

The intersection of youth and disability:

Disabled young people's experiences of violence,
abuse, neglect, and exploitation in Victoria



**YDAS' submission to the Royal Commission into Violence,
Abuse, Neglect, and Exploitation of Disabled People**

December 2022

About YDAS

Youth Disability Advocacy Service (YDAS) is a Victorian advocacy service that works alongside disabled young people between the ages of 12 to 25 to raise awareness of their rights and to support them to achieve their goals. Our work is underpinned by the international human rights principles articulated in the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) and the *United Nations Convention on the Rights of the Child* (CRC).

We provide high quality advocacy representation to disabled young people in human rights cases through our individual advocacy service. We also tackle systemic issues affecting the full and equal participation of disabled young people through our policy work and programs.

YDAS is guided by a youth participation framework that includes young people with a range of experiences of disability. YDAS operates as a core agency of the Youth Affairs Council of Victoria (YACVic) and is funded by the Department of Families, Fairness and Housing Victoria (DFFH), Department of Social Services (DSS), and a philanthropic grant.

Youth Disability Advocacy Service

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YDAS is thankful to the many disabled young people who contributed to this submission, including the DRC working group, individuals who provided case studies, and the young people who participated in our consultations and responded to our DRC survey.



YDAS respectfully acknowledges the Aboriginal and Torres Strait Islander people of this continent. We respectfully acknowledge the traditional custodians of the Aboriginal nations within Victoria where our work takes place, and we pay our respects to Elders past and present. Bunjil's lore states that those who walk on this land must care for the Country and waterways as well as care for the children and young people. This always was and always will be Aboriginal land.

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Executive summary and overview

The Youth Disability Advocacy Service (YDAS) welcomes the opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC). This submission centres the diverse experiences, voices, and recommendations of **92** disabled young people consulted by YDAS between November 2020 and March 2021 and draws on the 16 years of experience accumulated by YDAS working with and on behalf of disabled young people.

This submission provided disabled young people with an opportunity to conduct research within their own community to investigate experiences of violence, abuse, neglect, and exploitation amongst disabled young people in Victoria. Consisting of five disabled young people, YDAS's DRC working group guided this first ever peer-led research project involving disabled young people in Victoria. Nine areas of concern were identified by the working group. These include: Education; Intersectional Experiences; Transport; NDIS; Justice and Policing; Employment and Economic Security; Housing; Health and Medical Mistreatment; and Mental Wellbeing.

The working group facilitated focus groups with disabled young people. Focus group participants presented insightful, impactful, and achievable solutions to safeguard themselves and other disabled young people from further violence, abuse, neglect, and exploitation. The disabled young people in the focus groups emphasised the need for:

- opportunities to participate in co-design processes to re-design systems;
- the inclusion of disabled workers in healthcare and support roles;
- increasing awareness about social and human rights models of disability to combat ableism;
- self-determination and autonomy over medical treatment and supports;
- ending restrictive practices;
- greater cross-sector collaboration to reduce service gaps;
- the delivery of disability awareness training across all sectors and education settings;
- minimum accessibility standards across all industries;
- extra funding for healthcare, mental healthcare systems and the NDIS;
- increasing awareness of and implementing strategies to support people with invisible disabilities.

These perspectives and suggestions were expanded into 60 recommendations with the guidance of the working group. These recommendations will help direct Government and policy decision makers to address issues that are specific to the experiences of disabled young people. This will inform the development of a fairer, more accessible, and inclusive Australia.

Summary of recommendations

Overarching recommendations

- 1.1 Use co-design methods with disabled young people and ensure their voice and expertise are meaningfully included when developing policy responses or designing services that will have an impact on disabled young people. We recommend that these include measures to:
 - 1.1.1 Identify where accessibility can be improved and create best practice standards for disability access measures that all organisations, educational institutes, and public services must adhere to.
 - 1.1.2 Develop the content and format of disability awareness and inclusion training for all sectors and ensure the training is tailored to each sector's particular requirements.
 - 1.1.3 Update inclusive education legislation and policy including the development of a disability-specific anti-bullying program delivered across schools nationwide.
 - 1.1.4 Create a campaign informing the public about invisible disabilities on public transport and update priority seat signage to include invisible disabilities.
 - 1.1.5 Re-design the healthcare system to alleviate ingrained ableism and promote inclusive and responsive care for the unique needs of disabled young people.
- 1.2 Embed mandated accessibility measures across all education facilities, housing and construction industries, transport infrastructure, healthcare facilities, and mental healthcare settings in Australia and require reporting on compliance.
- 1.3 Provide disability awareness and inclusion training, delivered by disabled people, across all sectors with regular refresher training that includes updated best practice to ensure that:
 - 1.3.1 Teaching courses in TAFEs and universities nationwide are embedded with best practice on how to support disabled students.
 - 1.3.2 The national curriculum is embedded with a focus on preventing stigma and discrimination against disabled people.
 - 1.3.3 Workers who interact with disabled young people know how to best support disabled people. This includes those who work in healthcare, mental healthcare, education, justice and policing, employers, settlement services, and transport workers.
 - 1.3.4 Employees and managers are informed on how to create inclusive and accessible environments for disabled young people, and value the capabilities and skills held by disabled young people.
- 1.4 Resource community-led independent advocacy organisations to support disabled young people to have their rights and needs upheld, particularly when they are accessing public services, the health system and education system.

Intersectional experiences

- 2.1 Provide diversity training for disability services and organisations, delivered by disabled culturally diverse people.
- 2.2 Ensure culturally responsive practices are embedded into health, medical and disability services.
- 2.3 Increase the representation of culturally and linguistic diverse workers in disability services and organisations (including advocacy services, mental health services and education).
- 2.4 Ensure that registration schemes for disability support workers do not disadvantage culturally and linguistic diverse workers with benchmarks for fluency in English.
- 2.5 Resource and support self-advocacy, peer support and leadership programs for culturally diverse disabled young people.
- 2.6 Amend the Migration Act to prevent discrimination against prospective migrants on the basis of their disability or a family member's disability.

Education

- 3.1 Prioritise and support the active involvement of disabled students in the development of their individual learning plans and consult students about adjustments and supports they require.
- 3.2 Mandate the inclusion of disability liaison officers across all education settings, with a focus on hiring those with lived experience of disability.

Transport

- 4.1 Increase the number of accessible seats, especially in new vehicle models that prioritise standing room.
- 4.2 Empower regulatory bodies to fine or sanction public transport providers for failing to provide accessible services.
- 4.3 Include large print visual information, audio announcements, and digital display boards at all stops and in all vehicles, to support a range of access needs.

NDIS

- 5.1 Establish a nationally consistent legal framework to eliminate all forms of restrictive practice and amend the timeline for mandatory reporting of the unauthorised use of restrictive practice to 24 hours.
- 5.2 Improve communication with young people about the NDIS, the processes to access support, the intention of the scheme, and what to expect when accessing the NDIS.
- 5.3 Provide support and training for disabled young people aged 15-25 to self-manage their plans.
- 5.4 Review and expand eligibility for young people with mental health conditions.
- 5.5 Increase resourcing to the NDIS to reduce the wait time for applications.
- 5.6 Introduce mandatory time limits for NDIS to respond to young people and ensure that they are not left in unsafe situations.

- 5.7 Set higher targets to hire disabled staff across all levels of the NDIS and Partners in the community (PITC) providers, especially in client-facing and decision-making roles.
- 5.8 Improve collaboration between the NDIS, medical professionals, youth workers, social workers, teachers, psychologists, specialists, and service providers.

Justice and Policing

- 6.1 Explore the use of transformative justice instead of sentencing for disabled young people, particularly for low level offences and petty crime.
- 6.2 Mandate the nationwide provision of necessary supports for disabled young people while in police custody, including mental health support.
- 6.3 Increase funding for legal aid services that support disabled young people and improve communication on how to access these services.
- 6.4 Prohibit inhumane practices against disabled young people such as seclusion, physical and chemical restraint, and indefinite detention, and implement accountability mechanisms for when this occurs.

Employment and Economic Security

- 7.1 Subsidise traineeships and cadetships for disabled young people in state and federal governments, statutory bodies, NGOs, and the private sector.
- 7.2 Provide disability-specific career guidance for disabled young people and hire career guidance counsellors with lived experience of disability. This would include training about their rights at work, managing taxes, superannuation, and how to communicate with employers.
- 7.3 Increase the awareness of Job Access and other funding available to employers to implement reasonable adjustments for disabled employees.
- 7.4 Legislate an enforceable positive duty on employers to prevent disability discrimination.
- 7.5 Explore increasing and mandating disability employment quotas in the public service and private sector companies.
- 7.6 Review the eligibility criteria for the DSP including the hours-based requirement and raise the rate to adequately cover the elevated costs of living with a disability.

Housing

- 8.1 Raise awareness of accessible housing options, including SDA, amongst disabled young people.
- 8.2 Expand the eligibility criteria for SDA using a youth lens which acknowledges that disabled young people may need additional support when transitioning to independence.
- 8.3 Ensure that the SDA consults with potential participants, particularly disabled young people, on housing needs and preferable locations for housing.
- 8.4 Ensure that new social housing projects have a quota for accessibly and adaptably built housing with a percentage reserved specifically for disabled young people.

- 8.5 Introduce nationwide mandatory adaptable housing standards in building regulations for residential housing.
- 8.6 Increase the availability of resources to assist disabled young people in locating disability inclusive accommodation and ensure they have a level of choice on par with other young people about their living arrangements.

Health and Medical Mistreatment

- 9.1 Shift focus within healthcare policy towards a social and human rights model of disability rather than focusing solely on treating impairments.
- 9.2 Require health providers to provide disabled young people with information about their medical care in an accessible format and involve them meaningfully in decisions about their care.
- 9.3 Make 'no wrong door' complaint processes readily accessible in health facilities.
- 9.4 Invest in creating cohesive cross-sector collaboration to ensure continuity in disabled young people's care, including the transition from paediatric to adult care and provide support for disabled young people when they transition from paediatric to adult care.
- 9.5 Increase funding to all health care facilities to address excessive wait times for appointments and treatments.

Mental Wellbeing

- 10.1 Fund telehealth for all mental health services and invest in improving the accessibility and quality of telehealth.
- 10.2 Increase awareness and recognition of mental illness as a disability.
- 10.3 Reinstate 20 Medicare-subsidised therapy sessions to provide young people with adequate support to address their concerns, especially those with complex issues.
- 10.4 Increase the number of workers with lived experience of disability to work alongside disabled young people with mental illness.
- 10.5 Support disabled young people to attain qualifications related to the mental health sector by offering scholarships, financial assistance, and mentorships.
- 10.6 Resource fast track referral pathways for mental health support between disability-focused and mainstream organisations.
- 10.7 Invest in flexible service delivery and a range of mental health treatments tailored for disabled young people's diverse needs.

Methodology

Youth Participation

This submission is guided by a model of youth participation developed by Youth Affairs Council of Victoria (YACVic). YACVic's model of youth participation (MYP) emphasises empowerment, meaningful engagement, and the inclusion of all young people.¹ MYP is underpinned by Article 12 of the United Nations Convention on the Rights of the Child (CRC) which states that "States Parties shall assure to the child who is capable of forming [their] own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child."² MYP is also informed by Hart's Ladder of Participation, and aligns with Participatory Action Research and Co-design methods. These models support young people's active participation in guiding and developing research, provide opportunities to share decision-making, and empower young people and other stakeholders to learn from each other to collectively create better outcomes.³ These principles of youth participation are foundational to this submission and have been implemented in all stages of its development.

Participants

DRC working group members

This submission was created with guidance and input from YDAS's DRC working group. The DRC working group was made up of 5 disabled young people. The working group identified and agreed on 9 areas of focus to include in this submission, as well as assisting in the development of the recommendations. The working group provided periodic feedback and suggestions for improvement until the completion of this submission. Working group members also worked alongside YDAS staff to facilitate focus group consultations and develop focus questions to guide discussions.

Focus group participants

Focus group participants consisted of 26 disabled young people. Nine online focus group consultations were attended by focus group participants, with a minimum of 3 participants and a maximum of 4 attending each consultation. Each consultation addressed one area of focus included in the submission. These were: Access; Intersectional Experiences; Education; Transport; NDIS; Justice and Policing; Employment and Economic Security; Health and Medical Mistreatment; and Mental Wellbeing.

YDAS staff and working group members invited focus group participants to reflect on their personal experiences, as well as the experiences of their friends and families, for each topic. Participants were encouraged to examine strengths and limitations of each topic. They explored

solutions to their negative experiences through collectively brainstorming the ways in which these can be addressed by the Australian Government and decision makers. YDAS staff encouraged a strengths-based approach to invite participants to generate solutions that build on the positives within each area of focus.

YDAS did not facilitate a consultation for Housing. However, this was identified by the working group as a key topic for disabled young people. In addition to the insights provided by the working group YDAS contacted a young person known to the organisation, who provided a personal account of their experiences with housing as a disabled young person.

Survey Data

YDAS collected responses from 61 young people aged between 14-24 through an online survey designed using the Terms of Reference set out by the Disability Royal Commission. This survey invited young people to share their experiences of violence, abuse, neglect, or exploitation and asked them to provide suggestions on how they think the Australian Government should address these issues. Their responses have been de-identified and are included throughout this submission.

YDAS Case Studies

Data from YDAS's individual advocacy service was collected and formatted into case studies. The disabled young people who chose to include their stories as a part of this report provided YDAS with consent to do so. Their names have been changed to maintain confidentiality.



Definitions and key concepts

Young people

YDAS considers young people as those aged between 12 and 25.

The social model of disability

The social model of disability originates from the disability rights movement in the mid-1970s.⁴ The social model argues that disability is a socially produced form of oppression which results from environmental and societal barriers that limit the capabilities and participation of disabled people.⁵ This approach locates disability outside of the individual and instead diverts attention to how society excludes, and isolates disabled people, and the subsequent responsibility it has in removing disabling barriers.⁶

The human rights model of disability

The human rights model of disability is informed by the Convention on the Rights of Persons with Disabilities (CRPD) which recognises disabled individuals as rights-holders with decision-making capacity and personal agency.⁷ The human rights model has similarities to the social model in that it recognises the responsibility of governments to remove barriers that prevent disabled people's full inclusion in society. However, this model differs from the social model as it acknowledges the impact of individual impairments such as chronic pain and early death.⁸ The human rights model also values impairment as a part of natural human diversity.⁹

The medical model of disability

The medical model of disability is the earliest model that still tends to dominate policy, practice, and discourse around disability, especially within the medical field. The medical model positions abled-body people as the norm, and disabled people as “defective”, thereby requiring treatment or a “cure” for their impairments.¹⁰ Locating disability as a deficiency within the individual exposes disabled people to discrimination, perpetuates stigma, and creates misguided narratives that associate disability with tragedy and helplessness.¹¹

Identity first language

YDAS uses identity-first language (*disabled young people*), as per the advice of the YDAS Steering Committee, which is comprised of disabled young people. However, YDAS recognises that language and identity are personal choices, and that some people may prefer to use other terms including person first language (*young people with disability*). Identity-first language is used throughout this submission.

Ableism

The concept of ableism originates from the disability rights movement in the mid-1970s. In a similar way to how racism describes the oppression of marginalised races, and sexism describes the oppression of women, ableism describes the oppression of disabled people. Ableism is a system of beliefs that relies on social constructions of normality, privileging those who are able-bodied and minded and viewing disabled people as inferior.¹² Ableism can also be defined as “ideas, practices, institutions, and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalized ... and largely invisible ‘others’.”¹³

Intersectionality

Intersectionality is a tool to understand and examine the complexity of how systems of oppression intersect, and the impacts this has on categories such as ability, age, race, class, gender, and sexuality.¹⁴ These categories are interrelated and build on one another, multiplying experiences of disadvantage or privilege.¹⁵ Having multiple marginalised and intersecting identities such as ‘disabled’, ‘young’, and ‘queer’, means that an individual must navigate multiple forms of structural oppression and face more barriers than individuals without marginalised identities.¹⁶

Adultism

Adultism is a concept that is addressed in youth work and in the academic field of youth studies.¹⁷ Like ageism describes age-based discrimination against older people, adultism describes age-based discrimination against young people. Adultism can be defined as a belief system that views adults as inherently superior, while positioning young people as subordinate, and not deserving of the same rights, freedoms, and civic participation.¹⁸ Adultism is underpinned by a homogenous view of adults as sensible, cautious, with capacity to make good decisions, and young people as impulsive, risky, and biologically incapable of making considered decisions.¹⁹

Highlighting the intersection of youth and disability

This submission explores the unique, and often overlooked, experiences of disabled young people. Youth is a stage of life that is commonly associated with attaining milestones and building capacity.²⁰ These traditionally include transitioning from education to work, from dependence to independence, or changes in living arrangements which may include transitioning from residing with family or caregivers to living alone or with friends.²¹ However, many disabled young people are excluded from this normative construction of youth, and instead face a plethora of societal barriers that limit and/or delay independence and participation in society on the basis of their disability.²²

CRPD recognises that disabled young people have rights equal to their non-disabled peers.²³ Article 7 of the CRPD states:

- State Parties shall take all necessary measures to ensure the full enjoyment by children with disability of all human rights and fundamental freedoms on an equal basis with other children.
- In all actions concerning children with disability, the best interests of the child shall be a primary consideration.
- States Parties shall ensure that children with disability have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.²⁴

Despite this, disabled young people continue to face intersecting experiences of ableism and adultism.²⁵ Both forms of oppression subject disabled young people to paternalistic and disempowering policy and treatment that relies on assumed incapacity and deficiency.²⁶ Disadvantage is further compounded when a disabled young person has additional marginalised identities²⁷

Disabled young people therefore require a youth-specific approach to removing the barriers that disable and exclude those with impairments. To create effective youth-centred policy, young people must be actively involved in the policy-making process via meaningful consultation and shared decision-making to ensure their needs and interests are best represented.²⁸ This is supported by Article 4 of the CRPD which calls for the inclusion of disabled young people in the development of legislation and policy relating to them.²⁹

Overarching themes

Our consultations with disabled young people revealed recurring themes throughout each topic. These themes inform all ideas and topics discussed in the submission and guide the overarching recommendations.

Access

Barriers to access in day-to-day life was raised as a common experience amongst focus group participants. Participants agreed that access underpins all topics covered in this submission. Participants voiced concern about how a lack of accessibility measures could result in disabled young people being segregated from parts of society, limit their quality of life, and place them at risk of harm.

Participants suggested that accessibility should not be an afterthought and should be considered from the outset when planning and designing services, facilities, information, communication, and transportation.

“Good access is when something has been done with intent and right from the start.”

– Focus group participant

While physical accessibility is an important factor when discussing access, participants also highlighted that service providers need to develop a better understanding of the ways in which accessibility can be implemented for a greater range of disabilities. Participants considered how those with sensory needs, mental illness, chronic pain, learning difficulties and other ‘invisible’ disabilities are regularly unable to access services and public facilities.

“I think a lot of people think that accessibility stops at wheelchair access, when that’s not the case.” – Focus group participant

Disability awareness and inclusion training

Many of the focus group and survey respondents had interacted with professionals who lacked knowledge and understanding of disability and were unsure of how to appropriately support disabled young people. Experiences of this were raised in each topic. It was recommended that disability awareness and inclusion training was delivered by disabled young people themselves.

In the Education focus group, participants suggested that training needs to be delivered to educators to target assumptions and stigma about disability. It was also suggested that training would instruct educators on how to provide best practice support to meet disabled students’ educational needs.

In the NDIS focus group, participants suggested that all health professionals who prepare supporting documents for applications to access the NDIS should receive training to allow them to assist their clients with accessing the NDIS. One participant suggested that:

“We should be educating doctors on the (NDIS) process. I had a room full of doctors telling me I had to do this this and this. When I went home, I tried to do it, but I couldn’t.”

– Focus group participant

Some participants reported having negative experiences with NDIS workers who lacked empathy and understanding of their disabilities. To address this a participant suggested that:

“I’ve had some pretty bad experiences with NDIA staff. They should all get empathy training or something. They just don’t make any effort to understand me.” – Focus group participant

In the Justice focus group, participants highlighted a major gap in disability awareness and inclusive practice across the justice system. Sector-wide disability awareness training was suggested as a way to address this, with a specific focus on the police force.

In the Health and Medical Mistreatment focus group, participants reported frequent interactions with medical professionals who had misconceptions and discriminatory ideas about disability. The need for disability awareness training was suggested again. A survey respondent shared their experience of this, which resulted in diagnostic overshadowing:

“My experience of violence occurred in a health care setting. Because I had a history of ill mental health I was treated poorly regarding my physical chronic illnesses.”

– Survey respondent

In the Mental Health and Wellbeing focus group, participants suggested that mandatory, regular, and assessed, disability-focused training should be delivered to mental healthcare providers. Participants suggested that this would encourage providers to treat disabled young people with respect and dignity, enable providers to feel confident in supporting disabled young people with complex needs, and allow disabled young people to feel more comfortable in engaging with services.

Co-design

Focus group participants and Working Group members frequently suggested that to improve existing systems, facilities, and resources, disabled young people must be actively involved in the design process via co-design methods. Participants and the working group highlighted the value of including people with a lived experience of disability in the development and re-structuring of systems, policies, and programs that impact disabled young people. Co-design with disabled young people was suggested to help formulate disability awareness and inclusion training, to help guide accessibility standards across all sectors, to update inclusive education legislation, and to guide inclusive mental healthcare and healthcare policy.

Recommendations

- 1.1 Use co-design methods with disabled young people and ensure their voice and expertise are meaningfully included when developing policy responses or designing services that will have an impact on disabled young people. We recommend that these include measures to:
 - 1.1.1 Identify where accessibility can be improved and create best practice standards for disability access measures that all organisations, educational institutes, and public services must adhere to.
 - 1.1.2 Develop the content and format of disability awareness and inclusion training for all sectors and ensure the training is tailored to each sector's particular requirements.
 - 1.1.3 Update inclusive education legislation and policy including the development of a disability-specific anti-bullying program delivered across schools nationwide.
 - 1.1.4 Create a campaign informing the public about invisible disabilities on public transport and update priority seat signage to include invisible disabilities.
 - 1.1.5 Re-design the healthcare system to alleviate ingrained ableism and promote inclusive and responsive care for the unique needs of disabled young people.
- 1.2 Embed mandated accessibility measures across all education facilities, housing and construction industries, transport infrastructure, healthcare facilities, and mental healthcare settings in Australia and require reporting on compliance.
- 1.3 Provide disability awareness and inclusion training, delivered by disabled people, across all sectors with regular refresher training that includes updated best practice to ensure that:
 - 1.3.1 Teaching courses in TAFEs and universities nationwide are embedded with best practice on how to support disabled students.
 - 1.3.2 The national curriculum is embedded with a focus on preventing stigma and discrimination against disabled people.
 - 1.3.3 Workers who interact with disabled young people know how to best support disabled people. This includes those who work in healthcare, mental healthcare, education, justice and policing, employers, and transport workers.
 - 1.3.4 Employees and managers are informed on how to create inclusive and accessible environments for disabled young people, and value the capabilities and skills held by disabled young people.
- 1.4 Resource community-led independent advocacy organisations to support disabled young people to have their rights and needs upheld, particularly when they are accessing public services, the health system and education system.

Intersectional Experiences

The lower rates of participation in NDIS and underutilisation of other disability support services by First Nations peoples and culturally diverse communities is well documented.^{30, 31} Ensuring that disabled young people with intersecting identities can access culturally safe support services was a recurrent theme in the focus groups facilitated by YDAS. Focus group participants spoke about the difficulty in accessing services and cultural events when they had intersecting identities.

First Nations Peoples

The experiences of First Nations disabled young people were highlighted in submissions and briefing papers prepared by First Peoples Disability Network (FPDN)^{32, 33} and Victorian Aboriginal Child Care Agency (VACCA)³⁴ for the Disability Royal Commission.

YDAS strongly endorses the solutions and recommendations proposed by FPDN and VACCA and emphasises the importance of community-led solutions.

Culturally diverse young people

Focus group participants described the difficulty in accessing services that understood their experiences and which met their needs. They also spoke about gaps in services for second generation migrants.

The importance of having peer support and diverse workers in the workforce was emphasised by focus group participants.

“I want my supports to understand the complexities of me. To understand my experience.”

- Focus group participant

The experiences of culturally and linguistically diverse disabled people are comprehensively described in the submission made by Power in Culture and Ethnicity (PCE) Self Advocacy Group³⁵ and the joint submission made by National Ethnic Disability Alliance (NEDA), People with Disability Australia (PWDA) and Federation of Ethnic Communities Councils of Australia (FECCA)³⁶.

YDAS strongly endorses the solutions and recommendations proposed by PCE, NEDA, PWDA and FECCA.

Recommendations

- 2.1 Provide diversity training for disability services and organisations, delivered by disabled culturally diverse people.
- 2.2 Ensure culturally responsive practices are embedded into health, medical and disability services.
- 2.3 Increase the representation of culturally and linguistic diverse workers in disability services and organisations (including advocacy services, mental health services and education).
- 2.4 Ensure that registration schemes for disability support workers do not disadvantage culturally and linguistic diverse workers with benchmarks for fluency in English
- 2.5 Resource and support self-advocacy, peer support and leadership programs for culturally diverse disabled young people.
- 2.6 Amend the Migration Act to prevent discrimination against prospective migrants on the basis of their disability or a family member's disability



Education

Despite legislation, policy, and investment to create equitable access to education across Australia^{37,38}, focus group participants reported difficulties in accessing safe and inclusive education. Inclusive education provides disabled young people with opportunities comparable to those provided to their non-disabled peers to develop their talents, skills, and connections. This in turn creates opportunities for social and economic participation.³⁹

Education is a human right

Ten percent of Australian school students aged 5-18 are disabled.⁴⁰ Of these disabled students, 89% attend mainstream schools, and 12% attend specialist schools.⁴¹ Disabled young people make up 7.7% of university graduates in Australia, with a steady increase in enrolment over the past five years.⁴² As a signatory to the CRPD, Australia has an obligation to prevent exclusion from education based on disability.⁴³ The right to education is recognised in article 24 (1) of the CRPD.⁴⁴ Article 24 (2) of the CRPD, places obligations on States Parties to provide access to quality, free, primary education, and to offer reasonable supports within the mainstream education system with the goal of full inclusion.⁴⁵ To comply with this, the *Disability Discrimination Act 1992* (Cth) (DDA) and the federal *Disability Standards for Education 2005* (Cth) (the Standards) were introduced, requiring equal enrolment and participation for disabled students. Despite this, Children and Young People with Disability Australia (CYDA) found that 12.5% of disabled students were refused enrolment across both government and non-government schools in 2019.⁴⁶ The reason for exclusion provided by these schools was a lack of necessary supports and resources to accommodate disabled students.⁴⁷ Disabled people also continue to face barriers to accessing and participating in higher education, with only 18.4% of disabled people aged between 15-64 possessing a bachelor's degree or higher, compared to 32.8% of non-disabled people.⁴⁸ The Student Experience Survey (SES) from 2021 reveals that over the past three years, disabled university students have consistently reported lower levels of learner engagement, student support, skills development, and overall quality of experience compared to non-disabled students.⁴⁹

Nationally Consistent Collection of Data

Despite the recent introduction of the Nationally Consistent Collection of Data (NCCD), a gap between inclusive education policy and practice persists.⁵⁰ The NCCD was introduced to ensure that teachers and education providers across Australia report and monitor disabled students' educational adjustments for which funding is then allocated.⁵¹ The NCCD places responsibility on teachers to follow eligibility criteria to categorise disabled students' educational adjustment into one of four levels. Three of these levels include varied funding for reasonable adjustments:

supplementary; substantial and extensive adjustments. The fourth level, Quality Differentiated Teaching Practice (QDTP), acknowledges a student's disability but views them as being adequately supported by their teacher, therefore not requiring funding for support. This process can leave disabled students vulnerable to discrimination, exclusion, and neglect if education providers deem them ineligible for funding and reasonable adjustments to support their learning.⁵²

CYDA found that 48.9% of disabled students do not receive adequate support in their education, and 10% of students do not receive any support at all for their disability.⁵³ Consequently, the responsibility of providing disabled students with adequate and consistent support throughout their schooling continues to fall on students and their families.⁵⁴ CYDA found that 57.2% of families of disabled students had individually financed supports, equipment, specialist health workers, and support workers to create equal access to education for their child.⁵⁵ Where this was not possible, 40.5% of disabled students were excluded from school events such as excursions, sports, incursions, as well as academic activities such as NAPLAN testing.⁵⁶ The failure to successfully implement NCCD means that educators and education departments are not complying with the DDA and the Standards to ensure that *all* disabled Australian students have access to inclusive education.

As a result, disabled students are increasingly relying on segregated education settings to receive appropriate support.^{57, 58} Other factors that have contributed to this increase include persistent societal stigma and oppression that results in bullying,⁵⁹ and a lack of support and training for educators to deliver inclusive education.⁶⁰ To rectify these issues, changes need to be made to improve current legislation and ensure that it is implemented uniformly across Australia.⁶¹

Bullying and discrimination within education settings

Disabled young people across Australia face higher rates of school-based bullying compared to their non-disabled peers.⁶² Forty-three percent of disabled young people experienced bullying in 2019, compared to only 19% of those without a disability.⁶³ Almost half (46%) of this bullying was from other students, and 9.1% was from teachers and other school staff.⁶⁴ As most disabled young people participate in mainstream schooling,⁶⁵ many are confronted with negative beliefs and stereotypes about disability from peers who do not share experiences of disability.⁶⁶ This ableism is made more complex when a young person faces intersecting experiences of discrimination such as racism, classism, homophobia, and transphobia.⁶⁷

Disabled young people's experiences in education settings and their suggestions for improvement.

A lack of accessible and inclusive education

All focus group participants were undertaking secondary or tertiary education. Participants described not being able to always access to safe and inclusive education. Denial of necessary supports and reasonable adjustments by educators was a common experience amongst participants. Some participants and working group members had experiences of their reasonable adjustments being denied or ignored:

“My teachers didn’t give me extra support because they thought I didn’t need it. They didn’t realise that I required special support” – Focus group participant

“I started a youth work degree but had to drop out because the program was not accessible to me. They wouldn’t implement any adjustments or flexibility so I couldn’t continue. We need to make courses more accessible.” – Working group member

“At school there was someone who needed a ramp – the school said they’d put one in, but they didn’t.” – Focus group participant

In many cases participants were made to feel ‘difficult’ or ‘demanding’ when requesting supports or adjustments for their disabilities. Some participants had experienced teachers who would only consult with their parent or guardian. Many participants who did not receive adjustments were excluded from opportunities and lessons and felt that this disrupted their social and educational development. Some participants had no option but to change schools or attend a specialist school.

Inconsistency between education providers

A few participants spoke about their experiences of transitioning from a supportive primary school to a secondary school that did not replicate the same level of inclusion. This caused school to become a source of stress and anxiety for these participants. In addition to shifting levels of support, participants also experienced a shift in attitude towards disability. This included victimisation and bullying from their peers and teachers. One participant described their experience:

“I was in mainstream school nearly my whole life. Then year 7 happened and I got bullied.”
– Focus group participant

Abuse and victimisation within education settings

All focus group participants had encountered *at least* one teacher or pupil who had directly or indirectly bullied or humiliated them while at school. These experiences occurred in mainstream public and private schools, and specialist schools. Many participants reported that this harassment and bullying caused them to feel fearful whilst at school, negatively impacting their overall attitude towards school. This was made particularly distressing when the bullying was inflicted by teachers. A participant described their experience of this:

“Because I have low levels of executive function, I have had teachers routinely humiliate and yell at me for struggling to keep things organised or for not paying attention.”

- Focus group participant

Another participant described how humiliation by from their teacher about their disability led to a cycle that caused their meltdowns to increase in frequency:

“She berated me for having autism and experiencing meltdowns in her class”.

- Focus group participant

The need for disability-specific anti-bullying policies in schools

Some participants suggested that instances of bullying and humiliation continue to occur as some schools have a culture where disabilities are viewed as ‘inconvenient’ and requests by disabled students are ‘unreasonable’. These participants discussed how some education facilities have anti-bullying policies in place however they tend to be ineffective and ‘surface-level’.

YDAS case study

Timothy's story

Timothy* studies medicine at one of Australia's top five universities. During his degree, Timothy sent several emails to his clinical coordinator and senior staff members at his medical school requesting reasonable adjustments to accommodate his disabilities. Timothy also met with the Disability Liaison Unit (**DLU**) at his university who recommended that Timothy should be allowed flexibility in his attendance.

The medical school failed to respond to Timothy's requests and invited him to a disciplinary meeting for failing to meet attendance requirements. During his disciplinary meeting it was explained that the reason for why Timothy was missing classes was because the university had not made reasonable adjustments to accommodate his disabilities. Senior staff at the medical school refused responsibility to provide reasonable adjustments for disabled students and stated that it was up to students to make their own adjustments. University staff also made several derogatory comments relating to Timothy's disabilities. This resulted in Timothy experiencing an anxiety attack. Timothy said that the behaviour shown by university staff made him feel "defeated, disrespected, and made him lose hope in his ability to complete his studies". Timothy decided to defer his medical course due to becoming unwell.

A complaint was lodged with the Dean of the medical school who apologised to Timothy, agreed to change the university's policies, and encouraged him to re-engage when he felt ready. When Timothy recovered, a meeting was scheduled to discuss necessary adjustments to support him with his studies. After Timothy had expressed his requirements at this meeting, a senior staff member of the medical school said, 'I don't know why we are having this meeting and why we have to bend over backwards for you.' This prompted an anxiety attack and Timothy ended the meeting early.

After this another complaint was lodged with the Dean of the medical school. The Dean agreed to be present in all meetings with university staff and apologised again on behalf of the university. Timothy is currently unsure as to whether he will continue with his university studies due to the refusal of staff to make reasonable adjustments for his disabilities.

*Timothy's name has been changed to protect his privacy

Recommendations

- 3.1 Prioritise and support the active involvement of disabled students in the development of their individual learning plans and consult students about adjustments and supports they require.
- 3.2 Mandate the inclusion of disability liaison officers across all education settings, with a focus on hiring those with lived experience of disability.

Transport

A safe, accessible, and affordable public transport system is essential for empowering disabled young people to lead lives of agency, dignity, and freedom.^{68,69} Young people are more likely to rely on public transport than other groups,⁷⁰ however the existing transport network is not always safe or accessible for disabled young people.⁷¹ Focus group participants reported facing barriers to transport due to inaccessible infrastructure and exclusionary policies.

The current transport landscape for disabled young people

Many young people across Australia rely on public transport to access work and education, participate in social interaction and civic life, and reach essential services such as healthcare.⁷² In Melbourne, 80% of young people aged 17-25 use public transport at least once a week.⁷³ Public transport provides young people with important opportunities to develop independence and identities away from parents and caregivers.⁷⁴ However, due to a lack of accessible public transport, many disabled young people rely on family members or carers to drive them to where they need to go.⁷⁵ This reliance on family and carers can limit disabled young people's opportunities to socialise, push boundaries, and develop independence.⁷⁶

The *Disability Standards for Accessible Public Transport 2002 (DSAPT)*, were created to ensure that public transport providers, employees, and the surrounding infrastructure, comply with minimum accessibility requirements for disabled people.⁷⁷ DSAPT is informed by the DDA and aims to provide disabled people with equivalent access to public transport.⁷⁸ Equivalent access is defined within DSAPT as an 'equivalent standard of amenity, availability, comfort, convenience, dignity, price, and safety'.⁷⁹ Despite this, AHRC found that 1 in 6 (16%) of disabled people across Australia had difficulty using public transport, and a further 11% were unable to use public transport at all.⁸⁰

Barriers to transport in Victoria

For many disabled young Victorians public transport raises complex risks and challenges.⁸¹ Disabled young people in Victoria are frequently confronted with inconsistencies in accessible infrastructure, unreliable information about accessibility, and the risk of abuse and discrimination from other passengers and transport employees.⁸² The transport campaign delivered by Disability Resources Centre in 2021 highlighted that only 15% of Melbourne's tram network is accessible, despite targets for full accessibility by 2022.⁸³ At this current rate, it is projected that Melbourne's tram system will not be fully accessible until 2066.⁸⁴

As a result, many disabled people with mobility aids report being forced to wait for an accessible vehicle while other passengers board freely, or depend on expensive taxis or unregulated Uber Assist to substitute inaccessible public transport.⁸⁵ Neurodiverse young people can experience difficulties with overcrowding and the subsequent sensory burden, anxiety around transport information, the potential for negative social interactions, and fear of harassment from other passengers.⁸⁶ This can lead to exhaustion and subsequent avoidance of public transport amongst neurodiverse young people.⁸⁷

Harassment and abuse on public transport

Discrimination on public transport can include staring, infantilising, providing unwanted or inappropriate assistance, distancing, verbal abuse, harassment, and physical violence.⁸⁸ Disability Resources Centre found that 61% of disabled people reported feeling unsafe or vulnerable when using public transport, and 44% of respondents had experienced verbal abuse, physical violence, or intimidating behaviour.⁸⁹ Interpersonal discrimination on public transport has been shown to impact young people's confidence and willingness in using public transport.⁹⁰ This avoidance of public transport reduces opportunities for social and economic participation and can negatively impact disabled young people's existing social, working and/or educational lives.⁹¹

Invisible disability and public transport

Disabled young people with invisible disabilities face unique challenges when travelling on public transport.⁹² Disability Resources Centre found that a lack of clearly labelled priority seating for invisible disabilities resulted in people with invisible disabilities experiencing judgement, verbal abuse, and refusal from other passengers to vacate priority seats.⁹³ Disability Resources Centre suggested this was due to limited public awareness as well as intentional discrimination from other passengers and public transport staff.⁹⁴ As a result, Disability Resources Centre found that many people with invisible disabilities avoided public transport during peak hour services, impacting engagement with employment and education.⁹⁵



Disabled young people's experiences with transport in Victoria and their suggestions for improvement

A lack of accessible public transport

Many focus group participants had experienced a lack of accessibility while travelling on public transport. These participants suggested a need for infrastructural change to ensure that disabled young people are comfortable and safe on public transport.

“They should build more trains with more space for people with disability.”

- Focus group participant

“There are a lot of routes that don’t have low floor trams. Those trams with stairs need to be phased out” – Focus group participant

Some participants had experienced being left behind at bus stops and train stations because drivers would not use the ramp. One participant described the inconvenient methods of accessibility that are currently used:

“Even newer trams, you need to flag them down, and the driver needs to pull out the thing, it becomes a debacle, and it makes everything take longer. Surely there’s a way they could have it built in, instead of something that takes so much time and effort.”

- Focus group participant

Some participants expressed concern at having to disclose their disability to receive necessary supports on public transport and felt exposed to ridicule and harassment from the public. In addition to this, many participants reported that they were frequently made to feel like an inconvenience when having to ask for accessibility supports on public transport. A participant shared their experience of this:

‘It’s hard to constantly be asking for help [when using public transport], it’s very tiring to always have to ask to be able to use access needs.’ - Focus group participant

People with invisible disabilities are not supported on public transport

Focus group participants highlighted that disabled young people with invisible disabilities are not adequately supported by current accessibility measures on public transport. Participants discussed how priority seating signage appears to be only for those with a physical disability and does not currently mention invisible disabilities.

The participants who had lived experience of invisible disabilities expressed feeling as if they were not able to access priority seating and that they were ‘afraid to ask’ for a seat. This was due to past

experiences of abuse and harassment from other passengers who had questioned the extent of their disability.

“I’m always a bit nervous about catching public transport because I’m never sure how other people will act towards me.” – Focus group participant

Participants concluded that disabled young people should not need to explain or ‘justify’ their use of accessible seating. To solve this, participants suggested that the current disability signage should be modified to communicate to the public that people with invisible disabilities are entitled to use accessible seating.

“I don’t think people realise that priority seating is used by a whole range of people. I’m still getting yelled at on trams. I’d love to see something like a safety campaign, like a short ad saying, ‘not all disabilities are visible’. Some trams have a picture of an elderly person, a picture of a person using a wheelchair, and a picture of a pregnant person near the priority seating. I want to see pictures of people that don’t have a visible disability and a sticker that says: ‘Not all disabilities are visible’. If someone gives me a dirty look or starts yelling at me for sitting in a priority seat, I should just be able to point at the sticker and they’ll understand.” – Focus group participant

Public transport information must be accessible

Focus group participants suggested that before any upgrades or improvements are made to Victoria’s public transport system, information about existing services must be made more accessible. A participant expressed the value of public transport having accurate information about times and routes:

“Taking public transport is a lot easier than driving because you don’t have to think about it all the time. If you’ve been on the service before and you’re getting really good information about times, routes, whatever, it’s fantastic”. – Focus group participant

Many participants expressed that a lack of accurate information about public transport services can increase feelings of uncertainty and anxiety about whether the vehicle, infrastructure, and environment will be accessible, where they are headed, and when they can expect to arrive.

YDAS case study

Alex's story

Alex* is a young person with multiple disabilities, including invisible disabilities. Alex usually uses public transport to access the community. Due to the impact of their disabilities, Alex often relies on priority seats on trams and trains to provide them with support and ease of access.

Alex has experienced frequent judgement and hostility from other passengers while sitting in priority seats. This was particularly noticeable when trains and trams were crowded during peak hour times. This hostility ranged from glares to verbal and physical abuse. Alex explained this as resulting from being viewed by other passengers as “not disabled enough to need the priority seat.”

Alex ended up requiring a cane as a mobility aid to support their disability. Alex reported that this helped with the level of abuse they faced while on public transport. Despite this, Alex still experiences harassment while travelling. A recent incident resulted in Alex being hit by an older person who did not notice their cane and wanted them to stand up so that they could sit down.

Having disabilities that fellow passengers could not visually identify, and having aids that make their disabilities more visible, both resulted in Alex facing harassment on public transport.

To address this, Alex suggested that a campaign that raises awareness of invisible disabilities should be run by Public Transport Victoria, and other public transport companies across Australia. Alex added that this could include adding invisible disabilities to priority seat stickers, as these stickers currently only display people with visible disabilities. Alex felt that this would help them feel justified and comfortable in using priority seats.

*Alex's name has been changed to protect their privacy

Recommendations

- 4.1 Increase the number of accessible seats, especially in new vehicle models that prioritise standing room.
- 4.2 Empower regulatory bodies to fine or sanction public transport providers for failing to provide accessible services.
- 4.3 Include large print visual information, audio announcements, and digital display boards at all stops and in all vehicles, to support a range of access needs.

NDIS

The National Disability Insurance Scheme (**NDIS**) plays a vital role in the lives of many disabled young people.⁹⁶ The NDIS aims to assist young people in accessing supports so that they have the resources to be able to participate fully in society and reach their goals.⁹⁷ However, some focus group participants reported difficulties in getting their plans approved, and faced extensive wait times, placing them at risk of neglect and harm.

Young people and the NDIS

As of June 2021, the National Disability Insurance Scheme (NDIS) reported that 74,213 young disabled people from ages 15-24 had approved NDIS plans, making up about 16% of participants nation-wide.⁹⁸ The most common disability amongst this age group is autism, followed by intellectual and psychosocial disabilities.⁹⁹ The majority of disabled young people aged 15 to 24 receive plan management from the NDIS or independent plan management agencies.¹⁰⁰ However, the NDIS identified in 2021 that there is a continuing trend for young participants to self-manage their own plans.¹⁰¹

The goal of the NDIS is to provide disabled people with choice and control over their lives, and access funding for supports that best suit them.¹⁰² This promise of choice and control is inclusive of children and young people.¹⁰³ The NDIS Act encompasses the obligations Australia has according to the Convention on the Rights of the Child (CRC), which recognises a young person's ability to make decisions on issues that impact them.¹⁰⁴ This is recognised in the NDIS (Children) Rules which stipulates that young people are consulted about, and are included in decision-making about their NDIS plan. The NDIS (Children) Rules also notes that the CEO can determine whether a young person is able to represent themselves.¹⁰⁵ Despite this provision, disabled young people under the age of 18 are automatically appointed a representative.¹⁰⁶ This is in most cases a parent, who then has control over all decisions relevant to the NDIS.¹⁰⁷ This undermines the integration of the CRC into the NDIS (Children) Rules and the NDIS Act, as there is limited scope for disabled young people under the age of 18 to make decisions about their NDIS plan and NDIS funded supports.¹⁰⁸

Barriers to accessing the NDIS

Disabled young people face unique challenges when trying to access the NDIS compared to adult participants.¹⁰⁹ One of these challenges is the reduced likelihood of accessing NDIS funding due to not receiving a diagnosis of permanent impairment.¹¹⁰ This is especially prevalent for disabled young people with psychosocial disabilities caused by mental illness.¹¹¹ Many medical

professionals view mental illness during the life stage of youth as temporary and likely to improve, which lessens the chances of them being deemed eligible for NDIS funding.¹¹² This group of young people also commonly don't view themselves as disabled which also impacts the likelihood of receiving NDIS support.¹¹³

Another barrier faced by young people are the significant wait times for being approved entry to the NDIS.¹¹⁴ The Federal Government's 2019 review of the *NDIS Act 2013* revealed that participants waited an average of 88 days to have their funding plans approved.¹¹⁵ However, CYDA found that 17.1% of disabled young people and their families reported waiting more than 12 months to enter the NDIS.¹¹⁶ A delay in necessary supports disrupts the positive impacts that early intervention can have for many disabled young people during this period in their lives.¹¹⁷ This includes support for their physical, mental, and emotional wellbeing and development, and economic and educational inclusion.¹¹⁸

CYDA found that 50% of disabled young people and families or caregivers of disabled young people had experienced barriers to accessing the NDIS.¹¹⁹ These barriers included difficulty understanding the information provided by the NDIS, and a lack of support during the planning stage.¹²⁰ CYDA found that families of disabled young people are burdened with the responsibility to provide diagnostic evidence in order to access the NDIS.¹²¹ Previous diagnostic evidence is not accepted by the NDIS, which places significant financial strain on families and young people to redo costly assessments.¹²² CYDA also highlighted that many disabled young people have comorbid diagnoses, including mental illness, and suggested that the NDIS should provide funding for all their needs.¹²³

Disabled young people's experiences with the NDIS and their suggestions for improvement

Wait times and limits on eligibility

Only a small proportion of the focus group participants had access to the NDIS. Others were waiting for their plans to be approved or were preparing an application. Those who had approved plans under the NDIS emphasised how the funding had improved their lives by allowing them to access supports. Those who were still waiting for their application to be finalised or had been deemed ineligible, questioned the limited eligibility criteria of the NDIS.

I'm not able to get on the NDIS because my condition is deemed as one that can be fixed; however, I can't have the operations due to my other medical condition."

- Focus group participant

Participants expressed frustration at the current wait times to access the NDIS. A few participants reported waiting years to access the scheme, facing additional wait times due to rejections and reviews of their application in the process.

"I just got on the NDIS. I was waiting for nearly 6 years."

- Focus group participant

"They are so slow to get back to you."

- Focus group participant

Lack of NDIS knowledge amongst GPs

Many participants reported relying on their GPs to sign their access forms to begin their NDIS application. Participants found that the current lack of knowledge held by GPs creates a barrier for young people. In some circumstances participants reported being turned away from GPs and told to return when they could explain the NDIS process to their GP. Some participants reported finding this exhausting as it placed pressure on them to have a detailed understanding of the NDIS.

"We should be educating doctors on the (NDIS) process. I had a room full of doctors telling me I had to do this this and this. When I went home, I tried to do it, but I couldn't."

- Focus group participant

Ineffective communication between the NDIS and disabled young people

Focus group participants identified significant communication issues in the NDIS. Many participants had trouble receiving information in accessible formats about their plans and

funding. Other communication issues that were identified by participants were the use of bureaucratic language; gaps in publicly accessible information for common issues; and a lack of communication with young people on issues that directly impact them as a cohort.

“Sometimes I can’t get the information I need to organise my plan.”

- Focus group participant

It was suggested by participants that the lack of accessible and relevant information places disabled young people in a vulnerable position where they are dependent on guardians, parents, or NDIS workers to convey important information to them. Participants described this as creating a power imbalance for disabled young people.

Meaningful control over plan

A few of the focus group participants reported feeling empowered by managing their own plan. These participants expressed that as disabled young people, having opportunities for independence and responsibility such as this is rare and valuable. Being in control of their plans allowed these participants to receive the most relevant supports, enabled them to pursue their own goals, and created a sense of ownership over their lives.

Although some participants had positive experiences, others had challenges in self-managing their plans. These participants described the NDIS planning process as ‘difficult and inaccessible’ which resulted in them relinquishing control of their plans to parents or guardians, private companies, or the NDIS. Some participants felt excluded when their parents controlled the relationship with the NDIS.

“Disabled young people should be able to make their own decisions. Make it mandatory for disabled minors especially to be asked about their preference for NDIS funding, surgeries, mobility aids or schools. Just because we are disabled does not mean our parents/guardians/carers can make decisions based on their opinion. Disabled people are too often taken advantage of by their guardians to suit them. disabled people want choice. individual choice.”

- Focus group participant

Participants suggested that the NDIS should include training for young people on how to manage their own plans. Participants said that this would increase their agency and self-determination, help build capacity, and protect them from violence, abuse, neglect, and exploitation.

Negative experiences with NDIS workers

Some participants reported having negative experiences with NDIS workers who lacked empathy and understanding of their disabilities. These participants described having to ‘self-advocate’ to

their planners to be respected and listened to and have their plan objectives implemented. It was also reported by some participants that their NDIS planners took minimal notes during meetings and that frequent changes in plan managers meant that participants had to repeatedly re-tell their medical history. A participant shared that this made them feel as if they are “just a number in the system” and not an individual with unique needs and goals.



YDAS case study

Kai's story

Kai* is a young person who has epilepsy in addition to two other disabilities. Kai's additional disabilities impacts his ability to notice early warning signs of a seizure and communicate these signs to others. His family currently provides him with 24/7 support to ensure his safety during a seizure. Kai's medical team have expressed their concern that Kai is at a high risk of fatality if he does not receive adequate support.

Kai currently receives NDIS funding for his two other disabilities, but his epilepsy has not yet been included in his plan. Kai requested additional funding for supports related to his epilepsy so he could access support workers, fund capacity building for the support workers, and a seizure alert mat. These supports are essential due to the impact his two other disabilities have on how he manages his epilepsy. The NDIS rejected this request on the basis that these supports were unrelated to the two disabilities that are currently listed in his NDIS plan. Kai has applied to the NDIS to include his epilepsy twice, but he was rejected both times on the basis that his functional impairments are only related to his other disabilities.

Kai's family submitted an internal review with the NDIS to dispute this decision. After 3 months of waiting, Kai's support requests were denied again. With each rejection, the NDIS instructed Kai to lodge an application through the NDIS for his epilepsy diagnoses, all of which were unsuccessful.

Kai has now been waiting for his case to be heard by the Administrative Appeals Tribunal for several months, with further wait-times anticipated. During this time, Kai has run out of core funding in his current plan and is yet to receive an outcome regarding the requested funding. This meant Kai's family had to pay for necessary supports using their own finances. This, coupled with Kai's high risk of fatality, has placed Kai and his family under significant stress.

Kai has been unable to engage in community activities, develop independent living skills, or work towards his goals. He is left at high risk as long wait times and bureaucratic processes means Kai is unable to access lifesaving supports.

*Kai's name has been changed to protect his privacy

Recommendations

- 5.1 Establish a nationally consistent legal framework to eliminate all forms of restrictive practice and amend the timeline for mandatory reporting of the unauthorised use of restrictive practice to 24 hours.
- 5.2 Improve communication with young people about the NDIS, the processes to access support, the intention of the scheme, and what to expect when accessing the NDIS.
- 5.3 Provide support and training for disabled young people aged 15-25 to self-manage their plans.
- 5.4 Review and expand eligibility for young people with mental health conditions.
- 5.5 Increase resourcing to the NDIS to reduce the wait time for applications.
- 5.6 Introduce mandatory time limits for NDIS to respond to young people and ensure that they are not left in unsafe situations.
- 5.7 Set higher targets to hire disabled staff across all levels of the NDIS and Partners in the community (PITC) providers, especially in client-facing and decision-making roles.
- 5.8 Improve collaboration between the NDIS, medical professionals, youth workers, social workers, teachers, psychologists, specialists, and service providers.

Justice and Policing

Australia's justice and policing mechanisms are vital to ensuring communities remain just, safe, and fair. However, focus group participants expressed frustration at the lack of understanding of disability held by those who work in the justice system. Focus group participants viewed the justice system as a source of abuse, violence, neglect, and exploitation against disabled young people.

Disabled young people face criminalisation

Despite efforts by state and federal governments to improve support for disabled young people in youth justice settings, the overrepresentation of disabled young people within the justice system persists.¹²⁴ Several studies have found a high prevalence of cognitive disability and neurodivergence amongst young people in contact with juvenile justice system in Australia.¹²⁵ In 2016, NSW Health and NSW Juvenile Justice found that 83% of young people in custody in NSW displayed symptoms consistent with a psychosocial disability.¹²⁶ This was higher (87%) amongst First Nations young people.¹²⁷ It was also found that 18% of young people in custody had an intellectual disability, and 39-42% had a borderline intellectual disability.¹²⁸ Young people in youth justice settings also have high rates of head injury and acquired brain injury; language and speech impairments; and foetal alcohol spectrum disorder (FASD).¹²⁹

Due to poverty, ableism, and structural exclusion, young people with intellectual and cognitive disabilities are significantly more likely to be victims of family violence; face trauma and abuse; have poor education attendance and outcomes; experience homelessness; and have problematic drug and alcohol use.¹³⁰ These intersecting and complex experiences of disadvantage exacerbates existing emotional, cognitive, and behavioural difficulties faced by disabled young people, resulting in further vulnerability to prolonged contact with the juvenile justice system.¹³¹

Contact with the police

Many disabled young people have intersecting, stigmatised identities that place them in marginal positions in their communities.¹³² This social exclusion, along with behaviour associated with their disability, can draw unwarranted attention from the police.¹³³ When a disabled young person encounters police, communication difficulties can cause complications, which can potentially intensify the severity of their treatment and legal outcomes.¹³⁴ Some disabled young people, especially those who are neurodiverse or who have intellectual disability, may have difficulty understanding legal situations they find themselves in, have insufficient knowledge of their rights, and fail to accurately recall or re-tell events.¹³⁵ Disabled young people are also more likely to relinquish control to the police by being overly compliant to police demands and confessing to

crimes they did not commit.¹³⁶ This places disabled young people in positions where they are vulnerable to exploitation, abuse, and human rights violations if police are not properly trained to support those with disability.¹³⁷

Most jurisdictions in Australia legally require police to provide disabled people with reasonable adjustments to ensure their disabilities are accommodated.¹³⁸ Some examples of this include providing disabled young people with a support person and altering communication styles or methods to best suit the individual.¹³⁹ In 2018, DFFH updated its guidelines to align with this, outlining several general considerations that police should take when interviewing a disabled person.¹⁴⁰ Despite these changes, many police continue to mistreat and criminalise disabled young people.¹⁴¹

A key contributor to this is a lack of training in recognising and interacting with disabled young people, as well as a disregard for best-practice guidelines such as those released by DFFH.¹⁴² However, some research suggests that a culture of entrenched ableism within the police force is responsible.¹⁴³ This culture consists of a conscious disregard towards the presence of disability and instead positions disabled young people's behaviour as deviant and dangerous.^{144,145} This results in the dehumanisation of disabled young people who are subsequently viewed by police as a threat to the community and are therefore deserving of punishment and confinement.¹⁴⁶ This is especially pervasive for disabled First Nations young people who face even higher levels of surveillance, racialisation, and persecution.¹⁴⁷

Disabled young people's experiences with the Victorian justice system and their suggestions for improvement

Disabled young people's human rights are frequently violated

Focus group participants suggested that change is needed within policing and justice practices to uphold the rights of all people before the law. Participants expressed that their rights should be protected, valued, and respected in the same way that non-disabled members of society are. Participants suggested that the current system fails disabled people because it was not designed with disabled people in mind. Participants identified many examples of human rights abuses within the justice system. Some of these included:

- Laws and policies that deny legal capacity
- Unauthorised restrictive practices
- The use of prisons for the management of disabled people who were not convicted or sentenced.

Participants stressed that these rights violations should be addressed urgently to ensure that the justice system provides equitable treatment to disabled young people.

Justice officials lack awareness of disability, including mental illness.

Some participants suggested that a lack of awareness and understanding of disability and mental illness underpins flaws across the justice system. Participants felt that this lack of awareness has led to the stigmatisation of disabled people, resulting in over-policing and violence when disabled young people are apprehended by police.

“I would say people [with] disability get arrested for their behaviour, not [their] crime.”

– Focus group participant

One participant felt that the police hold a bias against disabled people, viewing them as inherently criminal:

“We don’t get a presumption of innocence, we are criminalised.”

– Focus group participant

As a direct result, many participants described that they felt unsafe when interacting with police, and preferred indirect reporting methods such as via phone or by emailing Crime Stoppers.

“I still wouldn’t go to them [the police] because they are likely to see me as inherently untrustworthy – just because I’m disabled.”

– Focus group participant

“I’ve been in contact with police many times. It has been awful, not good at all.”

- Focus group participant

When some participants did report a crime, they described not being taken seriously by police officers. One participant shared that they had been a victim of crime and contacted the police for assistance. They felt that the police viewed them as untrustworthy and questioned their intentions for reporting, rather than providing them with assistance.

“[The police] are more likely to turn around and go for me.”

- Focus group participant

Restrictive practices – the use of chemical restraints

Participants expressed concern about the use of seclusion and restraint on disabled young people who come into contact with the criminal justice system. They were particularly concerned that police have the power to impose a chemical constraint on a disabled young person without their consent. Participants asserted that they did not consider the use of chemical restraint appropriate under any circumstance. One participant shared their experience of witnessing police using chemical restraints on a disabled young person:

“I saw police sedate a person with intellectual disability and they just didn’t know what to do with them” – Working group participant

Participants suggested that the use of chemical restraints demonstrates that police do not know how to interact with disabled people who may be exhibiting behaviours of concern. Participants noted that the use of chemical restraint against one’s will is a violation of human rights. Participants agreed that the use of chemical restraints should only ever be administered by a qualified medical doctor.

Funding for legal support services

Many participants voiced appreciation for services like Victoria Legal Aid Villamanta and Disability Discrimination Legal Service. These participants agreed that these services are crucial in providing legal support to disabled young people, and are integral in identifying and preventing violence, neglect, and abuse within the justice system.

Participants stressed the need to increase funding to free legal services so that organisations could promote their resources more widely in more accessible formats for those with disability. They acknowledged that these services are under high demand for legal representation in Australia, placing free legal services under considerable strain.

“Legal aid has a massive missing middle.”

– Focus group participant

“There is an inherent privilege to being able to navigate and access legal services, even free legal services.”

– Working group participant

Participants suggested some ways that additional funding would remove strain on legal advocacy services. These included:

- Providing free legal hotlines that are tailored to disabled people.
- Increasing access and availability of resources that inform disabled young people of their rights and what to do when those rights are violated.

A suggested solution: transformative justice

Focus group participants suggested that the overrepresentation of disabled people within the criminal justice system can be addressed by exploring transformative justice solutions, such as the decriminalisation of petty crime.

“I think a lot of the problems we’ve come across is because of police and prisons expanding. So, we need to look at stuff around decriminalisation. We need to decriminalise drug use, providing mental health support, decriminalising sex work, (crime) reporting that moves away from cops, and limiting police powers.”

– Focus group participant

A participant suggested providing alternatives to police involvement when disabled young people are involved. Another participant proposed that police can play an effective role in keeping communities safe, but only if they receive proper training, treat all members of the community with dignity and respect, and do not exceed their authorised power.

Another transformative solution suggested by participants was resourcing preventative or protective supports in the community. Participants suggested funding youth services to run social activities for disabled young people. Participants highlighted the value of positive social connection and hoped that providing community support for disabled young people would help prevent criminalisation.

YDAS case study

Christian's story

Christian* is a young person with several disabilities. Police arrested Christian and transported him to a police station. A family member contacted the police to explain that Christian required a support person as a reasonable adjustment. He explained that Christian's disabilities cause Christian to feel confused and stressed, which could compromise Christian's right to a fair interview.

Police allowed this family member to be his support person via telephone call. However, police did not allow Christian privacy as the telephone call was put on speaker. Police advised Christian's family member that "he (Christian) is an adult", and that he has to "deal with the consequences of his actions". A second family member contacted police and reiterated the importance of Christian having a support person present during interactions with police officers. The second family member also informed police officers that Christian's disabilities meant he had limited capacity.

After the police interview, Christian told his family that he felt stressed, frightened, and anxious. Christian was also upset at his inability to recall everything that had happened at the police station due to being in a disassociated state.

Christian was provided with paperwork by police at a later date. Police advised Christian that he had failed to show up to a court date. Christian was not aware that he had to be at court, as police did not adequately explain the paperwork when it was initially served. Police handed Christian another copy of this paperwork. Again, police did not explain the contents of this or supply any reasonable adjustments to accommodate Christian's disability. This conduct by police occurred again, with repeated failure to provide reasonable adjustments.

Police have agreed to drop the charges against Christian; however, Christian has not recovered from these incidents and his mental health has declined

*Christian's name has been changed to protect his privacy

Recommendations

- 6.1 Explore the use of transformative justice instead of sentencing for disabled young people, particularly for low level offences and petty crime.
- 6.2 Mandate the nationwide provision of necessary supports for disabled young people while in police custody, including mental health support.
- 6.3 Increase funding for legal aid services that support disabled young people and improve communication on how to access these services.
- 6.4 Prohibit inhumane practices against disabled young people such as seclusion, physical and chemical restraint, and indefinite detention, and implement accountability mechanisms for when this occurs.

Employment and economic security

Employment can serve as a protective factor against social exclusion and poverty for disabled young people.¹⁴⁸ However, a lack of safe, meaningful, and appropriate options often leaves disabled young people vulnerable to unemployment and marginalisation.^{149, 150} Focus group participants emphasised that safe and inclusive job opportunities will provide disabled young people with independence and freedom to lead the lives they want.

The current employment landscape for disabled young people

Young people have to navigate complex challenges related to employment such as the normalisation of the gig-economy, short-term contracts, unpaid internships, lower wages, pressure to acquire higher levels of qualification than in the past, and job scarcity.^{151, 152} This produces a precarious economic landscape for young people that delays independence and stability.¹⁵³ These issues are compounded when a young person has disability.¹⁵⁴ Disabled young people in Australia are nearly three times as likely to be unemployed as their non-disabled peers.¹⁵⁵ Disabled young people also face underemployment with 23% wanting to work more hours.¹⁵⁶ Equal participation in the workforce is paramount to social inclusion and self-worth.¹⁵⁷ It is also a primary determinant of a person's success in securing and maintaining employment in the future.¹⁵⁸

Some of the key barriers that prevent disabled young people from entering or remaining in the workforce include: misconceptions around the capacity of disabled people¹⁵⁹; discrimination and bullying from employers and other employees; and a lack of employer knowledge and training about how to accommodate disabilities.^{160, 161} In addition to this, a lack of support for school to work transitions and a shortage of disability-specific career guidance workers^{162, 163} has resulted in 18% of disabled young people not entering the work force within the first seven years of finishing secondary school compared to 5% of non-disabled young people.¹⁶⁴

The recent Disability Support Pension (DSP) rate increase is insufficient

Disabled people who are unable to work or face barriers to stable employment because of their disability should be provided with adequate financial support from the Australian Government. The recent rate increase of the DSP is the largest in thirty years, however, the payment remains inadequate in offsetting additional costs faced by disabled people. The increase of \$38.9 per fortnight for singles receiving the DSP has been met with concern from social service advocates such as Australian Council of Social Service (ACOSS).¹⁶⁵ ACOSS maintains that an increase of at least \$100 per fortnight is necessary to lift recipients out of poverty and provide them with the same standard of living as those receiving other pension payments.¹⁶⁶

Disabled young people's experiences of employment and economic security and their suggestions for improvement

Discrimination and exploitation in the workplace

Some participants highlighted organisational cultures within workplaces that minimises disability discrimination. A few participants suggested that disabled young people may feel as if they need to tolerate exploitation or abuse at work due to facing difficulties in finding secure employment. Many participants disclosed that they were unclear about the rights of disabled young people in the workplace. Some agreed that employers use disabled people as cheap labour. A survey respondent shared their experience of this:

“I am desperate for work. No place is giving me a chance, so I work 12 hours for \$120”

– Survey respondent

Participants suggested that education on workplace rights should be offered to disabled young people to address power imbalances between employers and employees, and reduce instances of exploitation, discrimination, and abuse. One participant shared their experience of bullying in the workplace:

“At my workplace, I had other staff member talk behind my back and say mean things about me. [They would] snap their fingers when I couldn't give eye contact, and my boss treated me very unkindly and never listened to my ideas.

– Focus group participant

Some participants agreed that some workplaces, particularly those that work extensively with disabled communities, should have mandated disability employment quotas.

The Disability Support Pension (DSP) needs improvement

Participants who had experience with the DSP found that it presented a range of issues for them. One of the key areas of concern for these participants was the restrictive, hours-based rules of the DSP. The DSP limits the number of hours recipients can work to 30 hours per week before being potentially cut off from their payments.¹⁶⁷ This leaves disabled young people vulnerable to having their DSP payments reduced or suspended, even if their income is less than the DSP itself.¹⁶⁸ As a result, some participants expressed that they are faced with a choice between being employed or retaining their DSP payments. Some participants pointed out that many young people are paid less per hour and are commonly hired on a casual basis with unpredictable working hours, making it harder for young people to find work that they can sustain themselves with while adhering to the strict hours-based rules. These participants also highlighted that the hours-based requirement

fails to acknowledge how fluctuations in some disabilities limits chances of retaining payments long-term or being deemed eligible for the DSP.

These participants agreed that the DSP seems to be designed to deter recipients, rather than provide a financial safety net for those in need. As a response to these concerns, participants recommended that the DSP be amended. Participants suggested that eligibility and hours-based requirements should be reconsidered so that people who are required to self-fund their disability supports due to not being eligible for NDIS or other support services can live a life of dignity and choice.

Employers are unfamiliar with existing support for young people

Many focus group participants reported that businesses and employers they had worked for generally lacked confidence and knowledge around how to support workers with disability. To address this, some participants suggested that the Australian government should increase funding to Job Access and review the eligibility criteria to ensure all workplaces have adequate funding so that employers can implement necessary supports for disabled employees. Participants were hopeful that this would improve the standard of accessibility across all sectors and would allow employers to feel confident in hiring disabled young people.

Accessible career guidance

Many participants agreed that targeted support that addresses gaps in current careers guidance options would be beneficial to disabled young people and improve employability outcomes. One participant shared their view:

“There is no framework to give them [job agencies] minimum standards for dealing with [disabled] young people. So, you have a job agency that has no idea how to deal with young people with a disability. Just because they are certified to deal with clients, they might not know how to talk to young people with disabilities.”

– Focus group participant

Traineeships and cadetships for disabled young people

Some participants identified traineeships and cadetships as effective pathways to employment for disabled young people. These participants agreed that this provides opportunities for employers to learn about disabled young employees and their needs, so that adjustments can be implemented prior to being hired. These participants suggested that traineeships and cadetships should be flexible and provide a range of options that accommodate access requirements, allow time for study and other commitments, and include people with different levels of skill and experience. Participants were hopeful that if executed well, traineeships and cadetships would be a highly positive experience for both the disabled person and the employer.

YDAS case study

George's story

George* is a young person who is legally blind. George completed two internships. Prior to starting his first internship, it was made clear to him that his disability would not be a barrier to his application, and that he would be able to choose his hours of work as long as he completed the required hours for the internship program.

During the interview stages, George was informed that to meet the requirements of the position, the company would provide him with resources, make any necessary adjustments, and ensure that the workplace was a safe and comfortable place for him. He was given a dedicated laptop on his first day which had pre-installed magnification and speech software. When George experienced visual fatigue during his first week, he was given permission to take regular breaks by his manager. George never felt that these adjustments were difficult for his workplace to arrange and manage.

George's second internship did not begin as smoothly as the first. While the laptop he was provided with had magnification and speech software pre-installed, the software failed to run. George informed his manager who arranged for the magnification software to be replaced. This new software was successful, but the speech software was unable to be fixed or replaced. Later in his internship, George realised he was still experiencing some difficulties seeing his work. When he brought this up with his manager, they immediately provided him with a monitor to help him complete his work.

While the second internship posed some challenges, George describes both experiences positively, noting that any issues he had were addressed quickly. He felt safe and supported by his managers and colleagues in both internships and felt that his workplace's policies and procedures for inclusivity and alternative employment pathways were exemplary.

'If employers recruit and value employees for the diverse skills, talents, and experiences that they can bring to the workplace and provide all employees with the support that they need to perform the tasks required of them in a safe and supportive environment, this will go some way towards bridging the gap that exists currently. Recognising that people with a disability know their own needs best and asking them what they need is also vital to truly bridging this gap.'

- George

*George's name has been changed to protect his privacy

Recommendations

- 7.1 Subsidise traineeships and cadetships for disabled young people in state and federal governments, statutory bodies, NGOs, and the private sector.
- 7.2 Provide disability-specific career guidance for disabled young people and hire career guidance counsellors with lived experience of disability. This would include training about their rights at work, managing taxes, superannuation, and how to communicate with employers.
- 7.3 Increase the awareness of Job Access and other funding available to employers to implement reasonable adjustments for disabled employees.
- 7.4 Legislate an enforceable positive duty on employers to prevent disability discrimination.
- 7.5 Explore increasing and mandating disability employment quotas in the public service and private sector companies.
- 7.6 Review the eligibility criteria for the DSP including the hours-based requirement and raise the rate to adequately cover the elevated costs of living with a disability.

Housing

Disabled young people experience poorer housing outcomes than non-disabled young people across all housing indicators such as affordability, accessibility, and the quality of housing.^{169,170} It is imperative that housing is made accessible and available for disabled young people as they navigate significantly more barriers to securing secure, safe, affordable, and accessible housing compared to non-disabled young people.¹⁷¹

Adequate housing is a human right

Having access to appropriate, safe, affordable, and accessible housing is a fundamental human right.¹⁷² The right to an adequate standard of living and appropriate housing is enshrined in Article 28 of the CRPD.¹⁷³ Article 19 of the CRPD states that disabled people should be afforded choice and control of where and with whom they reside with.¹⁷⁴ The CRPD also calls for governments to take appropriate measures to ensure that disabled people can access housing on an equal basis with others.¹⁷⁵

Australia is currently not meeting its obligations under the CRPD.¹⁷⁶ The failure to implement appropriate housing for disabled young people is a breach of international human rights law.¹⁷⁷ The Committee on the Rights of Persons with Disabilities (the Committee) recognised issues with Australia's treatment of disabled people with respect to housing in its 2019 Concluding Observations, advising Australia to:

*'Increase the range, affordability and accessibility of public and social housing for persons with disabilities, including by implementing a quota for accessible social housing and by developing regulations and standards to guarantee the progressive application of universal design principles in accessible housing'.*¹⁷⁸

Disabled young people face barriers to adequate housing

Many young people face barriers to securing a reasonably priced rental property, accessing social housing, and receiving adequate rental assistance through Centrelink.¹⁷⁹ Family violence, mental illness, relationship breakdowns, substance use, and transitioning out of the justice system or out-of-home care, place young people at risk of homelessness.¹⁸⁰ These issues are exacerbated when living with disability.¹⁸¹ Disabled young people, especially those with complex needs, face a chronic shortage of affordable housing across Australia.¹⁸² As a result, many disabled young people are forced to reside in residential aged care facilities (**RAC**), institutions, and group homes; rely on parents and caregivers for accommodation; or remain stuck in hospitals while they wait for appropriate housing and supports to be approved.¹⁸³

A significant portion of housing that is available for disabled young people is not usually located in areas that allow for engagement in all aspects of society.¹⁸⁴ This, in conjunction with the unaffordability of the private rental market, reveals an urgent need to provide appropriate housing for disabled young people.¹⁸⁵ Despite this, a continued under-investment in social housing has restricted the availability of housing options. The introduction of the Victorian Government's \$5.3 billion *Big Housing Build* in December 2021 is a welcome investment and should look to best practice methods for building accessible housing for disabled young people. This should include addressing the underlying barriers to housing faced by disabled young people, accounting for complex needs and adaptability in housing design.¹⁸⁶

A move towards specialist disability accommodation (SDA)

SDA is a scheme introduced by the NDIS in 2016.¹⁸⁷ The aim of SDA is to create an open market where people with disability have access to high-quality housing that meets their individual accommodation goals and needs.¹⁸⁸ The NDIS plays a significant role in the SDA market through setting prices, determining eligibility, and allocating SDA funds in NDIS plans.¹⁸⁹ SDA has been promoted as a solution to prevent disabled young people from entering or remaining in RAC, with an aim to end this practice by 2025.¹⁹⁰ However, the scheme is currently only providing payments for approximately 54% of 28,000 eligible NDIS participants.¹⁹¹ This leaves over 12,000 people who continue to reside in government housing, hostels, RAC, or with family and carers.¹⁹²

One of the main reasons for this is the lack of transparency on how to access the scheme, resulting in participants not being informed of their eligibility for SDA.¹⁹³ This has led to a lack of demand which is crucial to help inform the SDA market on how much housing will be needed, what locations are suitable, and the type of adjustments that are required to meet the needs of participants.¹⁹⁴ In order to address this, the NDIS needs to increase awareness of SDA amongst participants and collect data from participants to ensure the provision of suitable housing.¹⁹⁵

YDAS case study

Isabelle's* story

I am a 26-year-old female (she/her), with a physical disability - specifically cerebral palsy spastic diplegia - as well as anxiety and depression. These impairments impact me on a day-to-day basis. The most obvious is I walk on forearm crutches or use a wheelchair, have fine and gross motor skill issues, fatigue, and balance issues. When I am experiencing mental health problems, I cut myself off from the world and struggle with personal care tasks beyond the already tricky situation my physical challenges present. Growing up, my mum always made sure that we were living in a house that was suitable for me. I did not realise how difficult this was until 2018, when I was ready to go on to further education and move out of the family home.

After I graduated high school in 2016, I was accepted into university. However, I took a gap year due to finding out that the university's student housing could not accommodate me. The existing physically accessible room was not reserved for students with disabilities as there usually wasn't demand. The next year new student accommodation was available however their accessible rooms weren't truly accessible. I lived with the bare minimum adaptations to function, and it was up to my mum and me to find the laws and building codes necessary to modify certain things in the room. The on-campus accommodation was also extremely expensive, which was a huge financial pressure on my mum, and caused an emotional strain on our relationship. Housing law was unclear and hard to find so the main way I got adaptations was by relying on the education system. The building was associated with the university so as per educational laws they had to accommodate me. This would not work outside of a student rental.

"Inaccessible housing has not just affected my living situation but my social opportunities."

I also had to live alone to get an accessible room. This meant that I was incredibly isolated despite living in the main residential building for students. This manifested in more anxiety and a tendency to keep to myself. While there were plus sides to having my own space, I ultimately missed out on most of the social connections and life lessons that often come with university living. Even if accessible shared rooms were available there, there's no support to help young people with disability communicate and adjust to living with housemates safely without risks of abuse or neglect.

By the time I graduated I was a NDIS participant. Despite this, I again realised how inaccessible housing was to me. I couldn't find anything accessible within my budget, and I couldn't search on mainstream websites for accessibility features. In Victoria there are laws that allow modifications to rentals however there are no time limits on how long workers can take, and there are ways for landlords to challenge these laws. This option was ruled out for me, and I had to leave university

housing by a certain date. Most of my friends moved away post-university so I was not able to live with people I felt comfortable with, and I could not leave my other formal and informal supports. In the end I went overseas on a university approved educational/work program for graduates and students. I was again relying on the education system to provide me with inclusive supports as this was easier than trying to find accessible housing in Australia. I recognise a lot of young people don't have this option. I kept looking for housing while overseas but didn't have much luck. I always worried about what was next and whether my independence would be taken away when I got back. I was also unable to apply for SDA or other supports partly because I didn't even know these programs existed. All of this led to overwhelming anxiety and depressive episodes as I felt useless and unable to access independence.

“I was also unable to apply for SDA or other supports partly because I didn't even know these programs existed.”

I returned home during the pandemic and moved back in with Mum due to the lockdowns. I applied for SDA and waited over a year just to be rejected. I am currently appealing this decision. This (process) has constantly impacted the last two years of my life. I am always stressed, and unable to have any autonomy in housing. The SDA paperwork only focused on what I was unable to do, instead of looking at how accessible housing could help me. This made my mental and physical health significantly worse.

Applying for jobs was difficult as my confidence was decimated due to not being able to take care of myself properly in my home, and job rejections made it worse. I considered studying again because I felt like education was my only option for accessible housing. I managed to come up with an alternative option, but I felt like my opportunities and career choices were not the same as my friends.

Without bare minimum accessibility features (step-free access and one railing in the bathroom) I am often unable to go and visit my friends or attend social events. I cannot enter the door or go to the bathroom, and I do not want to put myself in bodily harm every time. This means I must invite my friends over to my house. Non-disabled friends often call me 'boring' as they don't have understanding about how visiting their houses can be dangerous for me.

I feel unable to access opportunities in all aspects of my life and feel like a burden as opposed to a person. I would love to not rely on parental support so much, but it's just not possible. Once accessible housing is cheaper and easily available, I would love to see resources on how to navigate conversations around accessibility with housemates and support as I have no idea how to approach these conversations and explain what a support worker is etc.

*Isabelle's name has been changed to protect her privacy

Recommendations

- 8.1 Raise awareness of accessible housing options, including SDA, amongst disabled young people.
- 8.2 Expand the eligibility criteria for SDA using a youth lens which acknowledges that disabled young people may need additional support when transitioning to independence.
- 8.3 Ensure that the SDA consults with potential participants, particularly disabled young people, on housing needs and preferable locations for housing.
- 8.4 Ensure that new social housing projects have a quota for accessibly and adaptably built housing with a percentage reserved specifically for disabled young people.
- 8.5 Introduce nationwide mandatory adaptable housing standards in building regulations for residential housing.
- 8.6 Increase the availability of resources to assist disabled young people in locating disability inclusive accommodation and ensure they have a level of choice on par with other young people about their living arrangements.

Health and Medical Mistreatment

Interaction with health care services is vital for all disabled young people.¹⁹⁶ Focus group participants reported being vulnerable to abuse and neglect when health care professionals devalue their lived experience and gatekeep information regarding their medical care. Focus group participants expressed that this limits their self-determination over their treatment and prevents them from receiving appropriate care that addresses their individual needs.

Poor health outcomes and barriers to care

Disabled young people experience poorer health outcomes compared to non-disabled young people.¹⁹⁷ This is often impacted by social determinants such as high rates of poverty, unemployment and low income, homelessness, social isolation, and exclusion.¹⁹⁸ The development or increased severity of a disability may also entrench pre-existing disadvantage through loss of income and increased cost of living due to medical treatment.¹⁹⁹

Australian data has revealed high rates of avoidable death amongst young people with intellectual disabilities aged 25 and under²⁰⁰ - the largest population of people with an intellectual disability in Australia.²⁰¹ A recent review by the NSW Ombudsman revealed that preventable deaths commonly resulted from delays in treatment due to late responses from support staff, and incorrect administration of medications due to negligence and/or diagnostic overshadowing.²⁰² Additionally, disabled young people aged 0-24 are 86% less likely to see a GP, see a GP for urgent medical care (15%), or be admitted to hospital (18%),²⁰³ and are more likely than other age groups to rely on informal care (care provided by family and friends) to supplement healthcare requirements.

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Disabled young people face a multitude of complex organisational and societal barriers to accessing appropriate and timely healthcare.²⁰⁵ Organisational barriers that have frequently been identified in research include: a siloed healthcare system resulting in difficulties transitioning from paediatric care to adult care²⁰⁶ and insufficient education and training for healthcare staff working with young disabled people.^{207,208} Societal barriers that have been identified in research include entrenched adultism and ableism in healthcare systems,^{209,210} and a significant lack of youth participation in the development of healthcare policy and research.^{211,212}

Ableism and adultism in healthcare settings

Despite disability being less common amongst young people compared to older populations, disabled young people face higher levels of discrimination in healthcare settings.²¹³ A recent study

found that this may be due to the increased chances of developing disability in mid to late adulthood, as many older people who work in professional healthcare roles are able to self-identify with people of a similar age who have disability, thereby reducing the likelihood of discrimination.²¹⁴

In a recent Australian study, young people with chronic illness reported experiencing frequent age-based discrimination when interacting with healthcare staff.²¹⁵ Participants were often told that they were “too young” to be experiencing their symptoms, which lead to misdiagnosis or delayed diagnosis.²¹⁶ Participants also reported frequent condescending and dismissive attitudes from healthcare staff, with some accusing participants of lying and explicitly denying them care.²¹⁷ This discrimination was reported to be physically, emotionally, and financially detrimental for participants.²¹⁸

Research has shown that people who experience disability discrimination in healthcare settings are less likely to access health services, seek preventative treatment, and delay or avoid treatment.²¹⁹ Disabled young people aged between 15-29 have the highest rates of medical avoidance, with 18% evading necessary care.²²⁰ Those who have multiple diagnoses are also more likely to avoid medical care.²²¹ This compounds existing poor health outcomes amongst disabled young people, and increases the risk of developing undiagnosed conditions and likelihood of premature death.^{222,223}

Implications for healthcare policy and service design

To reduce neglect and discrimination in healthcare settings, research suggests that healthcare policy needs to reconsider its over-reliance on the medical model of disability^{224, 225} and meaningfully include disabled young people in service design via co-design methods.^{226, 227} Current healthcare policy embeds medical models which often group ‘disability’ and ‘health condition’ as two interchangeable concepts, while ignoring how social structures and environments disable people.²²⁸ Including the heterogeneous experiences of disabled young people in policy-making processes could help develop inclusive, holistic, healthcare policy that looks at the whole individual rather than focusing on impairments alone.^{229, 230}

Disabled young people's experiences with healthcare and medical mistreatment, and their suggestions for improvement

Defining 'health' and medical mistreatment

Focus group participants began this consultation by defining what health means to them and discussing what constitutes medical mistreatment. Participants were invited to interpret 'health' in any way that was most meaningful to their day to day lives. Participants shared that they have had experience interacting with general practitioners (GPs), specialist mental health services, NDIS funded disability-related health supports, and medical specialists.

When discussing medical mistreatment, participants voiced support for a medical system that evolves beyond the medical model of disability to a model that prioritises the social and human rights models of disability. Participants were hopeful that this would prevent the following:

- misdiagnosis;
- inappropriate or harmful medical treatments;
- failure to act on young people's medical concerns;
- emotional and physical abuse from medical professionals;
- ableism in medical policies and systems, and from medical professionals.

Good medical professionals listen to disabled young people

Several participants discussed positive interactions with the medical system. Medical practitioners who genuinely engage with a disabled young person on their own terms, was a consistent theme throughout these positive experiences. A focus group participant suggested that a good medical professional is someone who:

"Trusts that I was telling the truth, they were interested in me and my experiences, rather than dismissing me or believing all the other doctors."

- Focus group participant

Many participants agreed that good medical professionals act as an ally by valuing the disabled young person's lived experience and taking time to understand their needs. A participant described their experience of this:

"The good eggs understand that you know your body better than everyone else."

- Focus group participant

Mutual trust was a key factor in creating a positive patient-doctor relationship for all focus group participants. Participants described this as trusting their doctor's abilities and knowing that their

doctor trusts their description of their experience. To encourage relationships of trust, participants suggested that medical professionals need improved attitudes towards disabled young people. Participants also suggested that the duration of appointments need to be increased to facilitate time and space to build positive patient-doctor relationships, and to ensure that the disabled young person's concerns are adequately addressed.

Neglect in the healthcare system

Several participants shared experiences of medical mistreatment. This included being physically hurt by a medical professional who lacked knowledge around how to provide appropriate care for their disability. For some participants, experiences of this had occurred because of miscommunication between the medical professional and the participant. This was due to the participant not being provided with support to communicate their needs to medical professionals. Other participants described being able express themselves clearly, but their experiences were not taken seriously or were minimised by the medical professional. This was particularly apparent when receiving treatment in hospital. One participant shared their experience:

“I had my shoulder dislocated twice when a nurse moved me when I shouldn’t have been moved. I had to explain my entire medical history over and over again”.

– Focus group participant

Young people are left out of medical conversations

Many focus group participants reported being repeatedly left out of conversations that directly concerned their health and wellbeing. These participants stressed the importance of being able to have choice and control over their treatment options. Many participants felt like they were not provided with choice over which doctors they could access, particularly in relation to specialists. Additionally, participants reported that medical professionals would frequently ‘gate-keep’ important information about clinical decisions or would not deliver information to them about their health in an accessible way. One participant shared their experience with their doctor:

“They refused to tell me their diagnosis because they didn’t want me to challenge it.”

– Focus group participant

As a result, some participants spoke about experiencing significant stress, and described being in vulnerable positions where their self-determination and autonomy over their medical treatment is removed. A survey respondent shared their experience of being ignored and devalued by their doctors, resulting in another instance of diagnostic overshadowing:

“I was an inpatient several times at a private psychiatric hospital. While this is obviously a voluntary admission (being a private facility), the staff failed to recognise my physical health requirements. [They] ignored the treatment I required for an obvious flare in a pre-existing

neurological condition and failed to understand management of my conditions and pain, making me feel belittled for asking for medical assistance.”

- Survey respondent

A focus group participant described their experience with medical professionals who provided them with information they did not understand. The participant reported that when they asked questions, the doctors replied that “there’s just no one to talk to” and refused to communicate the information in an alternative way.

“Things are usually explained to my mum. I’ve been deliberately left out of the conversation. They [the doctor] wouldn’t explain anything to me. [The doctors] grabbed me and performed procedures on me, and it hurt!”

- Focus group participant

Young people with invisible disabilities

Participants who had invisible disabilities reported frequently experiencing scepticism about their condition compared to young people with a visually identifiable disability. These participants suggested that this may be due to the assumption that young people are supposed to be healthy. One participant told YDAS:

“I’ve had doctors call me liars, told me that I just need to get friends. I’ve been told I just need to get a boyfriend or [that I’m] faking it to get out of school. People assume that I’m a kid and I just want to get out of school.”

- Focus group participant

These participants spoke about their frustration at having to consistently justify and explain their disability. A participant with mental health challenges shared their experience of being dismissed by doctors:

“I have underlying mental health issues and I assumed that it was causing my pain. The doctors saw I had mental health issues and deemed me an unreliable narrator”

- Focus group participant

Improving the complaints system

Participants suggested that complaints systems should be improved and standardised across all health care facilities. Feedback forms were viewed by participants as crucial to identifying and reporting misconduct, neglect, and abuse in healthcare facilities. Participants suggested increasing the accessibility of feedback forms and ensuring that multiple formats that support a diverse range of disability are available. Participants expressed that it was often very difficult to know where to locate feedback forms and where to send their form to. They recommend

implementing a clear, safe, and anonymous mechanism which allows young people to submit their complaint. Participants suggested that complaints should have a 'no wrong door' function so that they can be assured that it will be received by a person or department who will investigate and respond to their complaint. Two focus group participants shared their experiences with current complaints processes:

“It was like shouting into the air when we were talking about doctors that shouldn’t be there. We didn’t have enough energy to fight it because we were fighting other battles.”

- Focus group participant

“I got laughed at because I told my doctor about my diagnosis... I got him fired... they wouldn’t do anything after I did the complaints form, but then I spoke to my former doctor, and he said to ring and make a complaint about that doctor.”

- Focus group participant

YDAS case study

Ameena's Story*

Ameena is a young neurodivergent person who also has a physical disability.

When Ameena needed to be admitted to the hospital for a surgical procedure, the hospital initially told her that they were unable to provide the adjustments required for her physical disability. After extensive liaison with the hospital, they finally agreed to accept her.

However, when Ameena attended a pre-surgical consultation the staff spoke to her in a patronising manner and initially refused to believe that she had the capacity to consent to the procedure. This caused Ameena distress, as she had to repeatedly explain that she understood the procedure and the associated risks.

Ameena did not feel comfortable or safe with the hospital staff after this discussion. She was concerned that staff would refuse to go ahead with the procedure if she explained the reasonable adjustments she needed to prevent sensory overload.

When she woke up in the recovery ward after the surgery, she was in a bed near the nursing station. This was a bright and noisy environment with a high volume of pedestrian traffic going past her bed. Ameena subsequently had a panic attack. One of the nurses who was on duty fortunately realised what was happening and was able to move Ameena to a quieter part of the ward.

*This is a composite case study derived from a number of stories shared with YDAS and reflects the issues commonly experienced by disabled young people in the health system.

Recommendations

- 9.1 Shift focus within healthcare policy towards a social and human rights model of disability rather than focusing solely on treating impairments.
- 9.2 Require health providers to provide disabled young people with information about their medical care in an accessible format and involve them meaningfully in decisions about their care.
- 9.3 Make 'no wrong door' complaint processes readily accessible in health facilities.
- 9.4 Invest in creating cohesive cross-sector collaboration to ensure continuity in disabled young people's care, including the transition from paediatric to adult care and provide support for disabled young people when they transition from paediatric to adult care.
- 9.5 Increase funding to all health care facilities to address excessive wait times for appointments and treatments.
- 9.6 Increase funding across health care facilities to address excessive wait times for appointments and treatments.
- 9.7 Support transitions from in-patient treatment in hospitals to at-home care.

Mental Wellbeing

Mental illness* has been rated as a major concern by disabled young people in Australia.²³¹ Focus group participants highlighted how unsafe and inaccessible mental health services can contribute to violence and neglect against disabled young people. Focus group participants suggested that collaboration between disability and mental healthcare systems would reduce the likelihood of abuse and neglect of disabled young people, and lead to improved mental health outcomes.

Mental illness as a disability

*YDAS uses the term mental illness. However, YDAS recognises that there are a wide range of views and preferences about the language used, and that some people may prefer to use other terms. Mental illness is included in YDAS's definition of disability. However, YDAS acknowledges that identifying as disabled is a personal choice and that some people with experiences of mental illness may not identify as disabled. This can be due to a range of reasons including assumptions about the permanence of disability whereas mental illness is often seen as fluctuating or temporary, with an emphasis on recovery,²³² or due to stigma about disability.²³³

Applying the social model of disability positions mental illness as a disablement that results from external structures and environments.²³⁴ When exclusionary external structures and environments are altered to be inclusive, those with mental illness and other disabilities can participate as equal citizens in society.²³⁵

Disabled young people report higher rates of mental illness

Nearly half (45.5%) of disabled young people in Australia have experienced mental illness, compared to 32.4% of non-disabled young people.²³⁶ The prevalence of mental illness amongst young people with an intellectual disability is 3-4 times higher than non-disabled young people.²³⁷ Almost twice as many disabled young people report concern about suicide (25.6%) compared to their non-disabled peers.²³⁸

For many disabled young people, mental illness is interconnected with experiences of disability.²³⁹ Due to historical ableist medical research and practice, it was previously believed that disabled people, particularly those with intellectual disabilities, could not experience mental illness due to limited cognitive capacity.²⁴⁰ Evidently this belief is unfounded and discriminatory. Disabled people experience stress and stressful life events at higher rates.^{241, 242} Seventy-six percent of people with psychosocial disabilities and 60% of people with intellectual disabilities report high or very high levels of psychological distress, compared to 8% of non-disabled people.²⁴³

Barriers to accessing mental health treatment

Many disabled young people find accessing mental health care treatment difficult.²⁴⁴ In Australia, only 10% of disabled young people with a mental illness received treatment over a 14-year period, compared to 35% of non-disabled young people who sought treatment for mental health concerns.²⁴⁵ Some of the barriers to accessing treatment commonly faced by disabled young people include; an overall lack of services, inconsistency between service providers and sectors, diagnostic overshadowing resulting from a lack of professional knowledge and training amongst mental health providers, and disability discrimination.²⁴⁶

Due to the siloing of disability and mental health services in Australia, disabled young people with mental illness experience challenges in moving between the two systems.^{247, 248} This systemic division manifests as inadequate cross-sector communication, competing philosophical and operational models, and inconsistent eligibility criteria - resulting in confusion about which services can provide appropriate support for disabled young people.^{249, 250} Many disabled young people and their families lack co-ordinated support to navigate these barriers and are left struggling to find adequate care.²⁵¹ This is especially apparent during transitional periods between childhood and adolescence and when moving from youth services to adult care.^{252, 253}

Another barrier to accessing mental health support is the lack of professional training and confidence amongst mental health workers when working with disabled young people.²⁵⁴ A recent Australian study investigating the experiences and attitudes of those employed in the mental healthcare sector, found that although 89.4% of participants had professional contact with people with an intellectual disability, only 30% felt they had sufficient training to effectively support disabled clients.²⁵⁵ A consequence of this is disabled young people facing discrimination in the form of 'diagnostic overshadowing'.^{256, 257} Diagnostic overshadowing is where a person's mental illness is attributed to their disability, or where physical health is overlooked due to a focus on mental health.²⁵⁸ This results in the potential for incorrect diagnoses, leading to inadequate support and care and exposing disabled young people to medical neglect and harm.²⁵⁹

Disabled young people's experiences with Australia's mental healthcare system and their suggestions for improvement.

Increasing awareness about mental illness as a form of disability

Working group and focus group participants suggested that understanding mental illness as a psychosocial disability provides a stronger framework for disabled young people's treatment and recovery. Most participants agreed that understanding mental illness as a disability would allow for a shift from the current deficit-based, medical model, and position mental illness within the social and human rights-based frameworks for disability.

Make mental health services disability-specific

Many focus group participants reported that approaches to mental illness in the mainstream mental health system are often not accessible for disabled young people. Some participants described barriers to accessing safe and relevant mental healthcare. An example of this was a lack of access requirements that support disabled young people engagement with services. Some participants emphasised that a 'one-size-fits-all' mental health system is not suitable for the diverse needs of disabled young people. One working group participant shared their view:

"CBT [Cognitive Behavioural Therapy] is not for everyone. Disabled people need a range of treatment options that are responsive to their mental health needs, their access needs, and their disability. We need alternative support types and flexible pathways."

- Working group member

Focus group participants stressed the importance of flexibility in service provision for disabled young people to ensure they are receiving treatment and support based on their individual needs. Focus group participants also suggested that collaboration between mental health and disability services would ensure that disabled young people's needs are better communicated between services. Participants were hopeful that a detailed handover would ensure continuity in treatment.

The benefits of telehealth

The COVID-19 pandemic highlighted the importance and benefit of flexible service delivery for disabled young people. Focus group participants discussed how the pandemic provided opportunities to access services and supports that they have been unable to access in the past. As the world returns to a 'new normal', most of the focus group participants were hopeful that telehealth services will continue post COVID-19.

"Telehealth is so accessible, it's so easy to do. It's really awesome. It should continue [after COVID-induced restrictions on movement and in-person service delivery]."

- Focus group participant

Many participants described how telehealth has allowed them to access mental health support from the safety and comfort of their own homes. Prior to the wide availability of telehealth many of the participants faced barriers in getting to and from appointments, often due to the accessibility of the facilities.

Working group members highlighted that telehealth also allows disabled young people who have experiences of trauma to engage with their mental health professional in a familiar and safe environment. Working group participants suggested that this approach acknowledges the need for emotional safety to be determined by the service user, which is an integral component of trauma-informed care.²⁶⁰

Insufficient Medicare sessions

Many focus group participants emphasised that 10 subsidised therapy sessions funded through Medicare is not enough to meet the needs of disabled young people with complex mental health issues. Participants agreed that mental health services should be free and accessible for all disabled young people in Australia.

Priority on mental health service waitlists

Participants expressed their frustration at having to wait excessive amounts of time to access mental health professionals. Some participants shared their experiences:

“I’ve booked to go to a Zoom psychologist, but I’m on the waitlist until February. That was in June, so an eight month wait. We need to shorten the waitlist. Eight months is far too long!”

- Focus group participant

“They should give some more money to headspace or another organisation. It’s awesome because it’s free, but they have a massive waitlist.”

- Focus group participant

“I know there’s been a massive increase in demand for mental health services, especially because of COVID and especially among disabled people. But this increase isn’t being matched by an increase in supply of practitioners.”

- Working group member

To address this, working group members and focus group participants suggested that disabled young people should be given priority on mental health service waitlists.

The value of lived experience workers

Both working group members and focus group participants suggested that their negative experiences with the mainstream mental health sector could have been prevented if more lived experience workers were employed in the mental health sector.

Some participants and working group members suggested that having a lived experience of disability enables practitioners to meaningfully understand clients' experiences of ableism and exclusion. It was also suggested that practitioners with lived experience are more likely to identify discrimination and ableism, allowing disabled young people to feel safe and included within services. Participants and the working group proposed that this would create job opportunities and provide role models for disabled young people. Working group members shared their views:

“The exclusion of disabled people in roles with power in the mental health system directly contributes to abusive policies and practices.

- Working group member

“People with lived experience aren’t only valuable in lived experience specific roles. We need to be in all sorts of roles within the sector to make any meaningful change in the experiences of clients.”

- Working group member

YDAS case study

Luke's story

Luke* is a young person with several disabilities. Luke's mental health deteriorated after the outbreak of COVID-19, resulting in frequent suicidal ideation. Luke lives alone after a change in his family circumstances. He receives occasional support from a family member however this is not adequate to address his daily needs. Luke is unable to cook or clean for himself, has no NDIS supports in place and is unable to engage with services.

Luke is case managed by a public mental health service (**MHS**). In 2021, Luke's MHS arranged to update his Emergency Management Plan (**EMP**). This was updated incorrectly and included outdated information about Luke receiving adequate support, which impacted Luke's ability to present at hospital emergency rooms without being turned away.

Luke's MHS failed to understand the impact of his disabilities and how to implement reasonable adjustments. The MHS was informed that Luke does not understand how or when to take his medication and has accidentally overdosed on several occasions as a result. After several months of inaction, the MHS provided Luke with a Webster-Pak to prevent this from happening again. Luke also requires a support person to explain information conveyed to him by doctors. The failure of MHS to ensure that information was adequately explained to Luke led to an incident where Luke walked home from the hospital barefoot in the dark as he did not understand staff when they told him that an admission had been arranged for him.

During another hospital admission, the MHS was advised to make sure that one of his family members was listed as next of kin on his hospital records. This family member also asked the MHS to instruct the hospital to notify her of Luke's discharge and to provide her with information about his prescribed medication. These requests were overlooked. Luke was sent home in a taxi with no support person or medication and experienced severe withdrawals from his medication. To alleviate the withdrawal symptoms, Luke consumed old antipsychotic medication that he found in his bedroom.

*Luke's name has been changed to protect his privacy

Recommendations

- 10.1 Fund telehealth for all mental health services and invest in improving the accessibility and quality of telehealth.
- 10.2 Increase awareness and recognition of mental illness as a disability.
- 10.3 Reinstate 20 Medicare-subsidised therapy sessions to provide young people with adequate support to address their concerns, especially those with complex issues.
- 10.4 Increase the number of workers with lived experience of disability to work alongside disabled young people with mental illness.
- 10.5 Support disabled young people to attain qualifications related to the mental health sector by offering scholarships, financial assistance, and mentorships.
- 10.6 Resource fast track referral pathways for mental health support between disability-focused and mainstream organisations.
- 10.7 Invest in flexible service delivery and a range of mental health treatments tailored for disabled young people's diverse needs.

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