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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)



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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.



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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.



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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."



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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.”



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“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.



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"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."



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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.



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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.



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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>.