









# LivedX Series: What Young People Said

Inclusion and Decision Making

December 2022 **cyda.org.au** 





### **Authorised by**

Skye Kakoschke-Moore, Chief Executive Officer

### **Contact details**

Children and Young People with Disability Australia e. skye@cyda.org.au t. 03 9417 1025 w. cyda.org.au

#### Author

CYDA Policy & Research team staff Ebe Ganon, Youth Council Anderson Christie, Youth Council

### **Contributors**

Anderson Christie, Margherita Dall'Occo-Vaccaro and Chloe Polglaze (Youth Council members)

### Language

The LivedX working group chose to use a mix of person-first and identity-first language ("person with disability" and "disabled person" respectively) throughout this paper series to reflect author preference and the diversity of preference in the disability community.

## **Acknowledgements**

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.

We would also like to acknowledge the important contributions of our community to our work. This platform draws on the insights and lived expertise of young people who participated in our 2021 LivedX focus group series.

This activity received grant funding from the Australian Government.



### **Overview**

Acknowledging the important role that decision making and inclusion play in the lives of young people with disability is critical to achieving the goals around individual power and autonomy in Australia's Disability Strategy<sup>1</sup>. To understand the experiences and perspectives of young people with disability around decision making and inclusion, CYDA hosted a consultation in August 2021 on 'decision making' with six participants and another one in June 2022 on 'inclusion' with nine participants. These consultations were co-designed by an internal working group of young disabled people.

Young people participating in these consultations overwhelmingly wanted to make their own decisions about both high stakes and more mundane things, but they also wanted access to support for instances where they recognised, they needed assistance. When considering the role played by identity in decision making and inclusion, many participants thought those in positions of authority should use an intersectional approach to prevent instances of infantilising and underestimating the ability of young people to make decisions for themselves and therefore feel included. They appreciated when others intuitively understood their support needs but also wanted to be asked directly in circumstances where that was required. The barriers they faced to inclusion and decision making included overt ableism² and discrimination, inherent bias and gaslighting, and outdated professional and institutional cultures, all which prevented them from accessing a range of educational, recreational, and economic activities.

Participants described a range of solutions that would increase inclusion and address current barriers to decision making. They suggested education and training for community members and service providers on how to support young people with disability in decision making and address bias and power imbalance. Participants also noted that more accurate media representations of young disabled people would be helpful in addressing ableism and harmful stereotypes that persist in the community. Finally, young people wanted more opportunities for young people with disability to move into leadership positions – especially in disability organisations.

<sup>&</sup>lt;sup>1</sup> Commonwealth of Australia. (2021). Available at: <u>Australia's Disability Strategy 2021–2031</u> (disabilitygateway.gov.au)

<sup>&</sup>lt;sup>2</sup> 'Ableism' describes the process of negatively stereotyping individuals or groups on the basis of a perceived 'difference'/ disability and, often, discriminating based on such stereotypes at individual and systemic levels



### Recommendations

### 1. Recommendations for governments:

- The federal and state and territory governments should provide pathways for young people with disability to enter positions of leadership and expertise through training and education opportunities that enable them to learn the skills and gain the experience required.
- State and territory governments should advance inclusive education by funding a scoping study into making existing schools and universities more inclusive.
   This should include a roadmap to inclusivity that sets out goals and a timeline.
- Professionalise the support worker sector through additional training and education standards to introduce a higher level of skill and professionalism to this industry. For example, training in how to engage in supported decision making with young people.
- Further investigation of supported decision making tools. For instance, Douglas and Bigby<sup>3</sup> have developed a set of steps and principles, *The La Trobe Framework*, based on the Medical Research Council four-phase approach to development and evaluation of complex interventions. This tool, or one like it, should be promoted by the NDIS and other agencies and institutions that engage with young people with disability.

## 2. Recommendations for community services and organisations:

Disability services and organisations should develop and deliver a
comprehensive training program revealing the nature and types of ableism that
young people with disability endure each day, the ways in which their
intersecting identities (race, gender, sexuality) impact on their experience, and
education to combat ableism and prejudice. This should be delivered as part of
regular professional development and induction processes to service providers
such as NDIS staff, Centrelink staff, support workers, teachers, and front-line
workers (police, health care professionals). This should be funded by the federal
government as part of meeting the goals of Australia's Disability Strategy.

<sup>&</sup>lt;sup>3</sup> Douglas, J & Bigby, C. (2020). Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability, Disability and Rehabilitation, 42:3, 434-441



# 3. Recommendations for industry and peak bodies:

- Generate a media strategy and guidelines for promoting messages about disability and ableism more broadly. Include the media guidelines developed by the Disability Royal Commission. Aim to demonstrate the diversity and pride in disability as well as competence to combat 'tragedy' narratives and other harmful stereotypes.
- Create a campaign to introduce inclusion more widely into workplaces so that young people have more opportunities in the workforce.
- Create up to date evaluation and best practice guides to workplace inclusion.
   For example, the Australian Human Rights Commission has a guide, 'Creating an accessible and inclusive workplace' that can be used as a basis for this program. An evaluation of one or more workplaces incorporating these principles could then form case studies and a business case for further work in this area.

<sup>&</sup>lt;sup>4</sup> Australian Human Rights Commission. (2021). Available at: <u>Creating an accessible and inclusive workplace (includeability.gov.au)</u>



# About Children and Young People with Disability Australia

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.

CYDA's Youth Council is a group of 12 young disabled people that engage in CYDA's projects and provide lived expertise. The primary focus of the council this term has been on its two working groups: LivedX and NDIS In Control My/Our Way. Additionally, the members have undertaken professional development in media and governance.

# **Background to the LivedX consultations**

The LivedX consultations were designed to capture the Lived-Experience and Lived-Expertise of young people with disability on topics and issues they value and deemed important. The series brought together young people from around Australia to share their insights, experiences and ideas for a future that embraces young people with disability and enables them to thrive.

The project is a component of CYDA's Our Voices Our Visions: Youth Advocacy project and is funded by the Youth Advocacy Support Grant from the Australian Department of Education, Skills and Employment.

There were seven sessions held over the course of seven months in 2021 covering:

- Inclusion
- Decision making
- Employment
- Tertiary education: university
- Tertiary education: TAFE and Vocational Education and Training
- LGBTQIA+<sup>5</sup> people with disability: community
- LGBTQIA+ people with disability: healthcare

<sup>&</sup>lt;sup>5</sup> LGBTQIA+ stands for Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Aromantic/Asexual, with the '+' being an umbrella for all other gender, sexual, and romantic minorities. Detailed definitions available at: <u>Your guide to words and definitions in the LGBTQIA+ community (minus18.org.au)</u>



A total of 63 participants attended across the sessions. There was representation from many different disabilities, age (15-29) and all states and territories except Northern Territory. Participants included LGBTQIA+ people, people of colour, Aboriginal and/or Torres Strait Islander people, people who speak a language other than English at home, and people who are living in regional, rural, or remote areas.

These consultations have been synthesised into a series of five papers:

- Tertiary Education and Learning
- Financial Security and Employment
- Healthcare Settings for LGBTQIA+ Youth with Disability
- Community Spaces for LGBTQIA+ Youth with Disability
- Inclusion and Decision Making

LivedX has been designed by and for young disabled people. Co-design with young people was integral to this project and consequently LivedX was steered by a working group of the Youth Council.

This policy paper series was written by members of the working group<sup>6</sup>, who also participated in the consultation design, topic selection and facilitation, and conducted the data analysis. The working group was supported by Policy and Research team staff, however as a principle, the decisions were made by the young people involved.

# Background on inclusion and decision making for young people with disability

Australia's Disability Strategy 2021-2031<sup>7</sup> states that, "People with disability are experts in their own lives and have the same rights as people without disability. Community acceptance of these rights and experiences will maximise individual power and autonomy, and support economic participation, social inclusion, safety and equality". Making decisions such as what to eat and how to dress, through to where to live and what service providers to use, is a dignity that is the right of all people. In fact, the rights of people with disability to participate in decision making is enshrined in the United Nations Convention on the Rights of Persons with Disabilities<sup>8</sup>. In Australia these rights have been operationalised by the Australian Law Reform Commission who set the guidelines to support decision making that affects people's lives, including how to support people who require assistance to make decisions and how to be guided by

<sup>&</sup>lt;sup>6</sup> With the exception of the *Inclusion and Decision Making* paper, which was written by Policy and Research team staff, however, it was shaped and approved by working group members

<sup>&</sup>lt;sup>7</sup> See footnote 1

OCC IOOHIOIC I

<sup>&</sup>lt;sup>8</sup> United Nations. (2006). Conventions on the Rights of Persons with Disabilities. Geneva.



their own preferences and will<sup>9</sup>. Having the autonomy and support to make both mundane and complex decisions fosters the experience of inclusion in all aspects of life and has implications for evolving expressions of citizenship<sup>10</sup>.

However, the experiences of young people with disability expressed across consultations on decision making and inclusion highlight the work yet to be done to achieve this goal. Young people with disability are often unfairly prevented from making decisions about their life – big and small – and their right to dignity of risk is not respected. Without effective decision making power, young people with disability cannot enjoy the inclusion that comes with it. According to a 2019 survey<sup>11</sup> of young people with disability across Australia, 55 percent of respondents stated that their disability made it hard for them to feel like they fit in at school, work or socially. As such, there is still work to be done to realise the vision of Australia' Disability Strategy for children and young people with disability, and to help them feel that they truly belong.

# Young people with disability's perspective on inclusion and decision making

CYDA has reviewed, analysed, and collated the participants' ideas into five key themes that emerged throughout the consultations.

Key theme	Theme description
Identity	How young people with disability define themselves
Enablers	The factors that enable or support young people with disability to live the lives they would like to live
Barriers	The factors that inhibit or prevent young people with disability to live the lives they would like to live
Solutions	How organisations, government, and the community can contribute to the greater social movement young people with disability want to see in the world
Social Movement	How organisations, government, and the community can contribute to the greater social movement young people with disability want to see in the world

<sup>&</sup>lt;sup>9</sup> Australian Law Reform Commission. (2014). *Equality, capacity and disability in Commonwealth laws (DP 81)* 

<sup>&</sup>lt;sup>10</sup> MacIntyre, G. (2014). *The potential for inclusion: young people with learning disabilities experiences of social inclusion as they make the transition from childhood to adulthood*, Journal of Youth Studies, 17:7, 857-871

<sup>&</sup>lt;sup>11</sup> Mission Australia. (2019). Young, willing and able: Youth Survey Disability Report 2019. Available at: Young, willing and able (voced.edu.au)



# What young people said

### **Identity**

Discussions revealed the ways in which young people understand and construct their identities and the implications of this on decision making and inclusion. Young people felt strongly that those in leadership and positions of power, especially within the services they access, should consider their identities through an intersectional framework. Young people spoke of their experiences of being infantilised, demeaned, underestimated, or dismissed as a result of actual or perceived elements of their identity and this led to limitations and restrictions on their right to make decisions about their lives and care.

One young person reflected, "I'm also Indigenous and transgender, so it's like three different things", demonstrating that when thinking about their experience in the world as a disabled young person, their Indigenous and transgender identities should also be considered.

Other participants highlighted the difficulties faced by many young people when seeking recognition and acknowledgement of their intersecting identities from service providers and the broader community.

"I find that [medical staff] don't believe me because they think I'm young and also that I'm confused by my disability. So, I find that a lot of people think a lot of things can't overlap, like say ADHD and autism. Or being trans and something else. I just find that a lot of people think things can't overlap, [when they can] very easily overlap."

"I'm autistic. I'm also asexual and a lot of doctors who I have talked to don't think you can be both because they think I'm just I'm confused because I'm autistic and that I have just not figured out the feeling yet. But I know who I am."

One young person reflected on the fatigue resulting from such interactions:

"I'm sick of the misgendering and decisions about my body".

Others experienced having their identities as disabled people questioned by the institutions designed to serve them.

"I actually had issues with NDIS trying to tell me that I was too young to use [...] mobility aides".

Additionally, there was evidence that many young people regularly have their competence and personhood questioned in casual everyday settings.



"I know that I go into chemists or the doctors or something, and I'll be with my carer. They'll straight away see me in the wheelchair and straight away start talking to anyone else but me. And straightaway they think that I can't make my own decisions."

Instances such as these clearly impact on the decision making ability and experiences of inclusion of young people. Despite their articulate and insightful descriptions of themselves, their inner-worlds, and their identities, they find themselves regularly dismissed and not taken seriously. Young people have the right to choose how they identify and the intersectional identities of this cohort must be acknowledged and accommodated in order to achieve inclusivity.

### **Enablers**

"[I want to decide] where I live, who I engage with, what spaces are safe for me, and what I do with my money."

This compelling statement reflects the clarity and confidence that many participants felt about what enables them to be independent decision makers and feel included in day-to-day life, both important factors to ensure they are supported to live according to their own goals and wishes.

The discussions around what enables young people to live the lives they would like to live broadly came down to the application of accommodations and proactive supports. Firstly, in thinking about everyday supports, one young person described, "People taking the time and effort to check for my needs. Example, when catching up with friends" as helping them to make autonomous decisions and feel included in day-to-day experiences.

Another shared their experience of having a nurse accommodate their needs during a hospital stay:

"I did have this one really lovely nurse who, she realised that I was a bit awkward with eye contact, so she made sure she wasn't always looking at me. Say we were playing a card game, she realised that I was better when I had something else to interact with as well."

Feeling like they have an ally enables young people to be autonomous decision makers and feel a sense of inclusion in their lives.

Many participants described CYDA's approach—asking what supports and accommodations they required to take part in the consultations—as an example of proactive support.



"[CYDA's] email, it was the first organisation [...] 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".

Another young person added, "putting your answers in the chat or being able to speak verbally or using the slides was also pretty inclusive and it made me feel like I could actually do something in the format and I've never felt like that before, so it made me feel really empowered".

The discussions clearly demonstrated a desire for accommodations and how these might address barriers to participation by removing uncertainty about access.

### **Barriers**

"It's like a systemic issue, ableism, and stigma against mental health and disability".

During the consultations, young people spoke at length about the various barriers that impacted their ability to make decisions independently, as well as the ways in which a sense of inclusivity helps them to feel safe in their communities. The experiences they shared of being dismissed, disbelieved, underestimated, ignored, and treated negatively because of their disability, can be categorised according to the types of ableism they stem from.

Systemic and institutional ableism includes both hostile and indirect ableism and results from the failure to comply with the various laws and guidelines governing disability rights. It is also born out of internalised attitudes. Participants provided multiple examples that fit this category.

"I go to [get] on the train and there's nowhere I can actually strap my chair to so I'm just moving around, and that's the supposed accessible spot for wheelchair users. And these are brand new trains."

This young person, like many, is dealing with the frustrating reality of a physical environment that does not catering for their needs. Someone shared a similar example, saying:

"I've had experiences where [bus drivers] refused to lower the bus so I could actually get in when I was using a rollator or my walking stick."



Many people described their interactions with the services and institutions in their lives they engage with regularly. One young person shared their experience of being stopped by the police:

"I've got cerebral palsy, I walk a little bit funny, and I got stopped by a cop and they wanted proof that I had a disability, so they wanted me to show them the actual diagnosis papers. Do I carry them with me in my bag? No. So I had to ring one of my teachers—it was so embarrassing".

This experience highlights the institutional ableism at play in the approach of the police officers involved.

Experiences with doctors and the healthcare system were common discussion topics in the consultations and demonstrated ableist attitudes and approaches to young people with disability. One person stated:

"I think as a disabled young person, decisions around my health and my treatment and things like that are really important—a lot of the time those are taken away".

"And doctors for disabled people are constantly trying to push various treatments on us and they're not listening to what we think is best for us".

There was some discussion around problematic interactions with the NDIS and the limiting impact on independent decision making and feeling in control of the process:

"I often find that I don't have my own choice and control. I have not liked my plan. I have not liked the review process. 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".

Outdated professional and institutional cultures led to barriers to inclusion in economic participation. For instance, one young person explained:

"I could lose my registration as a provisional psychologist specifically because I'm disabled, and a lot of programs where you have to be AHPRA registered, the Australian Health Practitioner Registration Authority".

Participants were particularly concerned that educational settings were not supportive of them or accommodating of their disability. One young person explained their experience of access at university:

"I asked my university many times if I could call into my classes, especially because some of my classes were not accessible for mobility aids, and they would not let me, but as soon as COVID happened they suddenly were able to do distance classes".



The other type of ableism that was highlighted as a major barrier to inclusion and decision making was a type of 'casual ableism' and prejudice. This type of treatment was common, showing up as ignorance and assumptions in daily interactions, and it is the cause of emotional fatigue in many of the consultation participants.

"Maybe I want to have a choice, but everything just gets planned for me, which isn't really fun"

"Just because you're disabled you get talked to like you're five, even when I'm 22".

This was echoed by another who described the "inherent undermining, and [...] gaslighting, [as though] we are not capable of making decisions". Although these experiences are reported across all age groups, young people with disability appear at increased risk of exclusion because of socio-cultural assumptions about the competence of younger people.

Finally, the uninformed and biased attitudes of some people in the community, prevent young people from engaging in their preferred economic activities:

"I applied for a job at [a pizza chain] a couple of years ago[...] and I basically got told that I couldn't work there because [...] all [disabled] people have hygiene issues[...] You should've seen me. It was just heartbreaking".

### **Solutions**

Participants indicated the importance of creating advocacy spaces and opportunities to foster autonomy, independence, and power in the lives of young people with disability.

Young people care about how they are portrayed and how disability is portrayed in media content – such representations offer important advocacy opportunities. One participant described the diverse and accurate representations that were important to them, saying:

"If you're going to provide representation of people with disabilities — you do it accurately. You're not engaging in harmful stereotypes."

Participants also wanted to see more strategies for young people with disability to move into leadership positions.

"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 recognised as experts in our field if we can't get qualifications that are recognised by abled<sup>12</sup> people as making us experts."

<sup>12</sup> Non-disabled



"I want organisations to have more [people with] disability on the board, and then [we] can have a say where the organisation can go in the future."

Creating accessibility was another important topic in the discussion around solutions to promote autonomy, independence, and power for young people with disability. One young person reflected on their experience working for a large multinational organisation, the accessibility that was provided within the organisation, and the experience of inclusion that this afforded them:

"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."

Many young people suggested increased breadth in disability education as a way to generate additional accessibility.

"I think that in an ideal, inclusive society there would be more education around different types of disabilities [...] like various neurodivergent<sup>13</sup> conditions and how they present, like stimming<sup>14</sup> 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."

Others proposed better promotion of existing services so that the right people know about them and can access them.

"After I got my diagnosis, it took me about six months of being in relevant Facebook groups and following things on Instagram to work out that I would be able to access a [...] Chronic Health Plan, which gets you stuff cheaper. Like physio, nutrition, that sort of stuff cheaper. And I also didn't know that I could get a Mental Health Care Plan through my GP, as a part of my diagnosis as well. I think if I knew those things, it would have saved me a lot of money."

There was also a lot of discussion around presenting information in accessible formats for diverse audiences.

"Having the information we need to make the right decisions presented in an accessible way to us, in a way that we can understand is really important."

<sup>&</sup>lt;sup>13</sup> 'Neurodivergent' is a non-medical umbrella term for people whose brain works differently. It typically refers to, but is not limited to, conditions such as autism, ADHD, epilepsy and Tourette's syndrome

<sup>&</sup>lt;sup>14</sup> 'Stimming' refers to self-stimulating behaviour, where a person stimulates their senses for regulation or joy. It often involves repetitive movements or sounds.



"Having information at the correct height [...] menus not being halfway up the roof or really small, so information being physically accessible."

A third discussion topic centred on accountability. It was important to participants to address the power differential that is often present in relationships between young people with disability and the various providers and services they access. One young person explained:

"I think the things that would have helped me in that situation is being able to have a second opinion from a different doctor. That doctor not being responsible for all of my care i.e., if I were to disagree with them, then I was to lose care."

### **Social Movement**

"I think if it's always come at from the perspective of it is human rights and [...] the system ultimately needs to enable us and not disable us, and we need to be able to make our own decisions."

Many of the discussions that young people engaged in during the consultations pointed to opportunities for organisations, government, and the community to contribute to the greater social movement they wish to see in the world. Young people were keen to see more disability-led organisations and projects, education on stereotypes and prejudice, and the role of power between young people with disability and society addressed.

Young people made clear their desire for disability-led organisations and projects:

"If they want to be inclusive then they need to actually have us involved and not just the whole like, 'We'll do it for you because disabled people are incapable of doing anything', which is how it feels like they see us."

"Honestly I feel like organisations that are for disabled people should be headed by disabled people."

Young people told us they wanted to be involved in organisational and environmental accessibility:

"Instead of having ableds [non-disabled people] design what they think we need and what they think we want, actually having us do it ourselves because there are plenty of ways to facilitate that. It's not just organisational, it can be things like accessible buildings like architecture."



Education to address stereotypes and prejudice was also an important part of the discussion. One participant pointed out the friction that sometimes exists between young people and the institutions they engage with, explaining that sometimes professionals simply do not know how to engage with young people with disability:

"Something I'm thinking about a lot is how often young people in our expansive coolness, me with my purple mullet and scandalous pronouns and facial piercings and stuff, is inherently challenging to a lot of what medical, educational, financial institutions expect for people. In being those things, which I have no intention of changing, that means that professionals or people or institutions I engage with feel threatened [...] because I don't fit a certain box it means that they're [...] feeling intimidated so that they double back on how they engage with me and how they view me, which can be obviously really harmful."

Another participant suggested ending segregated education as a way to expose people to diversity and address stereotypes and prejudice about disability:

"For me, an inclusive society [...] would include education in schools from a young age on different disabilities and abilities, how we can support them, make sure everyone feels included [...] that they aren't viewed as different or weird and that that's just part of the norm."

Picking up on the topic of media portrayals and everyday examples of disability, another young person proposed that diversity in media would be a positive step towards addressing stereotypes and prejudice:

"Seeing people with all different abilities, different ages, disabilities both visible and invisible all represented as one not in an example of difference or when showing support, but in everyday things like fashion when you go to the shops, when things are promoted."

Some of the participants felt powerless in the face of governments who have previously failed to show leadership on important topics.

"What [is the] likelihood [that...] 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."



Many young people were very aware of their own inner resources and power but were frustrated at being prevented from actively using them.

"Something to consider is making sure that when decision supporters are working with us, that they're not using patronising language, and that they're being really aware that a lot of the time having disabilities makes us grow up pretty quickly. We know what we need. We know our own bodies."

One person boldly stated their solution to the inherent power imbalance in the medical system, which many young people with disability are obliged to regularly engage with:

"So, decolonising and deinstitutionalising the hierarchies of medical systems and medical power I think is the thing."

Another pointed to educational opportunities for this sector, "[It's important to help] medical professionals to understand how to communicate honestly and on an equal level."

### Where to from here?

During the consultation sessions, young people with disability demonstrated confidence in their identities and bodily autonomy, a sophisticated understanding of the prejudice and ableism that limits them in daily life, and insightful ideas about solutions and social movements to address their challenges. Below are recommendations that will improve the decision making process and inclusivity for young people with disability, thereby enabling them to live the life they want to live and experience the safety, justice, and rights that they are entitled to.

# 1. Recommendations for governments:

- The federal and state and territory governments should provide pathways for young people with disability to enter positions of leadership and expertise through training and education opportunities that enable them to learn the skills and gain the experience required.
- State and territory governments should advance inclusive education by funding a scoping study into making existing schools and universities more inclusive.
   This should include a roadmap to inclusivity that sets out goals and a timeline.
- Professionalise the support worker sector through additional training and education standards to introduce a higher level of skill and professionalism to this industry. For example, training in how to engage in supported decisionmaking with young people.



Further investigation of supported decision-making tools. For instance, Douglas and Bigby<sup>15</sup> have developed a set of steps and principles, The La Trobe Framework, based on the Medical Research Council four-phase approach to development and evaluation of complex interventions. This tool, or one like it, should be promoted by the NDIS and other agencies and institutions that engage with young people with disability.

## 2. Recommendations for community services and organisations:

• Disability services and organisations to develop and deliver a comprehensive training program revealing the nature and types of ableism that young people with disability endure each day, the ways in which their intersecting identities (race, gender, sexuality) impact on their experience, and education to combat ableism and prejudice. This should be delivered as part of regular professional development and induction processes to service providers such as NDIS staff, Centrelink staff, support workers, teachers, and front-line workers (police, health care professionals). This should be funded by the federal government as part of meeting the goals of Australia's Disability Strategy.

### 3. Recommendations for industry and peak bodies:

- Generating a media strategy and guidelines for promoting messages about disability and ableism more broadly. Include the media guidelines developed by the Disability Royal Commission. Aim to demonstrate the diversity and pride in disability as well as competence to combat 'tragedy' narratives and other harmful stereotypes.
- Create a campaign to introduce inclusion more widely into workplaces so that young people have more opportunities in the workforce.
- Create up to date evaluation and best practice guides to workplace inclusion.
   For example, the Australian Human Rights Commission has a guide, 'Creating an accessible and inclusive workplace' that can be used as a basis for this program. An evaluation of one or more workplaces incorporating these principles could then form case studies and a business case for further work in this area.

<sup>&</sup>lt;sup>15</sup> Douglas, J & Bigby, C. (2020). Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability, Disability and Rehabilitation, 42:3, 434-441

<sup>&</sup>lt;sup>16</sup> Australian Human Rights Commission. (2021). Available at: <u>Creating an accessible and inclusive workplace</u> (includeability.gov.au)





# **Children and Young People with Disability Australia**

Suite 8, 134 Cambridge Street, Collingwood VIC 3066 • PO Box 172, Clifton Hill VIC 3068 **t.** 03 9417 1025 or 1800 222 660 (regional or interstate) • **e.** info@cyda.org.au • **w.** cyda.org.au **ABN** 42 140 529 273

fb./CydaAu li./CydaAu tw.@CydaAu ig.@CydaAus