Children and Young People
with Disability Australia

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Early Childhood Education and Minister for Youth
Office for Youth
Department of Education
GPO Box 9880
Canberra ACT 2601
01 September 2023

Dear Hon Dr Anne Aly MP,

Response to Australia's youth engagement strategy

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. 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.

Please accept this letter and attached policy papers, entitled the LivedX series, as CYDA's formal submission to the Australia's youth engagement strategy.

Through this submission CYDA aims to bring your attention the issues for young people with disability as discussed in the attached LivedX Policy Papers. (Refer appendix on page two for explanation and background to the papers).

As the LivedX series has been designed and written by young disabled people from the CYDA community and it is our vision to give direct voice to young people, this submission is focussed on the section of the discussion paper targeted to young people.

Each policy paper, in its own right, addresses the following questions from the discussion paper:

1. What are the top issues that the Government should work with young people to address?
2. What are some of the ways Government can improve how we engage with young people?

If you would like to know more about this submission or the LivedX series, please feel free to contact Liz Hudson, Policy and Research Manager on 03 9417 1025 or lizhudson@cyda.org.au.

Kind regards,

Skye Kakoschke-Moore
Chief Executive Officer

Appendix A: Background to the LivedX Policy Papers

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. 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, 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.

LivedX Series: What Young People Said

Tertiary Education and Learning

December 2022

cyda.org.au

Children and Young People with Disability Australia

Authorised by

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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

Young people with disability are not accessing education, including university and Vocational Education and Training (VET), on an equal basis to their peers without disability[1]. To understand the experiences and perspectives of young people with disability in tertiary education, CYDA hosted two consultations and a one-on-one interview, with a total of 17 participants in September and October 2021. These consultations were co-designed by an internal working group of young disabled people.

Discussions with participants, spanning pre-enrolment activities and course selection through to their time in their course, identified significant barriers to engaging in tertiary education. Young people identified issues such as reduced study and course options, lack of meaningful supports, poor attitudes and misconceptions from professional and academic staff, and overall inaccessibility and inflexibility in the tertiary environment as key limitations to their participation.

Participants also shared ideas and solutions to improve tertiary education access for their cohort. These included improved accountability systems for education providers, additional education and training for staff and peers, universal design approaches to learning and education, and increased holistic supports for young disabled people.

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[1] AIHW. (2022). *People with disability in Australia.* Available at: [Engagement in Education (aihw.gov.au)]()

Recommendations

1. Tertiary institutions must provide adequate holistic supports for students with disability

This includes:

- Providing individualised and consistent academic and social supports, such as peer mentoring. These supports should create space and support all aspects of students' identities, including disability, gender, sexuality, and culture
- Employing more disabled people, particularly in disability services
- Providing career counselling and supports that understand disability, the systemic barriers in the workforce for employees with disability, and knowledge of services and supports available that support inclusive employment.

2. Tertiary institutions must provide adequate education about disability to staff and students

This includes:

- Equipping staff with knowledge about disability, accessibility, universal design, discrimination, and legal obligations
- Developing compulsory, introductory units for all students on basic disability knowledge and awareness to foster an inclusive education culture.

3. Tertiary institutions must ensure courses are accessible

This includes:

- Taking a universal design approach to teaching to support diverse learning needs and strengths across the student cohort
- Retaining online learning to provide students flexibility in their learning.

4. Tertiary institutions must protect the education rights of students with disability

- Make sure supports are followed through and there is ongoing connection between disability services and educators, so students do not have to continuously advocate for their needs across units and classes. This could be achieved by adopting a case manager approach
- Ensure accessible complaints procedures so students with disability feel safe and confident to report incidents of disability discrimination.

5. The Australian Government must improve pathways and accessibility to tertiary education and learning, in line with Education and Learning Policy Priority 3[2] of the *Australian Disability Strategy*[3]

- Ensure tertiary institutions are adequately funded to provide for psychology and disability support services to meet student need
- Ensure there are mechanisms to hold tertiary institutions and educators to account when not meeting the rights of students with disability under the *Disability Standards for Education* and the *Disability Discrimination Act*
- Make sure transition from school to tertiary is smooth and supports can be carried across without administrative burden on the student
- Take a stronger role in convening a nationally consistent approach to supporting students in the VET sector.

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[2] Improve pathways and accessibility to further education and training for people with disability

[3] Commonwealth of Australia. (2021). Available at: Australia's Disability Strategy 2021–2031 (disabilitygateway.gov.au)

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+[4] people with disability: community
- LGBTQIA+ people with disability: healthcare

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[4] 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: Your guide to words and definitions in the LGBTQIA+ community (minus18.org.au)

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.

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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[5], 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 tertiary education and learning for young people with disability

Young people with disability are not accessing tertiary education, including university and Vocational Education and Training (VET), on an equal basis to their peers without disability[6]. While it is encouraging to see that the enrolment rates of students with disability as a whole in tertiary education have increased[7], the group remains grossly underrepresented when compared with the proportion of people with disability in the general population (Figure 1).[8]

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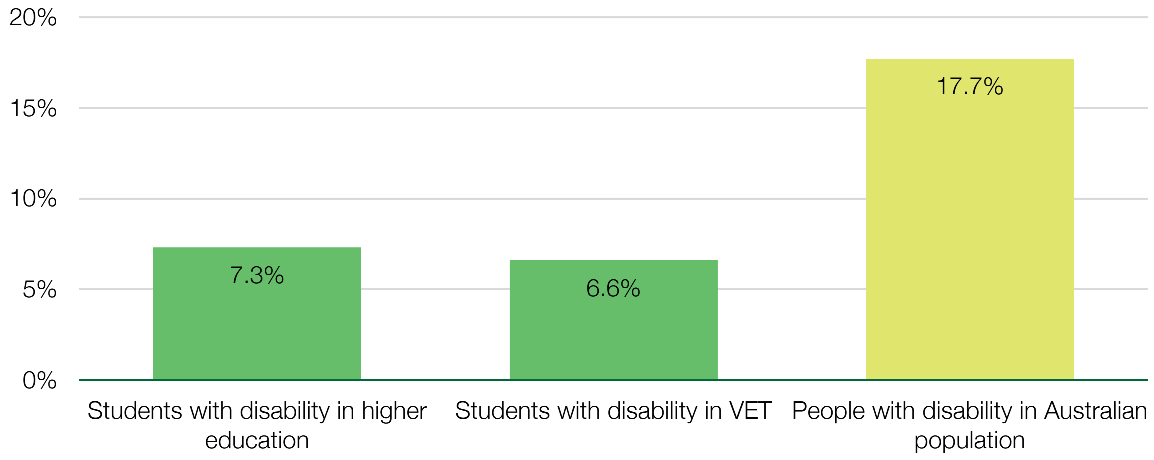
[5] With the exception of the *Inclusion and Decision Making* paper, which was written by Policy and Research team staff, however, it was shaped and approved by working group members

[6] See footnote 1

[7] Koshy, P. (2020). *Equity Student Participation in Australian Higher Education: 2014–2019*. National Centre for Student Equity in Higher Education (NCSEHE), Perth: Curtin University. Available at: NCSEHE Briefing Note (ncsehe.edu.au); Australian Disability Clearinghouse on Education and Training. (2020). *Higher Education Statistics* & *VET Statistics.* Available at: Understanding disability (adcet.edu.au)

[8] ibid; ABS. (2018). *Disability, Ageing, and Carers Australia*. Available at: Summary of findings (abs.gov.au); Adapted from Ford, E., & Swayn, D. (2021). National Disability Coordination Officer Program: DRAFT tertiary education policy advocacy paper

Figure 1: Proportion of people with disability in tertiary education settings and the proportion of people with disability in the general population



A major barrier preventing students with disability from participating in tertiary education is the inadequate funding and effort allocated to providing educational supports and reasonable adjustments. Despite the *Disability Discrimination Act 1992* and the accompanying *Disability Standards for Education 2005* requiring providers to take reasonable steps to enable students with disability to participate in education on an equal basis as their peers without disability, many students' rights are not being upheld. As this paper will go on to demonstrate, young people tell us that the system places an onus on students to understand their rights, fund the cost of required assessments for supports, self-advocate for supports, and challenge their institution when being treated unfairly.

In addition to this, students with disability who do access tertiary education aren't experiencing improved employment outcomes on an equal basis to their peers without disability. VET graduates with disability were found to be 1.5 times more likely to report no improved employment status after training, and twice as likely to not be employed after training, than those without disability.[9] Graduates with disability from undergraduate courses were found to be 1.5 times more likely to not be employed, and graduates with disability from postgraduate courses were almost twice as likely to not be employed, than graduates without disability.[10]

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[9] VET graduates with disability less likely (37%) to report improved employment status after training than those without disability (58%) and less likely (45%) to be employed after training than those without disability (71%); AIHW. (2020). *People with disability in Australia.* Available at: Educational attainment (aihw.gov.au)

[10] Graduates from: undergraduate courses who reported they had disability (79%) were less likely than those without disability (86%) to be employed, postgraduate coursework courses who reported disability (85%) were less likely than those without disability (92%) to be employed; ibid

Young people with disability's perspective on tertiary education and learning

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

What young people said

Identity

Although participants were not asked questions specifically related to identity, the topic was raised in relation to other discussions, with participants emphasising the importance of intersectional approaches in tertiary institutions.

> *"I think basically the gist of this is being better prepared or just more aware of intersectionality in access. At my university we have a program for Indigenous students [...] You go into this foundation course and you're in the cohort of all Aboriginal and Torres Strait Islander students, which is great [...] But we would have our classes on the third floor of this old building, where there was no elevators, no accessibility [...] and especially in Indigenous demographics where the prevalence of physical disability is a lot higher [...]. It was pretty bad, honestly."*

This was echoed by another participant, who highlighted the positive impact made by an intersectional space they had access to at university:

> *"I think my university has been very good about having spaces for people with intersectional identities with disability. For example, I often attend a queer disabilities collective […]. I think these spaces are really good because there is a real understanding. You could be a lot more open about your experiences in your life in those kind of areas. It's great."*

Enablers

When recalling what had been a positive and enabling experience during their tertiary learning, many young people spoke of supportive, consistent, and person-centred approaches to both teaching and providing accommodations.

> *"I like how in my uni there's a specific person assigned to my case rather than switching around every time I need help."*

> *"Whenever lecturers make an effort to connect with me individually."*

> *"I've had some staff who have actually checked in when they noticed me struggling and asked what they could do."*

One participant explained how a practical assessment supervisor created a safe environment for them to talk about their wheelchair:

> *"The actual supervisor that did our assessments for how we work with children–and she was brilliant–she spoke to the children about my wheelchair and the safety around it, but also let me tell my story to make it a more safe and accepting environment."*

Flexibility and online learning are also key enablers for young people to study, with many participants highlighting the importance of not being penalised for non-attendance and being able to come to campus only when they need.

> *"[My university] let you be an online student and go into the in-person classes, so you don't have any pressure to go into the in-person classes, which is really great for me."*

As one participant put it, "*assum[ing] students with disability are always going to be in the room*" is key to the success of disabled young people in tertiary settings. Having systems in place to proactively support young people and remove administrative burdens is vital.

> *"When I started university and approached the correct accessibility teams and boards, organisations, they were able to really quite easily facilitate what I needed, just taking all the information off what you provided the [state accessibility service] back at school. It made it really simple to not have to go and explain the whole situation. It was just really it was one meeting for an hour at the beginning of my university, just exactly saying what provisions I need."*

> *"The other thing I did really like was the fact that when it came time to exams, I didn't have to do anything. It was really just – they set it up for you. They tell you where to go. You rock up to the room […] and then they'll say to you, 'Yep, you're in this room at this time with a scribe. This is the scribe.' Really, really simple."*

Barriers

Before students even get a chance to begin studying, their options and prospects are significantly limited by inaccessibility to courses and campuses.

> *"I had to choose a campus largely due to accessibility purposes and picked my major based on the lack of travel or movement needed as an IT personnel, even if I don't really like the subject myself."*

Just as supportive staff are a key enabler for young people's success and inclusion, unsupportive staff present a considerable barrier.

> *"We had two teachers for the class, they wouldn't jot down notes for me, or they wouldn't have a small script of what they had gone over in class so I could revise. Which really, really made it hard for me to be able to remember because I couldn't take it in, but I couldn't write it down because I struggle to keep up with my handwriting, having low muscle tone."*

One participant shared that academic staff told them they "*couldn't do their course, because of my Tourette's.*" Another participant was kicked out of their course once they started using a wheelchair:

> *"I had a major issue with my first course after I got put into the wheelchair. I was actually kicked out of my course, saying that I couldn't do my course as a disabled person. Because 'you can't do that course from a wheelchair'."*

Work placement services and processes that support tertiary education were flagged by multiple young people as a roadblock in their courses, with students often ending up in inaccessible or ill-suited placements.

> *"Placement have absolutely no idea what's going on behind the scenes, and they're really slack at bridging that information gap, and so ultimately you end up with placement offers that aren't appropriate."*

Many participants further lamented broken channels of communication causing significant barriers to their learning. Often plans and supports would be set up with the wellbeing officer or disability liaison unit but students wouldn't see this followed through, as either educators weren't properly informed of the plan, or the plans were just "*never followed*".

Long wait times of three to five weeks were raised by a number of participants, for on campus psychology and counselling services, as well as disability support services.

> *"It's not as easy as just calling up. […] Ninety per cent of the time you won't even get through or there's massive backlogs. I think it's due to understaffing or just massive over demand. But it is very disheartening, and I think because of that, a lot of people who need that support just aren't getting it."*

Assumptions about what supports someone might need or using one-size-fits-all approaches are unfortunately common. One young person shared that their university insisted on them having a note-taker, despite them stating that not only do they not need one, but that it would be actively "*detrimental*" to their learning.

Another shared that extra time during assessments felt like a "*band-aid measure*", as it meant that the source of the inaccessibility of the assessment was never addressed, and more suitable accommodations were never explored.

Social isolation was another barrier for participants, ranging from a lack of peers to being segregated from the rest of the class.

> *"I didn't see myself within my peers. There was no queer people, or out queer people, no vocally disabled people. So, I wouldn't say that I didn't feel safe, but I didn't feel comfortable. I didn't feel safe to be myself. So, I just didn't bother with the socialising aspect."*

Participants also indicated that their social isolation was caused by indiscrete and insensitive actions by teaching staff, including one instance where an entire class was asked to raise their hand if they had a learning access plan, and another where a teacher announced that someone had a learning access plan in front of their class.

Although online learning was hailed by some, others noted that it didn't work with everybody's access needs, highlighting the need for flexible approaches.

> *"Online schooling hasn't been a positive experience for everybody with a disability. I know for me personally it has been hell. [With] executive dysfunction, it's hard to get yourself [to do work] […] It's even harder with online schooling. I feel like I've learnt nothing this entire semester honestly […] Even though I know for some people it's been great, for others it has been so horrifically terrible."*

Solutions

Education on disability is critical for those who interact with students with disability. Many young people raised that the staff who interact with them should have at least basic knowledge of their disabilities to enable staff to support them properly.

> *"Research beforehand. If you know that you're going to have a student with some type of disability, research [work] placements for them and what will be inclusive and be prepared."*

Participants proposed that staff should also be taught about accessibility generally, to ensure there is a "*standardised [level of] accessibility across teachers*" rather than the current situation, where the experience as a disabled student is highly dependent on whether a teacher has a personal interest or experience with disability.

Universal design was a significant recurring theme amongst participants when discussing solutions. This included the physical campuses – "*the architecture itself should be designed with disability in mind." –* to the course delivery:

> *"Don't make accommodations for students, assume that there are students are going to almost definitely be in those classes. And make it just a part. Always have captions on. Always have signage. Just assume we're going to be there."*

Courses should have *"different options for assignment formats"*, and accommodation for different learning paces and styles.

> *"I think a lot of the supports and accommodations should benefit all [...] not just people with accessibility needs."*

Participants stated that accountability is "*so important*" and that there needs to be clear and well-defined pathways to report teachers and support staff when they "*do something wrong*", are discriminatory, or are just *"not helping"*.

Personalised and consistent support is crucial to young people to ensure their success:

> *"Having a one-to-one support staff/advocate would be amazing. Someone who actually has knowledge and expertise about accessibility needs."*

Not only that, but young people need choice, control, and flexibility in terms of the supports they receive.

> *"[I wish staff would] see where I was at with my health when I was sick, and give me options on what I could do, whether that be repeat some of the things, or continue in some way while I was bedridden."*

> *"[Institutions should be] allowing students to come and actually say what they themselves need, instead of universities making these decisions based on assumptions or what not."*

Finally, more proactive pathways and support should be available to students with disability, such as *"equity scholarships for disabled people"* or role-models in their chosen fields.

> *"If they know a student in their tutorial or in their degree has a particular disability, if they are aware of what that disability is, seeing if they can find a mentor within the career that they've trying to head to, to show, 'Hey, you can do it'."*

Social Movement

Leadership by disabled people is key to breaking down the barriers faced by young people in participating in tertiary education. Institutions should be *"actively seeking to employ and enrol disabled people and provide support"* and *"actively consulting with disabled staff, students, prospective students and alumni"*. There should also be *"lived experience [of disability] involved in developing and delivering content"*.

Positive portrayal of people with disability through awareness and education campaigns is needed to drive attitudinal change.

> *"If there's greater awareness as to potential disabilities or inabilities that some people may have, that could shape the way that obviously the people are viewed, particularly through tertiary education. To be more open, more understanding."*

Young people with disability want to be included and embraced as part of their communities, and that includes their education communities too.

> *"I got to join a club at my uni. And they've really embraced me into it. I got to run a disability week for my whole university. The club let me run that and it got shared all over my university."*

> *"I've found that everyone at uni won't talk to me. They see the wheelchair and run away, or just stare at me, but in this club, I actually get treated like a person and I've just found that absolutely amazing. There's actually a club that can accept me. I've tried asking any other club and all those ones said no. I've finally found a club who accepted me, and it was amazing."*

Where to from here?

Tertiary education opens up opportunities for young people to contribute their skills and talents to society, meet new people, develop new skills, and explore new interests. In line with the perspectives of young people who participated in this consultation, CYDA recommends the following:

1. Tertiary institutions must provide adequate holistic supports for students with disability

This includes:

- Providing individualised and consistent academic and social supports, such as peer mentoring. These supports should create space and support all aspects of students' identities, including disability, gender, sexuality, and culture
- Employing more disabled people, particularly in disability services
- Providing career counselling and supports that understand disability, the systemic barriers in the workforce for employees with disability, and knowledge of services and supports available that support inclusive employment.

2. Tertiary institutions must provide adequate education about disability to staff and students

This includes:

- Equipping staff with knowledge about disability, accessibility, universal design, discrimination, and legal obligations
- Developing compulsory, introductory units for all students on basic disability knowledge and awareness to foster an inclusive education culture.

3. Tertiary institutions must ensure courses are accessible

This includes:

- Taking a universal design approach to teaching to support diverse learning needs and strengths across the student cohort
- Retaining online learning to provide students flexibility in their learning.

4. Tertiary institutions must protect the education rights of students with disability

- Make sure supports are followed through and there is ongoing connection between disability services and educators, so students do not have to continuously advocate for their needs across units and classes. This could be achieved by adopting a case manager approach
- Ensure accessible complaints procedures so students with disability feel safe and confident to report incidents of disability discrimination.

5. The Australian Government must improve pathways and accessibility to tertiary education and learning, in line with Education and Learning Policy Priority 3[11] of the *Australian Disability Strategy*[12]

- Ensure tertiary institutions are adequately funded to provide for psychology and disability support services to meet student need
- Ensure there are mechanisms to hold tertiary institutions and educators to account when not meeting the rights of students with disability under the *Disability Standards for Education* and the *Disability Discrimination Act*
- Make sure transition from school to tertiary is smooth and supports can be carried across without administrative burden on the student
- Take a stronger role in convening a nationally consistent approach to supporting students in the VET sector.

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[11] Improve pathways and accessibility to further education and training for people with disability

[12] Commonwealth of Australia. (2021). Available at: Australia's Disability Strategy 2021–2031 (disabilitygateway.gov.au)

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Financial Security and Employment

December 2022

cyda.org.au

Children and Young People
with Disability Australia

Authorised by

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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

Young people with disability are one of the most disadvantaged cohorts in the labour market, experiencing discrimination and exclusion on the dual basis of age and disability. To understand the experiences and perspectives of young people with disability in employment, CYDA hosted a consultation with nine participants in September 2021. The consultation was co-designed by an internal working group of young disabled people.

Young people participating in the consultation shared their perspectives and experiences, identifying significant barriers to meaningful employment, which for many started in high school. These included low expectations, poor attitudes by employers and employment service provider staff, and overall inaccessibility and inflexibility in the labour market.

In addition to identifying barriers, young people shared ideas and solutions to improve employment outcomes for their cohort. These included improved accountability systems, greater education and training for both young people with disability, and employers and employment service provider staff, and improved and increased pathways to aid young people to gain meaningful employment.

Recommendations

1. The Australian Government must protect the employment rights of young people

This includes:

- Introducing Disability Standards for Employment to clarify the obligations of employers under the Disability Discrimination Act 1992. These Standards should include a clear definition of what constitutes a reasonable adjustment, with examples for employers of varying scope and across different industries
- Increasing funding to the Australian Human Rights Commission to support greater accountability and consequences for cases of employment discrimination.

2. Governments at all levels should invest in the enablers of successful employment service outcomes

Governments should listen to what young people from the CYDA community recommend, to provide effective employment support. This includes:

- Person-centred practice and holistic approaches to service delivery prioritising the employment aspirations of service users

- Increase disability awareness among service providers and employers
- Focus on transition from school and provide earlier employment support to young people
- Develop clear mechanisms for feedback and continuous improvement, ensuring that the experiences of people with disability remain at the heart of Employment Service practice
- Place-based and community focused service delivery.

3. The Australian Government should ensure service contracts, funding models, and Key Performance Indicators of employment programs address systemic barriers to employment and incentivise supporting the needs of individual jobseekers

This includes:

- Providing sufficient and up-front funding to support young jobseekers to overcome systemic barriers in the labour market
- Ensuring caseloads allow service providers to deliver personalised supports and demand-based activities, such as building employer networks
- Incorporating participant experiences and feedback as a measure of success
- Formally measuring and recognising human capital development as a service offering
- Recognising and building on the diverse strengths and employment barriers of different community settings
- Introduce initiatives and quotas to support the employment of people with disability within employment programs.

4. Governments at all levels should deliver consistent post-school transition supports for students with disability in line with priority area two[1] of the *Employ My Ability* Disability Employment Strategy[2]

- The Australian Government should commission a review of funding arrangements in all states and territories for school and post school programs for students with disability
- Together with state and territory education departments, the Australian Government should develop and implement a nationally consistent post school transition supports framework.

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[1] Building employment skills, experience, and confidence of young people with disability: Ensuring young people with disability are supported to obtain work and careers of their choice.

[2] Commonwealth of Australia. (2021). Available at: Employ My Ability (dss.gov.au)

This framework should:

- Include the core requirements of quality post school transition support as outlined in *Post School Transition: The Experiences of Students with Disability*, including beginning conversations and support in year nine
- Be evidence-based and outcomes orientated
- Include 'high-expectations' information resources for families and students with disability about post school options, application processes, and funding and subsidies available
- Be adequately resourced
- Include resources and follow up supports and programs for young people no longer in school
- Include a strategy and linkages between schools and outside stakeholders, such as TAFEs, universities, and disability organisations
- Include data collection mechanisms that measure uptake, implementation, and outcomes of post school transition programs
- Include information about young people's employment rights.

5. Tertiary institutions should support students with disability to transition into employment post qualification

This includes ensuring career counsellors:

- Understand employability challenges students with disability face
- Have adequate knowledge of disability
- Have connections with disability-confident organisations that will support graduates with disability
- Understand what government services and supports are available to support students and graduates with disability.

About Children and Young People with Disability Australia

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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+[3] people with disability: community
- LGBTQIA+ people with disability: healthcare

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[3] 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: [Your guide to words and definitions in the LGBTQIA+ community (minus18.org.au)]

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.

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This policy paper series was written by members of the working group[4], 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 financial security and employment for young people with disability

Young people with disability are one of the most disadvantaged cohorts in the labour market. They experience intersectional and systemic oppression on account of their status as both young people and people with disability, meaning the barriers they face in finding quality and stable work are complex and multi-faceted. This disadvantage is then compounded by additional factors, such as socio-economic status, ethnicity, gender identity, sexuality, or living in a regional or rural area.

Recent data shows this group is more than three times as likely to be unemployed than older adults[5] with disability (24.7 per cent compared to 7.9 per cent).[6] Additionally, young people with disability are also close to three times more likely to be

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[4] 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

[5] Aged 26-64 years old

[6] AIHW. (2020). *People with disability.* Available at: [People with disability in Australia (aihw.gov.au)]

underemployed[7] – meaning they have the capacity and desire to work more hours than they are currently employed for.

As a young person entering the labour force, their ability to participate is impacted by a range of external factors. These include the decrease in entry-level roles, decrease in wage growth, increase in professionalised occupations and the larger cohort of older workers[8] remaining in the workforce.

As people with disability, this group are also more disadvantaged because of the systemic discrimination and lack of reasonable adjustments that enable disabled people to participate on an equal basis to their non-disabled peers in the labour market.

Young people with disability's perspective on financial security and employment

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

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[7] 23.1% rate of underemployment compared to 8.3% of older adults with disability; AIHW (2020)

[8] AIHW. (2021). *Older Australians: Employment and work.* Available at: [Older Australians (aihw.gov.au)]

What young people said

Identity

The use of an intersectional understanding of identity is key when considering how best to engage young disabled people in employment. Many of the young people emphasised the difficulty of securing safe employment, not only due to being disabled, but due to their intersecting gender identity and sexuality.

> *"Often, you're viewed as like just a disabled person – which I am a disabled person, and happy to be seen that way – but when I'm also like, 'Well, I'm also trans, and I'm also gay, and I need a workplace that is affirming of those parts of my identities', it's just like is too complex, and too overwhelming for other people to handle, and then support."*

Young people emphasised the importance of being considered in their entirety, recounting times where only one aspect of their identity or disability was considered:

> *"I'm in a wheelchair and so people then give you jobs that would be accessible for wheelchair users, not taking into account that I had dyslexia as well. So I can't work at a cashier because I just can't do money and numbers, so I think they don't often take a whole picture of who you are and your experiences."*

Regional barriers were also discussed, noting that it was "*definitely harder to work*" in regional areas in comparison to a metro area.

Enablers

From the consultation it was clear that there are few enablers currently empowering young people to work. However, those that do enable young people with disability to work are invaluable. Proactive support for people with disability was the most significant enabler for young people across all stages of employment.

For job searching, "*clear commitment to diversity and inclusion on workplace websites*", "*Q and A sections on websites that cover work leave policy, and work flexibility*", and statements, such as "*we are disability friendly*", or "*we strongly encourage people with disabilities to apply*" were all said to be enablers for participation.

Additionally, interviewers who provide "*an accessibility map for the office and the interview space*", "*multiple ways to submit CV/interview*", and send the interview questions beforehand were held up as examples of good practice.

> *"We had our [interview] questions already given to us about what they would ask us, so we could just set it out really calmly and know what we wanted to say but they also made such a welcoming environment so that we were able to just be ourselves and speak our truth."*

Finally, these proactive supports must continue once employment has been secured to truly enable young people to thrive in employment.

> *"With [my employer], I found that they were very open […]. They say, 'If you need any help, just let us know. We're happy to accommodate for you'."*

> *"They even provided me with a buddy, and a mentor, knowing that this is my first job, and it's just good to have. Especially being young. You need a mentor."*

Barriers

Unfortunately, barriers were a persistent theme throughout the consultation. Employment barriers sadly began in high school for many:

> *"One [career support] that didn't necessarily work for me – was school and education associated employment. Like a career counsellor, or whatever, because they're […] not only not disability informed, but actively like ableist*[9] *a lot of the time. And very much follow kind of traditional pathways, which is not something a lot of disabled people can access."*

> *"There was no sort of option for teenagers – disabled teenagers who wanted to have the same, you know, like part-time casual work experiences as able-bodied peers. You had to wait until you were 18, at least where I'm from to access that sort of support."*

Many participants reported a range of negative experiences with Disability Employment Services (DES), ranging from the service being "*incredibly ableist*", "*really hit or miss*", and having low expectations.

> *"The Disability Employment Services, I found that they were just happy to give me money. And I was for a long time, for the […] first few months after I finished Uni, I was looking for a job. I wasn't really encouraged to keep pursuing for a job, [or] see what is current. I had to push myself."*

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[9] '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

Low expectations were also pervasive within other career services:

> *"[Career services] just didn't have contacts for clinical professional roles. They wanted to offer sort of part-time work, or they wanted to offer things at the supermarket and things like that, which are fantastic avenues but coming out of my Masters, I wanted full-time permanent employment in my field."*

The participants had a lot to say about the barriers they experienced with DES, however it should be noted that these barriers are not limited to DES and are instead emblematic of the general attitudes and barriers young people face finding employment.

> *"I think they just kind of lumped disabled people together. They didn't really see their diversity, and what levels of disability were like. [...] the employment service wasn't tailored to me."*

> *"I found that they pigeon-holed my disability. As an autistic person, some autistic people are great at handling large chunks of data and sorting through data sheets. Which is awesome. The DES I accessed only offered these kinds of jobs for autistic people, ignoring that it isn't something I'm interested in/doesn't fit into my career aspirations."*

> *"I just think my issue that they try to help people with disabilities, but they just have no training, and they just have no awareness."*

> *"In my experience, the DES operators are quite ableist. And just try and fill a box without seeing me as a person with interests, needs, and passions. One DES recommend[ed] that I work in a call centre, despite me being situational mute in social settings."*

Lack of flexibility in the labour market was another significant barrier for young people, from "*the need to be able to pick up 15 kilos in a job description when you're in an office*", to being refused part-time employment because the hours aren't flexible.

> *"[My friend] doesn't just need part-time, she needs reduced hours within the part-time days as well [but employers] are still expecting an eight-hour workday."*

One participant explained that their long-term employment had been impacted by unplanned hospital visits, doctor appointments and therapies. After being unable to accept all the shifts they'd been offered, their boss stopped giving them shifts:

> *"I think for me maintaining [a] job, if anything, is harder than getting a job."*

Young people also detailed many accounts where unfounded assumptions had impacted their employment opportunities.

> *“I was advised to choose a course that wouldn’t require a face-to-face interview as I was unlikely to get through the interview process as a person in a wheelchair”.*

> *“Sometimes I struggle in workplaces. When [employers] look at my resume, and they look at all of my work samples, they have a particular idea of how I function, and that that can change daily, or even throughout the day. So, I’m able to do things to a high standard some of the time, but not all of the time.”*

One young person described how despite being accepted into multiple programs in response to emails they had sent seeking employment, once they disclosed that they were in a wheelchair, those offers were revoked:

> *“The whole thing went really well. And then at the very end, I’m like, ‘I know I didn’t really mention this in my resume, but I am in a wheelchair. I hope this doesn’t change much’. And then they’re like, ‘Oh, I’m really sorry. You need to have this core ability – like a certain level of ability’.”*

Inaccessibility was also a key theme preventing young people from working, or at the very least making it very difficult.

> *“I was denied a job because the physical space did not fit my wheelchair.”*

> *“When [job advertisements] ask for contact details, if they only ask for a phone number, and don’t give you the chance to enter an email address, or your preferred method of communication.”*

One young person, who drives a wheelchair-adapted vehicle and needs an accessible parking space, was told that the accessible spaces in the carpark were only allowed to be used by clients and patients, not staff.

Overall, participants made clear that attitudes towards people with disability need to be changed.

> *“Sometimes [with internships] they’re like, ‘Oh, well, a disabled person couldn’t do it’. Rather than, ‘I could do it, with a couple of adjustments’.”*

> *“In HR, disabled people are viewed as a liability, non-asset, or diversity.”*

Solutions

Accountability was a major theme when discussing solutions to the barriers that limit engagement in employment among consultation participants.

> *"I think they need something that's going to be accountable for the decision-makers […] make it an obligation within workplaces that they meet accessibility requirements or anti-discrimination policies for hiring. […] Build in the culture on top of that, but I do think we need that sort of legal accountability as a starting point."*

> *"Something that could be really valuable is regular assessments of Disability Employment Services […] actually having the government paying a disabled person to enter a Disability Employment Service and try to use the service. And then provide feedback on how it was."*

Pathways were another area that young people identified as crucial to employment outcomes, including more work experience and internships for people with disability, such as those provided by *Australian Network on Disability*. Schools were also highlighted as a key opportunity to provide young people with employment pathways.

Education is vital to empowering young people to work. Young people emphasised the importance of being taught their rights and noted that employers should be the ones providing that information to encourage employers to be accountable. Examples of reasonable adjustments and access needs that employers should be able to support need to be readily available to support young people in self advocacy.

Training and education around disability should be provided to all who interact with young people, including DES providers and employers. A public education campaign would also go some way to challenging the harmful and limiting stereotypes that young disabled people come up against in the workforce.

> *"I think the kind of messaging that our mainstream disability organisations like the NDIS can do better [is] to give meaningful experiences and showcase disabled people in professional roles […] I think the way we show disability should reflect the way we want disability to look in the workplace."*

Sustainability of employment is also crucial for young people, by providing not only "*longer contracts*" and "*more security*" but also considering accessibility and support as an ongoing process, not just an onboarding one.

> *"[Employers should not be] viewing how they make things accessible [in] just the first two weeks when they're setting you up and they're giving you your access needs. It's a continued process to keep us actually meaningfully engaged and show that they're continuing to commit to us."*

Social Movement

Having disabled people in leadership roles is key to breaking down the barriers faced by young people in securing employment. This is especially important for roles designed to support and advise young people.

> *"[We should be] ensuring that all, as much as possible, employers and organisers of disability employment services, and disability specific roles are disabled."*

Disability leadership should be the goal of all employers, just as we have seen for cisgender[10] female leadership.

> *"To ensure that it's meaningful employment, there needs to be a commitment to disabled leadership at all levels of the organisation, not just casual contractors. There needs to be the ability for disabled people to move up and take on more responsibility."*

Young people also stressed that accountability processes, such as accessibility auditing, should be led by them and crucially, this must be work that is remunerated.

> *"I think the key thing is that we're the ones determining all of this. It's not a government – it's not a government employee. It's not a disability employment service. It's not an employer. It's disabled young people. And there is meaningful paid scope for us to provide feedback and that to be listened to."*

Finally, cultural changes relating to how disability is valued and understood are pivotal to the success of young people.

> *"You can say that you value diversity, but you've actually got to back it up, and actually have values around that, and actually have a culture around that."*

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[10] "Someone who is not transgender or gender diverse, and who identifies with the sex they were assigned by doctors at birth. Sometimes written as 'cis' for short." Your guide to words and definitions in the LGBTQIA+ community (minus18.org.au)

Where to from here?

Participating in employment supports a person to contribute their skills and talents to society, be independent, meet new people, develop new skills, and explore new interests. In line with the perspectives of young people who participated in this consultation, CYDA recommends the following:

1. The Australian Government must protect the employment rights of young people

This includes:

- Introducing Disability Standards for Employment to clarify the obligations of employers under the Disability Discrimination Act 1992. These Standards should include a clear definition of what constitutes a reasonable adjustment, with examples for employers of varying scope and across different industries
- Increasing funding to the Australian Human Rights Commission to support greater accountability and consequences for cases of employment discrimination.

2. Governments at all levels should invest in the enablers of successful employment service outcomes

Governments should listen to what young people from the CYDA community recommend, to provide effective employment support. This includes:

- Person-centred practice and holistic approaches to service delivery prioritising the employment aspirations of service users
- Increase disability awareness among service providers and employers
- Focus on transition from school and provide earlier employment support to young people
- Develop clear mechanisms for feedback and continuous improvement, ensuring that the experiences of people with disability remain at the heart of Employment Service practice and;
- Place-based and community focused service delivery.

3. The Australian Government should ensure service contracts, funding models, and Key Performance Indicators of employment programs address systemic barriers to employment and incentivise supporting the needs of individual jobseekers

This includes:

- Providing sufficient and up-front funding to support young jobseekers to overcome systemic barriers in the labour market
- Ensuring caseloads allow service providers to deliver personalised supports and demand-based activities, such as building employer networks
- Incorporating participant experiences and feedback as a measure of success
- Formally measuring and recognising human capital development as a service offering
- Recognising and building on the diverse strengths and employment barriers of different community settings
- Introduce initiatives and quotas to support the employment of people with disability within employment programs.

4. Governments at all levels should deliver consistent post-school transition supports for students with disability in line with priority area two[11] of the *Employ My Ability* Disability Employment Strategy[12]

- The Australian Government should commission a review of funding arrangements in all states and territories for school and post school programs for students with disability
- Together with state and territory education departments, the Australian Government should develop and implement a nationally consistent post school transition supports framework. This framework should:
  - Include the core requirements of quality post school transition support as outlined in *Post School Transition: The Experiences of Students with Disability*, including beginning conversations and support in year nine
  - Be evidence-based and outcomes orientated
  - Include 'high-expectations' information resources for families and students with disability about post school options, application processes, and funding and subsidies available
  - Be adequately resourced

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[11] Building employment skills, experience and confidence of young people with disability: Ensuring young people with disability are supported to obtain work and careers of their choice

[12] Commonwealth of Australia. (2021). Available at: Employ My Ability (dss.gov.au)

- Include resources and follow up supports and programs for young people no longer in school
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LivedX Series: What Young People Said

Healthcare Settings for LGBTQIA+ Youth with Disability

December 2022

cyda.org.au

Children and Young People
with Disability Australia

Authorised by

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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

To date, the experiences of accessing medical and healthcare services for young queer[1] disabled people have remained relatively underexplored. To address this, CYDA hosted a consultation in December 2021 with 11 participants that sought to understand the intersecting experiences of LGBTQIA+[2] young people with disability in medical and healthcare settings. The consultation was co-designed by an internal working group of young disabled people, who identified this topic as poorly represented in the research literature, and therefore in need of deeper exploration.

Consultation participants had a lot to say about their experiences as young disabled queer people in healthcare and medical settings. Key themes that emerged included the need for a more intersectional approach in healthcare, inadequate understanding and confidence around gender diverse and neurodivergent[3] people, limited instances of healthcare providers with lived experience of these intersecting identities, a systemic issue of medical practitioners making incorrect assumptions, and a lack of dedicated or appropriate services to affirm people's identities.

Throughout the discussion, young people also made a number of suggestions for improvements to the healthcare sector. These included how to work collaboratively with young queer disabled clients, how to make clinical spaces more inviting, how to ask the right questions of clients, and educating medical practitioners and service providers on the necessary cultural competencies to provide the quality care that young people have a right to expect.

As a result of this consultation, the following recommendations outline opportunities for healthcare stakeholders to create and foster safe and inclusive spaces and practices for young LGBTQIA+ people with disability to receive the support and treatment they need and are entitled to.

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[1] A community term, used interchangeably with LGBTQIA+

[2] 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: [Your guide to words and definitions in the LGBTQIA+ community (minus18.org.au)](https://minus18.org.au)

[3] '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

Recommendations

1. Recommendations for government:

- Commit to the development of a national LGBTQIA+ Healthcare Strategy, which includes a focus on healthcare for disabled clients, young clients, gender diverse clients, and neurodivergent clients.
- Invest in research exploring the experiences of LGBTQIA+ disabled young people, including a focus on transgender and gender diverse-specific health outcomes and treatments. Provide additional funding under the National Disability Advocacy Program[4] to work in collaboration with specialist advocacy organisations to develop tailored advocacy approaches for LGBTQIA+ people with disability.

2. Recommendations for healthcare settings and medical service providers:

- Investigate opportunities to de-clinicalise medical spaces and to make them more inviting for queer disabled clients.
- Implement the suggestions to improve patient-care for young queer disabled people made in this paper, including ensuring spaces meet physical accessibility requirements and utilising digital platforms, such as social media, to support engagement.

3. Recommendations for healthcare regulators and peak medical bodies:

- Engage collaboratively with LGBTQIA+ and Disability Representative Organisations to develop accredited LGBTQIA+ cultural competency training for health professionals, as well as improving existing training through engagement with lived experience.

4. Recommendations for medical professional development and education providers:

- Engage with LGBTQIA+ and Disability Representative Organisations to collaboratively examine opportunities for improvements to the education and development pipeline to support more LGBTQIA+ and disabled people entering healthcare professions.
- Work with healthcare settings and medical service providers to identify opportunities for on-the-job, ongoing education and training which is co-designed with the LGBTQIA+ disabled community.

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[4] Commonwealth of Australia. (2022). Available at: National Disability Advocacy Program (dss.gov.au)

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- LGBTQIA+ people with disability: healthcare

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

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Background on healthcare settings for LGBTQIA+ youth with disability

Broadly, the intersection between the disabled community and the LGBTQIA+ community is an under-researched topic in the Australia context. This research gap is even more glaring when layered with a focus on young people and healthcare settings. However, we do know that while people with disability are more likely to use healthcare settings than those without disability, they are also more likely to experience barriers to access, including accessibility, discrimination, affordability, waiting times and lack of communication and coordination between medical professionals.[6] We also know that LGBTQIA+ patients experience distinct barriers to accessing and feeling safe in healthcare settings.[7]

Recent publications have called for the need to de-gender our approach to healthcare in Australia.[8] Others have suggested that diversity training in the healthcare sector is

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[5] 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

[6] ACTCOSS. (2017). *Disability and access to health services: Fact sheet*. Available at: Factsheet: Disability and access to health services (actcoss.org.au); AIHW. (2022). *People with disability in Australia*. Available at: People with disability in Australia (aihw.gov.au)

[7] Dean, M.A., Victor, E. & Guidry-Grimes, L. (2016). *Inhospitable Healthcare Spaces: Why Diversity Training on LGBTQIA Issues Is Not Enough*. Bioethical Inquiry 13, 557–570

[8] Geale, S. "Changing the Paradigm: Gender orientated healthcare needs to embrace the LGBTQIA+ community", *Australian Nursing and Midwifery Journal* Vol. 26, No. 5, Jan-Mar 2019: 52

not enough to improve the state of healthcare for LGBTQIA+ people.[9] These calls were echoed by participants of this consultation, particularly those with lived experience of gender diversity and gender transition. Notably, however, these studies did not directly focus on young or disabled perspectives.

CYDA was overwhelmed by the response to the call out for participants for the LGBTQIA+ healthcare consultation. A substantial number of young people agreed that this area is largely under-researched, is especially important to them, and that they wanted to participate in this consultation to help CYDA lead the way in helping young queer people with disability advocate for their rights.

Likewise, several organisations in the youth, LGBTQIA+, and disability sectors expressed a strong interest in the results from this consultation. It is clear that there is a demand for insights from this intersectional community. As such, this paper presents perspectives on healthcare from young LGBTQIA+ people with disability and provides recommendations for healthcare providers and support services to refine and improve their practices and approaches.

Young LGBTQIA+ people with disability's perspective on healthcare settings

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

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[9] See footnote 6

What young people said

Identity

Throughout the consultation, participants shared that they strongly believe that the success of healthcare services for queer disabled people is underpinned by a deep and nuanced understanding of intersectionality. Services which have affirmed their identity as both queer and disabled, as well as their identities as culturally and linguistically diverse, Indigenous, and more, are those which reflexively apply an intersectional approach. Conversely, services which have not appropriately recognised and affirmed a young person's disabled and queer identities have not succeeded in making these young people feel welcomed or accommodated.

> *"I always have to compromise one part of myself."*

> *"We have this added burden […] there are so many different parts of our lived experience that we have to try and explain to people."*

> *"I've never found any healthcare service that is [both] queer and disability-affirming."*

> *"I am as disabled as I am queer, and as queer as I am disabled, because I am both."*

In particular, transgender (trans) and gender diverse young people explained the additional challenges they experience in navigating healthcare settings. Healthcare professionals are often unaware of how to approach the intersection between gender diversity and disability, from both a cultural and a logistical perspective.

> *"If I do have a really good doctor, they're never good with both [identities]. So, I just don't talk about being trans, and just don't bring it up, because I'm like cool, I've found the specialist, I need to hold onto them, so we're just going to seem as un-difficult as possible."*

> *"I've yet to have a specialist who can give me answers [about how I can get top surgery[10] as a wheelchair user] […] [F]irstly, top surgery is seen as cosmetic, so therefore not medically necessary, and so a lot of disabled people are denied it. But just like, that intersect is never really talked about."*

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[10] "Reconstructive chest surgery, commonly referred to as 'top surgery' is typically sought […] to remove breast tissue and sculpt the chest into a pectoral form." Top surgery (transhub.org.au)

> *"If I'm getting good medical care for my disabilities, and they understand I'm disabled, [I'm] probably going to let a few misgenderings*[11] *[go…] because it will compromise my medical treatment. And if I'm getting really affirmed in my gender and my queerness, and my gayness, and I'm not going to bring up how un-comfy I am that they're using person first language about my autism, and that they're not recognising some of my conditions as disabilities, and that sort of thing."*

> *"And binding*[12]*, how does that work as a disabled person, what are some more things I should be concerned about? Same with hormones, I think just more conversations that already exist, but just making sure they're a little bit more intersectional in that respect."*

Young people also identified that both their disabled and LGBTQIA+ communities were important in helping them to locate appropriate services.

> *"[…T]rusting the community and asking other people in the community to vouch for people, and then going in that way. But it's quite difficult, because if you are not a part of those networks, then how do you know?"*

Enablers

Many young people explained that it was more important to them that healthcare providers display empathy and ask the right questions when engaging with the queer aspects of their identity, than educating them on all the possible unique intersectional identities.

> *"I think empathy is the big thing. You don't have to be trained, you don't have to be like super, 'Oh, I've read every single research paper on how gender diverse people relate to reproductive rights'. But you just ask – just ask the question, and just listen to what people have to say."*

> *"I don't necessarily want them to know about my identity, but I wish they knew to actually ask me about it, rather than make assumptions."*

> *"When doctors ask open-ended questions, especially for someone who is questioning, it's really helpful to have the space and confidence that you can explore yourself and your health status in a safe way."*

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[11] "'Misgendering' is a term used to describe accidentally or intentionally using incorrect pronouns about or towards a person." What are pronouns and why are they important? (minus18.org.au)

[12] 'Binding', short for 'chest binding' "involves the use of tight fitting sports bras, shirts, ace bandages, or a specially made binder to provide a flat chest contour." Binding, packing, and tucking (transcare.ucsf.edu)

> *"The first question I would [like to be] asked would be, 'What are you hoping for?', and then [the doctor] fulfilling that, making the experience patient-led."*

> *"Because even in this room I've already heard people use very different language to describe themselves, whether we have similar experiences or different ones. So, it's important to always check in."*

Barriers

Throughout the session, participants noted that a lack of lived experience of queerness and disability in healthcare services led to barriers in receiving the appropriate care. In the absence of lived experience, the need for education on issues pertaining to the queer community was made clear.

> *"[The problem for me has] not been that they don't know that [trans people] exist, because we're at a point where they know trans people exist. But that [they don't know] actually it is their legal obligation to gender me correctly, to not deadname*[13] *me, et cetera, et cetera. So, that's actually their responsibility, I wish they knew that. Or I wish they knew that that's also just like the bare minimum."*

> *"There really needs to be lived experience within service providers, because otherwise it creates a barrier of self-disclosure, and receiving adequate care."*

> *"I'm also on a Disability Royal Commission group, which is also excellent. But that happens to be because the two people who run the group are trans. I think if they weren't, I couldn't expect the same."*

> *"It sounds like we need more queer people to become doctors and nurses. Wow, almost like there's pipeline issues. What?! Couldn't even suggest that, right!?"*

Young people participating in the consultation reported many instances of healthcare providers making assumptions about their condition because of their queer identity. More specifically, they shared how misconceptions and practitioners' lack of education in gender and sexuality led to negative and disempowering experiences and healthcare outcomes. This was particularly true for participants who were neurodivergent, trans or gender diverse, or had lived experience of trauma.

> *"[I feel] as though I'm not offered the same services in terms of access to birth control and STI checks simply because of my sexuality in that I primarily have had same-sex partners, so I was questioned as to why I wanted birth control and that [an] STI check probably wasn't necessary."*

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[13] "'Deadnaming' means using a person's former name without their consent." Pride, respect, equality (respectvictoria.vic.gov.au)

> *"[Gender] dysphoria is often viewed like as a mental illness, which it is not. Dysphoria is society not seeing me as I am, and me not having access to the things that make me feel like I am myself. So, it's very much an external thing that I am forced to experience. And so, when they lump in dysphoria with things like depression, and yes, a lot of trans people are depressed, but when dysphoria is like a flavour of depression or anxiety, rather than something with a distinct societal cause, that then means I am the problem as the trans person, rather than transphobic society. And I wish that they knew that that's just not good enough."*

> *"When a service knows that you're trans, they then are more likely to infantilise you, and not believe you can make your own decisions, and get your parents to play a larger role in decision making."*

> *"My queerness sits very closely with my dysphoria around childbearing, and the way that treatment for one of my disabilities is predominantly approached, is through fertility treatment, and through, 'Oh, well you must want to have children, therefore I can't give you this option, because that's going to reduce your opportunities to have children. But I can give you this, and that will help you.' When that's just not my priority. And the vast majority of specialists that I've seen in that space, have made no attempt to understand how that part of my identity relates in with very complex relationships, with getting treatment, and improving my quality of life around that particular condition."*

One young person shared how lack of disability awareness impacted the way practitioners viewed their gender and identity:

> *"I also wish that [healthcare professionals] knew that my autism doesn't invalidate my transness and my queerness. In fact, it double validates it, because it means my understanding of gender and queerness has been solidified, literally by my brain, and the physical wiring of my brain."*

Another common topic of discussion was how existing systemic issues in healthcare settings made it difficult to seek support or justice following an experience of discrimination. Participants noted that sensitivities, such as practitioners talking about gender and sexuality with a young patient whilst their parent was in the room or working in medical settings without a trauma-informed approach, created challenges for young people accessing adequate and appropriate care.

> *"So, yeah, when I had many, many experiences of transphobia while in an inpatient admission, just like routine health stuff, I was like, cool I'm going to make a complaint, I'm going to bring this up to all of the levels. And I kind of got told, 'there's nothing we can do about that.' Or 'That's just interpersonal things, it's just what happens when people are in hospital.' Rather than like, 'You have been actively discriminated against, here's what we're going to do about it'."*

> *"So, when you're in inpatient for example, changeover which happens three times a day, name, pronouns, always misgendered every single time. But they are really sweet about it, but they also don't realise that this is the third time it happens every single day [… so], there's a lack of understanding of how what they say is not isolated, it's often a repetitive experience […] so it's kind of more hurtful."*

> *"When I got admitted to the [children's psych] ward, there was a ridiculously long list of questions […] so the nurses get to know you. Then there was, 'What's your gender identity? What's your sexuality?' But they said it with my mum in the room, and they were trying to be like really inclusive. I'm out to my family, so it didn't matter, but it was also like, some kids aren't going to be able to give you that information in front of their parents, and it's really a question you should be asking without your parents. It was just kind of like yeah, we're going to be inclusive. But also, the execution was really poor."*

Young people reported that there are not many places they can turn to locate services that will affirm their intersectional identities. Further, the geographical location of services can impact access to a full range of providers.

> *"I don't feel like there are many resources that help queer communities find services or practitioners who explicitly express familiarity and knowledge with working with queer people."*

> *"I find that being queer makes me just very ambivalent, or maybe anxious in the lead-up to actually reaching out and engaging with mainstream services."*

> *"It hasn't necessarily been my disability itself, but rather how I identify as someone with an accessibility need, which just makes me much more nervous or uncertain about how and where I can go to access care."*

> *"I have epilepsy, so I'm never going to drive a car, and so every single time my GP refers me to a specialist that is like off the public transport route, I'm like, 'Bro, I would love to see that person, but I literally can't.'"*

Solutions

Throughout the session, participants made a number of suggestions that could be implemented to make healthcare settings and services more welcoming and accessible to queer disabled young people. These include:

- creating more inclusive spaces by making them less clinical and more comfortable and inviting
- implementing basic physical accessibility measures, and ensuring that healthcare providers know their legal obligations around providing these
- making services free or heavily subsidised
- ensuring that more medical professionals are equipped with either lived experience or more education around disability and LGBTQIA+ matters.

Other suggestions young people made to improve services include:

> *"[Nurses during handover at a hospital] kind of explain[ing] [my gender and pronouns] outside of the room, so then I didn't have to deal with the whole being misgendered during handover."*

> *"[G]iving away free things that are super important for us. So, like free condoms, free dental dams, lube, things for safe sex, but also for queer sex. I think like where possible, binders would be really epic, information sheets, like that sort of thing."*

> *"Initial appointment before the actual appointment to properly evaluate needs, unrushed appointments as many clinics are overbooked and these things feel very rushed, client focused."*

> *"[An ideal service] would partner with queer organisations to engage cohorts on specific issues. It would have regular feedback sessions, and not just, 'Complete this survey,' but community conversations, like let's have a cup of tea, let's have a board game night with the doctors, and the doctors are going to listen to your grievances, whatever that looks like."*

There was strong support for healthcare settings to be more digital-first, and to be using the platforms that queer disabled youth use to support engagement.

> *"I think it's really important that the services use the platforms that we feel comfortable using."*

> *"[I would love to see a] 'Rate the doctor', online systems like Yelp for medical practitioners. I find that so often, unless you are connected in with your local queer community, you're not going to know if you're going to see a medical practitioner who is queerphobic[14] or transphobic. And so yeah, it would be really good to have more of those online systems, so that you don't have to rely on your own networks."*

> *"[S]ocial media presence that is actually run by queer young disabled people, so that you don't have to just like Google, a map comes up of where are the different doctor clinics. It's like they have a social media presence, they advertise that they exist, and it's advertised directly to me. Because I know I'm way more likely to go and click something from an Instagram ad, than I am from like a newsletter that gets sent to my parents' house."*

Some young people supported the idea of education for healthcare providers in order to provide more appropriate services, however, it was important to the group that education not be a one-off and that proof of continuing professional development in this area be maintained. Participants also noted that it would be beneficial for professional accrediting bodies to require this continuing professional development as a condition of accreditation and registration.

> *"[There needs to be] [t]raining delivered by folks with identities in this context, gender sensitivity and general queer education, disability sensitivity and responsiveness and of course, the other intersectional identities."*

> *"I don't think [education is] how we solve the problems. It can be a step […] I think it should be in uni curriculum that you need to get a degree, but I think more than that, there needs to be proven competence regularly."*

> *"So, I think the solution, which can be connected with an education program, could be like queer people […] go into shops and test them to see how good they are. Like that, but with queer people receiving medical services. And if [the services] don't do a good job, they have to – I would say get their medical licence revoked, but that feels a bit dramatic. But some sort of big punishment, and then here are the things that you have to do before you can start practicing again."*

It was also made clear by participants that young queer disabled people should not be burdened with educating these professionals in the context of them receiving healthcare.

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[14] 'Queerphobia' is an umbrella term for hatred and discrimination against LGBTQIA+ people at individual and systemic levels

> *"I'm happy to educate people if they're paying me for it in a different setting – I'm not happy for my healthcare to be like taken over by someone else's education."*

Social Movement

LivedX consultation participants recognised the importance of the use of a strengths-based or social model[15] in healthcare settings. Where a medical model[16] was used, young people reported feeling less affirmed in their disabled identity, even if their queer identity was affirmed.

> *" [A Victorian hospital] has been great in affirming my queer identity, but in regard to disability, it's very medical model based. So, it's been helpful at times, but also not super helpful at other times."*

> *"I think it really is a big thing with the medical model of disability, and the way that we're seen as impaired, without looking at the way that society is built to render us, when they're inaccessible."*

> *"[F]or me, disability-affirming means not following the medical model, because that isn't why I'm disabled. And so, I haven't found a healthcare service that doesn't follow the medical model."*

Finally, education and reform needs to be led by disabled people. Young people said that the whole sector needs to connect and collaborate with the queer community to balance out the power dynamic that exists between formally educated clinical practitioners and queer disabled folk who have been systemically marginalised throughout their lives.

> *"Opportunities for queer and disabled people to become healthcare providers such as uni scholarships for disadvantaged people, traineeships and inclusive courses."*

> *"Including disability lived experience in tertiary education relating to healthcare, perfect."*

> *"And [a good service] would treat me like an equal from the beginning. So, it wouldn't be like this hierarchical, 'I'm the doctor, I know everything. You are the patient; you will pay me for my services'. It is, I'm a peer, this is what I'm offering you, and this is how you can pay me for that."*

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[15] "The social model sees 'disability' is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers." Social model of disability (pwd.org.au)

[16] "According to the medical model, 'disability' is a health condition dealt with by medical professionals. People with disability are thought to be different to 'what is normal' or abnormal. 'Disability' is seen 'to be a problem of the individual." ibid

> *"I think that coproduction is the way to go, so planning, delivery and then evaluation by consumers or folks with these intersectional identities so that it's theirs, it's by them, for them and it's not other people's ideas and assumptions on what people need."*

> *"Avenues for building capacity and spaces where we are deemed our own experts, whether that may be through advocacy with decision makers, workshops, service provider consultations."*

Where to from here?

The calls for culturally competent and inclusive healthcare settings providers were heard loud and clear. In line with the perspectives of young people who participated in this consultation, CYDA recommends the following:

1. Recommendations for government:

- Commit to the development of a national LGBTQIA+ Healthcare Strategy, which includes a focus on healthcare for disabled clients, young clients, gender diverse clients, and neurodivergent clients.
- Invest in research exploring the experiences of LGBTQIA+ disabled young people, including a focus on transgender and gender diverse-specific health outcomes and treatments. Provide additional funding under the National Disability Advocacy Program[17] to work in collaboration with specialist advocacy organisations to develop tailored advocacy approaches for LGBTQIA+ people with disability.

2. Recommendations for healthcare settings and medical service providers:

- Investigate opportunities to de-clinicalise medical spaces and to make them more inviting for queer disabled clients.
- Implement the suggestions to improve patient-care for young queer disabled people made in this paper, including ensuring spaces meet physical accessibility requirements and utilising digital platforms, such as social media, to support engagement.

3. Recommendations for healthcare regulators and peak medical bodies:

- Engage collaboratively with LGBTQIA+ and Disability Representative Organisations to develop accredited LGBTQIA+ cultural competency training for health

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[17] Commonwealth of Australia. (2022). Available at: National Disability Advocacy Program (dss.gov.au)

professionals, as well as improving existing training through engagement with lived experience.

4. Recommendations for medical professional development and education providers:

- Engage with LGBTQIA+ and Disability Representative Organisations to collaboratively examine opportunities for improvements to the education and development pipeline to support more LGBTQIA+ and disabled people entering healthcare professions.
- Work with healthcare settings and medical service providers to identify opportunities for on-the-job, ongoing education and training which is co-designed with the LGBTQIA+ disabled community.

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LivedX Series: What Young People Said

Community Spaces for LGBTQIA+ Youth with Disability

December 2022

cyda.org.au

Children and Young People
with Disability Australia

Authorised by

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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 intersection between queerness and disability is important as those who are both queer[1] and disabled experience queerphobia[2] and ableism[3] differently than those who are disabled but cisgender[4] and heterosexual or those who are queer but non-disabled. In December 2021 CYDA hosted a consultation with 11 participants that sought to understand the intersection between disability and LGBTQIA+[5] identity. The consultation was co-designed by an internal working group of disabled young people, who identified this as a topic that had been poorly researched and therefore in need of deeper exploration.

Many participants in CYDA's consultation felt marginalised as a result of their disabled identity not being considered in queer spaces, and their queer identity being ignored or erased in disabled spaces. The discussion revealed that most participants agreed that having the option between online and in-person events and being asked their pronouns were important enabling factors in feeling included and being able to participate in things that were important to them. Many participants felt their disability was ignored or infantilised in queer spaces, and the negative perceptions and ableist attitudes towards disability made queer spaces less accessible and welcoming.

The majority of participants acknowledged the need for greater accessibility measures within queer and disabled spaces, and described the major impacts that even small accommodations, such as seeing pride and trans stickers in disabled spaces, could have in making them feel more welcome and accepted. Participants also agreed that establishing spaces specifically for queer and disabled individuals would be extremely beneficial, and that more people who identify as queer, disabled, and both, need to be in leadership positions, both within these communities and outside of them. Young people participating also agreed that those who are queer and disabled need more of a voice, both within the queer and disabled communities, and in the broader community. Participants want queer and disabled groups, events, and spaces to be designed and operated by members of their respective communities.

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[1] A community term, used interchangeably with LGBTQIA+

[2] 'Queerphobia' is an umbrella term for hatred and discrimination against LGBTQIA+ people at individual and systemic levels

[3] '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

[4] "Someone who is not transgender or gender diverse, and who identifies with the sex they were assigned by doctors at birth. Sometimes written as 'cis' for short." LGBTQIA+ (minus18.org.au)

[5] 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 ibid

Recommendations

1. Recommendations for governments:

- The Australian Government should fund collaborative opportunities between disability and LGBTQIA+ organisations to enable disabled and queer people to develop best-practice guides for services and hosting events.
- Governments at all levels create graduate and progression opportunities within the public service to work towards having greater representation of disabled queer people in leadership and decision making roles.

2. Recommendations for community services and organisations:

- LGBTQIA+ services and organisations should implement accessibility and inclusion measures so young queer disabled people can access and feel safe in spaces and events on the same basis as their non-disabled peers. This includes, but is not limited to:
    - Providing a mixture of online and offline events
    - Installing ramps for wheelchairs and other mobility devices
    - Having quiet spaces at events, several designated accessible car parking spaces and accessible bathrooms.
- Disability services and organisations should implement accessibility and inclusion measures so young queer disabled people can access and feel safe in spaces and events on the same basis as their cisgender, heterosexual peers. This includes, but is not limited to:
    - Providing a mixture of online and offline events
    - Proactively asking for and using preferred pronouns in introductions and communications
    - ‘Welcome Here’ stickers and other similar symbols to mark spaces as being explicitly queer-friendly
    - Ensuring that disabled sexuality and gender identity is always acknowledged and respected.
- Disability and LBGTQIA+ organisations and local councils should develop targeted social opportunities and safe spaces for young queer disabled people to meet and network.

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+ people with disability: community
- LGBTQIA+ people with disability: healthcare

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[6], 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 intersectional experiences of LGBTQIA+ people with disability

The intersection between LGBTQIA+ identities and disability/disabled identity is significant yet understudied and unreported on, with queer intersectionality being a known data gap in national surveys of disabled individuals[7]. This issue is also partially caused by the general lack of quantitative data on queer young people in Australia[8].

Despite the lack of national, consistent data collected through formal government mechanisms, we know the intersection between queer identities and disability is significant. In a survey[9] of queer young people in Australia (n = 6,418), almost 40% of participants reported having a disability or long-term health condition, and young people with disabilities were much more likely to list queer issues as being of personal

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[6] 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

[7] Australian Institute of Health and Wellbeing. (2020). *People with disability in Australia 2020*. AIHW, Canberra, pages 337-338. Available at: People with disability in Australia (aihw.gov.au)

[8] Australian Institute of Health and Wellbeing. (2021). *Contributions from young people*. AIHW, Canberra. Available at: Contributions from young people (aihw.gov.au)

[9] Hill, A., Lyons, A., Jones, J., McGowan, I., Carman, M., Parsons, M. et al. (2021). *Writing Themselves In 4: The health and wellbeing of LGBTQA+ young people in Australia*. National report, pp. 32-33.

concern than their non-disabled peers (20.6% as compared to 9.6%).[10] Another study found that some queer groups, such as gender diverse individuals, have higher rates of autism and other neurodevelopmental/psychiatric diagnoses, than cisgender individuals do[11]. Further, a national youth survey conducted by Mission Australia in 2021 found that a larger percentage of gender diverse young people reported having a disability than cisgender respondents did (34.8% of gender diverse respondents compared to 9.3% of cis men and 6.7% of cis women).[12]

The intersection between queer and disabled identities is important to consider because the needs and experiences of queer disabled individuals differ from those of cisgender heterosexual disabled individuals and non-disabled LGBTQIA+ individuals. These individuals experience both queerphobia and ableism differently to their non-disabled or cisgender peers, along with experiencing different types of discrimination compared to those who are just queer or disabled in isolation. For instance, some studies suggest that around one third of autistic individuals have their gender identity questioned because of their autism. Further, longstanding notions that disabled people aren't gendered or sexual leads to the invisibility of queer disabled people, and historical practices of medicalising both disability and queer identity have functioned to delegitimise both[13].

These findings are an example of how the experiences of queer disabled individuals are distinct, and why considering the intersections between the two groups is important. As such, the LivedX consultation, designed and delivered by young people, aimed to provide a platform for young people to share their intersectional experiences, with a particular focus on community spaces and events.

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[10] Hall, S., Fildes, J., Liyanarachchi, D., Plummer, J. and Reynolds, M. (2020). 'Young, Willing and Able - Youth Survey Disability Report 2019'. Mission Australia: Sydney, NSW. pg 24

[11] Warrier, V., Greenberg, D.M., Weir, E., Buckingham, C., Smith, P., Lai, M., Allison, C., & Baron-Cohen, S. (2020). 'Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals', Nature communications; Nat Commun, 11(1).

[12] Tiller, E., Greenland, N., Christie, R., Kos, A., Brennan, N., & Di Nicola, K. (2021). Youth Survey Report 2021. Sydney, NSW: Mission Australia.

[13] Egner, J.E. (2019). "The Disability Rights Community was Never Mine": Neuroqueer Disidentification", Gender & Society, 33(1) pp. 123-147.

Young LGBTQIA+ people with disability's perspective on community spaces

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

What young people said

Identity

Throughout the consultation, many participants shared that they felt that their disabled identity was not acknowledged in queer spaces, leading to feelings of alienation from their non-disabled queer peers and spaces feeling inaccessible.

> *"I think when I think of queer spaces, I think of cis white gay men having a great time, which [is a] super important part of the queer community, but as a disabled trans person, that isn't my experience and so I often don't feel connected to those spaces and then therefore it's not accessible for me as a disabled person, especially as an autistic person, not feeling like I am actively a part of that space I think has been a big thing for me."*

Although there were numerous descriptions of queer spaces being inaccessible to disabled individuals, the failure to consider intersectional queer identity is worth pointing out specifically. Participants shared feelings of alienation and disconnection that appeared distinct from many of the other factors that can make queer spaces inaccessible for disabled individuals.

> *"I think often queer spaces think that making the space safe for queer people is them making it accessible and I think a lot of the time queer people think 'Well, I'm marginalised for my queerness, so therefore making it safe for other queer people involves doing what I need' and don't have an intersectional approach."*

Such exclusion also created barriers to disabled queer young people who would like to explore their identities through peer interaction, an important part of identity formation. Similar feelings were reported about the exclusion of queer individuals in disabled spaces:

> *"But yeah, like 40% of autistic people are gender-diverse or trans and it's something like 60 or 70% are queer in some capacity. That's not a coincidence, that is because of our interactions with sexuality and gender. So non-autistic and non-neurodivergent*[14] *queer people need to understand that and then that needs to validate our queer identity, rather than invalidate it."*

One space in which several participants were able to find community and belonging was on the internet. Many young people mentioned that the shift to online spaces during COVID-19 benefited them significantly and made queer and disabled spaces more accessible for them. However, it is also important to note there were still some accessibility issues in these spaces, and the change wasn't positive for everybody.

> *"I guess maybe one thing for me is like what [COVID-19] made not even necessarily queer spaces more accessible but just kind of like community is the push to existing online allowed me to find a community on social media, which was really cool."*

Enablers

When discussing what factors the participants felt enabled them to participate in both the queer and disabled communities, the two main themes that emerged in discussion were 1) the importance of individuals supports, and 2) the importance of ensuring their identities were respected.

One of the biggest enablers to accessing individual supports, was the ability to have options to either engage with these communities online or in-person. Many participants discussed how much easier it was for them to engage with communities and services online, however, several found engaging online harder and would prefer in-person options.

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[14] '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

> *"I've facilitated some queer youth groups, and you get people who are unable to leave their home for whatever reason, or maybe they live in remote or rural areas, so they can't travel out to the city, so it's been fantastic because they can literally access these groups that they haven't been able to in the past."*

With many events and groups shifting online because of the COVID-19 pandemic, many participants shared that they had gotten the opportunity to interact with the queer and disabled communities for the first time. Some participants added that they were worried that in a 'post-lockdown world' these online functions would decrease in frequency, and they would become unable to participate in these communities again.

> *"So, I think we should learn from the pandemic experience that actually obviously it sucks to be in a global pandemic but it doesn't suck that I got to attend things for the first and only time and that shouldn't end just because it's easier and we want to go back to the before times. I think especially in queer spaces that's like just been so apparent to me."*

The increase of online and remote options for engagement also created new, safer avenues to engage with services, as exemplified by the following comment from a young participant:

> *"I guess for me was when we were like normalising phone calls with health professionals, it was easy where you don't have to go into an appointment and you're committed to that and then you have to pay for it, whereas now I can like organise a phone call [in advance] with let's say a new kind of like healthcare professional before I commit to booking a telehealth appointment and I can be like 'Oh, what's your experience working with transgender people? And do you consider yourself educated on these issues? And are you accessible and do you provide like gender affirming care?' And I guess that's been really good because it takes the pressure off of in-person meetings."*

Another important enabling factor for the participants was having their identities respected. Things such as misgendering[15], assumptions about their sexuality or gender identity, or having their identities erased or ignored were all things that made spaces and experiences inaccessible. Participants agreed among themselves that even something as minor as being asked for their pronouns made them almost immediately feel significantly more comfortable. This, in addition to having their gender identities respected, were small courtesies that had major impacts in making spaces feel more inclusive and welcoming, enabling participants to engage within them.

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[15] "'Misgendering' is a term used to describe accidentally or intentionally using incorrect pronouns about or towards a person." What are pronouns and why are they important? (minus18.org.au)

> *"And so I think what makes them inclusive is no assumptions I guess when you enter the space, when you enter the door or call up for a referral. And like let you define yourself by yourself, so ask me 'What pronouns do you use, what language do you want me to use for you, how do you identify?' rather than waiting until I correct them but that I probably don't correct them because I'm dysphoric from being deadnamed[16] and misgendered."*

Barriers

Throughout the session, participants discussed a range of barriers to engagement with both disabled and queer communities. These included the negative perceptions of disability within queer spaces along with the erasure of disabled sexuality, as well as disabled spaces not being queer-friendly, and the lack of tailored and individual supports for participation.

> *"I think there's a lot of queer people who infantilise disability, and so I guess – I don't know how to address that, but it needs to be addressed because I've noticed in a lot of queer spaces, when I say, 'Oh, I'm autistic', I'll get like 'Oh, bless. My cousin's autistic. He's so cute.'"*

> *"[…] If you go into a disability provider, there's nothing on sexual health, there's nothing on reproductive health, there's nothing on – they don't have condoms or anything, or dental dams on their things. It's almost like there's this expectation that disabled people and sexual relationships, whether they're same sex, opposite sex, whatever, who cares, aren't compatible."*

The impact of infantilisation of disabled people and the erasure of disabled sexuality and queer identity were felt both inside and beyond the queer and disabled community. Participants were concerned that without access for disabled people they would be 'gatekept' from expressing their queer identity.

> *"I think particularly with the context of so many people have come into their queerness or been safe in their queerness for the first time in their lives, recognising how important queer spaces are coming out of lockdown and that if they're not accessible to disabled people, then we're gatekept from our own queerness."*

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[16] "'Deadnaming' means using a person's former name without their consent." Pride, respect, equality (respectvictoria.vic.gov.au)

Another barrier participants faced was disabled spaces not being queer-friendly. This also ties into the infantilisation of disability and the erasure of disabled queer identity. As one participant explained:

> *“I think often non-autistic people leading autistic spaces use the excuse that autistic people can't handle change, to mean that they don't have to change the ableist or queerphobic things that they're doing.”*

This was a common issue described by participants, with others mentioning having their gender identity ignored because people believed that being disabled somehow prevented them from being able to understand their own gender identity. This also plays into the infantilisation and erasure of disabled queer identity discussed above.

Another major barrier preventing queer disabled people from accessing queer and disabled spaces was the lack of supports designed to address the differing needs of individuals. Likely, due to the experiences of COVID lockdowns (and the timing of the consultation where many states and territories were ‘opening up’), the difference between the accessibility of online and in-person spaces was a recurring topic of conversation raised by the participants.

> *“[A]ll of a sudden, it's been really great and we can interact with different queer people from all over so-called Australia, and then as soon as lockdown ends, people are like, ‘Oh, I'm never going on Zoom again’, and it's really disappointing because for once we've been able to kind of like join spaces that otherwise haven't been great for us.”*

While online spaces and meetings worked well for some participants, for others remote appointments were incredibly inaccessible, and made accessing basic services vastly more difficult.

> *“It is too hard to tell a doctor what is wrong over the phone when they can't see what's wrong. Phones cut out and there is background noise. It is absolute hell for auditory processing issues but providers didn't really care.”*

It is important to understand that what can make a space accessible for some can make that same space inaccessible for others. The discussion around this shows that accommodations and supports have to be personalised and individual in order to allow for individuals to truly be included.

Solutions

Participants discussed various solutions to the barriers they faced. One idea that was raised and widely agreed on was that that queer spaces needed to become more accessible for disabled individuals. The suggestions proposed included having quiet spaces for those with sensory needs and better wheelchair accessibility. One participant also added that certain accommodations should be mandated:

> *"I don't know if there's a way to mandate accessibility measures, for in-person and online spaces. I don't actually see the government ever doing that but it'd be epic if they could because yeah, we shouldn't have to choose between two inaccessible things and then end up doing none of them. We deserve access to queer spaces."*

There were also discussions about how disabled spaces could become more queer-friendly, with participants discussing how even simple actions such as displaying pride stickers in a disabled space or service could make the space feel more accepting and welcoming.

> *"The stickers of pride and trans flags on [disabled space] windows help to be informing of welcoming [queer people]."*

One idea that gained enthusiastic support from the consultation participants was spaces designed specifically for queer disabled young people. They also thought that having more queer and disabled spaces that focus on hobbies might allow members of these communities to engage with their peers in ways that don't require significant emotional labour.

> *"[What] would be cool is a lot of the time there's either queer spaces or disabled spaces. Those spaces are inherently about our identities, which is great, but there's often not spaces that are just like for fun things that we all just happen to share lived experience in. And so I definitely think there should be spaces that are about our identity and talking about that and unpacking and supporting that, but I think it would be cool to see more spaces, specifically for queer disabled people who are about hobbies and things that we're interested in, like a queer disabled Dungeons and Dragons group or a queer disabled writing group or what have you, so you know it will be affirming and accessible but you don't have to like emotional labour every time."*

Social Movement

Discussion around disabled and queer leadership, correcting the balance of power, and recognising the experiences of queer disabled youth were the main points raised by participants in relation to the social movements theme.

> *"And I also think both like run by disabled queer people or just like decent queer people but also I think it's not just about the organisers having lived experience because often we don't get that much of a platform in the queer community, but it's about consultation and co-design of events and programs and that sort of thing."*

The topics of disabled and queer leadership emerged frequently in the discussions, which centred around the lack of voice and influence participants have in decisions that affected them directly. It was generally agreed upon that any event or program that would be for them or include them needed to do more to include them in the decision making process.

> *"I think [we need] more people like us given positions of power in government departments, if possible. So when the pandemic continues but also other crises happen, we don't have to be like 'You forgot about us' and them be like 'Oh, sorry. Whoops', because there's a person that they're paying to do that. I know we have commissioners and that sort of thing and we've got a chief disabled officer thing in transport, but I don't think it's enough to just have a person, I think it needs to be whole departments or people that actually have power."*

Participants thought that empowering more disabled queer people to gain leadership positions would go some way to correcting systematic power imbalances which see marginalised groups not properly represented within decision making processes.

> *"Actually have people of those communities as a part of the discussions and decision making so it isn't just a bunch of older men in suits."*

It was also agreed that disabled and queer leadership could be beneficial in a wide range of contexts. One participant discussed their experiences of running eating disorder recovery groups for disabled and queer youth.

> *"The first example that came to mind is not one that I've received but I guess one that I've delivered, I suppose, and that's like an eating disorder recovery support group. And so they are completely online and were only started during COVID and I run one for disabled people in recovery and then one for queer people in recovery. And so that's been really great and people who are participants have gotten a lot out of it, so I've been told."*

Participants said that groups run by and for queer and disabled individuals are important for forming a sense of connection and community. Having queer and disabled spaces led by queer and disabled individuals was thought to be beneficial beyond identity-based activities and groups.

Where to from here?

1. Recommendations for governments:

- The Australian Government should fund collaborative opportunities between disability and LGBTQIA+ organisations to enable disabled and queer people to develop best-practice guides for services and hosting events.
- Governments at all levels create graduate and progression opportunities within the public service to work towards having greater representation of disabled queer people in leadership and decision making roles.

2. Recommendations for community services and organisations:

- LGBTQIA+ services and organisations should implement accessibility and inclusion measures so young queer disabled people can access and feel safe in spaces and events on the same basis as their non-disabled peers. This includes, but is not limited to:
    - Providing a mixture of online and offline events
    - Installing ramps for wheelchairs and other mobility devices
    - Having quiet spaces at events, several designated accessible car parking spaces and accessible bathrooms.
- Disability services and organisations should implement accessibility and inclusion measures so young queer disabled people can access and feel safe in spaces and events on the same basis as their cisgender, heterosexual peers. This includes, but is not limited to:
    - Providing a mixture of online and offline events
    - Proactively asking for and using preferred pronouns in introductions and communications
    - ‘Welcome Here’ stickers and other similar symbols to mark spaces as being explicitly queer-friendly
    - Ensuring that disabled sexuality and gender identity is always acknowledged and respected.
- Disability and LBGTQIA+ organisations and local councils should develop targeted social opportunities and safe spaces for young queer disabled people to meet and network.

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LivedX Series: What Young People Said

Inclusion and Decision Making

December 2022

cyda.org.au

Children and Young People
with Disability Australia

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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[1]. 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 ableism[2] 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.

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[1] Commonwealth of Australia. (2021). Available at: Australia's Disability Strategy 2021–2031 (disabilitygateway.gov.au)

[2] '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[3] 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.

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[3] 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'[4] 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.

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[4] Australian Human Rights Commission. (2021). Available at: Creating an accessible and inclusive workplace (includeability.gov.au)

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+[5] people with disability: community
- LGBTQIA+ people with disability: healthcare

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[5] 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: Your guide to words and definitions in the LGBTQIA+ community (minus18.org.au)

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[6], 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[7] 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[8]. 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

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[6] 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

[7] See footnote 1

[8] United Nations. (2006). *Conventions on the Rights of Persons with Disabilities*. Geneva.

their own preferences and will[9]. 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[10].

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[11] 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

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[9] Australian Law Reform Commission. (2014). *Equality, capacity and disability in Commonwealth laws (DP 81)*

[10] 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

[11] 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[12] people as making us experts."*

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[12] 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*[13] *conditions and how they present, like stimming*[14] *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."*

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[13] '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

[14] '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 decision-making with young people.

- Further investigation of supported decision-making tools. For instance, Douglas and Bigby[15] 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'[16] 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.

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[15] 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

[16] Australian Human Rights Commission. (2021). Available at: Creating an accessible and inclusive workplace (includeability.gov.au)

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