A summary of Your Voice 2021 findings of the experiences of young people with a lived experience of disability.

A submission to the:

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

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In 2021, **yourtown** heard from over 3,500 young people, aged 15-24, through the Your Voice project. The project involved a national survey, national forum, and youth summit. It provided young people with the opportunity to voice their experiences in relation to services across a range of areas, and express their views on how services need to be improved. The final report is available online at https://www.yourtown.com.au/yourvoice.

In the survey, 467 young people drawn from across Australia indicated that they had experience with disability services. This included young people who: were carers; support workers for people with a disability; experienced significant functional impairment; or who had a diagnosed disability. This document sets out the findings and 'voices' of these young people.

Key findings

- 47% of young people found it difficult to get a diagnosis and access support;
- 20% of young people had positive experiences with disability support;
- 15% of young people felt that the professionals they interacted with to get a diagnosis and support treated them poorly, and had limited understanding of their needs;
- 7% of young people failed to access subsidised support which led to significant out-of-pocket expenses for assessment and treatment;
- While 11% of young people received NDIS support, 44% found NDIS support difficult to access;
- 39% of young people found their mental health was impacted when accessing support and the treatment they received;
- 29% of young people accessed disability services in an education setting;
- 25% of young people struggled to get appropriate support from job agencies;
- 6% of young people with a disability expressed difficulty in accessing income support.

What young people told us about living with a disability

"Please listen to us. In terms of disability, try living even one day in a wheelchair, not being able to do anything for yourself, constantly abused by the public and family, in constant pain, emotional and physical. Be told the waiting lists for supports are long and you are required to stay in your filth or situation for months at a time. Go to hospital for weeks at a time for mental and physical health because you are breaking. And be told when you get help you have to live in an aged care facility even though you are 21 because there aren't facilities for your situation or age."

Barriers to Diagnosis

Young people with a disability told us that access to support was dependent on their ability to afford health and diagnostic appointments. While this diagnostic process is required to access disability support, it can be both traumatising and time-consuming for young people with a disability.

Getting a spectrum test is too harrowing. I've been told it'd be good to get the funding and resources, but it's so expensive and time consuming!

Getting a reference from my GP to see a specialist was easy due to the nature of my condition. However, the specialist cost over $300 per session and only $200 of that was refunded through Medicare. If I had wanted to see this specialist 3 months prior, I would not have been able to afford it.

[Support is] Extremely expensive, difficult to access, diagnosis is inaccessible, ableist systems, not client-focused, uneducated.

[It] costs a lot of money to be diagnosed so I cannot access services.

Waiting lists and quality of services trying to get help for chronic pain and fatigue has been something that's extremely difficult to deal with.

I don't feel like there's enough resources for youth with chronic illness and I don't get the help I need.

Social and Economic Participation

Young people with a disability told us that accessing appropriate support was essential for their full participation, socially and economically in society.

I've used my University's equity and diversity program. I was given a learning access plan which has helped me with assignment extensions.

I'm with 'At Work' for looking for work and it is very helpful.

However, young people with a disability told us that a lack of understanding and inappropriate support negatively impacted their social and economic participation, limiting their potential.

I was given no other support [besides a learning access plan] and my disability supervisor was very rushed. At one point, when I mentioned I was struggling, she just emailed me a link to a "How to study better" guide. I have autism. I wasn't stressed about studying.

Unfortunately, there aren't many services available for students with dyslexia, besides psychology, tutoring and reading materials for parents. My experience is that I've been lucky enough to have found a tutor that caters for my learning disability and understands my way of learning, but there are times my tutor is away, so I have to have a new teacher for that lesson who I'm not familiar with and who doesn't understand my learning needs. This sets me back from my classmates because if my teachers were just aware of my disability needs as my tutor is, I wouldn't be disadvantaged and wouldn't have to constantly rely on tuition to understand classwork, but rather I would be just as equally supported in a class environment with the rest of my peers.

There is no support related to dyslexia besides tutoring. It is a very under looked disability that has not only impacted my education, but also my self-esteem. There needs to be more services related to dyslexia, especially in schools, so we feel supported and heard, and are not disadvantaged to neurotypicals.

I have found very little in the way of help with my disability, not even in school support systems. I had to transfer to online school, and it was still inadequate.

I keep getting refused Disability Support Payments, I cannot work, and job agencies put immense pressure on me to the point I can no longer receive income support.

I tried to go through a disability recruitment agency during my time at university to help me find a job out of university. The lady who had my case was extremely unprofessional as to even asking me specifically and writing down what my physical disability was called so she could google it later. As a young person, I felt like I couldn't say no, even though I didn't want her to know. She never helped me land an interview and never assisted in any way with finding a job.

I see a Disability Employment Services place through Centrelink, and they provide no proper assistance.

Mental Health

Young people told us that poor experiences with disability support and the lack of support available to them negatively impacted on their mental health and wellbeing. Further, young people with disability told us that they often felt unsupported, unsafe, and that their lives were limited in scope and value.

They didn't take me seriously and completely left me floating with no resources or support. Social media did more for me than the doctors it cost me hundreds and hundreds to see.

My brother is autistic and suffers greatly at the hands of those around him, any 'services' that have been requested or paid for have been (from what I've heard) well below the expectation)

As someone with a developmental disability, there are a very limited number of good, accessible services that allow me to function at my full potential in a system designed for neurotypical and 'able' people.

Difficulties Accessing Support and Assistance

Once diagnosed, disability assistance is not always available for young people due to:

- Having a disability/s that did not have a functional impact which met the criteria for accessing support;
- Difficulties identifying support which is appropriate for their needs and specific situation; and,
- The limited availability of support services for those with specific diagnosis.

The support for autistic people like myself who are verbal and capable of passing within social situations is very limited.

It's been difficult to find specialists related to tic disorders, and the wait time is extremely long.

My autism doesn't get classed as high enough to access the supports I could benefit from.

Community disability services are very hard to get into. NDIS is even harder to get into when you need the constant and urgent support. When you do finally get into either service, you have to do some mismatching until you get services that treat you correct.

Accessing appropriate income support can be a significant struggle for young people with a disability. Long and confusing processes mean that those that require support can be left without critical assistance. This can lead to functional and situational deterioration.

Even while I was experiencing homelessness, Centrelink didn't lift a finger to help me. They prolonged the process by putting me through assessments with 3 clinical psychologists, even after I already had a recorded formal diagnosis from a psychiatrist, and clinical psychologist, a hospital discharge letter and direct letters to Centrelink from my GP, a trauma specialising clinical social worker, a uni counsellor and youth homelessness casework. I was eligible for the disability pension from the beginning, but they made me jump through so many hoops to get approved, hence why I ended up homeless.

The disability payments are way too difficult and complex to access properly. The form is designed to confuse and there are so many things to fill out, and there is no information given to doctors and mental health professionals.

I know I will be unable to get disability payments through Centrelink as you must 'have been stable and treated for 2 years' which is completely impossible through the public system.

Young people told us that accessing specialist support through the National Disability Insurance Scheme (NDIS) can be difficult to access due to:

- Difficulties in understanding complex information and meeting the eligibility criteria;
- The complexities of the NDIS system and the accessibility of the planning process; and,
- Constant changes to NDIS rules and operational guidelines around planning and appropriate support.

I've been knocked back from NDIS funding twice and the application process was extremely hard to navigate with an ABI. I've recently been accepted for funding, but the process is slow, which I feel isn't appropriate for my needs.

NDIS is another big issue in the disability community. One person would not give me access to my own NDIS plan. The rules are constantly changing which also makes it an issue. I'm 15 years old and dealing with my own plan as my family don't understand NDIS. This makes it challenging. I disagree with the decision someone coming into your home to evaluate if you do require a particular thing. This should not be allowed. A stranger going into a disabled person's home could make the client feel very vulnerable and it is invasive of people's privacy.
I have NDIS and I found it very difficult to get onto and the system was very confusing once I got on.

The NDIS has been complicated to get into.

There is no standardised NDIS review process, and not all NDIS reviewers have the same opinions on what supports are necessary. It's luck of the draw.

NDIS decline every application and things they don't know in the too hard basket.

I have applied for NDIS once, and they told me I really should've have been granted it, but I wasn't because of a technicality (my psychiatrist didn't state the level of severity of autism). So now I have to go back to my psychiatrist, spend another two hundred dollars, and go through the whole NDIS application process all over again.

They are often dismissive and condescending. I have also had professionals make mistakes in admin that resulted in referrals I needed not being put through and necessary care being pushed back a whole year. Access to other support services (DSP/NDIS) are extremely difficult.

Young people told us that these difficulties in accessing disability support were amplified for those living in rural and remote areas due to:

- The lack of available disability support services for those living in rural and remote areas; and,
- Substantial financial costs, including travel costs, to obtain a diagnosis or access support in other areas.

Living rurally, I, along with many other people, have found services for non-mental health are very hard to *come by where they're either greatly discounted or free. Services often are too expensive for people to use, or they are required to travel which again means it's too expensive.*

Quality of Support

Young people told us about the poor treatment they have experienced with services. Of concern was their experiences of ableism, professionals' lack of understanding regarding disabilities, as well as systems, while designed to support them, impairing their ability to access support.

Also having extremely dismissive doctors who are unable to help me and tell me that isn't psychosomatic

The system is designed to give us disabled people as little support as possible. We are assumed to be faking our disabilities unless we can provide a mountain of evidence from a variety of specialists, which costs A LOT of money.

I am not taken seriously because my disability is not obvious.

I was given a learning access plan which has helped me with assignment extensions, but no other support, and my disability supervisor was very rushed. At one point, when I mentioned I was struggling, she just emailed me a link on "how to study better" guide. I have autism. I wasn't even stressed about studying.

Young people with a disability told us that the quality of support they received through the NDIS could be poor due to:

- The treatment they received;
- Complexities with accessing and understanding their NDIS plans; and,
- The result of changes to the cost of services that reduced the amount of support they could get or afford on the plan they were given.

It's a broken system for people who don't have resilience and too unwell to continually advocate and complain about the need for funding or plan changes, and it's too hard when my mum gets sick to wait 9 months for a plan review to get funding changed is ridiculous. So, I do the jobs and care for my mum and my siblings as well.

However, young people told us that the quality of support they received through the NDIS was positive when they were offered appropriate support that helped them to feel more included.

The NDIS is great for my brother and Dad and helps them loads.

I am under the NDIS for my mental health and my autism. It provides support workers coming to the house on a regular basis and has been really helpful for my mental health as well.

Lot of ranges of services you can access. NDIS is great.

Overall, experiences with support significantly contributed to young people with a disability's quality of life, their ability to interact socially, live independently and achieve at study and work.

I'm on the Autism Spectrum and have ADHD, sensory processing disorder and hyper-mobility. I have been to physios, doctors, and therapists, and have been very satisfied with accessing them and the quality of their services, and how knowledgeable they were in many different areas of their profession.

I have autism and it has been good to be matched with a great support worker who helps me get things like groceries done.

My older sister receives NDIS funding and this has helped her with engaging with the community, as well as being able to afford her needs.

Guide Dogs SA/NT is the best! They have friendly people working there, support when you need it, and so many other reasons why they're great.

I have a fused spine and that is my disability. All services are very helpful and can assist me if I need a wheelchair or anything else when my back gets really bad and painful.