



What young people said

Diagnosis



About this paper

This paper is a summary of the thoughts and reflections of young people with disability who attended the 2023 National Youth Disability Summit (the Summit) on the topic of diagnosis.

The 2023 Summit was run by Children and Young People with Disability Australia (CYDA). It was a two-day hybrid event, with participants from all over Australia, taking part online or in person at Burgmann College in Canberra. It was attended by 60 young people with disability between the ages of 12 and 25.

The Summit was co-designed by CYDA's Youth Council, made up of 12 young people with disability. The Youth Council chose the topics for discussion, the speakers, the location and the activities of the Summit. They also facilitated discussion and activities on the day.

The three discussion topics chosen by the Youth Council for the 2023 Summit were:

- **diagnosis**
- **inclusive education**
- **self-care**

This paper is one of three, summarising what young people said at the Summit about each of the three topics.



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Summary

When discussing the topic of diagnosis, young people spoke about the good things that come with a diagnosis. These included access to community, supports and services.

Young people emphasised that not having a diagnosis doesn't mean that a person is not disabled or doesn't need support. They acknowledged that neurodivergent and chronically ill people, and people with undiscovered conditions in particular, might have difficulty being diagnosed. They also acknowledged that some diagnoses are also not readily accepted in application processes for the National Disability Insurance Scheme (NDIS) or Disability Support Pension (DSP), or to access community services and supports.

Young people discussed how a diagnosis is often not a single event. Diagnosis can be a lengthy, expensive, inaccessible process taking months or years. People who have been looking for a diagnosis for a long time, without answers, can need breaks and self-care before engaging with the health system again.

Young people spoke about how a diagnosis can be affirming for people who have previously been told that there is nothing *really* wrong with them, or conversely, that there's something very wrong or not "normal" about them. Positive and negative emotions can also exist together when someone receives a diagnosis, and some people might need emotional support with this.

Young people talked about how stereotypes, or religious ideas, around disability, can make it hard to access or talk about a diagnosis. Some had chosen not to disclose their diagnoses so that they could fit in or avoid bullying.

Young people emphasised that disclosing your diagnosis is a personal choice, though the choice is not always available to some visibly disabled people.

Young people pointed out that a diagnosis does not signify the start of being disabled. People are often diagnosed long after their disability begins. They spoke about the impact of parents who ignore signs of disability in their children, or feel guilt around genetic disability, and choose not to seek a diagnosis.

They also spoke about the impact of choosing not to disclose a diagnosis to a child. They identified Autism and ADHD in particular as diagnoses that might not be disclosed to young people by their parents, and felt strongly that parents should *not* be keeping these diagnoses from children.

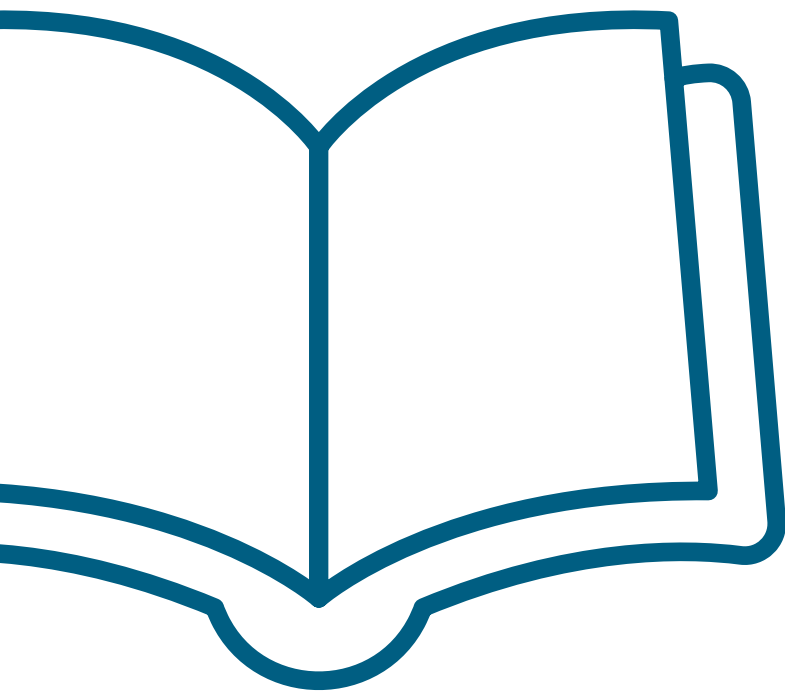


Summary

Young people talked about some of the problems with official processes around diagnosis. They identified the DSM-5 as a diagnostic tool out of step with current research. They were particularly concerned about mental health diagnoses creating barriers to accessing gender affirming care.

Young people spoke about the difficulty of having to prove yourself to new medical professionals before accessing supports. They talked about how disabled people often know their own situations better than the specialists they see, especially when specialists only see them sporadically or for a limited time.

Young people spoke about how a diagnosis is often seen as the first step toward fixing a medical problem. For them, a diagnosis is more about getting the right support and accessing community. They spoke about the benefits of seeing adults with similar diagnoses living fulfilling lives.





What young people said

The following quotes have been de-identified to protect the privacy of young people who attended the Summit.

On parents and teachers not disclosing disability:

'[M]y parents were speaking to this teacher later, my kindy teacher, and they said, "Oh, yeah, we knew your son was autistic. We just didn't want to do the paperwork.'"

'I wish parents and carers understood that not disclosing a diagnosis to a child doesn't necessarily reduce the impact of their disability.'



On the disadvantages of diagnosis:

'When I was 15, I got really sick out of the blue, and it had nothing to do with my primary diagnosis, and no doctor could see past my first diagnosis ... So, I think diagnosis can be quite restrictive.'

'So glad I didn't [have my diagnosis] 'til after high school, and my brother has actually had to drop out of school because it's been so horrible for him.'



What young people said



On stereotypes and negative ideas about disability:

'Please stop with the narrative that being diagnosed with Autism is the end of your child's life, that they're not normal, that it's such a burden ... and please let us feel hopeful and joyful, or just let us be humans.'

'When I get told my labs are clean, I get really annoyed. I'm like, very disappointed ... and that can be really strange for people because they're like, why do you want bad news? And I was like, because I want, I want answers. I want to know what to do.'

'When you're growing up, and you're non-disabled, a lot of the time you grow up with the notion that being disabled is the worst thing that you could possibly be.'

'For me, it was such a celebration ... I was so happy. And to take that to my parents and them be distraught about it was really, really tough, because it was such a contrast in, like, what I was feeling versus what they were feeling.'

'When I was diagnosed, my father said that I shouldn't label myself as Autistic because it is bad. Which I don't see that way. I'm now very proudly Autistic.'

'Everyone knew before me, and were calling me all the derogatory terms associated with my diagnosis, before I was diagnosed anyway. So, diagnosis to me was really a way of, like, reclaiming, like, who I am.'



What young people said

On needing a diagnosis to access support:

'It was quite hard [without a diagnosis] because a lot of services that are supposed to help you couldn't help me ... and so, my parents had to do most of the work ... [E]ven though [someone] might not have the diagnosis yet, doesn't mean that they don't have needs, and doesn't mean that they don't need help with things. And once they get the diagnosis, they're still the same person.'

'It's sad and disappointing that some supports are not given until there is a written diagnosis on a piece of paper.'

'If someone is truly so desperate for support and accommodation that they feel the need to lie or make things up, they need the support and accommodation.'

'I'm struggling to get diagnosis for my [physical health issues] but I'm taking a break from that so I can focus on my health.'



Thoughts for health practitioners:

'[R]eally trying to understand what we're going through and not jumping to what would be the most easy diagnosis to give out or the most convenient, like actually giving it a bit of thought and considering what Autism looks like in someone who isn't the prototype for it.'

'I remember literally sitting there with my parents talking to the doctors about me. And no one at any point through the process thought of actually stopping and talking to me.'



What young people said

The benefits of diagnosis:

'It also pointed me towards, like, looking at disability and reframing how I thought about disability. And now, like, most of my friends are disabled people, and, like, it's just who I surround myself with. And it's become, like, a really healing community. And I wouldn't have gotten that if I didn't go through my journey of diagnosis.'

'The way I would just describe it as, like, a path appearing in the forest. Like, yeah, you could navigate without the diagnosis ... You can still figure it out. It's your body. It's your mind. It's your whatever. But, like, having the diagnosis is like having a map ... it's like a path just appearing and you can then find so many more resources. You can find community ... it's a million times easier to find your way.'

'I finally had context. I had, like, an understanding of why certain things were the way they were or why I felt different, or isolated from people. So, just understanding that there wasn't anything wrong with me was really important. It was just that I was different. And that's okay.'

'I cried when I got my diagnosis for the ADHD because I'm like, my brain works differently for a reason. Like, I'm not being a hypochondriac.'





What young people said



General thoughts and advice:

'[Y]our diagnosis doesn't really have to define you, it can look so, so different for every person under the same diagnosis.'

'We need to be seen as independent beings who have our own thoughts, feelings, emotions, ambitions, feelings around diagnosis.'

'I view, like, my friends and family researching my conditions as an act of love ... in particular, my brother, when I had new diagnoses, went and sort of did a Google about what that meant. And he never told me that, but it sort of slipped out one point. And that was very heart-warming for me, because it showed that he was open to understanding my experiences.'

'I wish other people knew that it wasn't their place to, like, disclose your diagnosis, or talk about your access needs without you in that conversation.'

'It's just, like, what I have, but it's not really who I am.'

'I needed more support, immediately post diagnosis, so I could feel empowered and educated on what it all meant.'

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Acknowledgement of Country:

Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed, and produced. We pay our respects to their Elders past and present and acknowledge that sovereignty was never ceded. This is, was, and always will be, Aboriginal land.