, and we also recommend three things: the establishment of an independent enforcement mechanism for reasonable adjustments so that could be monitored; the treatment that specialist teachers for vision and braille is an essential component of the supports for kids who are blind and low vision; and the implementation of a formal process that will better link service providers and the education system to be able to work more effectively together. In conclusion, we are seeking an accessible and inclusive education system that provides consistent adjustments to best prepare our children into adults that can live effective lives that contribute to the community and be able to work in the job that they choose.

**The CHAIR:** I will now ask Deaf Australia if they would like to make a short opening statement.

**SHIRLEY LIU:** First, I would like to acknowledge the traditional owners of the land that we are meeting on today, the Gadigal people. I'd like to pay my respects to elders, past, present and those joining us today. We would also like to take the opportunity to acknowledge the deaf members of our community who have preserved and continued our language. Those who came before us that advocated for language and equality along with access, they are leading the community now and have done for many years.

Deaf Australia is the peak national advocacy organisation across Australia for people that are deaf and hard of hearing, in particular those who use Auslan as their language of choice. I would like to thank you for the opportunity to come and present today. Catherine and I, along with other deaf people, are the experts in our community. I was the president of the World Federation of the Deaf Youth Section. I come from a migrant family. They can all hear, and I went to a special school in Sydney. Catherine is a qualified teacher of the deaf based in Victoria. Catherine is also from a deaf family and went to a mainstream school. So between us we have quite a rich experience and perspective.

Deaf children and adults are in quite a unique place in the world. We are seen as having a disability but we feel like we are not. We feel like we sit just outside the disability community but within the CALD community, culturally and linguistically diverse. We have our own language, Auslan, we have our own culture and traditions, and we value our community and our shared history. Yet society limits us simply because we cannot hear. Deaf Australia has been working tirelessly to identify issues and to work our way around those issues, considering Auslan is a key part of our everyday life and it's how we interact with society. Deaf Australia is part of the World Federation of the Deaf and we follow the UN level of advocacy. We also follow the CRPD, the Convention on



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the Rights of Persons with Disabilities. With these things in mind, we follow the same philosophy of encouraging language and access, and in Australia that means Auslan.

There are many key issues we see in our society today but I'll take you through just a few. Mainstream schools do not provide bilingual opportunity. The research shows that they should have equal access to language and mainstream does not allow the opportunity for a student to be able to feel like they are one with community. It doesn't allow them to feel like they're in a safe space and able to learn on par with their other peers. Assistive technology such as a cochlear implant or a hearing aid is just a tool. It is not a cure, and it should be viewed simply as a tool.

In mainstream schools we see many deaf children who have experienced language deprivation. Those that come from a hearing family, when they leave high school, we see that they have limited opportunities with their life and employment. They struggle to find work. They also start disconnecting with their family. They start experiencing mental health issues, and it can impact the rest of their life. Compared to someone who has been nurtured within a deaf school, evidence shows that they thrive after education, and the key difference there is language, having access to the Deaf community, having deaf role models, having other members of the community around you where you can learn and take in the culture and the experience. And you get that from a deaf teacher, a teacher of the deaf.

A third key issue that I wanted to raise today was that we see that many deaf teachers who study to become teachers and want to teach within the public system currently cannot in New South Wales. There are barriers to them registering with the Department of Education, and we think this is a key issue because this allows deaf children to be able to connect with somebody like them, to be able to be educated by someone like them. Other States don't have this barrier in place but New South Wales seems to be the one State in Australia barring deaf teachers from teaching in public schools.

I do have a few solutions to propose to allow the opportunity for deaf teachers to be employed by the Department of Education. Look at best practice in terms of a bilingual model and how it's so important for children to access both languages. Look at hubs to allow children to thrive and to have the same experience as their hearing peers. Encourage deaf schools, not only special schools but bilingual schools; they're so key to the development of students and staff where other students can learn how to sign as well. They can foster a community. They can learn to communicate with each other, provide support, peer role models. It's so key. I think the profound impact of that would be quite amazing.

I have plenty of research that would also back that up as well but also linked to the Deaf community. We are a community and I know that there's a push for special schools to be closed, and I think that's distracting from the actual serious issues that we need to discuss. Looking at those serious issues I think will reduce the concerns about special schools or segregated education. In closing, I'd just like to say thank you so much for your time.

**The CHAIR:** Mr Phillips, would you like to make a short opening statement?

**BRENT PHILLIPS:** I would and thank you for the opportunity. I would like to acknowledge the traditional owners of the land upon which we are all meeting today, and the Elders past, present and emerging. I also would like to acknowledge, like Shirley, deaf leaders who've advocated for our language, our culture and our community and got us to the stage where we are today in regard to access. I am Brent Phillips. I am deaf and I come from a deaf family. My journey has been a successful journey, and I got where I am because of my family, the exposure to language at an early age and a robust education system that I had access to. I am in the minority. There are many deaf people, children in particular, in New South Wales who constantly run into barriers for education, for growth and for learning in their first language, being Auslan.

I'll speak from Deaf Connect's perspective, and that is that we are a national service provider and social impact organisation. Our brand is new, but it has a rich history attached. Four deaf societies have merged over the last several years, one of those being the Deaf Society of New South Wales who were established in 1913—so 111 years of providing service in New South Wales. Deaf Connect provide a breadth of services, from early intervention to aged care and everything in between. Through our experience in early intervention, seeing people utilise our support and services and coming to us for those services really emphasises the point of a strong, robust educational system to ensure that deaf children are allowed the opportunity to thrive. With the correct infrastructure investment providing deaf children the opportunity to be exposed to Auslan from an early age, the more likely they are to enter the educational system with confidence, to feel that sense of identity and being able to communicate rather than having the educational system and having to try to fit into how they run.

Having access to Auslan leads to further educational opportunities and to being able to participate in society. As a service provider, we see a lot of people come to us who rely on our services and support because the education system failed them. They rely on us to provide them support in navigating life, to support them in

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getting the appropriate information access, employment support, interpreting support and one-on-one support, simply because they didn't have the foundational fundamental skills afforded to them to be successful in life. I would like to commend the New South Wales Parliament in opening this inquiry. I truly hope you understand that deafness isn't just a disability; we're more than that. Just like our friends from Deaf Australia said, we identify as being culturally and linguistically diverse. So if you think about ensuring deaf children are exposed to role models, that there is a spotlight shone on deaf people or Auslan-fluent teachers and support staff throughout the education system, then we're more likely to have confident, skilled children throughout their school years and beyond.

We acknowledge now there is a lot of political reform happening. There is a big shift happening in the disability sector, particularly with the disability royal commission, the NDIS Review and foundational support strategy. We are excited but cautious about what those changes may mean for us, to ensure that our cultural and linguistic needs are taken into consideration. At the end of the day, it is about deaf children getting access to education in their first language, being delivered by people who are skilled and fluent in Auslan, and understanding the cultural and linguistic needs of deaf children.

There are some best practice bilingual schools dotted throughout Australia, but they are very few and far between. There simply are not enough. There is one example in Queensland—Toowong State School—where they educate their students in a bilingual model. They have teachers who use Auslan. Regardless of whether the students are hearing or deaf, they use Auslan. We have seen families move from States to Brisbane to get education for their children in that form, which shouldn't happen. Families should have choices local to them, particularly in New South Wales. I encourage you to think long and hard about the value of bilingual education systems and embracing both Auslan and English throughout the New South Wales area. I look forward to furthering this conversation with yourselves and to the outcome of this inquiry.

**The CHAIR:** Thank you so much. I think it has come through loud and clear that when we are talking about people from the Deaf community, we are talking about a culturally and linguistically diverse community, and I think it is really fascinating to hear what you have to say about bilingual schools. It sounds fantastic. Is there an obstacle in terms of the number of Auslan interpreters and Auslan teachers that we have out there, and what can we do to improve the number of Auslan teachers coming through the system?

**CATHERINE MILLER:** I'm happy to answer that question. Just to clarify first—to make sure I truly understand your question, if I may—when we talk about Auslan teachers, are we talking about teachers who teach Auslan, or are we talking about teachers of the deaf who teach subjects using Auslan?

**The CHAIR:** That is a very good question. I was meaning teachers of Auslan, but I guess it is both if we are to have properly bilingual schools.

**CATHERINE MILLER:** Yes, they have very different roles. For example, I personally am a teacher of the deaf, as my colleague Shirley stated, but I don't teach Auslan. That requires a separate degree. To be a very effective Auslan teacher you need very specific qualifications in that area. To answer your question, I could answer it in two ways, effectively. To be a teacher of the deaf—I am not too sure about the New South Wales context; you may be able to support me with this answer—in Victoria we have a scholarship program for teachers who would like to become teachers of the deaf. At the moment we have roughly 12 students who are undertaking that course this year. It is a very small cohort. It is absolutely not enough. We need to encourage more people to become teachers of the deaf. The how is the big question and I, unfortunately, don't have an answer for that.

Auslan is different because you're teaching the language. We're not teaching English through the use of Auslan, as an example. We also need to consider that Auslan teachers should not be seen as providing inclusive education, because it is so very different. It is not about the deaf child. Teaching Auslan is about the wider class. It's about the mainstream community learning Auslan and that, within itself, is simply not enough. We need so much more than that.

**BRENT PHILLIPS:** If I could add to that as well—just a quick aside in relation to the teaching of Auslan in schools. Last year the New South Wales Government launched Auslan as a curriculum—so, to teach it in classes—which is just fantastic. There was no thought provided to the workforce or investing in the workforce, so we do have a problem where there are schools who want to teach Auslan to hearing students, but there are no teachers to teach the language. So that's a whole other separate conversation. We do have a sufficient shortage of skilled Auslan workforce in the form of teachers, interpreters, translators and support workers; there's just simply not enough of any of them. I do encourage the New South Wales Parliament to consider investing in a long-term approach to Auslan from all aspects, not just in the schooling environment, because it all ties into employment pathways, education, interpreting, mental health support, and the list goes on.

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We need a holistic approach to ensure safeguarding the future of Auslan so that we do have a pipeline of skilled Auslan workforce coming through. One final comment about interpreting: Quite often people think an interpreter in the classroom equates to access and accessibility, but it doesn't. We often see new Auslan interpreter graduates enter the school system when it should be the most professional and the most skilled interpreters, with 20 or 30 years of experience, entering the classroom and interpreting for our children, not a six-month graduate who enters the classroom. It should not be the case. It is a serious concern of ours. Again, interpreting is not the solution to that. It is to create an environment where conversations can be had in both Auslan and English with ease. That's the ideal model that we would be working towards.

**The Hon. ANTHONY D'ADAM:** I have a question about the curriculum. Is that a year 11 or year 12 stage 6 curriculum, or is it all stages?

**CATHERINE MILLER:** From kinder all the way to year 12.

**The Hon. ANTHONY D'ADAM:** Right. And it's offered as a HSC subject?

**BRENT PHILLIPS:** I believe we may have to take that question on notice. Last year in New South Wales there was the launch of Auslan as a language taught. There is a curriculum from K to 12. How that translates and how it's being delivered may be something we need to further investigate and to let you know.

**The Hon. NATASHA MACLAREN-JONES:** For Mr Edwards' benefit, my name is Natasha Maclaren-Jones. I'm one of the Committee members, and I'm also a member of the Liberal Party. My question to you is in relation to the educational adjustments. In your submission you've listed a range of adjustments that were made following a survey that you've done. In your opening remarks you also indicated that there were a number of inconsistencies in relation to those adjustments being made. Could you outline some of the inconsistencies that you referred to?

**CHRIS EDWARDS:** Yes, thank you. What we know is that there are some core skills that people who are blind and low vision need to develop to be able to be active learners and also active members of the community. One of those supports is around the visiting teacher service, or the itinerant teacher service. Only two out of three students that we surveyed actually had a teacher that had a specialist in vision. Only 13 per cent of those students in the survey were learning braille, which is a critical skill for people in the longer term.

What we're concerned about is that where you don't have the teachers and the schools with any competency in things like braille or things like teaching assistive technology to—currently I'm using JAWS, which is a screen reader application that my computer speaks to me. I can use that very quickly and be very efficient with it. But as a young student, you've obviously got to learn things like accessing a computer keyboard without sight. You have to learn to touch type. You have to learn what Windows looks like, which is obviously a very visually intuitive thing, but for someone who is blind, you've got to learn all those concepts. Then you've got to have access to that sort of assistive technology.

Our key concerns that impact the adjustments are not necessarily always a willingness of the school to make those adjustments; it's actually having the capability and competency around that, where someone should be offered braille as a student that has got low vision, and they should have access to those assistive technologies and to do that. And the third area, as I said in my opening remarks, is that where students are working with organisations like Vision Australia to help develop those skills to be able to be better learners and to be able to actually do mobility skills, to be able to go on camps and those sorts of things—there's often conflict between the two systems and we have been locked out of schools and not been allowed access.

**The Hon. NATASHA MACLAREN-JONES:** When you say you've been locked out of schools and not allowed access, what was the reason for that?

**CHRIS EDWARDS:** The schools have just said, "No, we think that the supports that we've got in place are adequate." Whereas, you know, the parents are saying, "No, they're not." And so we've got to work with those students, where those parents want it, out of school hours to be able to give them services.

**The Hon. NATASHA MACLAREN-JONES:** Is that a decision that has been made at a local school level or is it more the department statewide?

**CHRIS EDWARDS:** I think it's a local school level, and I think that's one of the challenges around those inconsistencies. There are schools that see that that collaboration between the supports students get to develop these skills out of school and within schools is a good thing, and then there are some principals that just determine that that's not in the best interest of that student.

**The Hon. NATASHA MACLAREN-JONES:** My final question is to Mr Phillips. In your opening remarks—and I apologise if I misquote you—you said you were cautious about the NDIS Review, the royal

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commission and also the foundational support strategies. What are your concerns, and what would you like addressed?

**BRENT PHILLIPS:** Cautious but optimistic. There is a window of opportunity for us as a deaf sector to really focus on outcomes. It's critical. It's more around ensuring that the policymakers or changemakers truly understand the cultural and linguistic aspects of the Deaf community and deafness, rather than looking at it from a medical fix-it model or an audio-verbal therapy sort of model. It's really understanding that Auslan is a language and what investments need to be made to ensure that it flourishes. That will then tie in to more access for children and adults throughout our lives so we can navigate at ease and get access from government. That's why I use the word "cautious". I think it's amazing that we're in this time of reform. But, that being said, I hope that it is the right outcome for the community and what our needs are.

**The Hon. SARAH MITCHELL:** Thank you all for being here today. I have one question at the moment. Ms Liu, picking up on what you said in your opening statement about the idea of having hubs for children to thrive, could you please elaborate a bit more on what you would like that to look like and what you think it should involve?

**SHIRLEY LIU:** Thank you for your question. The Deaf community has such a rich history and I have been lucky enough to have the opportunity to meet members who have come before me. There used to be, back in the day, a deaf club where people would come together, learn to sign and talk about job opportunities. There are no hubs anymore. They've all dissolved because we've seen the change of the medical model. Things are not being acknowledged the way they were. There's now no community model. The funding has been reallocated. It really means that those hubs aren't able to be maintained, so it's really difficult for deaf people to come together to talk about those things. Here in Sydney, Stanmore—it is a huge part of the Deaf community here in New South Wales. People talk and rave about Stanmore, and that was before my time. It closed in about 1994. I was a very young person at the time, so I didn't get to experience that. However, I'm lucky enough to have attended a deaf school where I was surrounded by culture and language and people like me.

People in mainstream schools were quite isolated. They felt on their own. They didn't feel like they had anywhere to connect with anyone like them. It's about deaf identity. A hub would allow people to find their identity. A safe space where deaf people could come together—at the moment, that doesn't exist. We would like to drive an idea of a hub where people can come together and connect. We often find that their education would thrive in that place because they have Auslan, they have each other and they have culture. We find the more that students are isolated, the more issues and barriers they experience.

**BRENT PHILLIPS:** If I may add to that, in the education context, rather than a deaf child being the only deaf student in a sea of 300, 400 hearing students with an interpreter—it's just a recipe for disaster. There's no identity. You don't have that same feeling of "I feel I'm the same as my classmates." When we look at a hub model, it's looking at the population and identifying a couple of schools in the north, west and south where you can really partner with schools, primary and secondary, to build bilingual pathways to enable families to attend that school where there is a cohort of students who are the same as their child. So they can have the play yard conversations and fun, but also enter a classroom and be educated in the appropriate way by the appropriate educators who have been appropriately trained. That can happen if it's done with the deaf sector.

If I could also add to that, if I may, speaking for myself—my own personal view—Shirley mentioned before that I grew up in a deaf family, but I attended a mainstream school. I have to be completely honest: If I didn't have a deaf family, I wouldn't be where I am today. I know that everyone has horror stories about high school, regardless of whether you can hear or not, but for deaf people it's different. I was the only deaf student in my entire high school—the single deaf student—and it was one of the loneliest experiences in my entire life. Even looking back now, I would never want to repeat that experience again.

The impact that that had on me—again, if I didn't come from a deaf family, I could have had severe mental health issues. I can probably say there's a high probability that I would have, but Brent and I are very fortunate. We are from a very small population in the Deaf community who have that support at home, coming from deaf families. There are a lot of parents who are concerned about academic achievements, speech or their child's ability to fit into a hearing world. But if you asked those children now, as adults, they would say it is not worth the focus. The critical part of life is the social aspect of education as well.

**The CHAIR:** I was wondering if I could ask a bit more about the barrier to deaf teachers being registered. Could you explain what's happening in New South Wales in relation to that, and how it differs from other States?

**CATHERINE MILLER:** I am from Victoria and I work in the Victorian public education system. It's extremely common in Victoria, WA and Queensland. There is a very strong model of deaf staff working in their schools. I believe it's the same in the Northern Territory and in South Australia and Tasmania. New South Wales

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seems to be unique in that respect. There are a lot of deaf teachers who are not allowed to work in the public education system. They can in the private education system, but for some reason they're not allowed to work in the public education system.

**The CHAIR:** How strange.

**SHIRLEY LIU:** If I could add to that, as well, there's not complete evidence about why that's the case. The deaf teachers are qualified. They have special education qualifications in addition to that, but their registration seems to be blocked simply because they can't hear. If they can teach deaf children, the system is somehow blocking them, to the point that they cannot register to work in our public schools. We would like to ask the Committee to help us understand why that is the case and if any reforms can be implemented to stop this from happening. There are such limited opportunities for our teachers of the deaf here in New South Wales and, in turn, for our deaf children, who are then receiving a limited education.

**The CHAIR:** We will indeed ask the Government tomorrow when they appear. Are there any other oddities of New South Wales compared to the other States that we should be taking note of?

**SHIRLEY LIU:** Just trying to get some of our thoughts together. There are a couple we had mentioned before today, but they're just not coming to mind right now.

**The CHAIR:** That's okay. You could take that on notice if that's helpful. It would be good for us to know if there are other places doing it better.

**The Hon. TANIA MIHAILUK:** We've heard evidence today from various different groups. Representatives for autism and different disabilities and their respective associations have given us a range of views as to how they think we should proceed in including people with a disability in the current education system. I understand from what you've said earlier, Ms Liu and Brent, that all three of you are indicating that perhaps it's better not to have an individual deaf child turn up to one school and be there on their own, but rather to have a specific school that might be allocated per region. How would you suggest?

I'm just trying to understand, because we're getting different views. Autism Awareness Australia have the view that every mainstream school should accommodate children with autism. We're seeing a different view from what you said earlier—that perhaps it's much better for a child not to be isolated but rather to be with a group of friends or their peers and to learn together. Can I understand that a little bit? I also don't know much about the statistics in New South Wales, either, on what schools are available. It would be good to have that available. I don't think you've made a submission. We can make those inquiries as well, but perhaps that could be made available.

**CHRIS EDWARDS:** I'm happy to lead it off from a blindness and low vision point of view. We certainly think that any of our students should be able to attend their local school and their choice of education system, whether it's independent or Catholic or public. It is about having the right supports around them—so those visiting teachers that can work with the school, the teacher, the student and other service providers to ensure that those core things are in place and to do that.

In Victoria there is, in addition, a program where some students go once a term for one day. That actually enables them to associate and learn from other students who are blind and low vision, and also focus very much on some of those compensatory skills in activities that potentially are beyond learning. Things like art and sport are common challenges for kids who are blind and low vision, and so there might be a particular focus on that within some of these joint programs. But we think that, with the right supports and some supports where people might get together to learn from each other, any kid should be able to go to any school.

**CATHERINE MILLER:** I agree with the philosophy, but the reality just doesn't translate. It's not realistic for a deaf child. The difference from other children is the language—is Auslan—and I don't think it's fair to expect all children to just know how to sign when they get to school. That's why it is extremely important to have cohorts of deaf students together, learning together. Yes, they will learn from other hearing students as well, through interpreters and through teachers of the deaf. It's such a different experience for a child with autism. Because they're all hearing, they share a common language. Deaf children, however, do not; it's very different.

**SHIRLEY LIU:** If I could add to that, as well, Victoria has a bilingual school but in New South Wales we see an array of deaf units. The exact numbers I don't have on hand, but there are a few of those units or whole of schools which we have collected data from in terms of how many use Auslan and how many use English to communicate, and then in terms of their barriers for their learning experiences as well. When the survey does become available, I will share that with the Committee, of course.

As Catherine has said, I have worked at a deaf school before, and I have seen children come with no language. Their language has been completely deprived. We see the teachers struggling and persevering to ensure



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that the curriculum fits with what each and every student needs, because language has been taken from them at such a young age. We believe that students should be able to access language as early as six months. If a child has no access to language after six months, it is considered language deprivation. Families need to be supported to have the right access and right information to ensure that deaf children receive a proper education. It's absolutely critical.

**BRENT PHILLIPS:** If I can also add to that, it returns to my point about a holistic approach to Auslan. There are a lot of parents that, when they have a baby who is newborn and diagnosed as deaf, they are strongly encouraged to take the medical route to fix them, without even being aware there are other options available to them around language, community, culture. A lot of children struggle on the oral pathway. They are the only deaf student in their school. They suffer mental health issues. They run into constant barriers. They leave the education system. And they meet a deaf person and wish they had come when they were little, or wish they had come to the Deaf Society for support, as in their parents. It's a whole-of-life journey.

**SHIRLEY LIU:** I will just add to that as well. I would like to ask the Committee to consider how you may be able to improve, or even consult, with people who have been through the education system. We see that the Department of Education, not only in New South Wales but in other States, do a set-and-forget. They set it up and think it's the greatest thing they've ever seen, but then they don't consult with anybody. They don't consider all the other services available. They don't consider the children. They don't consider how the children are presenting to school. There are so many barriers that are implemented straightaway because the Department of Education hasn't consulted. There needs to be reform. The medical model needs to be shifted to more of a social model. If there's an approach at collaboration, we'll definitely see success in this space.

**The Hon. ANTHONY D'ADAM:** Can I ask about the educational support for family members of people who are deaf and how they learn. How do we support them to learn Auslan?

**SHIRLEY LIU:** I'm not quite sure who's going to answer this one, but I'll take it. Like we said earlier, children are diagnosed at a very young age and they're directed straight down the medical model instead of being given options, such as Auslan courses. There are community courses through to certified courses, so certificate II through to Diploma of Auslan. There's also family-specific programs where we have deaf children come together, but also parents who have deaf children come together to talk about how they're feeling, how they're coping, what is the barrier this week? But those programs don't sustain themselves because of lack of funding. We see that Parents of Deaf Children is such a small organisation, but they keep on going with limited funding because there is such a demand for their services. Their resources are so limited because it's a difficult concept to understand, and I totally understand that. Brent might want to add.

**BRENT PHILLIPS:** The NDIS has been great, but it has a long way to go. The concept at the moment is that people take it as an either/or model where families say, "We choose hearing aids and speech therapy for my child, or Auslan," rather than bilingual approaches, and that's because that's what the NDIS often tells families. They're quite often told, "No, you can't have Auslan if your child is oral," because it might lead to one or the other being stronger, but it's about them complementing each other and providing all pathways available to a child. There needs to be some strategic thinking and investment done to ensure that parents and families have access to information first and foremost, and then they are able to make informed decisions around mentoring. Again, it ties into the Auslan workforce and not having enough teachers to be able to go to families' homes and teach them Auslan. Again, it comes back to the bigger picture of the approach to Auslan: the workforce, deafness awareness, training.

**The CHAIR:** Obviously the early years are incredibly important. Can you give us a bit of colour or examples around what the average family does in terms of finding appropriate early childhood education options when they have a child that is deaf or a child that is vision-impaired?

**CHRIS EDWARDS:** I can start. From our point of view, it is one of the things that, when a child is first diagnosed with vision impairment, they generally will go about and contact Vision Australia to say, "What services are available?" and get some of those supports to start their journey of building skills. The first hurdle that many families have is getting their kids into an early education setting, a kinder. The kinder is the first experience that parents have or realise the challenge they have to get an inclusive approach within a kinder setting. I think that whilst most kinders are happy to have someone like Vision Australia come along and work with them to look at what are the key supports to help make the child inclusive in the programs, there are a number of families that literally the early education program says, "No, we don't have the right supports for your child. You should find some somewhere else," which really is a big concern for the family and a big concern for society.

**CATHERINE MILLER:** When parents find out that their baby is deaf, it's one of the worst things to experience for them, especially after they've just given birth. The emotional experience can be horrible for them. Straightaway doctors will give them advice, "You need to make an appointment with an audiologist. You need to

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fit them with cochlea implants. You need to see the cochlea clinic. Don't use sign language because it will interfere with their spoken language development." There's plenty of research that proves otherwise: It's not true. Parents are overwhelmed with information that they're given. The Deaf community and deaf service providers are never asked to be a part of any conversations with parents in those early days, unfortunately.

**BRENT PHILLIPS:** There's one story I would like to share. It is a personal story. My wife is also deaf and we have two children, who can both hear. When our first daughter was born, the first or second day they did the newborn hearing screening, as they do. The nurse straightaway fitted the technology, tested my daughter, put her hand out and said, "Congratulations." My wife and I looked at each other and said, "Are you congratulating us? Why?" She said, "Your daughter can hear." So what would the nurse say to parents whose babies are diagnosed as deaf?

It's a pass or fail mentality from the day your child's born, and that struck me a lot when my daughter was born. That's the first barrier—cultural awareness, sensitivities to ensure that families have the right support to navigate, but also that they're provided with all information so they can be informed and they can try different pathways until they find one that fits them and their family. In our early intervention program, we provide speech, sign language and so on, and we see parents and children thrive when they have access to all options. It's critical to ensure that parents and families are informed; that they can make informed choices and informed decisions.

**The CHAIR:** Thank you so much. That's really valuable experience that you've shared with us. Unfortunately that is all that we have time for today. Thank you so much for coming along, for your submissions and for taking the time to thoughtfully answer our questions. To the extent that there were questions taken on notice or any supplementary questions, the Committee secretariat will be in touch with you. That concludes this session.

**(The witnesses withdrew.)**

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**Ms JANELLE BARNES**, President, Home Education Association, before the Committee via videoconference, affirmed and examined

**Ms LARA SAPPL**, National Committee Member, Home Education Association, before the Committee via videoconference, affirmed and examined

**Ms GABIE LE LIEVRE**, Special Education Portfolio Leader, Isolated Children's Parents' Association of NSW, before the Committee via videoconference, sworn and examined

**Ms ANNABEL STRACHAN**, Rural Schools Portfolio Leader, Isolated Children's Parents' Association of NSW, before the Committee via videoconference, sworn and examined

**Mr JASON WONG**, Executive Director, North Sydney, and Board Secretary, Federation of Parents and Citizens Associations of New South Wales, sworn and examined

**Mr LIAM BOWDEN**, Policy and Advocacy Officer, Federation of Parents and Citizens Associations of New South Wales, affirmed and examined

**Mr JONATHAN HARMS**, Chief Executive Officer, Mental Health Carers NSW, sworn and examined

**The CHAIR:** I'll start with HEA. Do you have a short opening statement you'd like to read?

**JANELLE BARNES:** I do. I'd like to thank the Committee for the opportunity for the Home Education Association to be able to contribute to this inquiry. As an association, we believe that it is important to acknowledge that many families of children and young people with disabilities are home-educating their children because educational settings are unable to adequately meet the needs of their children. It is widely acknowledged that disabled students are leaving the school system for a variety of reasons, including school-related trauma, bullying, a learning environment not suited to their needs and a lack of inclusion in the school system. They enter the home-education system not necessarily because they choose it but because they have no other option. Most home-educated students have been to school. Parents are not anti school; they are concerned about the wellbeing of their children and see home education as necessary. A term for this is "school refugees".

At HEA, we speak to parents who call our volunteer-staffed helpline each day telling us school isn't working for their disabled child. Their children are often experiencing "school can't", and parents tell us they need to look into alternatives. There are a variety of issues that lead to a lack of understanding of the consequences of and reasons for such a large number of families of students with disabilities turning to home education. These include a lack of data regarding the number of disabled students currently being home-educated in New South Wales, the specific needs associated with their disabilities and the reasons that parents and guardians are concerned about sharing this information with the authorities—we are aware that when these questions are asked, parents are often reluctant to answer them; the impact of insufficient funding of government schools creating an environment of unmet needs for disabled students; and the little to no resources being made available from the New South Wales Government to support families and children with disabilities who are homeschooling their children.

With a view to improving the outcomes for children and young people with disabilities in New South Wales, the Home Education Association wishes to recommend to the Committee the following. The NSW Education Standards Authority, NESA, should engage with home-educating families to determine the optimal way to obtain accurate data about the number of children and young people with disabilities who are currently being home-educated in New South Wales. The New South Wales Government should carefully consider the form and function of standardised information it seeks to collect and should engage in a thorough consultation process with home-educating families regarding this information collection to allay mistrust and make them feel part of this important process.

The Government should engage with disabled home-educated students to determine whether part-time home education and part-time mainstream education could be the best solution to meet their needs. This is something that is available to students in Victoria, but this is the only State in which this is possible. NESA, the NSW Education Standards Authority, should provide specific training in trauma-informed care for their staff who deal with home-educating families, especially those with children who have disabilities and may have left school in traumatic situations. It would also be wonderful if qualified psychologists could be employed by NESA to service the needs of home-educated students in the same way that mainstream schools have school psychologists. Thank you.

**The CHAIR:** Thank you. I go now to the Isolated Children's Parents' Association of NSW.

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**GABIE LE LIEVRE:** For over 50 years, ICPA New South Wales have been advocating for equitable access to education for rural and remote children and is entirely voluntary. We have over 23 branches across New South Wales and 711 member families. Our State counsellors hold specialist portfolios from early childhood through to tertiary, and today you have myself here representing the special education portfolio and Annabel is the rural schools portfolio holder.

The submission by ICPA New South Wales is very broad in nature. We would like to highlight the following issues: allied health support, early intervention, telehealth to be included under Medicare with a Medicare Benefits Schedule item number for telehealth consultations, and incentives for uni courses such as speech pathology and OT. In closing, we note that any questions outside these issues we have just presented may need to be taken on notice because we do not hold the expertise of all portfolios within ICPA New South Wales, but we can easily get more information from the subject matter experts, should you require it, on notice. We thank you for this opportunity.

**The CHAIR:** Thank you very much. I will now go to the Federation of Parents and Citizens Associations of New South Wales.

**JASON WONG:** The Federation of Parents and Citizens Associations of New South Wales represents almost 2,000 volunteer-led P&C associations of New South Wales public schools. With the signing of the 10-year partnership agreement between the federation and the New South Wales Department of Education in the middle of last year—the first formal partnership agreement between these two organisations—the federation now represents the voice of all parents and carers of the approximately 800,000 public school students in New South Wales, meaning that the number of public education constituents for whom we now speak numbers in the millions. The federation thanks the members of the Committee of inquiry for the opportunity to make our submission and to represent these diverse parent and carer voices.

However, any discussion of inclusive education for students with a disability is meaningless so long as the public school system remains so severely underfunded. We can't constructively talk about extra supports in the classroom for children with a disability, where we often don't have the supports for any student. We can't talk about how to include students with a disability on excursions when the school can't afford a bus for any child to attend their weekly school sport, much less a student with a disability. Parents and carers, via the P&C associations that they volunteer for, are having to fundraise for our local schools at levels never seen before, whether that is via a school community social event, increasing the profit margins of our school canteen or uniform shop or via constant application for grants. But, as you would appreciate, you can't prop up a school with a sausage sizzle, especially one that aims to be inclusive and educate all members of the community.

**The CHAIR:** Thank you. Mr Harms?

**JONATHAN HARMS:** Mental Health Carers NSW is the peak body undertaking systemic advocacy on behalf of families and carers of people who experience serious and persistent mental health concerns. While we acknowledge the importance of enhancing the supports provided through our mainstream educational institutions to people who experience mental health issues, we do have concerns at the idea that specialist services might be discontinued rather than expanded. We also consider that, in order to be able to accommodate the full range of needs of students in New South Wales, a very significant program of research, development and investment in the necessary services will have to be undertaken if we're not to wind up short-changing all of the students involved in our system. So, while we would welcome the expansion of that mainstream access, we do have concerns about our capacity to deliver it in the time frame and with the resources so far discussed.

**The CHAIR:** Thank you. I will start with a question to the ICPA. The added disadvantage that comes from living rurally or remotely when you have a child with disability—are you able to give us examples of how that plays out in practice? What sort of additional supports are required on the basis of having to do stuff from home a lot? Can you give us some case studies?

**GABIE LE LIEVRE:** First and foremost is the distance. If it's not a telehealth scenario for any said session, then it's the distance. It could be a 600-kay round trip or a 30-minute appointment in town. The logistics alone for us, before we even get to that said appointment, is something that is not experienced, obviously, by our city counterparts. For us, that's an added complication before we even get to an appointment. And then, if you do it over telehealth, sometimes it's bad internet that we all have from time to time out here, which is more frequent out here—well, no, it's not, because that is in the city. We don't have a choice then; you have to get in the car and go to town and do the 600 kays before you even get any help or any assistance.

**The CHAIR:** To tease that out a bit, I guess it's from the beginning of trying to get a diagnosis, trying to seek early intervention and supports and then to also find some form of education that satisfies or suits the needs

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in a place where all of those services are far more disparate and, perhaps, not really existing at all. Do many of your members have to move or go to the city? What happens there when there just aren't the services locally?

**GABIE LE LIEVRE:** Obviously telehealth is a big thing for us in being able to access services from a remote location. But I am sure there are families that have had to relocate because some children need specialist care and you can't get that when you live 300 kilometres or more from a base or its town, city, biggest centre where those services are available. That means splitting families—a whole range of other issues then come into play.

**The CHAIR:** The HEA's opening statement talks about there being a lack of data. Do you have any ballpark percentage of how many people are educating from home because they have been excluded from school—so multiple suspensions, expulsions et cetera—versus those that have just decided to educate from home because they know that their local school, or wherever, is not going to be able to look after their child? Do you have any sort of sense of the division?

**JANELLE BARNES:** No, that's not data that is collected by NESA or made available. It's also not necessarily information that parents feel confident sharing with the authorised person who is investigating them and their program of education. For New South Wales, the data shows that in 2018 there were 5,429 registered children being home-educated, and by 2022 it was 12,359 children. It had gone up, more than doubled, in only those five years, and the data for 2023 hasn't been released yet. Of those who are asked why they are home-educating, 50 per cent of those people say they are home-educating for other reasons, which is unspecified, or that they do not wish to say what their reasons for home-educating are. There is a lack of trust in what this information might be used for, especially for parents whose children have had traumatic school experiences and now may be experiencing mental health issues and that's the reason why their families are homeschooling them. It's very difficult for them to feel that they can truthfully share this information with government representatives. Lara, did you have anything to add?

**LARA SAPPL:** No.

**The CHAIR:** How does the situation in New South Wales, in terms of numbers of kids being homeschooled, compare to other jurisdictions in Australia? Do you know?

**JANELLE BARNES:** Percentage-wise, in terms of the increase of students being home-educated, there's been a similar sort of increase year on year in New South Wales compared to other States—except for Queensland, which last year jumped 63 per cent in the one year, which was well above every other State. Last year in New South Wales it jumped, I believe, 37 per cent compared to the 12 months before that. Western Australia and Victoria had similar numbers of increase. But even for the people who are prepared to indicate a reason as to why they're choosing to homeschool, the number of people saying that they are making that choice due to special educational needs is definitely a growing—it's slowly growing—area.

Anecdotally, we hear regularly on our volunteer staff helpline parents who are calling up saying, "I just don't know what to do. My child just can't go to school anymore. I can't get them there because it's such a difficult place for them. I feel I have to homeschool because their neurodivergence is not being taken into account, they're not being properly supported, they have autism with a pathological demand avoidance profile. It's very, very difficult and I feel that my only option is home-educating them."

**The Hon. NATASHA MACLAREN-JONES:** I might follow on from the Chair's question and your last answer in relation to parents and carers who feel that they've got no choice but to homeschool now because of what's happened. When you engage them on the helpline, are there services you can refer them to to get additional support to allow them to make a more informed decision or give them that assistance that they need, or are you the final point of contact for them?

**JANELLE BARNES:** We're often the first and final point of contact for them. We're a completely volunteer-run, volunteer-managed, no-paid-staff registered charity. We run an email helpline, registration support and a telephone helpline, all with no funding whatsoever from any governments anywhere in Australia. We are a national association but we have members across all States and volunteers across all States, in particular New South Wales, because that's where we started. For parents who are at that point, they feel that there isn't anywhere to go, except to come and speak to us about how they can get started in home education and what's involved in that. It's quite a complex process for them to begin, and we try and support them as much as we can when they have reached that point.

**The Hon. NATASHA MACLAREN-JONES:** In general, do you have many families that go from homeschooling back into the mainstream system?



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**JANELLE BARNES:** It's really varied. It depends what the reason is for choosing to homeschool. I have two children who I homeschooled for a period of time. One of my children has gone back into mainstream education; the other one still is at homeschool. It's not unusual for families, if they identify another opportunity or another choice, to sometimes decide to see if that works better for their family. At the end of the day, the parents are most concerned about helping their children become independent adults who can live a happy and successful life. So they will make whatever choice they can that they feel is going to best allow that to happen for them.

**The Hon. NATASHA MACLAREN-JONES:** I've got a couple of questions for the P&C around some of the things the federation is suggesting. We've heard a bit of evidence today, and in some of the submissions, pushing for the removal of specialist schools and to have all young people with disability in mainstream. In your submission you're saying both need to coexist. I'm interested to know, how realistic do you think it is to have all young people with disability in mainstream schools?

**JASON WONG:** In our submission we did land on the second of the disability royal commission's recommendations that essentially articulated that it's probably not realistic to have no SSPs at all. Echoing some of the thoughts that have already been mentioned by some of the organisations here, right now the vast majority of parents can't imagine a public education system without specialist schools. Obviously we know why that is. I think HEA made the comment about school refugees. That's consistent with conversations we're having in our community consultation and conversations on the ground that right now, yes, we need to retain the foreseeable future. I note the disability royal commission articulated a plan that went out to 2051, I think, to eventually envisage a world where there were no specialist schools.

The reality of what we're hearing, and also because we represent such a diverse range of parents and carers, is that ideally that would be the case, but the reality is that prospect is just unimaginable. Most of the parents that we speak to that want SSPs right now for their kids with disability also would much prefer their kids to be in a mainstream school. But, given the experiences they've had through gatekeeping through numerous schools and maybe even landing in a school where they weren't gatekept, their experience ended up being less than desirable. So they've had to drop the dream of their kid attending and getting educated in a mainstream school. Although recognising that disability royal commission—the first one—7.14 is aspirational and desirable, and I think where most of us want to get to, the sad reality is that 7.15 is more likely. We also need to accept that we do represent a diverse parent and carer community, where parent choice is paramount to us, and we can't necessarily go one way or the other.

**The Hon. NATASHA MACLAREN-JONES:** You've also recommended the idea of having carers being able to be with a young person in the school environment. Can you elaborate a little bit more? Is it just for full-time carers or for all carers?

**LIAM BOWDEN:** I think it's important to recognise there that one of the key aspects of what we said is we recommend the department explore this option, so there is some leeway for which way it goes. I think that a big part of this is about the fact that we have to recognise that children with a full-time carer, especially, have a bond with their carer, have a relationship with them and know their learning style. What we've tried to say is that we should be exploring the way that these carers can act as additional to SLSOs and be in that classroom supporting a kid that they know, trying to reduce teacher workload and reducing the workload of the other carers in a classroom but still making sure, whether that's a full-time carer or a part-time carer, that can be worked out by the department as part of this exploration process.

**The Hon. NATASHA MACLAREN-JONES:** Has it been canvassed with parents as to whether or not they would have any resistance or be supportive of that idea in a mainstream school as well?

**LIAM BOWDEN:** We have recently put out a survey regarding that. I will just find the data for you. At the last count of that, we had about 89 per cent of respondents who said that they would be supportive of allowing a carer in the classroom. It's important to recognise that these carers are already there. There are already people in the classroom. There's already someone sitting with that child. All that would change would be that it's someone the child trusts, knows and has a relationship with.

**The Hon. SARAH MITCHELL:** A lot of the things I wanted to ask other people have already covered, but I do have a couple of questions, firstly to the witnesses from the ICPA. How are you both? It's nice to see you again. I'm happy if you take this on notice, because it kind of goes to another organisation. In your submission you mentioned Royal Far West and their Better Learning Better Lives program, and that you would like to see that continue. Can you tell us a little bit more about what that program involves and how you've seen families, particularly in more remote areas, benefit from a program like that?

**ANNABEL STRACHAN:** It was a bus originally that used to come out to the rural and remote communities, and it was the early intervention. They would go to Bourke and they would do all the testing there.

**UNCORRECTED**

Then places like Louth and remote communities would come in and also have that testing available to them. Both had to stop that because of no more funding for our communities out here. It was really for rural and remote, so for us it has had a huge impact not having that available.

**The Hon. SARAH MITCHELL:** To follow on from that, I'm guessing that if there were children who were yet to get a diagnosis of a particular disability, that bus and those health experts and clinicians were part of maybe that screening process and picking up some of those disabilities as well?

**ANNABEL STRACHAN:** Yes. Bourke childcare centre would then help with that program and help that child through the Royal Far West or, in the case of distance ed or schools, you can do that through your school the same way, through the support of the teachers and the distance ed.

**The Hon. SARAH MITCHELL:** I have another question for Mr Harms, please. We've heard from many different groups today about students with lived experience of a range of different disabilities, and we've talked about reasonable adjustments and what's in place to support those students in a classroom setting. From your experience with your organisation and the parents that you advocate for, what do you see are some of the challenges around adjustments and supports, particularly for those children who might be managing mental health needs?

**JONATHAN HARMS:** I suppose the most challenging aspect is managing behaviour that can become escalated or disturbed due to whatever's going on in the person's life or going on around them in the classroom. That actually requires quite skilful staff that need to have been trained in how to manage those situations, and they need to be able to devote time and attention to that student while others are available to continue to look after the class. That means that reasonable accommodation for mental health concerns goes to basic things like class size for everybody.

Mental health is a pervasive quality that everybody has, and managing behaviour in a classroom would benefit—everybody would benefit from trauma-informed techniques and skills being imparted to educators. But also having the ability to take a child out of a setting where they might start to upset others—so the capacity for time out and things like that. It requires a certain amount of complexity in thinking through things like classroom design and so on. It's one that's good to engage as broad a cross-section of the community in when you're coming up with those sorts of supports as possible. It might also mean that sometimes some people, for some parts of their education, maybe shouldn't be in the mainstream but have more specialised supports being provided.

**The Hon. SARAH MITCHELL:** I've got a couple now for the Home Education Association. I wanted to ask about data collection, but I think that has been covered well. The recommendation around having psychologists employed by NESAs to support students who are being educated at home—at the moment presumably families need that support. They need to access private mental health supports and psychologists. Are there any barriers or any reasons why you think that NESAs might not have done this already? Is it something that you've raised with them, or is this a new recommendation through this submission?

**JANELLE BARNES:** This is certainly related more specifically to this submission based on the fact that we are really recognising the challenges for families who are home-educating disabled students. We have noticed a growing increase across Australia in the number of parents who are home-educating because of disability. Both Lara and myself are home-educating neurodivergent children because we felt that that was the best option for our particular children at this point in their lives. When families choose to home-educate, that usually means that one of the parents becomes the educator and they're living off one income. Therefore, accessing private mental health services is an expense that is often difficult for them to achieve.

There is little funding available for home-educating families. Some of them can get the isolated children's payment; some of them can't. Therefore, sometimes you're dropping from two incomes to one income and then also having to find ways to access mental health services for kids who are leaving school with a great deal of school trauma. In the same way that schools have school psychologists who are there to try to help children within schools, we believe that a similar service that could be made available to home-educating families would be really beneficial long term.

**The Hon. ANTHONY D'ADAM:** I just want to ask the P&C about—we've had a number of submissions that have made suggestions around a specific consultative mechanism for parents and people with a disability in the education system. I wonder whether you might offer some comments around that idea.

**JASON WONG:** Sorry, can you repeat the question?

**The Hon. ANTHONY D'ADAM:** I think People with Disability Australia was the primary one who suggested this, and that is that basically a committee be set up to advise the Minister, composed of people with disabilities and parents of children with a disability, as a mechanism to try to refine how the system is engaging.

**UNCORRECTED**

It sort of runs parallel to the kind of work that the P&C does day to day, and I wanted to get your views about that proposition.

**JASON WONG:** Definitely at face value we'd support any specialised community consultation process. I think one of the interesting challenges for us is recognising that basically throughout all the regions which we represent across New South Wales, every region, or even every subregion, has their own community consultation process. As I think is noted, I'm the northern Sydney councillor, and we have a very active inclusive education subcommittee of a district council in there, and that has been running for a few years now. We meet quite regularly to talk about these issues. The membership is growing every month really. We have webinars. We invite experts in. Gradually with every meeting we're able to canvass a broader range of lived experiences of what it's like to send a child with a special need to a public school. In general, if that could be supported, resourced, funded to happen at a broader level, yes, that's absolutely something we would support.

**LIAM BOWDEN:** Can I just add to that as well. The P&C Federation currently has an incredibly good relationship with the Department of Education, and we're meeting with them regularly. Jason and myself meet with the inclusion and wellbeing team once every couple of months and we do sit down and discuss these kinds of key issues in schools. We have an incredible board member Gabrielle, who couldn't be here today, who represents the disability area for the P&C board. So we are already starting to meet with the Government, meet with the department on these issues. Any opportunity to further that advocacy and further meet with the Government, advise the Minister regarding these issues, we will always jump at that and we will always try to do the best to represent our millions of parents across New South Wales.

**The Hon. ANTHONY D'ADAM:** Just on another issue that's sort of related to that, there have been a number of concerns raised about grievance and dispute processes, getting resolutions to issues, particularly around reasonable adjustments in schools. Do you have any comments about how those mechanisms might be improved?

**JASON WONG:** Following on from what Liam just said then, one of the reasons I mentioned the partnership agreement with the Department of Education in the opening statement was it has presented a change in the way that the Department of Education engages with us. We were previously very much focused on our member associations and we were indirectly representing the voice of parents and carers in New South Wales through there, and that was quite adequate for a while and I'm not dismissing that. But with the signing of the partnership agreement, as Liam mentioned, we now have regular discussions with Department of Education people on all matters across different portfolios. Our councillors who are elected across the different regions have a specialisation. As Liam mentioned, we have Gabrielle in disability; I am on inclusion and wellbeing. In terms of the grievance procedure, I imagine this is something that Gabrielle would already have started having conversations with the Department of Education. If you could add to that, Liam?

**LIAM BOWDEN:** We are already talking with the department on some of these things, and obviously there's always more. There's always an opportunity to do more, and in terms of reasonable adjustments and making these changes I don't think anyone can dispute the fact that more needs to be done. We need to be looking at ways that we can make sure that students from a wide array, whether it's the isolated children out west, our home-education children or just children at a mainstream school that need that additional support—I think there are always opportunities for more of that. One thing that we do offer at the federation is we do a lot of webinars with parents and the department—we're always looking at more of these things—meeting with the inclusion team to potentially let them chat to parents and give that information about how reasonable adjustments work, what they can do to get these reasonable adjustments and make sure that it's a fairer system for everyone. That's kind of the goal of all of us here.

**The CHAIR:** Thank you very much, to all of you, for attending. That was a lovely way to finish what has been a long day of hearings for us. To the extent there were questions taken on notice, or supplementary questions from the Committee, the Committee secretariat will be in touch. That concludes our session.

**(The witnesses withdrew.)**

**The Committee adjourned at 16:55.**