

nyds



National Youth
Disability Summit

What young people with
disability said:

The National Disability Insurance Scheme (NDIS)

Insights, ideas, and solutions from young people with disability
The outcomes of the inaugural National Youth Disability Summit
Presented by Children and Young People with Disability Australia
(CYDA)



Children and Young People
with Disability Australia



Children and Young People
with Disability Australia

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.

Background to the National Youth Disability Summit

At the end of September 2020, the inaugural National Youth Disability Summit ('the Summit') took place. The Summit was established with the vision to create an inclusive environment where young people with disability from across Australia could come together as a community and use their voices to shape the future.

The Summit was designed by and for young people with lived experience of disability. Over nine months, the Co-Design Committee, consisting of 20 young people with disability from across Australia, designed the vision, content and delivery of the Summit.

Hosted over five days, the Summit was an entirely online conference that offered young people a range of sessions and workshops, the opportunity to meet other young people, share their ideas, insights and expertise, and develop new skills and knowledge. Over 250 young people attended, with four of the five days being 'youth only'.

Each day of the Summit had a focussed topic, as chosen by the Co-Design Committee. The topics were:

- Education
- Employment
- Mental Health and Wellbeing
- **The NDIS and Housing**
- Awareness, Access and Inclusion.

This paper will focus on the findings that came out of the NDIS and Housing day (namely findings around the NDIS). Four different papers have been released to reflect the respective learnings from the other days.

The National Youth Disability Summit was presented by CYDA and funded by the National Disability Insurance Agency, with support from the Department of Social Services and Equity Trustees.



Children and Young People
with Disability Australia

Background on the National Disability Insurance Scheme and young people

The National Disability Insurance Scheme (NDIS) is arguably one of the Australia's largest systems reform in recent decades. The introduction of the NDIS saw governments shift away from block-funding disability services to providing individualised funding packages to people with disability to choose and hire their own services and supports.

As at June 2020, 391,999 people are participants¹ of the NDIS.² Of this group, approximately 16 per cent are young people aged 15 to 24 years old.³ While it is positive to see many young people accessing individualised funds, it is unclear how many have applied for the Scheme and been unsuccessful. However, it is widely acknowledged in literature that some groups are more likely to gain access or benefit from the NDIS than others. These groups include people from higher socio-economic areas, people with higher education attainment, people from metropolitan areas, people whose native language is English, and people with certain disability types.^{4,5,6}

On average, young NDIS participants 'utilise' approximately 68 per cent of their allocated budget. This means that despite being assessed as needing a certain amount of funds to meet their needs and goals, the average young person does not use nearly a third of what they are eligible for. This could be for many reasons, including the lack of available or appropriate services, long service waitlists, lack of support or knowledge in how to find and hire services and supports, or misaligned allocation of supports.

While the NDIS has the potential to offer people many new and positive opportunities, it is clear that there are still many kinks to be worked out to ensure people with disability can benefit from the Scheme on an equal basis. This paper steps out what young people see as working and not working in the NDIS, and where they believe change and improvements need to be made.

Young people with disability's perspective on the NDIS

CYDA has reviewed, analysed, and collated the young participants' ideas into five key themes that emerged throughout the Summit week. These five themes are: Identity, Enablers, Barriers, Solutions and Social Movement.



Children and Young People
with Disability Australia

| Key theme | Theme description |
|-----------------|---|
| Identity | How do 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 | Practical solutions for organisations, government, and the community to promote the autonomy, independence, and power of young people with disability |
| 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 |

Here's what young people said:

Identity

Young people at the Summit shared how their interactions with the NDIS helped shape or challenged aspects of their identity. Many young people saw the NDIS at odds with their identity and self-understanding of their disability. For instance, some participants commented on how different disabilities were not recognised by the NDIS, while others believed that common misconceptions held about their disability-type impacted the degree of support that they received from the NDIS.

"The NDIS doesn't recognise [my condition]. There would be a lot of supports that would definitely help me and help me manage my energy I have, but I'm not able to access it because it's very, very difficult for me or other people with [my condition] to get access to the NDIS."

Participants also shared how the process of accessing the NDIS often contradicted how young people understand their own strengths and needs, and ultimately, the underpinning values of the Scheme.

"The deficit model – you need to write down your worst day, instead of your best day. It doesn't really go with the whole model, because the model is about goals and being at your best. But to get access to supports, you need to sell yourself on your worst day. ... You've got to prove your disability. It's like, 'How disabled are you?'"

"It's almost like you need to be disabled enough."



Children and Young People
with Disability Australia

One participant also highlighted how the NDIS access process can fail to factor in intersectionality and different aspects of identity.

“For some women and girls with disability, there is no doubt that the NDIS has been beneficial and I would never deny that. But for the system to be equitable, it is essential that it recognises and does something to change these gender biases that happen in people’s assessment processes.”

Enablers

There was a consensus across sessions at the Summit that when the NDIS was good – it was great. The young people shared how the supports they receive through the NDIS has opened up new opportunities and enabled them to do the things in life they like to do. More specifically, some young people spoke how impactful the physical supports accessed through the NDIS, such as mobility aids and technology, are in helping them in day-to-day life. Others also spoke about how much they value support workers and coordinators and the practical and social support they provide.

“Having someone that helps me with cooking. I can cook what I want and learn new skills but not get too tired or miss out on things that I can’t do”

“... [T]he NDIS provided [me with] funding for support to go to training [and] to go interstate to play in tournaments. So that has been really helpful and it has made it easier to get to events.”

“Having easy access to supports and the technology and equipment you need is really important. I think things have improved with the NDIS and I hope they improve further.”

“I also found that since I joined the NDIS, having support workers is really healthy. My parents wouldn’t always listen to me ... so having support workers helped me gain independence.”

In terms of accessing the NDIS and implementing their plans, young people spoke about how supportive people in their lives, whether family, friends or advocates, helps them make decisions and manage the administrative workload.

“It’s not a one-person job. You sort of need to have a support system to help you access the support system. I don’t really quite see the sense in that.”

“I’m really glad I’ve got my mum to do all the medical stuff and log in to all the websites, because there are so many different things. It’s so confusing.”



Children and Young People
with Disability Australia

“She [a mentor provided through an organisation] helped me with choices, like helping me get on the NDIS, and choices to do with what therapies I want to do and all that. I’ve only really known her the last eight months, but she has given so many more options and ways that I can make choices about my life.”

“A lot of you have highlighted the importance of families or parents, but some may not have supportive parents or supportive families, so I think an advocate who is really involved can be really beneficial in your life.”

Barriers

Young people who attended the Summit shared the barriers they had experienced in accessing the NDIS and implementing their plans in a way that meets their needs and strengths. Largely, the young people saw these barriers as unnecessary “bureaucracy” and “red tape”.

Many young people commented on how lengthy and complicated processes were and how they have experienced difficulties “understanding the NDIS”. “Jargon” and inaccessible information and forms were frequently mentioned as contributing to this confusion.

“My experience with the NDIS has been a fascinating road. I mainly went on the NDIS to get a modified car. I have a car – they just need to modify it. It’s been four years since I applied and it hasn’t been modified yet. ... [T]he bureaucracy around the supports that we need – it’s just insane.”

“So what I’m saying is, for instance, you want to talk to someone with a bit more power ... and you have to go through certain links and it takes forever to go through each link of the chain. You just want to be able to jump to someone who has enough power that if you ask them to see if they can do it for you, they can say either yes or no, rather than wait for four months for them to get back to you.”

“All the pathways you have to go through. Like, a referral from a doctor just to go to another doctor”

One participant further added that these barriers are further entrenched when there are not adequate supports to help them through processes.

“[I have experienced] major hoops for accessing support and lack of available advocates and case workers to assist. Living years unsupported and in poverty, which makes it even harder to participate in these application processes.”

Beyond frustration, young people also shared how the rigorous and rigid processes are emotionally taxing.



Children and Young People
with Disability Australia

"I ... identify as an autistic person and I found the NDIS process to be incredibly painful. It wasn't easy, you had to go crawling through over ten-year-old documentation to get any form of approval from the NDIS."

"I had to provide more information to the NDIS ... detailing some of my hardest days, that random people had to read and see the most vulnerable parts of me. Other than my partner, now the people that know the most about me is the NDIS."

Young participants attending the Summit also shared instances where the NDIS missed the mark in providing them the supports they needed or wanted.

"Housing options for people with disabilities. I'd love to see a program in the NDIS in incorporating support systems with adequate housing. Not the cheap little shed on the back of someone's lot, but in a way that it can provide safety and in a way that your support network is built into it"

"It's like an all-or-nothing approach. They're sort of like, 'Oh, you need support? We'll give you everything', or 'No, you don't need this type of support? Well you can't have the other one because they come together'. It's very silly."

Solutions

Young people want the NDIS processes to be more efficient, more accessible, and easier to understand and navigate. As explained by one young person, going forward *"the main thing that the government can do is streamline the process of doctors and referrals, so everyone has clear information, and the forms are easy to understand."* Another young person also added that they would like to see the *"cutting down [of] the wait period for funding and the accessibility to funding."*

Participants also wanted the NDIS to be more responsive to individuals' needs and goals, and include a *"more personalised perspective of what will help [people with disability]."*

"Having a better understanding of the supports we need. Rather than going, 'Oh, they might need this' and they don't actually ask us, so how are they going to know exactly what we need? Because ... the person organising the funding might not think like the way the person with disability does. ... We shouldn't have to keep asking and asking for what we need and instead getting the wrong support."

"Let us tell you what we need, not [you] tell us what you think we need."



Children and Young People
with Disability Australia

Some young people also commented on how there needs to be increased training and standards for people who deliver services.

“A better quality of training or a higher bar for people who support people with disabilities. I have seen many a time that support workers have zero-to-no training. [There is a need to] attract passionate people who understand and are well trained to support people with disabilities.”

Social Movement

Young people highlighted the needs for politicians and people in power to be held accountable when systems, such as the NDIS, fail. As advocated by one young person, *“[W]e need to see accountability. We need to see justice. We need to see people referred to the police, fined and imprisoned for mistreatment. ... That’s your measure of success – when perpetrators of violence are held to account and face consequence for action and I think that’s what we have to move towards.”*

In an effort to keep people in power accountable to their choices and the failings of the system, the need for collaboration and unity among young people with disability was championed.

“Whether they would be the Civil Rights Movement, the Workers’ Rights Movement, movements for racial equality, gender equality – it is those basic principles of collective action. Building community support among each other. Being very clear on what our demands are; what is the change that we want to see? Bringing people into that movement and the working together to apply that pressure to people in decision making spaces. And if those decision makers don’t get the message and make the change, replace [them]!”

Where to from here?

As made clear by young people who attended the Summit – the NDIS can offer people with disability many new opportunities to live their lives in line with their values and goals, however there is still a lot of work to be done to ensure the Scheme is accessible, equitable and easier to navigate.

Echoing young peoples’ calls, more effort is required from government to ensure that people are accessing the Scheme of an equitable basis.



Children and Young People
with Disability Australia

This includes reviewing and removing unnecessary bureaucratic barriers to NDIS access and plan implementation and ensuring there is sufficient, age-appropriate and accessible information and supports that enable young people to gain access to the supports they are entitled to.

Throughout the Summit, many young people discussed how the supports they were allocated were not aligned with what they actually wanted or needed. The recent Inquiry⁷ into NDIS Planning received evidence that the Scheme fails to take in developmental stages and needs in planning processes. Subsequently, the Inquiry's Final Report recommended that the National Disability Insurance Agency "develop, publish and implement templates or guidelines to ensure that plans for children and young people take into account key developmental stages and life transition points"⁸. CYDA endorses this proposal, though emphasise that children and young people must be involved in the development of these guidelines to be reflective of the nuances of identity and needs across childhood, adolescence, and emerging adulthood.

CYDA acknowledges the NDIS is still a relatively new scheme and there is significant potential to learn and make improvements. This is clear from the government's investment into many inquiries and ongoing consultations. However, these processes lack genuine or consistent inclusion of children and young people. Considering more than half of current participants are aged 24 years or younger⁹, 'improving' a system without their inclusion will result in a service that does not meet the needs or wants of the people it intends to serve.

Calls to action

- Develop a family-centred planning framework for children and young people that factors in key developmental stages and life transition points. The development of this must include the meaningful involvement of children and young people.
- Ensure children and young people who experience barriers to accessing services are well supported by the NDIS through support coordination.
- Improve accessible, age-appropriate information resources available to young people. These resources should be delivered in a variety of methods, including factsheets, short videos, online forums, and peer groups.



Children and Young People
with Disability Australia

Calls to action

- Increase investment in individual advocacy services, particularly the development of child and youth specific disability advocacy organisations in each state, that can support young people to navigate systems.
- Develop platforms where children and young people can meaningfully participate in ongoing NDIS reform, including ensuring the voices of young people are captured throughout the Agency's formal consultative processes.

To learn more about what young people said at the Summit and this work, please feel free to contact CYDA's Youth Action Team at YouthActionTeam@cyda.org.au or on (03) 9417 1025.

Footnotes

¹ Bollier A, M., Krnjacki, L., Kavanagh, A., Kasidis, V., Katsikis, G., & Ozge, J. (2018). *Survey of Community Attitudes toward People with Disability: A report for the Victorian Department of Health and Human Services*. Melbourne, VIC: Disability & Health Unit, Centre for Health Equity, University of Melbourne.

² Ableism refers to the discriminatory perspective that able-bodied persons are viewed as 'normal' or superior. As a product of ableism, people with disability experience prejudicial treatment and/or their needs are not factored in.

¹ Meaning they have applied and been granted access to the NDIS and its supports.

² NDIA. (2020). *Explore data*. Available at <https://data.ndis.gov.au/explore-data>.

³ *ibid.*

⁴ Malbon, E., Carey, G., & Meltzer, A. (2019). Personalisation schemes in social care: are they growing social and health inequalities? *BMC Public Health*, 19(1), 805. <https://doi.org/10.1186/s12889-019-7168-4>.

⁵ Cortese, C., Truscott, F., Nikidehaghani, M., & Chapple, S. (2020) Hard-to-reach: the NDIS, disability, and socio-economic disadvantage, *Disability & Society*, AHEAD-OF-PRINT, 1-21. <https://doi.org/10.1080/09687599.2020.1782173>.

⁶ NDIA. (2020). *Young people in the NDIS*. Available at <https://data.ndis.gov.au/media/2485/download>

⁷ Joint Standing Committee on the National Disability Insurance Scheme. (2020). *NDIS Planning Final Report*. Available at [NDIS Planning Final Report – Parliament of Australia \(aph.gov.au\)](https://www.ndis.gov.au/ndis-planning-final-report).

⁸ *ibid.*, p. 197.

⁹ As at June 2020, 56.7 per cent of NDIS participants are aged 24 years or younger; NDIA. (2020). *Explore data*. Available at <https://data.ndis.gov.au/explore-data>.

nyds



National Youth
Disability Summit

What young people with
disability said:
Employment

Insights, ideas, and solutions from young people with disability
The outcomes of the inaugural National Youth Disability Summit
Presented by Children and Young People with Disability Australia
(CYDA)



Children and Young People
with Disability Australia



Children and Young People
with Disability Australia

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.

Background to the National Youth Disability Summit

At the end of September 2020, the inaugural National Youth Disability Summit ('the Summit') took place. The Summit was established with the vision to create an inclusive environment where young people with disability from across Australia could come together as a community and use their voices to shape the future.

The Summit was designed by and for young people with lived experience of disability. Over nine months, the Co-Design Committee, consisting of 20 young people with disability from across Australia, designed the vision, content and delivery of the Summit.

Hosted over five days, the Summit was an entirely online conference that offered young people a range of sessions and workshops, the opportunity to meet other young people, share their ideas, insights and expertise, and develop new skills and knowledge. Over 250 young people attended, with four of the five days being 'youth only'.

Each day had a focussed topic, as chosen by the Co-Design Committee. The topics were:

- Education
- **Employment**
- Mental Health and Wellbeing
- The NDIS and Housing
- Awareness, Access and Inclusion.

This paper will focus on the findings that came out of the Employment day. Four different papers have been released to reflect the respective learnings from the other days.

The National Youth Disability Summit was presented by CYDA and funded by the National Disability Insurance Agency, with support from the Department of Social Services and Equity Trustees.



Children and Young People
with Disability Australia

Background on employment and young people with disability

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

Young people¹ with disability in the labour force are more than twice as likely to be unemployed than older adults² with disability (24.7 per cent compared to 7.9 per cent).³ Young people with disability are also more than twice as likely to be underemployed⁴ – meaning they have the capacity and desire to work more hours than what they are currently employed.

As a young person entering the labour force, the ability to participate is impacted by a range of external factors. This includes the decrease of entry level jobs, the rise of professionalised industries, and the increased demand from employers for prospective employees to hold employability skills and work experience. Young people are also more likely to work in service-based industries (such as retail or food and accommodation), which commonly offers fewer hours, precarious employment and reduced economic security.⁵ It is widely acknowledged that within the youth cohort, those with disability face increased disadvantage in the labour market.⁶

Employment is inextricably linked with mental health. Evidence demonstrates that employment is related with good mental health outcomes.⁷ Similarly, research has shown unemployment and underemployment is associated with a negative decline in people with disability's mental health.⁸ Not only is it important to address the underutilisation⁹ rate of young people with disability in the workforce as socioeconomic issue, but it is also inherently a health issue.

Young people with disability's perspective on employment

CYDA has reviewed, analysed and collated the young participants' ideas into five key themes that emerged throughout the Summit week. These five themes are: Identity, Enablers, Barriers, Solutions and Social Movement.



Children and Young People
with Disability Australia

| Key theme | Theme description |
|-----------------|--|
| Identity | How do 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 | Practical solutions for organisations, government, and the community to promote the autonomy, independence and power of young people with disability |
| 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 |

Here's what young people said:

Identity

Young participants at the Summit had varying views on employment and how it was linked to their identity. Some young people commented on how having quality employment “gives them purpose” and can be “life changing”, allowing them to develop skills, find their passions and meet likeminded people that “understand all parts of you”. Others commented on how the process of looking for a job, particularly when confronted with the highly structured nature of formal employment, impacted how they viewed and understood themselves and their disability.

“I got really frustrated and thought something was wrong with me. I was like, ‘Do I just have a really bad work ethic? Why am I so tired compared to all of my colleagues?’. That was around the same time I was reckoning that I actually am disabled, that I actually do have conditions that limit the way that I work and how long I can work for. So that was something that was quite hard to deal with but has been something that I’ve accepted and learned to work with over the last few years.”

Many young people also expressed how having a job is an important part of becoming an adult and “being an equal citizen”. Young people value being able to be independent, earn their own money, move out of home if they would like to, and not having to “rely on an unreliable government system”.

Enablers

Young participants shared their experiences of what helps them to find and keep a job.



Children and Young People
with Disability Australia

Many young people discussed how beneficial it is when their employers provide accommodations, such as having the option to work from home, allowing them to take breaks when needed, and ensuring the environment is accessible.

One group member added that flexibility in the workplace allows them to do their job in a *“way that’s good for [them], and because of that, [they] feel really fulfilled”*.

The group also commented on how they value employers being assertive in asking about and supporting young people’s needs. This includes proactively asking about accessibility-related supports, encouraging authentic discussion around disability, and fostering a culture of acceptance around gender diversity. As expressed by one participant, when employers are proactive, *“it feels so much more welcoming and that you’re not the big elephant in the room”*.

“Employers that are not just patient but wanting to make sure they have what they need so you can do your job in a healthy way. As opposed to you having to fight for it every step of the way, it’s them reaching their hand out first, I guess, and saying, ‘What do we need for you to make this work?’ ... as opposed to being scared of what might happen if you speak up.”

Young people’s opinions on disability employment services and supports were varied. Some described their experiences as *“life-changing”* and *“really, really good”*, whereas others commented that they were *“ineffective”*, *“did not try enough”*, and *“didn’t want to get to know me or my interests or skills”*.

Many also added that COVID-19, and its impact on how workplaces operate, has created many new opportunities for people with disability. As expressed by one young person, *“I think it has shown the wider community that [creating flexible workplaces] is possible. They can do it – they just don’t.”*

Barriers

Young people shared the barriers they had experienced to securing employment were largely the attitudes and misconception of others. The group shared the belief that while they felt they have skills and talents they could contribute to the workforce, employers often do not give them a fair chance because of their own *“false assumptions”* about disability. Participants added during the application processes, they are concerned that disclosure of their disability, or *“the ‘D-word’”*, would impact their chances of getting the job. As described by one young person, *“[the application process] feels like they’re trying to cross you off, rather than see what attributes you actually have”*.

Young participants also discussed how employers need to do more to provide inclusive and accessible workplaces.



Children and Young People
with Disability Australia

Many commented that the typical jobs on offer and/or employer expectations are based on ableist¹⁰ understandings of what a 'good' or 'productive' employee is. Young people understood the widespread reluctance of employers and the community to push back on these norms as preventing their ability to participate in employment on equal terms.

"It's really important to view employment through the lens of social model of disability. ... [O]ur impairments have nothing to do with us lacking anything. It's more to do with the ways our workplaces are structured and the way that employers accommodate us. So they're the barrier. The barrier is not us."

"For me, a more disability friendly structure would have different views on how they handle work output and stress, and how supportive the work culture is."

"If people stopped listening to the things that are not true about us, and just saw us as people that are different, but still like them, because we're all different, wouldn't that help?"

Solutions

In creating genuine systemic change to make employment pathways more inclusive, the participants saw themselves and other young people with disability as being a core part of the solution. Through governments and organisations investing in the development of young people's leadership and advocacy skills, and providing platforms where they have power and can be heard, the group saw their generation as being in the best position to enact change within their communities. This includes young people being supported to lead the way in creating meaningful and inclusive employment opportunities. As advocated by one group member, "our needs get met the best when we're the ones that get to define what they are."

"Often you have to change the system to access it. So, through making it accessible for yourself, you're making accessible for everyone that comes after you."

"Lots of systems were designed in a way that don't reflect young people, and young people really want to shape these systems. And at the same time these systems are in crisis, and they really need to adapt to better meet the needs of young people. But also, young people within particular groups of lived experience."



Children and Young People
with Disability Australia

The group also saw the need for employees and job services to increase their awareness of disability and employment rights, and actively listen to young people with disability about their needs. While some young people believed education should be developed and targeted at employers, others saw it as a societal issue, and that intervention is required earlier in education settings, such as school and university.

“I feel like for everything to change in employment, it needs to come from the roots up.”

Social Movement

Employment, namely “meaningful employment”¹¹, was discussed as a human right that all young people with disability are entitled to. In disrupting the norm and moving towards more inclusive employment, the young people at the Summit saw it as vital to address existing power imbalances in advocacy and employment settings. This includes organisations implementing strategies that ‘level the playing field’, such as including young people on interview panels or providing interview questions before the interview.

The group also saw the need for social security reform to provide adequate safety nets and protect the rights of young people with disability when they encounter barriers in the employment system.

“[M]aking sure that people with disabilities have access to meaningful work, but [also] making sure that there is a safety net for us when we can’t engage in that meaningful work. So that means that there are welfare ... payments, like the Disability Support Pension and like JobSeeker, that actually exist above the poverty line and give us a chance to have dignified lives when we can’t engage in work for whatever reason.”

Where to from here?

Having a job 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 attended the Summit, we all deserve to enjoy the good things that being employed can provide, though we don’t all get to participate in this aspect of life on an equal basis.

As emphasised by the young participants, one of the biggest barriers to employment for young people with disability is the attitudes and misconceptions of others.



Children and Young People
with Disability Australia

As such, interventions targeting employers are required.

This includes addressing misconceptions about young people with disability's capabilities and informing employers of people with disability's legislative rights. The skills, talents and distinct worldviews young people with disability can bring to the workforce must also be highlighted.

In understanding the increased barriers young people with disability face in securing employment, CYDA echoes young people's call for social security reform that provides a dignified standard of living. These payments should reflect the contemporary cost of living, as well as the increased living costs incurred when living with disability.

Organisations and employers also have an important part to play. They should be proactive in their hiring processes and meeting the needs of their employees. This includes reviewing and amending hiring processes so that they are safe and more inclusive for young people. Employers should also reach out to their young employees to ensure they are receiving the appropriate supports and accommodations that they may need.

Government, organisations and the community alike should all reflect on and make the most of the employment learnings that came from COVID-19. Workplaces demonstrated through innovation and commitment, the 'typical' working day could be more flexible and supportive of different life circumstances. This creativity and understanding should be reflected in future job creation and solutions to employment inequities.

Calls to action

Governments:

- Increase targeted, evidence-based interventions addressing the negative and misinformed attitudes of employers. The development of these strategies must include the meaningful involvement of young people with disability.
- Provide an adequate safety net for young people with disability that reflects the contemporary cost-of-living.
- Invest in the research and development of creative employment opportunities for young people with disability. Meaningfully include young people in research design, implementation and evaluation processes.
- Invest in young people's skills development and provide platforms across government levels where they can be heard and enact change.



Children and Young People
with Disability Australia

Calls to action

Organisations and Employers:

- Review and amend hiring processes to ensure they are safe and inclusive. If unsure, reach out to youth representative and advocacy organisations for guidance.
- Offer information and suggestions around supports available for young people with disability at work. If unsure, reach out to youth representative and advocacy organisations for guidance.
- Proactively reach out to young employees to ask how they may be best supported. Then follow through.
- Leverage learnings from COVID-19 to offer roles that have working-from-home or flexible hours options.

To learn more about what young people said at the Summit and this work, please feel free to contact CYDA's Youth Action Team at YouthActionTeam@cyda.org.au or on (03) 9417 1025.

Footnotes

¹ Aged 15-25 years old

² Aged 26-64 years old

³ AIHW. (2020). *People with disability*. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/unemployment>

⁴ 23.1% per cent rate of underemployment compared to 8.3 per cent of older adults with disability; AIHW (2020).

⁵ The Smith Family. (2014). *Young people's successful transition to work: What are the preconditions?* Available at [https://www.thesmithfamily.com.au/~media/files/research/reports/young-people-transition-to-work-report.ashx?la=en](https://www.thesmithfamily.com.au/~/media/files/research/reports/young-people-transition-to-work-report.ashx?la=en); Skattebol, J., Hill, T., Griffiths, A., & Wong, M. (2015). *Unpacking youth unemployment: Final report*. Available at https://www.researchgate.net/profile/Jen_Skattebol/publication/292985748_Unpacking_Youth_Unemployment_Final_report/links/599a79abaca272e41d400911/Unpacking-YouthUnemployment-Final-report.pdf

⁶ Yu, P. (2010). *Disability and disadvantage: a study of a cohort of Australian youth*. Australian Journal of Labour Economics, 13(3), 265–286; Orygen Youth Health Research Centre. (2014). *Tell them they're dreaming: Work, education and young people with mental illness in Australia*. Available at <https://www.orygen.org.au/Policy>; Social Ventures Australia. (2016). *Fundamental principles for youth employment*. Available at <https://www.socialventures.com.au/assets/Fundamental-principles-for-youth-employment-report-FINAL.pdf>

⁷ Milner, A., Shields, M., King, T., Aitken, Z., La Montagne, A., & Kavanagh, A. M. (2019). Disabling working environments and mental health: A commentary. *Disability and Health Journal*, 12(4), 537–541.

⁸ *ibid*; Milner, A., King, T. L., LaMontagne A. D., Aitken, Z., Petrie, D., and Kavanagh, A. M. (2017).

Underemployment and its impacts on mental health among those with disabilities: evidence from the HILDA cohort. *Journal of Epidemiology & Community Health*, 71(12), 1198–1202. <https://doi.org/10.1136/jech-2017-209800>

⁹ The combined rate of unemployment and underemployment.

¹⁰ Ableism refers to the discriminatory perspective that able-bodied persons are viewed as 'normal' or superior. As a product of ableism, people with disability experience prejudicial treatment and/or their needs are not factored in.

nyds



National Youth
Disability Summit

What young people with
disability said:

Awareness, Access + Inclusion

Insights, ideas, and solutions from young people with disability
The outcomes of the inaugural National Youth Disability Summit
Presented by Children and Young People with Disability Australia
(CYDA)



Children and Young People
with Disability Australia



Children and Young People
with Disability Australia

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.

Background to the National Youth Disability Summit

At the end of September 2020, the inaugural National Youth Disability Summit ('the Summit') took place. The Summit was established with the vision to create an inclusive environment where young people with disability from across Australia could come together as a community and use their voices to shape the future.

The Summit was designed by and for young people with lived experience of disability. Over nine months, the Co-Design Committee, consisting of 20 young people with disability from across Australia, designed the vision, content and delivery of the Summit.

Hosted over five days, the Summit was an entirely online conference that offered young people a range of sessions and workshops, the opportunity to meet other young people, share their ideas, insights and expertise, and develop new skills and knowledge. Over 250 young people attended, with four of the five days being 'youth only'.

Each day of the Summit had a focussed topic, as chosen by the Co-Design Committee. The topics were:

- Education
- Employment
- Mental Health and Wellbeing
- The NDIS and Housing
- **Awareness, Access and Inclusion.**

This paper will focus on the findings that came out of the Awareness, Access and Inclusion day. Four different papers have been released to reflect the respective learnings from the other days.

The National Youth Disability Summit was presented by CYDA and funded by the National Disability Insurance Agency, with support from the Department of Social Services and Equity Trustees.



Children and Young People
with Disability Australia

Background on awareness, access and inclusion, and young people with disability

The extent to which young people can grow their skillset, personally develop, and continue to learn and be challenged is contingent on the opportunities they are provided. For example: a person needs to have opportunities to meet new people, grow their social circles, and build relationships; a person needs to be given a chance in a new job for them to build their capacity and go on to flourish in their career.

The opportunities we are provided in life can ultimately be determined by those around us. As a society, we decide who gets to be included and excluded. Those who are seen as holding 'valuable' roles in society are generally granted the opportunities to enjoy the good things in life, such as getting an education, having a paid job that meets their skillsets and interests, and participating in social and community activities. Whereas those who are viewed as holding less 'valuable' roles face increased, socially constructed barriers to accessing these important aspects of life.

People with disability have faced a long history of low expectations and this pervasive attitude remains today. As recently as 2018, a survey¹ of community attitudes and beliefs about people with disability showed that nearly one quarter (23.5 per cent) of survey respondents agreed or strongly agreed that people with disability have less to look forward to than others. The survey also demonstrated that 11.8 per cent of respondents agreed or strongly agreed that people with disability are a burden on society, and 21.9 per cent agreed or strongly agreed that people should not expect too much from those with disability.

These misinformed and discriminatory beliefs about disability have widespread impacts on the lives of young people. A 2019 survey² of young people across Australia found that over half (55 per cent) of young people with disability stated that their disability made it hard for them to feel like they fit in (at school, work or socially). Further, more than double the proportion of the young respondents with disability felt negative or very negative about the future compared to their non-disabled peers.

People's prejudiced attitudes can impact how young people see themselves, the opportunities they have to enjoy the good things in life, and ultimately, their potential to grow and thrive. By shifting these attitudes and setting new, more inclusive norms, society can support young people with disability to succeed.



Children and Young People
with Disability Australia

Young people with disability's perspective on awareness, access and inclusion

CYDA has reviewed, analysed, and collated the young participants' ideas into five key themes that emerged throughout the Summit week. These five themes are: Identity, Enablers, Barriers, Solutions and Social Movement.

| Key theme | Theme description |
|-----------------|---|
| Identity | How do 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 | Practical solutions for organisations, government, and the community to promote the autonomy, independence, and power of young people with disability |
| 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 |

Here's what young people said:

Identity

Across sessions on the Awareness, Access, and Inclusion day – and the Summit more widely – young participants expressed disability pride and a sense of community with other people with disability. Some young people also shared that being actively involved in the disability community can lead to feelings of disability pride.

"Getting involved in wheelchair sports has given me opportunities to form relationships, learn a new sport, and learn from others"

"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."

"Disability pride is about being proud of ourselves. It's about learning our history. It's about knowing that strength and creativity and courage that exists in disabled communities. It's about knowing that there are disabled communities. That disability is not just an individual experience or just an interaction between the individual and a broader society. There are disabled communities, there is disability culture, there are disabled arts groups, disabled activist groups, disabled people living and creating spaces together as disabled people, not in spite of disability, but actively, openly and proudly as disabled people."



Children and Young People
with Disability Australia

Young people at the Summit also shared a commitment to elevating the voices of more marginalised members within the disability community, who “*don’t have a voice*”. This includes young people with disability who face increased structural and systemic barriers, such as young First Nations peoples and young people in the LGBTQIA+ community.

“There is no one way to be disabled ... it’s really important that we show the diversity of the disability community through that.”

“Our story doesn’t have to look like anyone else’s. There is no one way to be disabled. I think it’s really important that we show the diversity of the disability community through that. So, don’t feel like you have to look, or act or talk a particular way, post in your underwear, etc. In my opinion, the more diverse backgrounds and different stories that we can share, the better.”

Enablers

A prominent theme that emerged across the Summit that enables young people to feel more included in the community is the presence of role models with disability. Young people value how role models present new options and help pave the way for different life pathways. One participant shared how having examples of athletes with disability influenced their own journey with sport, adding how by initially seeing clips of the wheelchair sport sparked a passion that has “*evolved over the years to get me to where I am now.*” One young person also added that they wished they had role models earlier in life to show them “*that this life [that they are now living] is possible.*”

Another enabler that was raised by young people was organisations proactively offering or detailing available supports and accessibility considerations. This includes events sharing details about the access procedures and the space the event will take place in. As shared by young people, this proactively removes pressure and feelings of uncertainty, and allows them to only make necessary disclosures about access.

“Expecting disabled people, especially those with multiple disabilities, to shed the immense levels of detail about every possible access need and hope we have thought of everything that might come up in your event, is a lot of work. So, talk about what you are already doing and then let us make additional requests if our needs are not covered.”



Children and Young People
with Disability Australia

Barriers

Ableism³ was identified by participants as a major barrier to young people with disability experiencing inclusion in their daily lives. Media outlets were highlighted as a source of these attitudes. As expressed by one young person, people with disability in the media are often depicted from “a place of pity” or on a “pedestal”. The young person continued that people with disability are “very rarely just seen [in media] as a person”. Participants also commented on the specific lack of representation of young people with disability.

“So often when we talk about disability, you know, in my head I often picture an old, 94 year old on a walker and I’m like, ‘But that’s not me and my mates’. ... When do we get represented?”

Harmful, ableist attitudes held by others have negative impacts on young people and their ability to participate in the community. Participants at the Summit shared that they did not feel heard when they expressed their feelings about inclusion or instances where they felt excluded.

“I think a lot of us find that we get discriminated against, or get turned down for jobs for reasons that don’t seem quite right, or maybe we have difficulty finding houses – and that just increases your anxiety and makes it harder. ... So people kind of question ‘Well, why are you anxious doing those things?’, and well because every time I’ve tried this before or whatever, it hasn’t gone well for numerous reasons and it just builds upon itself.”

Lack of access to support was also identified by young participants as a barrier to community inclusion. This includes access to broad supports in regional and remote areas, as well as lack of targeted supports, such as for young First Nations peoples with disability.

“Lot of people think people should just move to the city where they can get the help they need, No – regional communities need better infrastructure and accessibility.”

“Many of our First Nations young people with disability shouldn’t be in juvenile detention. They’re there because the system has failed them.”



Children and Young People
with Disability Australia

Solutions

Creating space for young people with disability was highlighted as a pathway toward a more inclusive society. Participants at the Summit emphasise that no one knows what young people need better than they do, so they must be supported to be at the centre of solutions for change to be effective.

“We need meaningful opportunities. We need career paths that put us in positions of power and authority to enact change, to create a more accessible society.”

“I believe that young people's voices need to be heard. ... [W]e have the future ahead of us and we see the changes that need to happen. It will be silly not to give young people a voice and input in the matters that affect them.”

“Listen to young people. Because there is not a decision that is not with us at the end of the day. The mistakes made today will haunt us in the future.”

Honest conversations about accessibility and access needs – and their sometimes competing priorities – was also viewed by young participants as essential in creating a more inclusive society.

“Sometimes they [access decisions] require compromise, sometimes they require acknowledging that not every space will necessarily be accessible for every person. And having those frank discussions can be tricky. It's about how we respond when someone says, ‘Actually, that doesn't work for me’ and it's something we didn't plan for. It's about understanding that accessibility changes depending on which groups you are working with.”

Social Movement

Addressing power imbalances that currently exist between young people with disability and non-disabled people (particularly those who are in position of power), was understood by participants to be fundamental in moving toward a more inclusive society.

“Governments have never decided to implement change because it's the right thing to do or it's the just thing to do. They did it because we advocated for it. We fought for it. In all the loud and shouty, soft and gentle, systemic and individual ways that we do. We need to keep fighting. We need to keep connecting with each other and working to towards a more just and equitable world.”



Children and Young People
with Disability Australia

“Young people in particular ... are not part of the conversation about what should be in those supports or plans or policies [that affect young people]. ... People very much think, ‘I know all about young people so I can put this policy together without talking to them’, but when you do that, there are so many stories, narratives, bits of information that you miss because you are not talking to the affected person.”

Storytelling was identified as a tool in the movement towards inclusion, as *“there is a lot of power to be found in being vulnerable.”*

“I think that authentically sharing your story and your experience is one of the most effective ways to raise awareness of the issues and the barriers that you face.”

Peer work was also viewed as an important strategy to break down power dynamics between young people and people in power, such as clinicians and health professionals.

“It [peer work] has really shifted the typical power imbalance between young people and those involved in our care. ... To be able talk to someone without the fear of judgement and to see that they have created a life worth living and instilled hope, that was something that no clinician, no professional, no academic [could have] given me.

“Having people with lived experience administering and/or providing your services makes a huge difference”

Where to from here?

Young people with disability deserve and are entitled to participate in social and community life on an equal basis. As CYDA heard from young people who attended the Summit, this is currently not happening – and it is largely because of the attitudes and barriers constructed by others.

In line with the insights of participants, CYDA values the importance of creating opportunities for young people to come together to share ideas, learn and grow. These networking opportunities are not only valuable to create safe spaces where young people can socialise and connect with others who share similar experiences, but are also an investment in creating a platform for emerging leaders to grow their skillsets and confidence.



Children and Young People
with Disability Australia

Governments, organisations, and the community members alike also need to reflect on how we think, talk about, and portray young people with disability. When we depict young people with as a homogenous group or through a lens of low expectations, as a society we limit their potential. However, when we promote the diversity and strengths of young people, and create meaningful opportunities in our community for them to contribute their skills and talents, we all benefit – culturally and economically.

Organisations should also review if the content they share and the events they host are accessible –and then amend if necessary. This also includes proactively sharing information about events or venues outlining the accessibility features, such as the use of Access Keys, that improve the experience of young people with disability and remove the burden of them needing to constantly follow up when information is ambiguous or non-existent.

Lastly, young people are hungry to hold positions of real power where they can enact change for the betterment of their community – now and into the future. It is one thing for young people to have a voice, but to improve systems so they are truly inclusive, young people need to be provided with meaningful platforms so they can be heard.

Calls to action

Governments:

- Create and resource opportunities and platforms where young people with disability can come together to build their skills, develop, and make networks and friends.
- Invest in community interventions, including media portrayal, that target misinformed and discriminatory attitudes and beliefs held about people with disability.
- Invest in young people's skills development and provide platforms across government levels where they can be heard and enact change.

Organisations:

- Review and amend organisational content and events to ensure they are accessible for a wide range of needs and strengths. If unsure, reach out to youth and disability representative and advocacy organisations for guidance.
- Proactively provide information about accessibility considerations for events.



Children and Young People
with Disability Australia

Calls to action

All community members:

- Critically reflect on our own beliefs or biases about young people with disability and how these attitudes can impact the lives and opportunities of others.

To learn more about what young people said at the Summit and this work, please feel free to contact CYDA's Youth Action Team at YouthActionTeam@cyda.org.au or on (03) 9417 1025.

Footnotes

¹ Bollier A, M., Krnjacki, L., Kavanagh, A., Kasidis, V., Katsikis, G., & Ozge, J. (2018). *Survey of Community Attitudes toward People with Disability: A report for the Victorian Department of Health and Human Services*. Melbourne, VIC: Disability & Health Unit, Centre for Health Equity, University of Melbourne.

² Mission Australia. (2019). *Young, willing and able: Youth Survey Disability Report 2019*. Available at <https://www.missionaustralia.com.au/publications/youth-survey/1610-young-willing-and-able-youth-survey-disability-report-2019/file>

³ Ableism refers to the discriminatory perspective that able-bodied persons are viewed as 'normal' or superior. As a product of ableism, people with disability experience prejudicial treatment and/or their needs are not factored in.

nyds



National Youth
Disability Summit

What young people with
disability said:

Mental Health + Wellbeing

Insights, ideas, and solutions from young people with disability
The outcomes of the inaugural National Youth Disability Summit
Presented by Children and Young People with Disability Australia
(CYDA)



Children and Young People
with Disability Australia



Children and Young People
with Disability Australia

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.

Background to the National Youth Disability Summit

At the end of September 2020, the inaugural National Youth Disability Summit ('the Summit') took place. The Summit was established with the vision to create an inclusive environment where young people with disability from across Australia could come together as a community and use their voices to shape the future.

The Summit was designed by and for young people with lived experience of disability. Over nine months, the Co-Design Committee, consisting of 20 young people with disability from across Australia, designed the vision, content and delivery of the Summit.

Hosted over five days, the Summit was an entirely online conference that offered young people a range of sessions and workshops, the opportunity to meet other young people, share their ideas, insights and expertise, and develop new skills and knowledge. Over 250 young people attended, with four of the five days being 'youth only'.

Each day of the Summit had a focussed topic, as chosen by the Co-Design Committee. The topics were:

- Education
- Employment
- **Mental Health and Wellbeing**
- The NDIS and Housing
- Awareness, Access and Inclusion.

This paper will focus on the findings that came out of the Mental Health and Wellbeing day. Four different papers have been released to reflect the respective learnings from the other days.

The National Youth Disability Summit was presented by CYDA and funded by the National Disability Insurance Agency, with support from the Department of Social Services and Equity Trustees.



Children and Young People
with Disability Australia

Background on mental health and wellbeing, and young people with disability

Our wellbeing is inextricably linked to the opportunities we have to connect with our communities, friends and families, opportunities to access supports when we need them and to lead fulfilling lives. Mental health and wellbeing looks different for each person, and so do mental health care needs.

Physical, structural and social barriers to education, employment and community life also, often concurrently, impact mental health and wellbeing. Choice, and the opportunity to make choices about our lives, significantly impacts our wellbeing as does the absence of decision-making power. Wellbeing is linked to all domains of our lives, and our inclusion in society.

Mental health and wellbeing is a major concern for young people with disability. Because of the increased barriers faced in education and employment settings and systems, young people with disability experience lower engagement rates and higher unemployment rates.¹ A 2019 national youth survey found that nearly half of young respondents with disability had experienced mental health problems, and one in four were concerned with suicide.² Young people with disability were also twice as likely as their non-disabled peers to be bullied in the past 12 months, with two in five young people with disability reporting being bullied (43 per cent compared with 19 per cent).³

People's prejudiced attitudes can impact how young people see themselves, the opportunities they have to make choices and enjoy the good things in life, and ultimately, their potential to seek wellbeing and thrive. By shifting these attitudes and setting new, more inclusive norms, society can support young people with disability to succeed.

Young people with disability's perspective on mental health and wellbeing

CYDA has reviewed, analysed, and collated the young participants' ideas into five key themes that emerged throughout the Summit week. These five themes are: Identity, Enablers, Barriers, Solutions and Social Movement.



Children and Young People
with Disability Australia

| Key theme | Theme description |
|-----------------|---|
| Identity | How do 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 | Practical solutions for organisations, government, and the community to promote the autonomy, independence, and power of young people with disability |
| 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 |

Here's what young people said:

Identity

Across sessions on the Mental Health and Wellbeing day participants discussed the ways in which disability identity impacts mental health and wellbeing. Some young people shared that the way society responds to their identity has a negative impact on their mental health, and described structural and systemic barriers faced in accessing support. Young people also shared the significance of intersectionality and how *“different marginalisations can obviously impact a person’s experiences differently and therefore that may impact their mental health differently as well”*.

“Mental health is a very important part of disability...But the kind of support that you are able to access is influenced by your age, your gender, your sexuality, your race, where you’re coming from, the kind of socio-economic background you’re from.”

“I also think it is important to understand that I am multiply marginalised in terms of being a queer person with disability. But I also acknowledge that I am - I experience a lot of privilege as well in terms of financial privilege, white privilege and also identifying as cis-gender. And I think all of those things are really important when talking about mental health.”



Children and Young People
with Disability Australia

Young people highlighted how engaging in work, hobbies and activities they enjoy has a positive effect on their mental health and identity. Many young people described being involved with sport and creative arts as having a positive influence on their mental health.

"I think it's important, like I said before, to understand what's feeding into your mental health in a negative way but then also what's feeding into it in a positive way. And if you identify those factors then you can make conscious choices around spending more time on the positive things when the negative things are building up. So that's probably my biggest tip: to understand what is influencing your mental health and spend more time on the positive."

"Through engaging with sport, I wasn't just a person with special needs. I was needed. I had a role to play on the team"

A prominent theme that emerged during the Summit was the amount of choice young people have in their lives, and how this impacts young people's wellbeing. Young people described having choice, such as *"having autonomy over how I dress, how I cut my hair, how I present myself to the world"*, as being part of a good life. Young people also highlighted the importance of choice when maintaining and treating their mental health.

"It feels satisfying because you know the choices that are happening are the ones you made, so there is a lot of contentment that comes with that"

Choice looks like... "the types of therapies I do, as well as how much I was to participate in them and what I want to focus on"

"Getting treated like an adult. People coming to talk to me about my own life rather than speaking directly to my parents, rather than to me"

Enablers

Young people who attended the Summit shared their insights on what helps them make choices that are important to them and supports their wellbeing. The responses were widespread and highlighted the importance of practical and tangible support and opportunities, as well as emotional and social support. Young people shared that the people in their lives helped provide both types of support.



Children and Young People
with Disability Australia

For many, it was their families and friends who supported their wellbeing and ability to make choices. Others also mentioned the positive impact that paid support, clinicians, and organisations had had on their lives.

“Having people around you that respect your right to make you choices, even if they don’t like your choice, they’ll respect you because it’s your own choice and your own life. So I think people have a really big impact, especially if they have any power.”

“Having access [to people] outside of my family. Previously, I’ve relied heavily on my mum to help me make decisions ... but I think it’s been really good having people that I can chat about stuff with outside of my family.”

More specifically, young people value when the people in their lives, including services and practitioners, actively listen to their wants and needs. As explained by one young person, *“when [people] listen to you, it opens up a whole new world where you get to ... become a better version of yourself. The dialogue can start a conversation that can change your life.”*

Another common theme that emerged was how choice, and the opportunity to make choices, impacts young people’s wellbeing.

“Choice is giving people dignity. Being able to have choices about your own life, like where you’re living – that’s dignified. Having that taken away from you, it doesn’t feel great – it sort of feeds into self-worth and how you see yourself. So, for me, choice is dignity in my life.”

“Being able to make choices is a huge part of taking control of our lives and just being who we want to be and not what society has pushed us into the corner as.”

“For me, [having choices] kind of just feels like independence ... reclaiming choices that abled people don’t think we can make. It’s setting our own benchmark.”

As a determinant to having choice, young people also highlighted the importance of information. Reflecting on their own experiences, one young person added *“If I had that information when I was 15, for example, how different it would have been for me in a lot of different situations. So yeah, information is huge.”*

Barriers

Young people at the Summit also discussed what negatively impacted their ability to make choices, and ultimately, their wellbeing.



Children and Young People
with Disability Australia

While the people in their lives can be an important support, young people wholly agreed that other people's attitudes and actions can also be one of the biggest barriers in getting what they want in life.

"Ableism and societal constructs and the fact that everyone with disability is thrown into a box and [people] going, 'No, you can't do that, so don't bother trying.'"

"One of the barriers I faced growing up was having therapists, or teachers, or whoever they were, thinking they knew what was best for me and making decisions for me thinking it's the best route, where it's like, 'Hang on, don't I get a say in this? Don't I get to know what's best for my life?'"

"[I]f we're seen as meeting a milestone that abled people meet, we're seen as an inspiration and I'm like, 'No, no. I just have to work a bit harder and I'm doing what I want to.' I'm not finding the cure for cancer or anything, I'm doing nothing that is special."

Young people also added that the perceptions of others also can impact how they their mental health and how they view themselves.

"[It's] infantilising people with disability. If we have choices in our lives and have the opportunities to make choices for ourselves, it helps not only other people see us as fully functioning adults, but it helps us see ourselves in that way too. That's so important."

"So for me, the main that relate to my experience of disability that impact me negatively really are to do with ableism. ... So obviously there are other things that can impact me negatively but I think really most of the things that have a long term effect on my mental health could be brought back to ableism as the key driver."

One young person also added that while it is important for their wellbeing to have choices and make decisions, it does not mean that they want to make every decision alone.

"Because I think I can be quite capable to make decisions in some instances, friends, therapists and professionals can assume I'm always good at making decisions independently and don't always need support, particularly around easy decisions. ... and because I'm not very good at communicating, or say, 'Sorry, I'm actually having difficulties answering this', I just leave it. That's a big barrier for me in making decisions."



Children and Young People
with Disability Australia

Solutions

Young participants who attended the Summit emphasised the need for a mental health system that is accessible and empowers them to make choices, in their mental health treatments and in their lives overall. This includes options for therapies and wellbeing activities that are accessible and person-centred.

“There needs to be a specific inpatient beds in these units. That can be accessed by people like myself with the appropriate help”

“To access therapy for mental health, therapy needs to be accessible to our disability. We need to be understood.”

Some young people described the benefit of accessing therapists with lived experience of disability who understand the impacts of disability on mental health.

“Imagine a psychologist who gets it because they are disabled too. I never thought it was possible before but why not? I mean, disabled people can do anything. And that would really have benefitted me knowing that someone else knows how tough it can be navigating an ableist world. Not because they just read it in a book but because they have lived it.”

“I think choices on what I get to do each day and not being forced to do certain things that someone else has made me do. ... Choices to go to health practitioners that I feel comfortable with, not just necessarily ‘oh, they’re the best, so you have to go to them’.”

Meaningful and positive representation of young people with disability was highlighted as a pathway towards increased wellbeing. The importance of seeing people with disability represented in all walks of life, across society was viewed by Summit participants as essential to combating internalised ableism.⁴ Young people highlighted the positive impact role models have on their mental health, and their desire to be role models themselves.

“So I think if we can continue to create more meaningful and positive representation for people with disability, the perceptions of us will begin to change for the better as well...So It’s sort of like, I guess, like a snowball effect. I feel that representation can be that really important, first kind of leap in terms of making positive change.”



Children and Young People
with Disability Australia

"I really had a lot of ableism in myself and thought about myself very negatively. It wasn't until I found other disabled people on Instagram and TikTok who were living their best life...being themselves proudly, that I thought "I guess that's an option for me". I didn't know any other disabled people who were... doing well and successful I guess."

Social Movement

Young people who attended the Summit emphasised access to mental health supports is a human right. They viewed accessible and inclusive mental health care as essential to social movements towards disability rights.

Young people championed the need for greater collaboration within the disability and mental health sectors. They expressed that there is a need for organisations, governments and services to create more spaces for young people with disability to advocate and lead the way towards a more inclusive mental health care system.

"We all have the rights to access therapeutic support for our mental health and that to be accessible to us, our Autism or our other disability. It's not our difference that is the disability but our environment and the approach not being accessible to us. That's disabling."

"So mental health is a crisis that we are all dealing with at the moment. And because we can't see it and because we are dealing with physical health crises it's something that no one is talking about. And I know a lot of you are listening in from isolated backgrounds. You're feeling alone or you've not seen your friends in a while. And so mental health is a conversation that is very important to be having. And I'm very glad to be here."

Addressing power imbalances that currently exist between young people with disability and non-disabled people (particularly those who are in position of power), was understood by participants to be fundamental in moving toward more accessible and inclusive mental health care. Young people highlighted that many inaccessible mental health supports need to be redesigned with young people with disability.

"And also the fact that generally it's non-disabled people who have the power to create these things [accessible events and spaces]. People with disability, I guess, still because of systemic ableism aren't being employed in those roles to create enough change to have that big impact. Yet!"



Children and Young People
with Disability Australia

Where to from here?

Young people with disability are entitled to accessible mental health supports, and to make choices about their care and their lives. As CYDA heard from young people who attended the Summit, this is not the current reality – and it is largely because of the attitudes and barriers constructed by others.

In line with the ideas, solutions and insights of participants, CYDA values the importance of creating opportunities for meaningful, positive representation of young people with disability across society. When role models with disability from all walks of life and in positions of power are elevated, the perception of young people with disability will change; both societally and internally.

Mental health care and wellbeing services should also review if their services and therapies are accessible –and then amend if necessary. This also includes proactively speaking about accessibility with young people who engage with their services to remove the burden of them needing to constantly follow up when information is ambiguous or non-existent. In-patient and acute care facilities must ensure they are equipped to support young people with disability.

CYDA also supports the calls of young people who attended the Summit for services and practitioners to meaningfully include young people with disability in the design, implementation and evaluation of policies, programs, and delivery methods. In 2014, CYDA released [Strengthening Participation of Children and Young People with Disability in Advocacy](#), a paper that outlines prerequisites and methods to ensure this type of work is done in a way that is safe and genuine.

Young people want to drive change in the systems they interact with, to ensure they are genuinely accessible and inclusive. Young people need to be provided with authentic opportunities to influence service design and delivery to ensure services meet their needs.

Calls to action

Governments:

- Invest in community interventions, including media portrayal, that target misinformed and discriminatory attitudes and beliefs held about people with disability.



Children and Young People
with Disability Australia

Calls to action

Governments:

- Invest in young people's skills development and provide platforms across government levels where they can be heard and enact change.
- Invest in in-patient and acute care settings which can adequately support young people with disability.

Services and Organisations:

- Review and amend service design and delivery to ensure service accessibility. If unsure, reach out to youth and disability representative and advocacy organisations for guidance.
- Increase diverse, meaningful representation of people with disability across sectors.
- Provide authentic opportunities for young people with disability to enact systems change through co-design of service design and delivery.

To learn more about what young people said at the Summit and this work, please feel free to contact CYDA's Youth Action Team at YouthActionTeam@cyda.org.au or on (03) 9417 1025.

Footnotes

¹ 10.9 per cent of young people aged 15 to 24 have left school before the age of 16 compared to 3.6 per cent of young people without disability; AIHW. (2020). *People with disability in Australia*. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment>

² Mission Australia. (2019). *Young, willing and able: Youth Survey Disability Report 2019*. Available at <https://www.missionaustralia.com.au/publications/youth-survey/1610-young-willing-and-able-youth-survey-disability-report-2019/file>

³ Ibid.

⁴ Ableism refers to the discriminatory perspective that able-bodied persons are viewed as 'normal' or superior. Internalized ableism refers to a person's self-image or understanding of disability as a concept characterised by internalisation of the ideas and prejudices of society that see disability as 'other', as something undesirable.

nyds



National Youth
Disability Summit

What young people with
disability said:
Education

Insights, ideas, and solutions from young people with disability
The outcomes of the inaugural National Youth Disability Summit
Presented by Children and Young People with Disability Australia
(CYDA)



Children and Young People
with Disability Australia



Children and Young People
with Disability Australia

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.

Background to the National Youth Disability Summit

At the end of September 2020, the inaugural National Youth Disability Summit ('the Summit') took place. The Summit was established with the vision to create an inclusive environment where young people with disability from across Australia could come together as a community and use their voices to shape the future.

The Summit was designed by and for young people with lived experience of disability. Over nine months, the Co-Design Committee, consisting of 20 young people with disability from across Australia, designed the vision, content and delivery of the Summit.

Hosted over five days, the Summit was an entirely online conference that offered young people a range of sessions and workshops, the opportunity to meet other young people, share their ideas, insights and expertise, and develop new skills and knowledge. Over 250 young people attended, with four of the five days being 'youth only'.

Each day had a focussed topic, as chosen by the Co-Design Committee. The topics were:

- **Education**
- Employment
- Mental Health and Wellbeing
- The NDIS and Housing
- Awareness, Access and Inclusion.

This paper will focus on the findings that came out of the Education day. Four different papers have been released to reflect the respective learnings from the other days.

The National Youth Disability Summit was presented by CYDA and funded by the National Disability Insurance Agency, with support from the Department of Social Services and Equity Trustees.



Children and Young People
with Disability Australia

Background on education and young people with disability

Gaining an education is an important building block that helps set us up for life. Having a good education is linked with better employment and health outcomes in adulthood. The skills, attributes and knowledge we gain through getting a good education also supports us to be active citizens in our community.

Young people with disability do not have equal opportunity to gain an education on the same basis as their peers without disability. A 2019 national youth² survey found that compared with those without disability, twice the proportion of respondents with disability reported that they were either dissatisfied or very dissatisfied with their studies.³ CYDA's own national survey⁴ also found that approximately half of respondents disagreed or strongly disagreed that students with disability received adequate support in their education.

Because of the increased barriers faced in education settings and systems, young people with disability experience lower engagement rates. Young people with disability leave school before the age of 16 at a rate nearly three times higher than that of their counterparts.⁵ Students with disability are also less likely to complete year 12 or attain a tertiary education, such as a gaining a bachelor's degree or higher.⁶

Young people with disability's perspective on education

CYDA has reviewed, analysed and collated the young participants' ideas into five key themes that emerged throughout the Summit week. These five themes are: Identity, Enablers, Barriers, Solutions and Social Movement.

| Key theme | Theme description |
|-----------------|--|
| Identity | How do 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 | Practical solutions for organisations, government, and the community to promote the autonomy, independence and power of young people with disability |
| 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 |

Here's what young people said:



Children and Young People
with Disability Australia

Identity

Young participants who attended the Summit discussed the importance of identity and how education settings need to recognise and be respectful of a diverse range of identities. This includes embracing and celebrating disability and the different ways young people identify. For instance, some young people prefer to use person first language to talk about themselves (e.g. 'person with a disability'), whereas others feel more comfortable when using self-descriptors (e.g. 'disabled person'). One young participant commented that the “*one-size-fits-all approach*” does not represent people’s differences, comparing it to a “*blanket thrown over people with disabilities that contains stereotypes*”.

Young people also shared the significance of intersectionality and how the recognition and promotion of different identities, such as ethnicity or sexual and gender diversity, in education settings is fundamental in ensuring that all students feel safe and included.

“I felt left out. Felt different. Felt like I don’t belong. Like the default is white, abled and heterosexual. I have experienced discrimination from teachers and lecturers, such as being told that I was ‘too sick’ to be at university, and constantly being in detention at school because the system just wasn’t designed for someone like me.”

There is a shared belief among young people that people in power should be proactive in asking students how they identify, and to “*just ask if you are unsure*”.

Enablers

Young participants at the Summit discussed the different factors that help them feel included and supported in education settings. One factor that was consistently highlighted across sessions was the importance of educators and education systems proactively asking young people what they need and then following through and implementing these preferences. The participants valued having “*solutions on their own terms*” and flexibility in their learning options.

“[Inclusive education] lets us decide what we want from our education. It will do anything in its power to achieve that. It would ask me, us, disabled young people, ‘what is it doing wrong?’, and it would listen to our answers. It would act on what we have told it. It would consider me the key stakeholder, not only in my life, but the education system overall. It would like me being viewed as somebody people can learn from.”



Children and Young People
with Disability Australia

Some young people also added that they appreciate when educators provide different information and options that enable them to determine how they can best learn. As explained by one group member, “*you can't ask for things you don't know about*”.

The group also expressed the importance of the allies in their lives, such as friends or favourite teachers, who help take the “*pressure off*” young people in navigating an imperfect system alone. However, it was also highlighted that ideally students would not need an ‘ally’, as the whole education system would be supportive of different strengths and needs.

Barriers

One of main barriers to experiencing inclusive education that was consistently shared across sessions at the Summit was the ableist attitudes of other people. In the words of one young participant, “*In the eyes of society, we are not seen as normal*”. As such, young people shared that their education needs are often disregarded, ignored and/or misunderstood:

“It shouldn't have to be the case that the greatest learnings in my life have come from discrimination, ableism and accessibility. But unfortunately, that is the reality of the world we live in today. With an education system that provides so inadequately for young people to get equal access to the supports we deserve and at the same time refusing to educate all, and in particular abled students and educators, on disability. It means we are forced to learn from adversity.”

A common occurrence discussed by the group was being punished for engaging in self-stimulating (or ‘stimming’) activities, such as listening to music, that allows young people to self-regulate or focus. One participant expressed their experience of getting a detention for stimming in the classroom as “*very painful and hurtful*”.

Young people also discussed how those in power in education settings often make assumptions about what is best for them and their education, resulting in students receiving supports that are inadequate and/or do not properly meet their needs and preferences.

I don't think anyone, regardless of what disability they have, should be seen the same. Teachers viewed us [students with disability] all the same and it was always negative. We weren't given the opportunity to be individuals and for people to get to know us.”



Children and Young People
with Disability Australia

Solutions

Young participants who attended the Summit see the 'education of educators' as a key step toward making education settings more inclusive and accessible for students with disability. This includes providing education to teaching, school and education staff about the experiences of young people with disability, different disability types and diverse learning needs and strengths. The group believed this education should be co-designed by those with lived experience of being a young person with disability at school, university or TAFE. There is also the belief that young people should be fairly compensated for their time and skills in co-design projects.

While some young people believe the 'education of educators' strategy would have positive 'trickle-down' effects on the attitudes and awareness of students, others think that education should also be specifically designed for and targeted at their peers without disability.

"One thing that schools can do to help, to like be educated, is understanding what different learning environments can look like, so then they know how to best be accommodate[ing]. So, for some people paying attention and concentration might look like fidgeting, drawing or listening to some music. Some students learn in ways that are not typically taught and therefore teachers assume the kids are disengaged"

"I would love disability to be more normalised and that people without disabilities got an education on how people with disability are valuable and someone they can be friends with."

"However, if people do need to understand the lived experience of disabled people, then hire us! Pay us for our emotional labour. Don't expect us to always educate you for free."

Social Movement

Young people who attended the Summit championed the need for greater collaboration within the disability and education sector. They expressed that there is a need for organisations, government and schools to create more spaces for young people with disability to advocate and lead the way towards a more inclusive education system.

"Politicians don't have lived experience of the systems they are designing. So, they don't necessarily know the ways of enacting systems change that are going to best benefit the people that exist within the system."



Children and Young People
with Disability Australia

“As a young person myself, I've been told 'no, you can't speak' or 'you're not old enough', so it's so lovely to see older people especially respect that the future is ours to take. And that our decisions and our voice is important.”

Where to from here?

In line with the ideas, insights and visions of the young people who attended the Summit, CYDA sees the need for major reform in the education system to ensure all children and young people have equal opportunity to thrive in their education. This includes providing safe and inclusive environments where students' individual identities and learning strengths are embraced, and different learning needs are appropriately supported.

The Australian Coalition for Inclusive Education (ACIE), an initiative which brings together organisations (including CYDA) that share a commitment to advance inclusive education in Australia, has developed a 10-year plan, known as the [Driving change: A roadmap for achieving inclusive education in Australia](#) (Roadmap). The *Roadmap* seeks to fulfill that every child and young person is welcomed and valued as a member of their school and receives a quality inclusive education on an equal basis with others in learning environments free of discrimination

The *Roadmap* steps out the key levers and outcomes required to achieve inclusive education, as defined by the United Nations Convention on the Rights of Persons with Disabilities (which Australia has endorsed, but not fulfilled). To achieve this reform, the commitment and shared responsibility of the Australian and all state and territory governments is required.

CYDA also supports the calls of young people who attended the Summit for education systems and institutions to meaningfully include young people with disability in the design, implementation and evaluation of policies, programs, and curriculum content and delivery methods. In 2014, CYDA released [Strengthening Participation of Children and Young People with Disability in Advocacy](#), a paper that outlines prerequisites and methods to ensure this type of work is done in a way that is safe and genuine.



Children and Young People
with Disability Australia

Calls to action

Governments:

- Commit to and resource major reform of the education system to realise inclusive education
- Meaningfully engage with young people with disability and their representative organisations in the design, implementation and evaluation of education-based policies, programs, and curriculum content and delivery methods.

Educators and education institutions

- Meaningfully engage with young people with disability and their representative organisation in the design, implementation and evaluation of education-based policies, programs, and curriculum content and delivery methods.

Organisations

- Pledge your support for inclusive education on ACIE's website.

To learn more about what young people said at the Summit and this work, please feel free to contact CYDA's Youth Action Team at YouthActionTeam@cyda.org.au or on (03) 9417 1025.

Footnotes

¹ Cassells, R., Dockery, M., Duncan, A., Gao, G., & Seymour, R. (2017). *Educate Australia fair?: education inequality in Australia*, Focus on the States series, no. 5, June 2017, Bankwest Curtin Economics Centre, Curtin University, Bentley. Available at <http://bcec.edu.au/publications/educate-australia-fair-education-inequality-australia/>.

² Aged between 15 and 19 years old

³ 16.1 per cent compared with 6.9 per cent of participants without disability; Mission Australia. (2019). *Young, willing and able: Youth Survey Disability Report 2019*. Available at <https://www.missionaustralia.com.au/publications/youth-survey/1610-young-willing-and-able-youth-survey-disability-report-2019/file>

⁴ Children and Young People with Disability. (2019). *Time for change: The state of play for inclusion of students with disability: Results from the 2019 CYDA National Education Survey*. Available at https://www.cyda.org.au/images/pdf/time_for_change_2019_education_survey_results.pdf

⁵ 10.9 per cent of young people aged 15 to 24 have left school before the age of 16 compared to 3.6 per cent of young people without disability; AIHW. (2020). *People with disability in Australia*. Available at <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment>

⁶ *ibid.*