



Children and Young People
with Disability Australia

PO Box 172, Clifton Hill VIC 3068
P: 03 9417 1025
P: 1800 222 660 (regional or interstate)
E: info@cyda.org.au
ABN: 42 140 529 273

The Hon Ronald Sackville AO QC
Chair of the Royal Commission
Royal Commission into Violence, Abuse, Neglect and Exploitation of People with
Disability
GPO Box 1422
BRISBANE QLD 4001

30th November 2022

Dear Commissioner Sackville and fellow Commissioners,

Please accept Children and Young People with Disability Australia's *submission on Targeted Engagement* (attached with this letter) as a formal submission into the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission).

The Targeted Engagement involved a series of consultation sessions with six young people with disability. A report summarising consultation participants' contributions forms this submission which urges the Disability Royal Commission to shine a light on the exclusion, discrimination and mistreatment of children and young people across all systems and areas of life, and in particular we recommend;

- that school, university and department staff regularly undertake disability awareness training
- incentivising and supporting accessibility and positive hiring practices (inclusive of training) in all employment sectors
- ensuring safe and quality supports for all by addressing the gaps in appropriate services for those not eligible for the NDIS
- funding, promoting, and supporting awareness campaigns and disability led research. This includes taking steps to encourage people with lived experience to take part in and lead/conduct research.

We urge the Disability Royal Commission to make bold and targeted recommendations to government to highlight systemic injustices, drive reform and coordinate action to ensure the rights of children and young people are upheld.

If you would like to know more about this submission or CYDA's work, please feel free to contact me on (03) 9417 1025 or lizhudson@cyda.org.au.

Kind regards,

Dr Liz Hudson
Policy and Research Manager
CYDA

Website www.cyda.org.au
Facebook facebook.com/CydaAu
Instagram [cydaaus](https://instagram.com/cydaaus)
Twitter [@CydaAu](https://twitter.com/CydaAu)

Submission to the Disability Royal Commission: Targeted Engagement with young people with disability

**Children and Young People with Disability Australia
November 2022**

Authorised by:

Dr. Liz Hudson

Policy and Research Manager

Contact details:

Children and Young People with Disability Australia

E. lizhudson@cyda.org.au

P. 03 9417 1025

W. www.cyda.org.au

Contributors:

We wish to acknowledge the six young people with disability who contributed their time and expertise to this project.

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Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

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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 make a submission to the Disability Royal Commission on behalf of a group of young people with disability who were involved in Targeted Engagement sessions with the Disability Royal Commission.

In enacting its strategic goal of supporting young people to take control and call out discrimination, abuse and neglect, CYDA collaborated with the Disability Royal Commission to undertake the targeted engagement, capturing the lived experience of several young people living with disability who have been involved in CYDA's programs.

This submission outlines the experiences and recommendations of these young people, with a focus on the following topics:

- Education
- Employment
- Access to quality and safe support in all settings
- Community attitudes and inclusion

About the ‘Targeted Engagement’

The Targeted Engagement involved a series of consultation sessions conducted collaboratively between the Disability Royal Commission (DRC) and Children and Young People with Disability Australia (CYDA).

While the Targeted Engagement was initiated by the Royal Commission’s community engagement team, CYDA had significant input into the structure and format (inclusive of discussion topics and individual questions) as well as recruitment. The topics discussed during the consultation sessions, aligned closely with the previously published *What Young People Said* papers which were developed by CYDA with input from young people following the 2020 National Youth Disability Summit¹.

The Targeted Engagement addressed multiple topics through a series of discussions with six young people recruited by CYDA. Participants were recruited from CYDA’s existing networks of young people with disability; inclusive of those individuals taking part in other CYDA programs/ projects (including the Young Leaders Program). Crucially, the group of young people remained consistent across multiple engagements. This ensured continuity, rapport and establishment of trust, allowing for robust, in-depth discussion.

Facilitators were drawn from both the DRC and CYDA and were supported by both a CYDA Safety and Wellbeing Officer as well as counselling support provided by Blue Knot.

The Targeted Engagement took place over three evenings. These three sessions were structured in the following manner:

Each topic was afforded 45 minutes for discussion (allowing for introductory activities and appropriate screen breaks throughout)

21 June 2021 - Session One served as an introductory information session that allowed participants to become comfortable with the process, being introduced to the facilitators as well as each other.

28 June 2021 - Session Two covered the topics of ‘education’ and ‘employment’.

5 July 2021 - Session Three covered the topics of ‘access to quality and safe supports in all settings’ and ‘community attitudes and inclusion’.

Each topic was presented to the participants of the Targeted Engagement as both an ‘overarching’ question and a series of more specific questions. These questions were made available to the participants before the session. Due to time constraints, not all questions were addressed directly; acting more as a framework and are outlined throughout this paper to provide additional context.

Consultation sessions were recorded via Zoom and then transcribed. These transcripts were relied upon to ensure integrity of the data in the development of this submission.

¹CYDA (2020) [National Youth Disability Summit - What young people with disability said - Awareness, Access and Inclusion Position Paper](#)
CYDA (2020) [National Youth Disability Summit - What young people with disability said - Employment Position Paper](#)
CYDA (2020) [National Youth Disability Summit - What young people with disability said - Education Position Paper](#)
CYDA (2020) [National Youth Disability Summit - What young people with disability said - NDIS Position Paper](#)
CYDA (2020) [National Youth Disability Summit - What young people with disability said - Mental Health and Wellbeing Position Paper](#)

What Young People had to Say

What follows is a collection of responses (anecdotes) relating to education, employment, access to safe and quality supports in all settings, and community attitudes and inclusion. These topics represent distinct sections in this report. The responses were provided by the participants of the Targeted Engagement via verbal conversation, zoom chat and google slides. Where possible anecdotes have been organised by theme. Participants have requested to remain anonymous and as such their responses are de-identified and attributed to 'young person with disability'. To highlight their responses, direct quotes from the participants are presented in italics throughout this report.

Education

Young people with disability do not have equal opportunity to gain an education on the same basis as their peers without disability. A 2019 national youth survey found that compared with those without disability, twice the proportion of respondents with disability reported that they were either dissatisfied or very dissatisfied with their studies. CYDA's own national survey also found that approximately half of respondents disagreed or strongly disagreed that students with disability received adequate support in their education.²

Questions

Overarching question: How was your experience of school/education?

1. What made you feel included or excluded at school?
2. How easy was it for you to access necessary support or adjustments at school?
3. What does inclusive education mean to you?
4. What was challenging about school?
5. How could these issues be addressed?
6. What support did you get to prepare you for life after school, including further education and work?

Key Themes

The Targeted Engagement began with participants being asked about their experiences in education (see questions above). The resulting conversation had a distinct focus on the persistent challenges young people faced in having their needs met. This difficulty endured across primary, secondary, and tertiary educational settings. According to consultation participants, this barrier is systemic and multifaceted as outlined below:

² CYDA (2020) [National Youth Disability Summit - What young people with disability said - Education Position Paper](#)

Educational institutions maintain rigid policy and practice that often prevents an individual's needs from being effectively met as they navigate complex systems and considerable red tape.

"I topped my cohort for the mid-semester for that subject and, due to that, my university was scared to give me my disability provisions as they wanted to prove that my marks were actually my marks and not just due to my disability provisions In the end I only just kind of finished - I even had to leave a few things blank, which is something that I haven't done in an exam since before I got any of my provisions. So that was a real I guess slap in the face of oh, if I want to be able to finish exams, I can't, I'm not allowed to do well in them"

"I do a course that doesn't have as much group work because my lecturers are always reluctant to apply my access requirement to group"

"Actually I'm made to feel like you're gaining the system when you get adjustments"

Participants reported that access to support and reasonable adjustments are primarily 'gate-kept' by a continual need to show evidence of diagnosis or a requirement to "prove your disability". This places a considerable administrative burden on individuals which frequently results in disengagement on the part of young people with disability.

"I acquired my disability whilst studying at university and my entire experience since that has just been about proving and justifying and explaining myself, having to actually prove that I have a disability and then provide further evidence if things change and having to have the same conversations each semester working out how I can fit in to the course or the unit or the university in general rather than it being designed for everyone."

"There's an expectation we should be grateful for just being given what we need."

It was noted there is a distinct lack of understanding or knowledge of disability within educational institutions and their power structures, including decision-makers and those individuals who can affect policy. This places the burden on young people with disability and/or chronic illness to educate those around them and take on the role of self-advocate. This process leads to considerable disengagement due to exhaustion and fatigue.

"It felt like a continual process of being reset. So it was like an ongoing cycle of having to remind people that I'm disabled, remind people that my needs are different".

"For me it's frustrating because.... my documentation that I have to provide every semester doesn't change. It still says that I have a permanent disability that's lifelong that needs this and this but, yeah, I still have to give it every semester"

"I have found it very frustrating because I have to do a lot of self-advocacy and still accept things that aren't fair even though the like reasonable adjustments that I ask for, I have to just accept things because it's either that or I continue fighting for another four months and just delay things forever".

According to the young people with disability, success in the school environment frequently depended on the individual's ability to employ self-advocacy skills, describing the experience as one of frustration;

"Similarly to the people that have just spoken, yeah, complete exhaustion and frustration"

There is also poor communication between students, education providers and families/caregivers.

"My meeting with the disability support service was good, but getting the staff to follow it is hard. They think group projects mean my access requirements are too hard to implement."

Participants reported that there is insufficient attention given to; accessibility, adherence to universal design and addressing ableism and discrimination.

"People would kind of point out that person is the disabled one in that year ... and obviously it creates a very toxic environment I ... vividly remember being in year 7 and going oh my goodness, I don't want to be seen as a disabled person.... there was both a social and system structure within the school that, yeah, ostracised disabled people."

"When I was in primary school I had a lot of surgery, I was in a wheelchair for quite some time and the school just didn't see a point of getting any access requirements. They just put literally they said get teachers to wheel me up, so that wasn't really accessible."

I went to a pretty big high school, had to push myself from one side of the high school to the other side, and it made me so exhausted. Then that sort of had an effect on my grading and schooling because I was so exhausted from going from one side of the school to the other side of the school in summer and being all hot and sweaty and couldn't concentrate because I was in that much pain. I think university it does good things, but it's still got a long way to go .."

"I would say for me, especially in primary and secondary education- secondary more- there was quite like an atmosphere of ostracisation for disabled people... For example, as an athlete with a disability, when we were awarded or did big achievements in athletics, it was in a separate category to the able-bodied sports players. Our photographs were in different sections."

Consultation participants spoke positively about supports that promoted inclusion and could be implemented without isolating the individual from their peers. This includes peer-based assistance during tertiary education such as the support provided by their student union. Participants also noted the importance of: a) universal design, b) adaptive and flexible supports, c) a strong focus on inclusion and; d) incorporating disability pride and visibility into student life.

Comments from participants included:

"Things such as the physical design of spaces, the only wheelchair-accessible table is down the very front of the lecture hall all by itself and also like cultural things such as like in general just university, I feel that there's not a real celebration of disability."

“Feeling very kind of siloed and othered and it’s just seen as disability is dealt with by those who are disabled and it’s not really seen as a collective responsibility, which means that kind of bureaucracy and red tape have been prioritised over things that could have real, meaningful change.”

“We’re not really taught about the celebration of disability because I even think of just an example of even when I got certain amendments done to exam conditions and that, I still felt this immense pressure to not take up to take up minimal space or to not use the extra time I’ve been given.”

Education recommendations

Targeted Engagement participants expressed that the experiences of young people with disability could be improved through:

- Encouraging or enforcing the consistent application of the principles of universal design.
- Requiring school, university and department staff to periodically undertake robust disability awareness training.
- Including disability awareness as a compulsory unit in university courses, laying the foundation for a workforce that understands disability.
- Adopting a holistic, whole-of-person approach, by addressing ableism in education.
- Encouraging flexibility and adaptability on the part of education providers.

Employment

Young people with disability are one of the most disadvantaged cohorts in the labour market. They experience the intersectionality of systemic disadvantage and oppression of both being a person with disability and a young person – with this disadvantage being even further amplified by other demographic factors, such as socio-economic status, ethnicity, gender or sexual diversity, or living in a regional or rural area.

Young people with disability in the labour force are more than twice as likely to be unemployed than older adults with disability (24.7 per cent compared to 7.9 per cent). Young people with disability are also more than twice as likely to be underemployed — meaning they have the capacity and desire to work more hours than what they are currently employed.³

Questions

Overarching question: What has your experience been with finding a job and working for an organisation?

1. Have you experienced any issues whilst looking for work after finishing school or further studies / training?
 - a) How could these issues be addressed?
2. Have any organisations or services supported you to find work?
 - a) Did you find them helpful?
3. Do you have a job at the moment? Are you happy with where you work and the opportunities you have in your job?
4. Have you faced any issues in your current or previous workplace? (E.g. discrimination, negative attitudes and stereotypes, issues around disclosing your disability, reasonable adjustments, workplace environment, etc.)
 - a) How could these issues be addressed?
5. What would make workplaces more inclusive?
6. What ideas do you have about how to make the transition from school / further studies into work more inclusive for young people with disability?

Key Themes

When asked about their experiences relating to employment (see questions above), participants spoke about the importance of having disability awareness and authentic inclusion entrenched from the ground up. Participants felt strongly that if inclusion is not

³ CYDA (2020) [National Youth Disability Summit - What young people with disability said - Employment Position Paper](#)

comprehensively embedded in an organisation's practices and procedures, ableism and tokenism would become all too pervasive.

When speaking about a systemic understanding of disability, participants reported;

"People need to have disability training ...If we really want to make an inclusive society, disability should be another part of HR "

Those present during the Targeted Engagement expressed concerns regarding a lack of flexibility when entering the workforce. Notably, it is the view of participants that mainstream employers are rigid when it comes to the requirement to work full-time. This creates a significant barrier to young people with disability seeking engagement in a flexible, part-time and other modes of employment .

Participants also emphasised that there is a significant burden on young people with disability to educate potential employers on disability and advocate for diverse hiring practices. It was recommended that this role should be largely carried out by disability employment services and government instead.

When referencing existing employment supports, several participants indicated that Disability Employment Services (DES) are extremely difficult to work with, noting that DES staff lack relevant expertise and up-to-date advice. They also reported significant staff turnover further emphasising the burden on young people to explain and re-explain their circumstances.

"But overall it was definitely a rolling door of like each phone call I had a new manager for my case and it was really confusing because it would be like, 'Hi, this is [Name omitted]', 'Hi, this is [Name omitted]'. I'm like, 'Whoa, who is dealing with my case?' It felt like they had no training with disabled people either because they're super - like a little bit patronising in being super impressed being, 'Wow, you went to university, how did you achieve that being disabled?' And then the same idea of wanting to hold on to be that success story because they're like, 'You're sure to get a good job.'"

Young people with disability described DES employees as having minimal disability-specific knowledge and being challenged by the prospect of appropriately meeting the needs of young people who have completed tertiary education.

"The disability employment service provider has been a constant headache. They have no understanding. They're not used to dealing with people in higher education trying to get jobs. ... I am very close to finishing a bachelor with honours and they referred to it as a diploma and they tell me it's about just getting my foot in the door and that I need to accept work as a receptionist and I tried to explain if I'm going to be an engineer, I need to spend that time doing engineering and doing engineering skills. I can't work my way up from receptionist to engineer at a company, that's not how that works. She's like when they look for a new employee, they're going to go to some random or the lovely lady in reception who they've come to know. I was like 'The person with engineering experience, why am I explaining this to you?'"

Concerningly, participants also questioned the reputation of the disability employment service system, and stories outlining unprofessional behaviour and in some cases incompetence by providers were unfortunately, all too common. This included having very low, or no expectations, and negative attitudes.

And she patronises me a lot and takes my questions trying to - it's very clear that they don't take the time to explain paperwork and forms to anyone because whenever I have questions, it's always because I'm autistic. It's like, "I knew you'd be one for details, I should have just explained it to you because I know you like to understand things." It's like everyone deserves to understand paperwork that they have to sign legally.

And it's just been - they screwed up my resume and basically put lies on it and so it was almost very embarrassing at the job interview that I went to and luckily, I ended up getting that job and my now manager, she says whenever they see that template that they know is from a disability employment service provider, they never hold the resume with any real regard. They don't hold it against the person because they know how bad the DES people can be with that and it's just been like horrific."

On the topic of government support, participants also described the negative impact of having job-seeking requirements directly linked to their welfare payments, creating unnecessary stress in the absence of providing effective solutions or employment options.

"I was forced into a disability employment service provider for welfare, because of welfare, because I was forced on to JobSeeker because I took too long to do my degree. I don't know how that neatly fits in there. If you take too long to study, you get forced off youth allowance and forced on to JobSeeker.

Furthermore, participants highlighted disclosure of disability or medical conditions as a key issue relating to employment outcomes. This included a discussion of the impact of the decision to disclose a disability or medical condition. Participants described a need to diminish their disability in interview settings whilst having to manage inappropriate interview questions.

"Just a content warning ableism [participant provides a content warning about ableism before making their point], I don't know what else I'd describe this as, but it's like I feel like when I would go to interviews and stuff I was going for a retail job and they said, 'Can you lift a box?' - it wasn't like a heavy box, it was a light box. I thought you're never going to ask this to someone else. Every time a disability comes up in an interview, undersell as much as possible because the more we talk about it, it's more I'm already done with this interview."

According to participants, engagement in employment is highly dependent on the sector as well as the attitudes of individual employers. This can include a lack of or low expectations, whether from the education system that would typically support young people to transition into work or from disability employment services.

To address barriers to employment in mainstream sectors, participants described an overreliance on seeking employment within a more supportive environment such as the disability sector or tertiary education sector. In some cases, these work environments were more understanding of the individual's need for adjustments as well as difficulty accessing

reasonable adjustments. However, such working environments did not always align with a participant's employment goals and were pursued out of necessity.

“Some of my own like ableist or tokenistic experiences ... it's kind of so much easier to find work as a disabled person in the disability sector - for example, doing internships through uni, wonderful opportunities where it's so easy to slide into amazing opportunities that gave me government experience, policy experience. It was really good. But at the same time, the downside, sometimes it was a little bit tokenistic. For example, one workplace I was on reception, and they made me a badge that just said "I am disabled" and I was like I don't know why I have this. So that felt a little bit tokenistic.”

Discussions also highlighted the prevalence of 'gaslighting' by mainstream support systems (medical, employment and social service). Participants described how 'gaslighting' occurs when a person with disability has their belief in themselves or their needs undermined by others. They outlined that this often occurs when interacting with powerful professions (e.g. doctors) or institutions (such as Centrelink, NDIS or DES).

Participants referred to experiencing exclusion from opportunities based on specific disability criteria, for example, discriminatory employment indicators such as a requirement to have a driver's license. According to participants, the online applications used by many large organisations were designed in a way that they could not be completed by an applicant once they had indicated that they had a physical disability. In contrast, participants spoke positively of hiring processes in the public service including disability-specific streams.

“With some of my first application experiences I had where they have like, I guess, the online applications and as soon as I clicked the button that said I had a physical disability, the site shut down and said, "You are not suitable for this role", but it was just to be a cashier at a local shop and I don't see any reason why my disability would have impacted my ability to perform that role. And there was no question of what sort of physical impairment I had. It was just, "Oh, you have a physical impairment. No, we don't want you.”

“To disclose your disability or not to disclose your disability, that's the question.... I steered well clear of disability service employment providers because I've heard horror stories of people with higher ed degrees like (engagement participant) said applying for grad programs myself”

Participants spoke about inefficiencies and awkwardness caused by a lack of representation of people with disability in workplaces. They noted that many negative experiences could be avoided if the average employee and organisational hierarchy had experience interacting with people with disability within a range of employment settings.

According to participants there is no exploration of ways to overcome barriers or nuance on the part of employers. They reported that, all too commonly, businesses were not receptive to employing people with disability. Participants felt that they are being put in the 'too-hard basket' by these employers; leading to young people feeling that mainstream sectors are inaccessible for disabled job hunters.

The stark difference about how inclusion—promoted as policy rhetoric on employer websites—translates to reality on the ground was evident in experiences shared. Participants noted that the true meaning of accessible and inclusive is misunderstood in mainstream society. The following quote illustrates the importance of entrenching meaningful inclusion over the use of superficial jargon.

“What I've learnt through my employment history is everyone can label themselves as inclusive, but once you get there you realise hang on, they're not inclusive and it's a marketing buzzword.”

Participants said inclusion should be the responsibility of the employer as a matter of course and the burden to ensure inclusivity should not rest on the person with disability.

Finally, employers view and assess the capability of young people with disability in isolation from their support networks. Viewing informal support as a negative rather than a positive.

“When you bring up having like parents or other people who act as supports. It shouldn't be seen - like we need to change that idea that having those supports is a negative thing and makes you inefficient, an inefficient worker, when instead that should be a good tick of, ‘Hell yeah, they've got these people who are helping them be workers, basically.”

Employment Recommendations

Targeted Engagement participants expressed that the experiences of young people with disability could be improved through:

- Developing and implementing a greater number of ‘on the job’ programs similar to the existing Stepping Into Program⁴.
- Incentivising and supporting accessibility and positive hiring practices (inclusive of training) in all sectors in preparation for hiring people with disability. This should include, promoting increased representation of disability in upper management.
- Implementing comprehensive disability literacy and accessibility training within all organisations spanning both mainstream and disability-specific sectors.
- Incentivising employers to offer diverse mainstream employment pathways that would allow greater flexibility (such as part-time work during graduate positions)
- Developing and funding programs that focus on ‘disability pride’; ensuring that employers see the strengths associated with lived experience of disability.
- Ongoing development of post-school transition activities that include a focus on diversity and disability, ensuring educators, employers and policymakers adopt a human-rights and strengths-based approach.

⁴ The Stepping Into Program is an internship program for university graduates with disability developed by the Australian Network on Disability. <https://www.and.org.au/students-jobseekers/start-an-internship/>

Access to safe and quality supports in all settings

According to the Australian Disability Strategy⁵, people with disability should be supported to live more accessible and connected lives within their communities so that they are able to fully participate in a way that is safe for them. This includes having access to a comprehensive and effective health, transport and service system tailored to individual needs. Importantly, this requires accessibility to be an integral part of the design of services and systems to overcome barriers and help support the inclusion of people with disability in their communities.

While the above claims by the Australian Disability Strategy focus on people with disability of all ages, many of the same issues resonate with young people, as highlighted in Mission Australia's 2021 youth survey⁶. According to the survey, "close to two in five (39%) young people with disability found it difficult to do things in public places with friends compared with 22% of young people without disability while nearly a quarter (23%) of young people with disability found it difficult to travel around the community compared to only 12% of young people without disability" (p.6). The young people participating in the Targeted Engagement also raised concerns about access to support services and inclusion in their community, further reinforcing the survey findings, as detailed in the following section.

Questions

Overarching Question: In your life, how have you found the services available to you as a young person living with a disability?

1. What services do you use regularly? For example: Support services, advocacy, health and fitness, recreational, online
2. Are these services / programs easy to access and use?
3. What would make them more user-friendly?
4. What make services safe? When you are in places like a public space, a hospital, a clinic, etc.
5. What makes you feel safe or unsafe?
6. Can you tell us about where you live? Do you live independently or with others? Is your home accessible (including accessible by public transport)? What makes you feel safe or unsafe at home?
7. If something went wrong or you were treated badly / unfairly, have you made (or would you make) a complaint or reported it? If you have made a complaint, how was this experience?

⁵ [Australian Disability Strategy 2021-2031](#), Inclusive Homes and Communities, Policy Priority areas 3-5

⁶ <https://www.missionaustralia.com.au/publications/youth-survey>

Key Themes

The main concerns identified by young people in this topic were about a) limits to service access and availability and b) the complexity relating to service navigation. Young people with disability described the many challenges associated with navigating both health and disability services, remarking that it can feel like being sent on a “wild goose chase” (just to get the help they need). Participants asserted that accessing services can be traumatic and deficit-focused. This can lead young people with disability to disengage in order to avoid bureaucratic processes within services such as Centrelink and/or the NDIS.

There is significant fear associated with being categorised as disabled by mainstream services, causing young people with disability to withhold information, due to a lack of disability awareness and understanding on the part of mainstream services who have consistently presented significant administrative burdens to young people. The NDIS has proven equally complex and difficult for young people navigate.

When asked about challenges to accessing safe and quality supports, participants highlighted a lack of mainstream and disability-specific support in rural and regional communities. This led to a discussion of the barriers associated with travel to major cities in order to access sufficient support.

“When I was younger, it was a lot of having to travel into Sydney, travel to the city to be able to get access to a lot of services. I guess now I'm older there's a few more that I can access a bit closer to home, but still if I want to see, say, a specialist, I would not ever expect to be able to see someone in less than an hour drive from home.”

Young people with disability described significant physical barriers to making use of public transport. Participants remarked that this creates an unwanted dependence on informal support, claiming that the NDIS enforces dependence on others, in particular reference to transport funding. The independence and capacity of young people with disability can also be significantly impacted by changes in NDIS policy and NDIS plan reviews.

When asked about what could alleviate this barrier participants spoke in support of telehealth; stating that it addresses many of the physical barriers to accessing certain supports. This included long travel times, maintaining COVID-19 safety, as well as managing symptoms such as pain and fatigue. However, participants made clear that telehealth does not resolve support availability or wait times.

Participants discussed the difficulty accessing support; expressing concern over the dependence on diagnosis (particularly associated with the NDIS). Results from the sessions also revealed that system-level structural barriers and rationing decisions applied by NDIS professionals (who serve as gateway operators to the scheme) lead to differential pathways for people with disability, exposing issues of social justice and fairness in the system. Young people expressed that the NDIS is dividing people with disability into unfair categories—where the closure of non-NDIS services is resulting in a division between those who are NDIS eligible and those who are not.

“Something that I wanted to bring up is the “cliff” between NDIS and not having NDIS support. There's quite a threshold to get on the NDIS the way the NDIS is set out, not every disabled person needs the NDIS, but there

are still many disabled people who might not need the NDIS but still need some support and like in Victoria there's the Home and Community Care program and there was like a youth-specific one as well which is supposed to pick up those people, but it's a very stretched service. Like you have to - the way it gets divided up is by like - they look at all the people and they're like this person has it worse, so that's who those supports are going to because they're not funded enough."

Young people expressed concern over the inadequate supply of specialist appointments under Medicare as resources are being diverted away from existing services towards the NDIS. Those deemed ineligible face an uncertain future in the absence of continuing community health support. Furthermore, the NDIS maintains a strong focus on diagnosis and this is a significant barrier for many young people. Those, who are NDIS ineligible suggested they are at a disadvantage when limited to mainstream services due to having a particular diagnosis. Additionally, participants cited a lack of disability-specific knowledge within mainstream health services as a considerable barrier to positive outcomes.

Conversely, participants expressed that dedicated support services can be effective during key transitions (such as when moving from youth to adult services). However, these services also suffer from many of the same shortcomings seen in other systems discussed in this report (staff turnover, lack of funding etc).

"What would make it easier? I guess for me there's a thing called I'm in New South Wales and there's a thing called Trapeze, which is meant to catch you from children's services and carry you across to adult services. Unfortunately it hasn't quite been a beautiful trapeze trip, it's kind of been a bit of a fall, and I think that largely comes from inconsistency with who's managing your individual case and then overall who's working in the department because every time I've like contacted them, it's been a new person. It's just been amazing cc'ing being like, "Hi, this person has left, I'm going to have to cc this person to then cc you into this other person" and so every time it's a new person and I think so a good thing would be to have consistency in who's managing your case and then consistency just generally with the department that's meant to keep these young adults afloat basically."

According to participants, the current rigidity of the mainstream medical system presents several challenges for young people. This includes a dependence on short-term referrals to see specialists, the cost burden associated with obtaining and reaffirming diagnosis and the limited availability of specialists.

"There are not enough specialist appointments (only 5 a year on Medicare). This is bad for young folks because it can worsen our disabilities by denying us care to stop it regressing/worsening which can take away opportunities from our future."

Participants further emphasised the cost of specialised services and the impact of the NDIS on the cost of services. This is particularly evident for young people with disability without access to the NDIS. The cost of private health insurance was also a concern for participants. This prompted a discussion of the economic disadvantage faced by young people living with disability and the impact this has on accessing support.

Accessing adapted vehicles⁷ and specialised licenses remains heavily dependent on the mainstream medical system. According to young people, these supports are heavily gate-kept by specialist assessments. Participants described difficulty in getting a license due to a lack of knowledge on the part of healthcare providers. There is also a significant cost and administrative burden associated with accessing vehicle modifications. The following is just one example of the impact of navigating bureaucratic red tape on young people with disability described in detail by one engagement participant:

"On the topic of driving, it was quite - so I got my licence, a full unrestricted licence. I worked really hard to be able to drive normally, I suppose, yeah, so I obviously did the full process and obviously ticked all the boxes necessary, but then - and I did it all as early as possible. I was a keen bean when I was 16 and did it as quick as I could.

And then last year I was seeking assistance for mods to help me drive without pain, I suppose, and to actually make it easier and what was meant to be a very simple process was definitely not and ended up getting to the rather traumatic situation of me being told that I was going to have my licence taken away, that I was going to have a restricted licence. And obviously for someone that I manage to get my full licence following the road conditions necessary as a "normal" person, it made - completely changed my relationship with, I guess, like government services in that I largely avoid it because it only causes pain and doesn't empower me as a disabled person. It in most cases restricts me or tries to take away liberties that I was able to get when I wasn't, I guess - on a piece of paper wasn't registered as disabled, which is obviously pretty awful and shocking to have.

So from then on henceforth - luckily that got sorted, but it was very, very traumatic - like very - lots of tears, to say the least. So now, yeah, I really try my hardest and kind of feel like I've learnt the lesson don't ask the government for help because it's only going to cause you grief. You're only going to have things taken away from you rather than actually be benefited.

I'm a very cautious person now when it comes to seeking mainstream assistance. So I either have to have a support (formal or informal) take me driving if driving is too much or I have to take public transport, but that's really difficult for me because I can't carry a bag for very long. So it's a bit of a pickle, yeah. So that's my little share."

The risk of losing access to services depending on funding can be incredibly stressful for young people. This can be a review of an NDIS plan, the closing of a program or reductions in advocacy funding provided by the government.

Participants highlighted the burden on young people with disability to ensure that their voices are heard and their needs are met, exacerbating burnout and a likelihood of disengaging from their community or services. This was particularly evident when making complaints. This is due to a lack of accountability on the part of services and action. When speaking about their experience with taxi services, one participant noted:

⁷ The NDIA defines 'vehicle modifications' as changes to a vehicle, without which, a person with a disability would be unable to drive the vehicle or travel as a passenger.

<https://www.ndis.gov.au/participants/assistive-technology-explained/vehicle-modifications>

"I've tried to complain a few times but I feel like it's a waste of effort and time because there's usually no action taken and nothing gets resolved and it's just, yeah, that's my experience with taxis and stuff. I did make a formal complaint, but even calling up saying "hey, this has occurred", and stuff, "Yep, yep, we'll get on to it" and no action is taken and if you know nothing is going to be done, I don't see the point of like complaining. Complain to the driver or person, complain to the organisation, I don't think they'll care, it's what is the point? That's my sort of mood."

Participants spoke repeatedly of the isolating experience of being a young person with disability due to the lack of awareness by mainstream services. They claim that as the primary holder of disability knowledge and experience, young people are required to relentlessly advocate for greater understanding by health professionals and service providers. Whilst this burden of self-advocacy and isolation remains unrecognised by the service system, discrimination and ableism will continue, unchallenged.

This was particularly relevant with transitional services. According to participants, there is an additional burden associated with telling their story due to staff turnover/loss of knowledge within service providers. Participants highlighted a need for greater consistency of staff and the role of government in providing this through sustainable funding models.

Participants note that the divide between state and federal support systems can be challenging; leaving young people unsure of where to get help. This includes state systems deferring to the NDIS or the NDIS deferring to the education system.

"There's a real issue between the interfaces between the state and federal care, so like education - like schools and stuff is one of those places that that happens because like - the best example I can think of is with the NDIA's proposal for early intervention supports for children on the autism spectrum. They're proposing cutting funding by 40% when a child reaches the age of 7 because in the agreement between the state and the Federal Government the state is supposed to pick that up with schooling, but we know that doesn't happen in practice and so the Federal Government is trying to propose these decisions, they're not working collaboratively, and it just continues to leave gaps and cliffs."

There are significant challenges to young people with disability moving out of their family homes. This includes gaining access to sufficient support to remove dependence on informal support.

"I live with my partner and both of us are disabled. The biggest barrier for me living here is not having a licence. The station near me doesn't have lifts or escalators, only a steep ramp, so some days I go to the next station down if I'm too sore for the ramp. I wish I could access some support to help maintain living independently. I do the best I can, but we are functioning off of the kindness of my friends. Being able to access food delivery is very useful. ...Growing up in the country I didn't have access to many things being able to be delivered. I live in a quite noisy location, which is very difficult some of the time."

Young people with disability often prefer informal support due to a sense of safety, exemplifying the need for better disability awareness and understanding within support sectors (mainstream and disability-specific alike).

Recommendations - Access to safe and quality supports

Targeted Engagement participants expressed that the experiences of young people with disability could be improved through:

- Broadening eligibility for the NDIS as well as ensuring access to appropriate services for those who are not eligible for the NDIS.
- Increasing mainstream funding to ensure the continuity of access to services. This includes maintaining and expanding access to Telehealth services beyond the COVID-19 pandemic.
- Ensuring comprehensive disability-specific training beyond that of the existing Cert III and IV, ensuring a robust understanding of disability. This includes embedding trauma-informed practice in all mainstream and disability-specific services.
- Promoting a diverse range of ways for people with disability to connect, communicate and gather (build community). Enabling the sharing of knowledge and experience.
- Strengthening existing and implementing new transition services, including transitions from youth to adult services.
- Improving enforcement of accessibility standards as well the dissemination of accessibility-related information. Central to this is the implementation of effective complaints and feedback mechanisms.

Community attitudes and inclusion

People with disability have faced a long history of low expectations and this pervasive attitude remains today. As recently as 2018, a survey of community attitudes and beliefs about people with disability showed that nearly one quarter (23.5 per cent) of survey respondents agreed or strongly agreed that people with disability have less to look forward to than others. The survey also demonstrated that 11.8 per cent of respondents agreed or strongly agreed that people with disability are a burden on society, and 21.9 per cent agreed or strongly agreed that people should not expect too much from those with disability.⁸

Questions

Overarching Question: What have community attitudes been like towards you and other people with disability through your life?

1. What are some examples of people's attitudes or beliefs about young people with disability? Both positive and negative.
2. What do you think is the impact of these attitudes?
3. What do you feel could or should be done to promote positive attitudes towards young people with disability?
4. Do you think community attitudes towards you have changed across different stages of your life?
5. Do you feel included and respected in your community? This includes all Communities.
6. Do you feel you have a voice and choice/s in your community?
7. What would need to change or how could you be supported to have more of a voice and choice/s in your community?
8. What does an inclusive society look like to you? What needs to change in Australia to make you feel included?

⁸ CYDA (2020) [National Youth Disability Summit - What young people with disability said - Awareness, Access and Inclusion Position Paper](#)

Key Themes

When asked about their experiences of community attitudes and inclusion, participants expressed concern with the prevalence of tokenism, sensationalism and being admired for just 'showing up'. Young people described these attitudes as pervasive across a range of settings including;

- witnessed experiences of the phenomenon of 'inspiration porn', - a phrase coined by disability advocate Stella Young. Participants described being made to feel like a commodity when treated as 'inspirational'.
- these assumptions that the actions of a person living with disability are inherently inspirational means that it becomes more difficult to talk about things that are hard.
- the pressure to succeed and "be that kind of disabled person".
- community attitudes towards disability can be mixed, depending on which space they are engaging in. This leads to young people having to deal with inconsistency.
- there is a distinct lack of community-wide disability awareness activities. Conversely, the International Day of People with Disabilities was viewed by participants as tokenistic, especially when adopted by the corporate community without full involvement of young people themselves.

There are challenges associated with young people being insulated within disability-specific spaces or the disability community. This can include the presence of lateral violence⁹ in many disability sporting communities. Young people with disability spoke about the challenges they face due to peer-to-peer conflict and competition. When asked how to address this lateral violence, participants outlined that the hierarchy that caused this lateral violence was imposed by mainstream society who create expectations of success. The way to address this is to allow disabled communities the autonomy to govern themselves.

Young people with disability spoke frequently about ableism in public spaces and how this leads to them avoiding/ not making use of public spaces.

"I will just give one story about a broader community situation where I have a local shopping centre which for many years I got to the point where I would only go there if I was with my parents or was with a larger group of friends because of the amount of ableism that I faced at that shopping centre in particular to the point of young kids following me around mimicking my walk or even emphasising and making noises that I don't make and they would only stop if I went and stood next to my mum. And this was still happening to me when I was maybe 18 and 19 and these kids doing it were maybe 13, 14.

It's probably - it's hard and it sometimes does still happen, but it's only I think during COVID times that I've actually now got to the point where I can now confidently go to that shopping centre without my parents with me or without all my friends with me because it's kind of just got to the point where I just try to block it out or I just am so focused on what I'm doing, I don't notice it. But that's a really sad thing that an entire shopping centre is not accessible in my own community."

⁹ Sandi Boucher defines lateral violence as occurring when people in marginalised groups fight between themselves, instead of fighting the powers that affect them and discriminate against them. <https://www.youtube.com/watch?v=ra1k9Lz589E&t=1m33s>

Furthermore, engaging in public spaces can result in young people being mocked, confronted by micro-aggressions¹⁰ and being made to feel ostracised and unsafe.

Disclosure of disability can be another key circumstance where young people with disability must consider the attitudes of others. Participants described facing damaging assumptions as well as a change in attitude when requesting adjustments (particularly in the context of education, employment and healthcare). Young people felt strongly that their identity as a person with disability greatly impacted or informed their experiences of mainstream systems such as the healthcare system.

Infantilisation is one attitude or approach to people with disability that participants indicated was widespread. The experiences of one participant can be found in the following quote:

“that happens so often when we bring up our needs in a space. It’s automatically like well, you have needs, you are now incapable of functioning as an adult or as an autonomous being. Especially I had that situation bringing up an example of infantilisation in a workplace. I was working with an artistic director and I had brought up my needs and her attitude did change to the point when discussions on disability - it was very weird. It was like my points no longer were valid to the discussion. So she was discussing with other creatives about terminology, like what’s the right terminology to use, ‘disabled people’ or ‘with a disability’ and it just wasn’t valid because I was now just infantilised. I just needed help all the time.”

Healthcare professionals were described as making incorrect assumptions i.e. that young people with disability don’t engage in sexual relationships or experience domestic violence. This can make it even more difficult to access crucial, life-saving support. Additionally, participants highlighted struggling with assumptions made about them based on age. A key example is that young people with disability can’t experience chronic pain because they are “too young”. Furthermore, experiences of ageism were evident when accessing healthcare where a provider may feel that a young person with a disability is too young to require particular support.

Participants made clear that these barriers to accessing support (as well as societal pressures) can often lead young people with disability to go without support to avoid social friction. Service providers are ever-present in the lives of young people with disability and play a role in establishing community attitudes and inclusion. This includes large providers having significant influence over how the community views certain treatments.

“Sadly, for autism the narratives are controlled by [the] ‘autism industrial complex’, [large financially motivated service providers]. ABA [Applied Behavioural Analysis] is a huge money maker and those services will do anything to keep that money rolling, which means making sure deficit narratives pervade so they can continue pushing their therapy. ABA is applied behavioural analysis and it’s the gold star for autism. It just tries to squeeze autistic people in non autistic little boxes Many autistic

¹⁰ Micro-aggressions are defined as commonplace verbal or behavioural indignities, whether intentional or unintentional, which communicate hostile, derogatory, or negative slights and insults in relation to developmental, emotional, physical, or psychiatric disability <https://simmons.libguides.com/anti-oppression/anti-ableism>

people call it abuse and lots of people, even previous practitioners, have come out saying that it's worse than dog training.

But I'm particularly motivated about this after today I learnt that Autism Queensland I thought that they were just a state peak, but they're actually a service provider and my co-worker and I looked up their financials on the like Australian charity listing and they made \$18 million in 2020 so 2019 to 2020 financial year from services, service providing. So it's just hugely profitable. But yeah, \$18 million, their entire revenue is ridiculously large and they do with this particular early intervention paper, special paper from the NDIA, they're lobbying because they charge \$90,000 for a person annually to get this therapy and that funding is going to be capped at like 35,000, 40,000. Funding capping is bad. Obviously, they have different interests in lobbying to keep that and have a lot of money and powerful people to be in people's ears to stop that and make sure the cash keeps flowing."

Participants noted the prevalence of therapy methods that prioritise minimising visible differences such as autistic traits like stimming¹¹. Signifying yet again, the role of therapists and service providers in establishing community attitudes and creating assumptions about disability. Participants were concerned about the impact of external attitudes and the significant burden placed on people with lived experience of disability to dispel negative attitudes and define positive ones.

"You're asking disabled people to break down a large complexity about community attitudes, I think ultimately it's so hard for us to do because it's a continual process of validating and invalidating our existence because so much of our lives are decided by external voices to the point that it is not just our access needs or our quality of life, it comes down to even our identity as disabled people, which is completely destructive to community attitudes within the disabled community because it means we're not even able to have our own community growth if external voices are always monitoring it."

Participants described how the stress of needing to be an expert on disability is invalidating. Community expectations and demands on young people to educate those around them was perceived as demoralising. This is especially when that expertise is expected without financial compensation. According to young people with disability lived experience of disability is rarely appropriately valued.

"Sharing lived experience, that being an expectation or providing accessibility advice just because you have a disability. It's our work kind of thing. We hear that a lot without remuneration . . . in the form of gift cards, which isn't as meaningful."

¹¹ The I Can Network defines stimming as behaviours used by neurodiverse people to soothe, stimulate, express emotions, communicate, take in information, process information, store information and/or recall information.
<https://www.facebook.com/theicannetwork/posts/8-functions-of-stimming1-to-soothe2-to-stimulate3-to-express-emotions4-to-commun/1092728560912353/>

In closing the topic, the group noted the prevalence of deficit-focused attitudes. These are often the default. The lives and experiences of young people with disability are significantly impacted when competence is never assumed.

Community attitudes and inclusion Recommendations

Targeted Engagement participants expressed that the experiences of young people with disability could be improved through:

- Normalising a broader range of human experiences and providing role models of young people with disability and their families. implementing more community-wide campaigns such as 'change your reactions'¹² will encourage people with disability to tell their stories in mainstream spaces.
- Funding, promoting and supporting more awareness campaigns and disability led research. This includes taking steps to encourage people with lived experience to take part in and lead/conduct research.
- Implementing disability education and awareness from a younger age through existing primary, secondary and tertiary education.
- Embedding an understanding of disability within all sectors, mainstream or disability-specific. Including the youth sector. Policies should 'activate' mainstream audiences. This should include stronger disability education across front-facing organisations and services.
- Implementing policies and programs that normalise positive, strength-based language around disability. This should include funding more inclusive events (talks, festivals, interactive activities) with universal design as the bedrock.
- Including young people with disability in advisory committees. Ensure lived experience is present from the ground up with appropriate financial compensation.
- Promoting increased awareness of the social model of disability.

¹² Autism Change Your Reactions is an awareness campaign developed by Amaze and the Victorian State Government intended to improve the attitude of the wider community towards people with autism.
<https://changeyourreactions.com/>