CYDA's response to the Disability Royal Commission's *Promoting Inclusion* issues paper

Young people's perceptions, experiences and insights on inclusion

Children and Young People with Disability Australia

June 2021

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Recommendation

That the Disability Royal Commission continues to shine a light on the exclusion, discrimination and mistreatment children and young people specifically experience across all systems and areas of life, and in particular:

- The over representation of children and young people with disability in the justice system and their experiences

- The over representation of children and young people with disability in the out-of-home care system and their experiences

- The use of restrictive practices on children and young people in education and other settings

- The continuation of governments allocating funding to segregated education settings and classes which contravenes Australia's obligations to achieve inclusive education under the United Nations Convention on the Rights of Persons with Disabilities

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

- Driving inclusion

- Creating equitable life pathways and opportunities

- Leading change in community attitudes and aspirations

- Supporting young people to take control

- Calling out discrimination, abuse, and neglect.

CYDA welcomes the opportunity to provide a response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability's (Disability Royal Commission) *Promoting inclusion* issues paper.

In June 2021, CYDA held a consultation session with young people with disability on the topic of inclusion. With CYDA's support, the session was developed and delivered by young facilitators. Nine young people aged between 18-25 participated in the session. There was representation from ACT, NSW, QLD, SA, VIC and WA (some metropolitan, some regional/rural) across the group. The participant group comprised young people who identify as male, female and non-binary.

The session was delivered as part of the LivedX Consultations Series, which is a component of CYDA's Our Voices Our Visions: Youth Advocacy project. The LivedX Consultations are being conducted to hear from young people with disability about what an ideal future looks like for them, by collecting their ideas and solutions on topics and issues they deem important. The project is funded by a Youth Advocacy Support Grant from the Australian Department of Education, Skills and Employment.

Young people were split into three 'break out rooms' where they participated in five activities exploring different themes on the topic of inclusion. In each activity participants could contribute by answering questions verbally, using the chat function, or directly inputting into interactive activity slides. This paper summarises the thoughts, perspectives and lived insights shared by the group across the five activities.

Throughout the stories shared by participants there is a recurrent, underlying theme that young people with disability are not heard and seen. Whether because of a lack of awareness or because of prejudicial attitudes, young people's needs, strengths and expertise in their own lives is often being dismissed and society is unnecessarily creating countless obstacles for the cohort that prevents them to lead the lives they wish, and have the right, to live.

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 feel and are fully

included across all systems and community life. We also acknowledge early experiences of inclusion and exclusion can have consequential impacts on one's life trajectory and as such, children with disability must experience full inclusion from birth. We wish to bring the attention of the Disability Royal Commission's policy team to CYDA's work that is pertinent to inclusion.

Education

CYDA is dedicated to the realisation of inclusive education, where every student is welcomed as valued learner and genuinely included in general education. This includes in their learning, but also in other important educational and social experiences, such as excursions, clubs, and play. In achieving inclusive education, we advocate that segregated education settings must be phased out and the use of restrictive practices must be eliminated.

CYDA's recent inclusive education work:

- Submission to the DRC: Education of children and young people with disability (2019)
- CYDA's response to the DRC's Response to Restrictive Practices issues paper (2020)
- CYDA's submission to the National Disability Strategy beyond 2020 (2020)
- Submission to inquiry into the education of students in remote and complex environments (2020)
- Driving change: A roadmap for achieving inclusive education in Australia (2021)

Employment

CYDA advocates that children and young people must be provided equitable opportunities to build their personal resources, explore career possibilities and prepare for their transition from education to the workforce. This involves promoting inclusion in school and tertiary education and training settings; career information and supports; work experience; and networking opportunities. Equally, once in the workforce, barriers must be removed to support young people to gain secure and meaningful employment with equal workplace and pay rights to employees without disability.

CYDA's recent employment work:

- CYDA's submission to the review of senior secondary pathways into work, further education and training (2020)
- CYDA's response to the DRC's Employment issues paper (2020)
- CYDA's submission to the Senate Select Committee on Job Security (2021)

Rights, recognition and attitudes

CYDA grounds our work in a human-right approach. Children and young people with disability are not and cannot be full members of society unless their rights are upheld. This includes the rights of children and young people with disability to express their views and have these views listened to.

The experiences of children and young people must be captured in data and accounted for in public policy. Too often children and young people with disability's specific needs and strengths are absent from both children and youth-specific and disability-specific policies.

CYDA's recent rights, recognition and attitudes work:

- CYDA's response to the DRC's Rights and Attitudes issues paper (2020)
- What young people with disability said: Awareness, Access + Inclusion (2020)

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- [Briefing Paper for the Families Australia and Children and Young People with Disability Australia (CYDA) Forum](#) (2021)

COVID-19

Children and young people with disability were largely forgotten in government responses during the height of the COVID-19 pandemic in Australia. In our recent policy work we highlighted how Australia lacked a coherent national information strategy and response for children and young people with disability, creating and exacerbating feelings of uncertainty and distress.

Our policy work also demonstrates the inadequacy of the education system to support students with disability and their families throughout remote learning.

CYDA's COVID-19 work:

- [Submission to the Disability Royal Commission: Emergency Planning and Response during COVID-19](#) (2020)
- [Not even remotely fair: Experiences of students with disability during COVID-19](#) (2020)

The NDIS and Independent Assessments

While acknowledging that the world-first and still relatively new Scheme has many areas for ongoing development and improvement, we hear from our community that when the NDIS is good — it's great. However, recent proposed reforms, namely the introduction of Independent Assessments, has the potential to have many negative and distressing consequences for children and young people with disability and their families and caregivers.

In our policy work we have emphasised that the root of this issue is that people with disability and their supporters have not being meaningfully included in any planning or decision-making processes behind these reforms.

CYDA's NDIS and Independent Assessments work:

- [Submission to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry into independent assessments under the NDIS](#) (2021)
- [Avoiding simple solutions to complex problems: Independent Assessments are not the way to a fairer NDIS](#) (2021)

In addition to the lived insights of young people raised in this report, we ask that the aforementioned work that is inextricably linked with inclusion is also included in our response to the *Promoting inclusion* issues paper.

CYDA encourages the Disability Royal Commission to continue to shine a light on the exclusion, discrimination and mistreatment children and young people specifically experience across all systems and areas of life. In particular, we call for the Disability Royal Commission to deeply explore the experiences of children and young in the justice, child protections and out-of-home care systems, the use and monitoring of restrictive practices on children and young people in education and other settings, and the continuation of governments funding segregated education settings which contravenes Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities.

Equally, CYDA urges the Australian Government to act on the recommendations that come from the Disability Royal Commission's findings so that people with disability are not sharing their experiences

in vain. This notion of disillusionment with the Government to act on systemic change was encapsulated in the following comment as made by a young participant in the session.

> *"What likelihood are we realistically going to have that they'll actually act on any of the proposed changes or actions that come from this Royal Commission? Considering that after the Indigenous Deaths in Custody Royal Commission, within the timeline that they set out to make changes to the system or whatnot, they didn't actually meet the vast majority of those goals. So I feel like that's a huge barrier for is that they want us to do this work, but they don't actually want to put in place any of the supposed changes that they are meant to be doing that comes from the finding of these sorts of meetings."*

Recommendation

That Disability Royal Commission continues to shine the light on the exclusion, discrimination and mistreatment children and young people specifically experience across all systems and areas of life, and in particular:

- The over representation of children and young people with disability in the justice system and their experiences

- The over representation of children and young people with disability in the out-of-home care system and their experiences

- The use of restrictive practices on children and young people in education and other settings

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What inclusion means to young people

In the session's first activity, the group were asked what inclusion means to them. The young participants understood inclusion as equality ─ where all people are treated, represented, included and supported fairly and equally. This includes day-to-day interactions, such as people taking the time and effort to check in on their friends' needs. It also includes representation in the community, such as in shops and fashion, and ensuring human rights are upheld.

Inclusion for young people also means that disability is seen as "*normal*" and "*not something less than*". Further, that people without disability would not use harmful labels and biases and are willing to educate themselves about others' experiences. One young participant added that inclusion requires that people with disability are always included from the beginning and not as an "*afterthought*".

Many young people also understand the concept as going together with "*respect*", "*dignity*" and "*acceptance*".

> *"To me inclusion means respect as well. It means consideration of people with all kinds of disabilities, not picking and choosing which ones you want to accommodate. And it means if you're going to provide representation of people with disabilities, you do it accurately, you're not engaging in harmful stereotypes."*

> *"I guess inclusion to me has always been about feeling represented. So seeing people with all different abilities, different ages, disabilities both visible and invisible, all represented as one, not in an example of difference."*

> *"It [disability] would be a more open everyday part of life that we're just like any other person. We're human. We have the same needs and wants just ours need to be adapted in a different way."*

One participant also added that while in a "*utopia*" all people would have equal access, they had observed that "*with Corona virus happening I think unfortunately some people who are disabled or identify differently or who aren't your typical, mainstream people have fallen a little bit behind and are further disadvantaged. Sometimes we can fall to the wayside, and yes, ideally that wouldn't happen.*"

Inclusion (and exclusion) in organisations

The group were asked to think about examples of inclusion that they had observed or experienced in different organisations and how this had made them feel. Answers for this activity were varied, with some young people discussing specific instances or organisations, whereas others spoke more to inclusion as a practice in general.

Positive examples of inclusion in organisations included an autism organisation changing their puzzle piece logo after listening to their community's feedback, use of interpreters at police press conferences, and proactive referrals for people who are experiencing a new disability to relevant organisations and people that can support them to understand that disability.

One young person spoke positively about a large organisation and how they valued the processes they had in place to promote inclusion.

> *"That organisation provided good support for Deaf and disabled people. And for Aboriginal and Torres Strait Islander people. And for women with children. They provide*

strong support for the LGBTIQA+ community as well. And for trans people. They provide interpreters, captions, access, they've modified their toilets. They make sure that everyone is aware of they and them pronouns. They do that education for staff, they do a lot of training for staff to make sure that diversity inclusion is promoted, so I like that organisation because their social justice and advocacy is a really top priority for them."

Another young person shared that their experience of sitting on a paid lived experience advisory committee in the mental health sector was the most inclusive organisation they had encountered. They also reflected that being involved in a committee that aimed to improve service development and policy also disheartened them about how widespread systemic disadvantage is.

"I mostly get frustrated because it really shows how many other issues there are that, like, we can't change without wider legislative-based changes. It's a systemic issue, ableism and stigma against mental health and disability. So it makes me feel frustrated. Being included reminds me of what's not inclusive."

During the activity, many young people shared their thoughts on communicating with CYDA in the lead up to the session and how important it is to have options for engagement and communication. One young person added that they appreciated when organisations take the burden off them and do the "*proactive asking*" about access needs.

"… [W]hat CYDA have done with putting your answers in the chat, or being able to speak verbally, or use the slides, is also pretty inclusive and it made me feel like I could actually do something in a format and I've never felt like that before, so making me feel really empowered."

"[CYDA's] email, it was the first organisation where I've ever experienced which asked what my preference was for communication access and how to support me to include me. I was really surprised because most organisations don't ask and they don't take responsibility. Sometimes it's an attitudinal thing — people just really don't care. And you have to speak up and advocate for yourself and ask for those captions or ask for the transcript or ask for interpreters and explain to have the PowerPoint separately rather than screen shared and it's really exhausting asking for all those things and advocating for yourself."

"I definitely struggle to find organisations that are inclusive, especially in my local area. Actually, starting to communicate with CYDA was the first time I felt like I could actually ask for something. Not only being Deaf and needing closed captions, with having low vision I also need breaks and other things too due to other disabilities. [It] makes it normally really difficult, but as soon as I started looking into things there are all these different options on ways that I could communicate that I needed instead of having to always disclose it in a way where most of the time the opportunity will be taken away because it was too difficult to provide captioning or other… breaks because everyone else accessing them didn't use them."

The activity also led to several young people sharing instances where they had encountered discriminatory and exclusionary organisations and practice.

"I applied for a job a few years ago … and I basically got told that I couldn't work there because I had a disability and that basically all people with disability have hygiene issues. And I was just, you should have seen me, it was just heartbreaking."

"… [M]any sort of 'normal' people, or even non-disabled people in the government think, 'Why should we provide interpreters [or] captioners? They're so expensive, why should we spend all that money?' And then we have to say, 'No it's a human right, disabled people have a right to access.' And it's called discrimination if you don't provide those things, but so many people just don't care it's just all about money. And so we just have to keep fighting for our rights."

"I use work at a car garage and [they] use say not nice thing about women at all."

What supports young people to feel included, independent and in control

Participants were asked what they need or want others to do so they feel included, independent and in control. 'Others' could refer to people directly in the young person's life or community members more broadly.

A common theme among the groups was that it was important to have options to make choices and for others to not ignore their preferences and ultimately respect their decisions. To support decision making, a young person added that it is essential to have information about different options.

"I guess it's always about having choices. So instead of being told what you need, being given options. Actually being educated on what choices there are. … [You] should be provided with all the different options instead of just the ones that someone may think are best for you."

"Everybody treats me like how I want to be treated."

Participants shared instances where interactions with professionals, services and systems made them feel as if they were not in control.

"… I find in terms of doctors and getting diagnoses for various disabilities, it really doesn't make you feel independent because they're often dismissing you and not listening. Doctors for disabled people are constantly trying to push various treatments, and they're not listening to what we think is best for us. If we tell them our medications aren't working, if we have mental health concerns, they dismiss us as trying to seek medication instead of seeking help."

"As an NDIS participant, you know, … I often find that I don't have my own choice and control. So, I have not liked my plan I've not liked the review process, and, you know, it's, it's really stressful, it's really difficult to try and make those choices yourself, because the NDIA still has control and we have to justify ourselves."

"Other concerns I have around independence and the NDIS is I've heard that it can be very hard to get various supports and equipment that you need because if the NDIS doesn't think that you need it, you'll be denied the ability to actually purchase that. So I think the NDIS really needs to kind of take a step back and realise that we're capable of making our own decisions as to what would help us, because they don't really know us,

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they read the reports from people who diagnose us and make a couple of phone calls, probably."

Young people commented that a solution to ensuring services and systems supported inclusion and control for people with disability is if they were developed and led by people with disability. One young person shared an example from their own employment as a teacher's aide, where they were able to draw on their lived experience to improve a program for students with disability which was previously ran by "*a teacher without a special ed degree and a 'normal, abled' person*".

> "*I feel like organisations that are for disabled people should be headed by disabled people. I don't know why they've got abled people in charge of NDIA, that's ridiculous. That's what I would want for inclusion – for disabled people to control things instead of abled designing what they think we need and think we want, but actually having us do it ourselves, because there are plenty of ways to facilitate that.*"

> "*I want organisation to have more disability on them board and then people with disability can have a say where the organisation can go in the future.*"

> "*I would also like to see more accessibility in tertiary education because it's hard for us to have our voices heard or to be recognises as 'experts' in our field if we can't get the qualifications that that are recognised by abled people as making us experts. I am a provisional psychologist, I study a Master of Clinical Psychology, and it's 80 per cent in person attendance required – even with COVID. And the program is very obviously designed to be talking about mentally ill people without including us in the discussion.*"

An ideal, inclusive society

In the fourth activity, young people were asked what an inclusive society looks like. Several prompts were offered to facilitate this discussion, including 'What does an inclusive society look like in a 'dream world?'', 'What you would do to make sure every person was included if there was unlimited money and no real life barriers?', and 'What would you change about society to make it more inclusive?'.

In an ideal society, young people want others to be more understanding, acceptive and inclusive of people with disability.

> "*I think that in an ideal, inclusive society there would be more education around different types of disabilities and the various ways that they could present and how we could be inclusive to different types of people and I think that being more inclusive, in an ideal society, would result in supports not being so expensive, because then there would be much less poverty. And having an understanding of the seemingly odd things, like various neurodivergent conditions and how they present like stimming and sensory overload and sometimes going non-verbal. If people knew about those, in an ideal world, we wouldn't really be looked at as badly for experiencing those. I just think that would be really good.*"

> "*For me, an inclusive society would … include education in schools from a young age on different disabilities and abilities and how we support them, make sure everyone feels included in a way that they're not viewed as different and weird. It's just part of the norm that they have different abilities to an able-bodied person. That everyone is treated the same way instead of how it's currently taught where they're different, there's something*

off about them or they're seen as less than. … At my school we were educated about disabilities and that they aren't always visible and in high school we included disabilities in health education, because whether you have a disability or not, you're going to meet people throughout your life that have various disabilities. You may end up becoming disabled yourself or you may end up serving people with disability, so I think ensuring that's included. In sexual education is a massive one. I know a lot of people who have been excluded from that class because of having disabilities."

"I would hope that I could teach everyone in Australia, how to become more inclusive and respectful of us, you know, of Deaf and disabled people. It would be lovely if all hearing people could sign, at least basically, to know a little bit of Auslan sort of, to say, you know, food, drink, sleep, hello, goodbye. I think that Deaf people will just have a lot less stress and anxiety if they were able to have some basic signing communication and wouldn't have to always lip read. And if people without disabilities could accept people with disabilities much more easily I think we'd all be a lot more relaxed, because we're always trying to, we're always been quite anxious about how we're going to have to communicate and working out what's the best way to communicate with this non-disabled person."

"I have autism as well, so back in those days I would do the **makes sound** and a couple of teachers decided to copy me and other students and that. I didn't tolerate that BS because that hurt me in a way and that's why I think they should be more inclusive of people with autism and other intellectual disabilities and physical disabilities and all the disabilities that are going around."

In thinking about inclusive societies, some young people also made comparisons between Australia and other countries and cultures. One participant understood that some European countries, such as Denmark, Sweden, Finland and Holland, have a "*very supportive culture for people with diverse backgrounds including people with disabilities*". Another young person added, "*I've noticed America and the UK have a lot more supports for youth with chronic illnesses and disabilities. A lot more awareness than we do here in Australia.*"

One young person added that in their dream world they would "*make everyone disabled*" because "*a lot of people don't really consider accessibility and disability until it affects them.*"

"[Inclusion is] not possible unless people emphasise, and people can't emphasise unless they experience it. Because otherwise they don't give a shit. They don't care. All they care about is themselves and making themselves feel good about like how they help us and stuff, so that's my dream. Let's make them care"

In one break out room, young people discussed how the believed the justice system was not inclusive and needing either fixing or a complete overhaul.

"My dream world the law system can more inclusive when you have a disability. I have money and power I make the law system more better for disability people."

"I went out to the city, before COVID, and I was drunk and cos I've got CP, cerebral palsy, I walk a bit funny and I got stopped by a cop and they wanted proof that I had a disability so they asked me to show them the actual diagnosis papers. Do I carry them with me in a bag? No! ... [L]ike, they just need support and education for people like us, y'know?"

"The whole system doesn't work and we know it doesn't work. The whole idea of prisons and police, it doesn't create change, it doesn't reform, it causes trauma, it heavily incarcerates disabled people and Indigenous people and queer people and we know it doesn't work."

While the discussion largely focussed on how society could be more inclusive for people with disability, many young people also shared that they wanted to society to be more allowing and fair for all people, including other minority groups.

"My dream world is where I get everybody a jobs."

"Respecting everyone regardless of sexuality, disability, race, religion and all of those kind of stuff."

"I think an inclusive society would be where people are equal as well. It wouldn't matter what your background was your age, your gender, your race, the colour of your skin, whether you're gay or lesbian, Aboriginal, it wouldn't matter if everyone accepted each other."

"I change how people [treat] black people the same like them want to be [treated]."

Barriers and challenges that prevent young people from feeling included

Although barriers and challenges people with disability experience was raised by the group throughout the entire session, the final activity specifically asked participants to consider what prevents them to feel included as a young person with disability. The responses included negative and prejudicial experiences across several systems, including the NDIS, education, employment, mental health, public transport, demonstrating how widespread and entrenched the discrimination young people with disability experience is. As put by one young person, "*I always get ableismed.*"

Mental health

One young participant shared the challenges they faced in the mental health system getting an accurate diagnosis and how this had flow on effects to their experience in the education system.

"One of the biggest barriers was in the mental health when I was younger and before I was able to be diagnosed as autistic, the people I was seeing for years were so uneducated. So my teachers wouldn't help me and I was continually being bullied. My teachers didn't know, my classmates didn't know, I didn't know, and so I was being put through hell for years because nobody knew and it was a huge barrier. I could have had such a better life in the education system. All the signs were there and it was just ridiculous."

Employment and social security

In one break out room, participants discussed their experiences finding employment, using government employment services and living on social security payments. One group member shared the challenges they encountered when applying for jobs after completing their studies.

"I would say is important at the moment is for CYDA, you know, really promote educate and inform Australian people, companies, politicians, government organisations, that it's

really good to have young people with disability working there. … So I had studied for five years, a graduate degree. … I wasn't receiving any pension supports and it was really frustrating. And then I sent application[s] in for many, many jobs to over, probably over 2000 jobs, and it was really difficult to communicate with interpreters, and I went for 38 interviews or so, and then three years ago, I was given an opportunity for casual work, and then I was employed [with an organisation] and you know that's a part time role, but my goodness, you know, Deaf people, people with various disabilities, blind people, Deafblind people face so many barriers to just gaining employment."

The young person continued to reflect on their experiences looking for employment and their interactions with disability employment services, which they described as "*not great*".

"They [disability employment service providers] say that I'm lazy. Yeah, they do they say, 'Oh, you just don't want to find work, you're just lying. You're just making things up', and I'm there proving that I do want to find work I'm actually really motivated to find work. And then, I feel that they're actually not helping me find the work and I feel they're the ones who are getting the benefits financially and they're getting all of this money from the government to do their job, and I don't feel they're doing it well and it puts the burden and the pressure on me and other people around me and yeah, that's very difficult."

The young person also added that more investment is needed to support people to *"get opportunities with work and not need the Disability Support Pension anymore"*

"… [I]t's a matter of not just getting a pension, it's enabling people to gain employment. So, you know, really without employment it's almost as if the brain cells in your brain stop working. So having employment gives you, you know, motivation, it gets those cells working, you know, it leads to other desires but when the barriers start at employment the barriers continue on and it is a form of discrimination."

Another participant shared their story interacting with "*disability employment services run by the government*" and how it has impacted their life.

"They [disability employment service providers] are not lenient at all. They force you to apply for so many jobs and if you have severe depression and really bad executive functioning and you have no energy to do anything at all because you just can't, they don't care. They are like, "No, you have to otherwise we'll cut your payments" and that obviously means you can't eat, you'll get kicked out of your house. And they don't care. And with autism specifically, it's very routine based and if your routine's changed your whole world is turned upside down and I have explained that to my job providers and they're like, 'Oh, well Centrelink say that if you can't do this on this day because you want to go and see one of your friends that's not a good enough reason' and I'm like, "Okay, but it's not just that.' And I think the employment service providers needs so much education on the disabilities they claim to support because there's none. They just accuse you of not trying hard enough and I've actively have had employment providers and their managers say to me that if I was really trying I'd be applying for more than my threshold. And it felt so horrible and I ended up crying."

"The government is making it harder because the Disability Support Pension is ridiculous to get on. I've submitted my application now that I have been diagnosed but

now I'm just waiting now. But they are making it harder for people on Jobseeker to even live because they're going to force us to do 20 [job applications] a month just for an increase of $50 a fortnight, which is still below the poverty line, and I'm already panicking about that. And I think the government really needs to take a step back and see what they're doing to disabled people and how it affects people with different disabilities, because it's ruining us, and I have told my employment providers that before and they don't listen. So that's my biggest barrier at the moment."

Intersectionality

One young participant raised that Australia still has *"a really heavy white privilege"* and that people of colour face increased barriers to inclusion.

"My point of view is that it's really important for [CYDA staff] to look within and see if you and anyone else would have any privilege. I think it's important because the experience of white people is that often they think they don't have white privilege because people of colour, like myself, have to do a bit of extra work just trying and catch up. So, you know, for white people success is a lot easier. It comes a lot more smoothly than for people of colour. I think it's important for maybe CYDA staff to try and look within, check their privilege, [and] try and remove any unconscious bias so it's easier for us to be equal."

Others' attitudes

Throughout the activity – and the entire consultation session – many young people shared how the attitudes and actions of others are a barrier to inclusion for young people with disability.

"I think a lot of it is around education, especially things like this [consultation session] – listening to young people – and making sure the people in charge to make decisions that they have an education on what they are making decisions about. Because being able to dismiss it for them is easy, but for those who are being dismissed, it takes a huge chunk of our quality of life and our ability to actually access the world, spend time with friends, and live life as a young adult just like any able-bodied can."

"My barrier is when people not like to learn and listen about when I talk about self-advocacy."

"When people don't listen and don't want to learn about my disability it infuriates me."

"Old people thinking I'm too young to be disabled and too young to use mobility aides. They need to change that perspective of disability. Because it's not visible if you take away my aides or if I'm masking really well, so they don't see me as disabled and they will like abuse and harass me for doing things like parking in disabled spots even though I've got my permit and even though I do use a chair, a wheelchair, so yeah, that's a barrier for young people specifically."

The NDIS

Participants discussed how the process of gaining access to the NDIS and applying for certain supports under the scheme has acted as barriers to inclusion in their lives.

"I think one of the biggest barriers I've found is that a lot of people that have [been] put in charge of making decisions for youth with disability, even in accessing the NDIS, have

no knowledge or education on disabilities or chronic illnesses. I was actually really shocked to find that the people put in charge of making the decision for whether or not I was accepted for supports in the NDIS, or even accessing it, knew nothing about most of the conditions and especially mine being rare, I was denied a lot of supports that they deemed unnecessary, but they had absolutely no knowledge on the actual condition and that those supports that they deemed unnecessary are actually life changing for me."

"I actually had issues with the NDIS trying to tell me that … my using mobility aides is in line with what's expected for someone my age. When I applied I was 21. I don't know what sort of 21 year olds they hang around, but I haven't met a whole lot that use like roll aiders or walking sticks or wheelchairs. … It took me two and half years to get approved because they just would not believe a young person with diagnosis and lots of reports and everything you needed to prove disability and permanence and all that stuff, they just could not believe that I was disabled. And I know so many people with the same experience."