

Submission to the Disability Royal Commission: Disability Pride Youth Forum

Children and Young People with Disability Australia

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Authorised by:

Skye Kakoschke-Moore

Chief Executive Officer

Contact details:

Children and Young People with Disability Australia

E. skye@cyda.org.au

P. 03 9417 1025

W. www.cyda.org.au

Contributors:

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

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

Introduction

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

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

- Driving inclusion
- Creating equitable life pathways and opportunities
- Leading change in community attitudes and aspirations
- Supporting young people to take control
- Calling out discrimination, abuse, and neglect.

CYDA welcomes the opportunity to make a submission to the Disability Royal Commission on behalf of a group of nine young people with disability who were involved in a forum held by CYDA about Disability Pride. In enacting its strategic goal of supporting young people to take control and call out discrimination, abuse and neglect, CYDA collaborated with the Disability Royal Commission to undertake the Disability Pride forum. The purpose of which was to hear the views of young people about identity, diversity, embracing and disability as well as the barriers and enablers associated with achieving disability pride. This report captures the experiences and recommendations of the young people who participated and should be read in conjunction with the two audio-visual recordings that also form part of the submission.

The Importance of Disability Pride

Disability pride means different things to different people. It can range from owning one's story to challenging attitudes and shifting away from negative stereotypes. For many, disability pride is seen as a practice, where disabled narratives matter and belong to people with disability. According to The Youth Disability Advocacy Service 'Disability Pride' means "being proud of who you are and embracing your disability. It can also mean feeling confident and not hiding your disability."¹ Pride can help young people with a disability to feel part of a community or group, as well as supporting them to feel more comfortable identifying with common experiences. The importance of promoting

¹ <https://www.yacvic.org.au/ydas/resources-and-training/map-your-future/disability-pride/#TOC-1>

disability pride is further articulated in the What Young People Said Papers², produced by CYDA in 2020: “I did find my way to disability pride, but it wasn’t until my mid to late twenties. And it was because I connected with another disabled person in my small country town.”

There is a role for those in positions of power from the non-disabled community to provide environments for young people with a disability where they can feel safe, form communities and express pride in their identities. This conceptualisation of the role of our wider society (inclusive of government and other power structures,) in enabling pride, led to a discussion between CYDA and the DRC about the development of a forum on the topic.

About the Disability Pride Youth Forum

As part of CYDA’s ongoing engagement with the Disability Royal Commission we planned a youth forum with a focus on disability pride. Through collaboration with the Disability Royal Commission and CYDA’s membership³, identity and pride were determined to be mutual topics of interest. These topics inspire frequent discussion throughout CYDA programs, such as the Young Leaders Program, National Youth Disability Summit and CYDA’s Youth Council. This shows that these issues are a priority for young people with disability.

The forum was held on the 28th of September 2022 over Zoom. The forum facilitated discussion among nine young people with disability supported by CYDA staff members who identify as living with a disability to create an inclusive and safe environment.

The forum was launched with a presentation by guest speaker Jax Brown who is a disabled LGBTQIA+ writer and advocate. The forum also featured brief presentations by the Disability Royal Commission to explain the role of the commission and outline what it means to make a submission and by Your Story Disability Legal Support who provided background on the legal implications of making a submission. This ensured all participants were comfortable and aware of the supports available to them.

The Disability Pride Youth Forum were group-based discussions. These discussions, recorded over Zoom, took place in two 30-minute blocks with a 10-minute break to meet accessibility needs. Participants were split into two smaller ‘break-out’ groups with four participants in each. Forum participants were able to contribute in a number of ways, including verbally, via Zoom chat or via live Google slides. The consultation focused on four questions (detailed below).

² CYDA (2020) National Youth Disability Summit - What young people with disability said - Awareness, Access and Inclusion Position Paper

³ CYDA’s membership comprises of young people with disability as well as their parents and caregivers. Many of these young people remain involved with CYDA after taking part in a program.

Disability Pride Questions:

1. In your experience: What is pride? What is confidence? How does this relate to your identity?
2. In your experience: What sort of activities put a focus on disability pride? What does our society do well? What can we improve?
3. In your experience: Are these barriers internal or external? Do barriers relate to people, places and systems? How do these barriers make you feel?
4. In your experience: Where do you go for help? Where do you find community? What activities would help you to embrace your identity as a person with a disability?

Participant contributions are summarised within this submission under the key themes of barriers and enablers and conclude with key recommendations that emerged from the discussion.

Guest speaker Jax Brown encouraged forum participants to think of 'disability pride' as something that needs to be worked on, taking a lifetime to embrace completely. There is no 'correct' way of expressing pride and pride can take many forms. With the goal of spurring on discussion of disability pride Jax shared a poem by American writer Laura Hershey. 'You Get Proud By Practicing,' written in 1991, speaks to the experiences of our forum participants over 30 years later and highlights strength inherent to all people with disability.

"You do not need a better body, a purer spirit, or a Ph.D. to be proud.

You do not need a lot of money, a handsome boyfriend, or a nice car.

You do not need to be able to walk, or see, or hear, or use big, complicated words, or do any of those things that you just can't do to be proud. A caseworker cannot make you proud, or a doctor.

You only need more practice. You get proud by practicing."⁴

⁴ Laura Hershey(1991), 'You Get Proud By Practicing'
<https://disabilityvisibilityproject.com/2014/12/01/poem-by-laura-hershey-you-get-proud-by-practicing/>

Barriers to Young People with Disability engaging in or expressing Disability Pride

When asked about what prevents (acts as a barrier to) people with disability(s) feeling, building and expressing pride, forum participants identified several prominent issues, including limited accessibility, stigmatising community attitudes (such as low expectations), lack of self-confidence and lack of appropriate support.

Participants reported that exclusion and segregation are major barriers to the development of pride among people with disability. This can include elements such as inadequate physical accessibility or discriminatory policies and procedures (such as in education and employment). Comments by Forum participants included:

“We need to be able to access society.”

“Just keep supporting people [and] listen.”

Forum participants noted that it is hard to overcome societal inaccessibility or practice pride when struggling to meet their basic needs. Many young people have expressed to CYDA that the barriers associated with the medical system, or the NDIS play a major role in the shame (anxiety, challenges etc.) associated with disabled identities.⁵ Forum participants told us:

“I can't access NDIS so all I have is my parents around me but I don't want to always do that.

“For me the barriers are systems such as the NDIS [and can] stop us [from embracing our identity]”.

Participants noted a lack of visible representation can make it difficult to find role models and grow their understanding of disability pride. It is important to have access to the experiences of other people with disability whether that is through books, television, podcasts or art.

During discussions one participant described how they ensure these influences are in their daily life.

“I've got positive words related to disability on my walls or diary...I've got great quotes from disabled authors and mentors...The stories [of other people with disability] spur me on. A good one is Stephen Hawking's [life and achievements]..Access to success stories gives me enough motivation to attain great heights....[also] listening to podcasts in line with [that are positive about] disability is therapeutic”

⁵ CYDA(2020), 'Submission to the Disability Royal Commission: Targeted Engagement with young people with disability'.

Due to inconsistent community attitudes towards disability, participants described experiencing stigma as well as harmful expectations in relation to how they express their lived experience of disability. This is reported to cause frustration for many forum participants.

"I just can't comprehend the audacity of people who tell us [people with disability] how to identify ourselves... even people within my personal disability community can get heated and passionate about how they identify themselves."

"A lot of people tend to think blind/ low vision [equates to] not being able to hear."

When further discussing problematic attitudes (and how they can impact confidence), one participant noted:

"I feel the same as an autistic female. A lot of people just think I'm weird due to lack of understanding"

"I have friends who are disabled themselves and are genuinely in shock as to the idea of non-disabled people dating disabled people. And wanting relationships with (?) them. So some of these attitudes are internalised."

Enablers of Young People with Disability engaging in or experiencing Disability Pride

When asked about what enables people with disability(s) to feel, build and express pride, forum participants identified several essential elements, including: safety, adequate supports, education (self-advocacy), empowerment, as well as the role of representation and public events. According to forum participants it essential to provide people with disabilities with safe environments where they can act with authenticity and engage in the building of community pride and self-confidence, including the freedom to stand up for what you believe in. Forum participants told us:

"[for me this means] taking pride in my existence regardless of my disability.... Being the best version of myself [and] not yearning to be like another person."

"I am proud of my diagnosis, and I use it as a super-power."

"For me disability pride would have to be being true and transparent to yourself."

"[I need to be able to] feel confident and love myself"

People with disability can act with pride when they have access to robust supports systems that facilitate their engagement in all aspects of social, economic, and political life. Discussions saw a forum participant suggesting that an effective way of strengthening disability pride within Australian society would be to have a person who identifies as living with a disability as Prime Minister.

"When [a person with disability] can go somewhere and talk about what [their] issues are, I like that."

"[to help us share in pride] we need to check [look out] for each other, makes sure we are included in government activities and politics."

"Many times I wonder why people with disability can't be key leaders, people [society and the wider public] tend to limit people with disability."

Participants articulated a need for events & educational programs (this includes opportunities to celebrate intersectional identities) that promote the skills of pride, strength based thinking and self-advocacy.

"There's a lot of learning and practice [needed] ... its taken me a long time [to feel and express pride]"

"I am a disabled person, and from a CALD background. And its hard finding spaces, or services that understanding these identities together, not just separately."

Disability Pride Recommendations

When asked how those in power could better support young people with disability to express pride in their identities, young people recommended government:

1. Encourage inclusion from the ground up (taking a grassroots approach) through supporting inclusive education and open employment, ensuring the visibility of people with disability across all domains of life.
2. Promote the continual strengthening of disability discrimination legislation including the ongoing enforcement of universal design principles to address physical inaccessibility.
3. Support the ongoing development and funding of programs that address broader community attitudes with the goal of supporting people with disability to become community and political leaders and role-models. This should increase the visibility of disabled experiences more generally as well as in leadership and decision making roles.
4. Ensure effective resourcing for self-advocacy programs as well as broader disability supports. ensuring people with disability can control their own lives.