



Children and Young People
with Disability Australia

Submission to the Senate Select Committee on Autism inquiry

**Children and Young People with Disability Australia
July 2020**

Table of contents

Introduction	1
Our recommendations.....	2
Develop a truly inclusive education system.....	3
Deliver strong post-school outcomes for young people with disability.....	7
Ensure access to appropriate disability services and support.....	11
Appendix A: Results from CYDA’s 2019 post-secondary survey and supplementary information	15
Appendix B: CYDA’s submission to the Tune Review, October 2019	24
Appendix C: <i>Driving change: A roadmap for achieving inclusive education in Australia</i>	25

Authorised by:

Mary Sayers, Chief Executive Officer

Contact details:

Children and Young People with Disability Australia

E. marysayers@cyda.org.au

P. 03 9417 1025

W. www.cyda.org.au

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0-25 years. CYDA has an extensive national membership of over 5,000 young people with disability, families and caregivers of children with disability, with the majority of our members being families.

CYDA's purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia. To do this, we focus on the following:

- Listening and responding to the voices and experiences of children and young people with disability
- Advocating for children and young people with disability for equal opportunities, participation and inclusion in the Australian community
- Educating national public policy-makers and the broader community about the experiences of children and young people with disability
- Informing children and young people with disability, their families and caregivers about their citizenship rights and entitlements
- Celebrating the successes and achievements of children and young people with disability.

CYDA appreciates the opportunity to provide this submission to the Senate Select Committee on Autism. Our submission primarily responds to items (f), (g) and (i) in the inquiry's terms of reference, and focuses on the need to implement genuinely inclusive practices for children and young people with disability in their early years, at school and in their post school transition.

CYDA operates from a human rights perspective, with all of our work informed by the United Nations Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child. As such, we advocate taking a strengths-based, developmental approach to providing support to all children and young people with disability, rather, including autism, rather than taking a diagnostic approach. We also recognise the diversity of disability and note that many children and adults with disability, including autistic people, experience more than one form of disability; therefore we are concerned that taking a diagnostic-specific approach can be limiting and may not encompass the individuals' experiences as a whole. Because strategies and approaches that might work for one type of disability work across disability, if you only take a diagnosis approach this misses the benefits of what can be achieved by adopting a social model of disability rather than a medical/diagnostic approach.

In response to item (h) in the inquiry's terms of reference, we provide our submission to the 2019 Tune Review as an attachment. This submission, *Improving the NDIS for children and young people with disability and their families*, outlines the key challenges facing children and young people, and their families and caregivers, through their interactions with the NDIS, and beginning even before they enter the Scheme.

We recognise there are considerable NDIS-related challenges facing autistic children and young people, however we consider that addressing the broader challenges facing all children and young people will go a large way to addressing these specific challenges, and will allow for a more inclusive Scheme in general.

Our recommendations

Develop a truly inclusive education system

- Promote inclusion from the early years of life
- Phase out the segregation of students with disability in Australian schools
- Address low expectations for students and young people with disability
- Boost investment from governments for students with disability

Deliver strong post-school outcomes for young people with disability

- Improve employment outcomes for young people with disability
- Ensure income support programs allow young people with disability to live above the poverty line
- Enable access to further education and training for young people with disability

Ensure access to appropriate disability services and support

- Ensure the NDIS is relevant and works for children and young people
- Guarantee direct supports are safe, appropriate, and come from a rights-based approach
- Address the interface issues between the NDIS and other systems
- Investigate and address gender inequality and promote inclusion.

Develop a truly inclusive education system

As well as the usual challenges students often face in their school lives and transitions out of school, students with disability, including autistic students, face a range of additional barriers. They generally do not have access to education of the same quality as students without disability, and are often segregated in special schools or excluded in mainstream schools. Students with disability are also significantly more likely to face restrictive practices such as restraint and seclusion.

During and after school, people often hold lower expectations for young people with disability, and they receive little tailored information or assistance around career planning and early employment. This discrimination and inequality continues throughout people's lives, with significantly poorer outcomes for people with disability in areas including higher education, employment, health, and social participation.

Extensive evidence shows that inclusive education is a major part of improving academic and social outcomes for students with disability¹, consequently having positive impacts for their adult lives. The right to inclusive education is protected under the United Nations Convention of the Rights of Persons with Disability (Article 24), of which Australia is a signatory.²

Promote inclusion from the early years of life

"Children with disability [including children with autism] are children first, and have the same core needs as other children. These core needs are: good health care and adequate nutrition, security and safety, responsive caregiving, opportunities for early learning, experiences of a range of environments, and opportunities for meaningful participation in home and community activities. In focusing too much on trying to address the child's impairments, it can be easy to lose sight of these basic needs."³

Therefore the focus for children with autism in the early years should be about supporting strong families, and inclusion in community activities such as high quality early childhood education and care, playgroup and having a strong transition to their local schools, not segregated from their non-disabled peers during these critically important early years. Extensive evidence shows the benefits of early childhood education on cognitive and non-cognitive outcomes for children, and that particularly large benefits can be seen for children experiencing socio-economic disadvantage.⁴

Phase out the segregation of students with disability in Australian schools

Improving post-school outcomes for young people with disability begins with positive and inclusive experiences in schools and supports wellbeing throughout their lives. People with disability in Australia are less likely to finish school and more likely to leave before the age of 16, and less than

¹ See Cologon, K. (2019). *Towards inclusive education: A necessary process of transformation*, for CYDA; and Alana Institute (2017). *A Summary of the Evidence on Inclusive Education*, available: https://alana.org.br/wp-content/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf

² Article 24.2 of the UNCRPD provides: "In realizing this right, State Parties shall ensure that: Persons with disabilities are not excluded from the general education system on the basis of disability...; Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live; Reasonable accommodation of the individual's requirements is provided; Persons with disabilities receive the support required, within the general education system, to facilitate their effective education; Effective individualised support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion."

³ Moore, T. (Forthcoming). *What supports the development of children and young people with disability?* Factsheet for CYDA. Centre for Community Child Health; Murdoch Children's Research Institute; p.1.

⁴ NSW Department of Education. (2018). *A review of the effects of early childhood education: Literature review*. Centre for Education Statistics and Evaluation.

a third of people with disability aged 20 or over have completed Year 12-level schooling – compared with 62 per cent of people without a disability.⁵ High rates of school disengagement, lack of tailored support, and continuing segregation in schools contribute to poorer post-school opportunities and outcomes for young people with disability.

Evidence shows that inclusive education “has positive benefits for everyone”⁶ – students with and without disabilities, as well as teachers and the broader school community – but a range of barriers prevent it from being implemented, and in many places the rate of segregated schooling is actually increasing.⁷

The United Nations Convention on the Rights of Persons with Disabilities emphasises that no form of segregation constitutes inclusive education,⁸ but many students with disability in Australia currently experience segregated education programs, including attending special schools, participating in special units in mainstream schools, or having no appropriate option except home-schooling. More students with disability are attending special schools over mainstream schools than a decade ago.⁹ For example, recent data shows that there are 15,521 students enrolled in 108 special schools across Victoria, with enrolment rates in special schools increasing by 53 per cent since 2010.¹⁰

Further data collected by CYDA through our 2019 National Education Survey¹¹ showed that:

- 12.5 per cent of the 505 respondents report were refused enrolment
- 16.6 per cent do not attend school full-time
- 14 per cent have been suspended
- 1 in 4 have been subject to abuse by being restrained or secluded.

These negative experiences through their school years, as well as a lack of appropriate transition support, contribute to lower school completion rates for young people with disability. Research from the University of Melbourne finds that at least 50,000 children and young people of school age are disengaged from the Australia education system, including students with disability, and to date there has been no national response to this issue.¹²

CYDA’s submission to the Disability Royal Commission around inclusive education makes extensive recommendations to address the violence, abuse and neglect of students with disability, and to deliver truly inclusive education for students in Australia.¹³

CYDA is also chair and co-convenor of the Australian Coalition for Inclusive Education and has provided a roadmap for transitioning Australia’s education to provide inclusive education, *Driving change: A roadmap for achieving inclusive education in Australia* (Appendix C).¹⁴ This roadmap provides recommendations for stepped changes to achieving inclusive education to ensure

⁵ Australia Institute of Health and Welfare (2019). <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/education-and-skills>

⁶ Cologon, K. (2019). *Towards inclusive education: A necessary process of transformation*, for CYDA, p.5.

⁷ Cologon (2019); Shaw, A. (2017). Inclusion: the role of special and mainstream schools. *British Journal of Special Education*, 44(3), 292-312.

⁸ United Nations Convention on the Rights of Persons with Disabilities, General comment No. 4 (2016) Article 24: Right to inclusive education

⁹ Australia Institute of Health and Welfare (2019). <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/education-and-skills>

¹⁰ Victoria Department of Education. (2019). Summary Statistics Victorian Schools July 2019.

<https://www.education.vic.gov.au/about/department/Pages/factsandfigures.aspx>

¹¹ CYDA. *Time for change: The state of play for inclusion of students with disability*. Results from the 2019 CYDA National Education Survey. https://www.cyda.org.au/education_issues

¹² The University of Melbourne. (2019). Those who disappear: The Australian education problem nobody wants to talk about <https://education.unimelb.edu.au/mgse-industry-reports/report-1-those-who-disappear>

¹³ CYDA (2019) *Education of children and young people with disability Submission No 1.*, Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

¹⁴ Australian Coalition for Inclusive Education. (2020). *Driving change: A roadmap for achieving inclusive education in Australia*.

Australia complies with the United Nations Convention on the Rights of Persons with Disabilities (CPRD)

Address low expectations for students and young people with disability

“Everyone just said I’d never get a job, even though I wanted to”

— *Young person with disability over 25 years old, regional New South Wales*

Low expectations for children and young people with disability throughout their schooling – from schools, communities, and government and policy approaches – significantly undermine inclusion and can affect students’ career planning and post-school outcomes. This is reflected by responses to CYDA’s 2019 survey, in which 70 per cent of students with disability and their families reported facing specific challenges in their post-school planning because they experience disability.

Low expectations can manifest in a lack of encouragement for students with disability to choose subjects that will lead to an Australian Tertiary Admission Rank (ATAR) score.

“Yes, I was told not to bother applying for postgraduate study due to my disability by a disability support officer.”

— *Young person with disability aged 19-20 years old, metropolitan Queensland*

Roughly 70 per cent of students with disability responding to our survey report they were not encouraged to complete or to choose subjects to lead a good ATAR score for higher education (Table 4 in Appendix A).

“Low expectations of students. Teachers told parents at an assembly that “most [students] would not “go onto university.” Situation even worse for those with both visible and invisible disabilities. My application for special consideration as part of HSC exams was denied by the school, without adequate explanation”

— *Young person with disability over 25 years old, metropolitan Victoria*

The need to improve career-planning supports for students with disability is recognised in a recent report from the Education Council, which recommends “all senior secondary students with disability... have access to work exploration in school and, in collaboration with disability support groups, have an individual post-school transition plan put in place prior to leaving school.”¹⁵

Boost investment from governments for students with disability

To date, there is little prioritisation or commitment shown by governments across the country for inclusive education, despite commitments through the UN CRPD. For example, the 2019 Alice Springs (Mparntwe) Education Declaration,¹⁶ which aims to improve outcomes for all young Australians and promote excellence and equity in the Australian education system, and has been endorsed by all Australian Education Ministers, only includes one mention of the word ‘disability.’ The Australia Coalition for Inclusive Education (ACIE), of which CYDA is the convenor, has expressed strong disappointment with the lack of recognition for the needs of children and young

¹⁵ COAG Education Council. (2020). *Looking to the Future: Report of the review of senior secondary pathways into work, further education and training*, Education Services Australia, p.130.

¹⁶ Australian Government Department of Education. (2019). Alice Springs (Mparntwe) Education Declaration December 2019. <https://docs-edu.govcms.gov.au/documents/alice-springs-mparntwe-education-declaration>

people with disability in this plan,¹⁷ which means the systemic barriers to implementing inclusive education remain unresolved.

Over 200 organisations have recently called for the development of a national Action Plan for inclusive education,¹⁸ and for it to “include a legislative and policy framework that fully complies with Article 24 and General Comment 4.”¹⁹ CYDA considers the development and effective implementation of an inclusive education Action Plan would ensure access to genuinely inclusive education for autistic students as well as students with dual disability and other primary disabilities.²⁰

“What would I like to see change?”

Cut the red tape, consider that as a human being I am entitled to a quality equitable education just like anyone else, with access to the curriculum, supports tailored to my needs, provide good communication, proper measures in place to support me socially and with mental health. Many of the things that can make it better for students with disability do not cost more, they just require someone to care enough to consider my needs, so attitudes here are very important.”

— Autistic university student in NSW

¹⁷ Australia Coalition for Inclusive Education ACIE. (2019). *Media Release: New national education policy ignores students with disability – again.* <https://acie.org.au/2019/12/12/new-national-education-policy-ignores-students-with-disability-again/>

¹⁸ Joint NGO Submission on behalf of the Australian NGO Coalition to Australia’s Third Universal Periodic Review by the United Nations. April 2020.

¹⁹ See CPRD Concluding Observations on Australia, UN Doc CRPD/C/AUS/CO/2-3 (n 61).

²⁰ Australian Coalition for Inclusive Education. (2020). *Driving change: A roadmap for achieving inclusive education in Australia.*

Deliver strong post-school outcomes for young people with disability

Inclusion begins before and at school. School systems that promote segregation and exclusion contribute to continued educational, economic and social exclusion for people with disability throughout their lives. Early school leaving and the disengagement of students with disability in post-school pathways also have an impact on the Australian economy, with direct fiscal and social costs, such as higher reliance on welfare and government health programs, reduced tax payments and productivity losses.²¹ In order to improve post-school outcomes for autistic young people and young people with disability in general, it is critical to address the attitudinal, structural and systemic issues facing these students and young people.

Improve employment outcomes for young people with disability

Compared with other OECD countries, Australia has one of the lowest employment participation rates for people with disability.²² Only nine per cent of people with disability report they have the same employment opportunities as other people,²³ and complaints about discrimination in employment make up a significant proportion of all disability discrimination complaints made to Australian anti-discrimination agencies.²⁴

The youth unemployment rate in Australia remains stubbornly high, generally around double the overall unemployment rate²⁵ – and there is evidence young people are among those most affected by the employment impacts of the COVID-19 pandemic.²⁶ There is little available data about unemployment for young people with disability in particular, but this rate is likely to be considerably higher as Australia has one of the lowest employment participation rates for people with disability.²⁷

According to the NDIS Employment Outcomes Report 2018, only 41 per cent of 15 to 24 year-olds have a paid job in open employment at full award wages, with a further 14 per cent in open employment at less than full award wages, and 35 per cent working in an Australia Disability Enterprise.²⁸ Like segregated education, segregated employment in Australian Disability Employment ‘sheltered workshops’ constitutes a form of neglect of people’s rights.

There is little evidence to date that the NDIS has improved employment outcomes for many people with disability, although an NDIS Participant Employment Taskforce was established in early 2019.²⁹ Collectively this means young people with disability are likely to rely heavily on income support such as the Disability Support Pension, Jobseeker (formerly Newstart) or Youth Allowance.

²¹ Lamb, S. and Huo, S. (2017). *Counting the costs of lost opportunity in Australian education*. Mitchell Institute report No. 02/2017. Mitchell Institute, Melbourne.

²² See Price Waterhouse Coopers (2011) [Disability Expectations: Investing in a better life, a stronger Australia](#).

²³ National CRPD Survey (2019) Findings. <https://dpoa.org.au/crpd-shadow-report-consultation-survey-results/>

²⁴ Australian Human Rights Commission (2016) [Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability](#), AHRC, Sydney. (2015)

²⁵ Brotherhood of St Laurence, Youth Unemployment Monitor, March 2019 http://library.bsl.org.au/jspui/bitstream/1/11134/2/BSL_Smashing_the_avocado_debate_youth_unemployment_hotspots_Mar2019.pdf

²⁶ Dimov, S., King, T., Shields, M. & Kavanagh, A. The young Australians hit hard during COVID-19. The University of Melbourne Pursuit; available: <https://pursuit.unimelb.edu.au/articles/the-young-australians-hit-hard-during-covid-19>.

²⁷ See: Price Waterhouse Coopers (2011) [Disability Expectations: Investing in a better life, a stronger Australia](#).

²⁸ NDIA. (2018). NDIS Employment Outcomes 30 June 2018. <https://www.ndis.gov.au/about-us/data-and-insights/reports-and-analyses/employment-outcomes-participants-their-families-and-carers>

²⁹ Federal Department of Social Services. (2019). NDIS Participant Employment Terms of Reference. <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-employment-for-people-with-disability/ndis-participant-employment-taskforce-terms-of-reference>

“Yes, more difficult to know of suitable work options. Hard to get work placements that are not lip service”

— Family of a young person with disability aged 21-22 years old, metropolitan VIC

National data is reflected by the responses CYDA received to our 2019 post-secondary survey. Survey participants who are no longer at school were asked about the activities they are currently undertaking. Almost 30 per cent are currently working in some capacity (ranging from full-time to casual), 24.5 per cent are undertaking volunteer work, 21.3 per cent participate in day programs, and 19.6 per cent are studying or training part time (Table 10, Appendix A).

However, less than half of the respondents who are currently in the labour force are working in open employment (Table 11, Appendix A). Additionally, around half of our survey respondents who are currently in work report that they are paid less than a full award wage (Table 12, Appendix A).

“Currently in open employment. However, after graduating from my degree, I spent about 1 year in unemployment and on Centrelink, with Job Active reporting requirements. I believe disability discrimination was a barrier to employment. Due to my disability type (mental health) did not even bother trying to go through DSP, went onto Newstart and was tormented by Centrelink staff and Job Active providers, making me more unwell, and destroying my confidence. However, have been in work since.”

— Young person with disability over 25 years old, metropolitan Victoria

Ensure income support programs allow young people with disability to live above the poverty line

As outlined above, a range of systemic factors contribute to higher rates of social security uptake and poverty for people with disability, including young people. Around 50 per cent of young people with disability aged 15 to 24 years rely on income support payments, compared to 14 per cent of people aged 15 to 24 years without a disability.³⁰ Changes to the eligibility criteria for the Disability Support Pension (DSP) since 2012 mean that many young people must instead apply for Jobseeker (formerly Newstart) or Youth Allowance, which provide a significantly lower rate of pay than the DSP.³¹

As at June 2019, data shows that approximately 10.5 per cent of all recipients of Newstart and Youth Allowance – 31,798 people – were people with a partial capacity to work from illness or disability, however, this public data is not broken down by age. Data obtained by CYDA from the Department of Social Services shows that:

- The number of Newstart recipients aged between 20 and 25 years with partial capacity to work has increased by 258 per cent in the decade from 2009, growing from 5,308 in 2009 to 19,017 in 2019
- The number of Youth Allowance recipients under 19 years old with partial capacity to work has increased by 121.8 per cent, from 2,299 in 2009 to 5,100 in 2019

³⁰ Brotherhood of St Laurence, Youth Unemployment Monitor, March 2019

http://library.bsl.org.au/jspui/bitstream/1/11134/2/BSL_Smashing_the_avocado_debate_youth_unemployment_hotspots_Mar2019.pdf

³¹ Services Australia (2020). *Centrelink payments and services*, available: <https://www.servicesaustralia.gov.au/individuals/services/centrelink>.

- The number of Youth Allowance recipients aged between 20 and 25 years with partial capacity to work has increased by 720.6 per cent, from 936 in 2009 to 7,681 in 2019
- The number of DSP recipients under 19 years old has decreased by 24.8 per cent, from 18,414 in 2009 to 13,843 in 2019
- The number of DSP recipients aged between 20 and 25 years has increased slightly, by 10.9 per cent, from 36,128 in 2009 compared to 40,092 in 2019.

These data are highlighted in Figures 2 and 3 in Appendix A.

Along with addressing the barriers facing young people with disability in employment, the additional challenges experienced in the social security and the high levels of poverty for people with disability must be urgently addressed. Social security payments need to be at a level that supports people to live above the poverty line.³² We have seen the positive impacts of higher Jobseeker payments through the COVID-19 pandemic, for example, with many people reporting they are now able to purchase three meals a day or fresh fruit and vegetables for their households.³³ The exclusion of DSP recipients from the COVID-19 supplement was another example of inconsistencies and exclusionary treatment for people with disability.³⁴

Enable access to further education and training for young people with disability

Students with disability continue to face significant barriers to accessing and participating in higher education and training. Within the 15-65 year age group, only 17 per cent of people with disability have a bachelor degree or higher, compared to 30 per cent for individuals without disability. People with disability are more likely to have attained a certificate-level qualification (28.4 per cent) than those without disability (22.5 per cent).³⁵

The impact of exclusion and poor post-school planning opportunities on students' further education is highlighted by our survey respondents. Almost half of the respondents to our 2019 survey have completed Year 12 but have not completed further education, and around 20 per cent have completed Year 10 or 11 as their highest educational attainment to date. Twelve per cent have completed some form of higher degree or certificate.

“I did not choose to have Autism, but the Uni has chosen to design their curriculum to not be flexible and include my needs”

— *Autistic university student in New South Wales*

Improving participation rates for students with disability in employment, education and training will require reviewing funding approaches to further education and post-school options. A recent paper from the Mitchell Institute recommends addressing the different funding arrangements for universities and the VET sector, and reforming the Australia Qualifications Framework (AQF) to removing inappropriate hierarchies in the descriptions of VET and higher education. It also

³² Australian Council of Social Service and UNSW (2020), *Research and insights into poverty and inequality in Australia: Causes and solutions*, webpage, available: <http://povertyandinequality.acoss.org.au/causes-and-solutions/>.

³³ Hermant, N. (2020). JobSeeker welfare recipients fear end of life-changing Coronavirus Supplement, *ABC News*, 24 June, available: <https://www.abc.net.au/news/2020-06-24/jobseeker-recipients-fear-end-of-coronavirus-supplement/12379806>

³⁴ Various advocacy organisations (2020). *Increase Disability Support Pension now to deal with coronavirus*, Joint statement. Available: http://www.neda.org.au/sites/default/files/2020-03/DSP%20Coronavirus%20supplement%20increase_1.pdf

³⁵ Australia Disability Clearinghouse on Education and Training. (2019). *Higher Education Statistics* <https://www.adcet.edu.au/inclusive-teaching/understanding-disability/Higher-Education-Statistics/>

recommends including micro-credentials as a recognised short-term learning program in the AQF structure.³⁶

CYDA agrees that a new, more cohesive approach to funding the tertiary education sector is required, and urges the consideration of appropriate funding and support for students with disability as part of this. The Education Council's 2020 report, *Looking to the Future*, provides 30 recommendations to improve post-school planning and opportunities for young people.³⁷

³⁶ Dawkins, P., Hurley, P., & Noonan, P. (2019). *Rethinking and revitalising tertiary education in Australia*. Mitchell Institute, Melbourne. <http://www.mitchellinstitute.org.au/papers/rethinking-and-revitalising-tertiary-education/>

³⁷ COAG Education Council. (2020). *Looking to the Future: Report of the review of senior secondary pathways into work, further education and training*, Education Services Australia.

Ensure access to appropriate disability services and support

The social model of disability, first articulated in the 1980s, holds that disability arises from the intersection of an impairment with the environment – that it is not the impairment itself that ‘disables’ but instead an inequitable society.³⁸ The social model does not discount the impact of impairments but focuses on the need for appropriate individual supports alongside structural change and progress towards inclusion. As such, access to safe, high-quality supports when and where they are needed is essential, and it is crucial these are delivered from a rights-based perspective with the individual’s rights and best interests at their core.

Ensure the NDIS is relevant and works for children and young people³⁹

The importance of early childhood, adolescence and early adulthood for lifelong inclusion, employment, economic independence and wellbeing is well known. The NDIS was essentially initiated in an adult paradigm, and then adapted to fit the context of children and young people with disability.

Even before entering the NDIS, families of children and young with disability often encounter challenges with eligibility criteria and difficulty obtaining medical diagnostic reports and assessments to ‘prove’ the child’s disability. This leads to significant costs and stress to families, and means there is inequitable access for children living in families experiencing poverty or hardship. Many find it hard to access to the Scheme without support or advocacy services. Families are also concerned their child only receives support for what is considered the “primary disability” rather than support for their full spectrum of needs.

Information about accessing the Scheme, and throughout the planning and implementation processes is often confusing. Families are unclear on what the Scheme can and cannot fund and are not supported to access services and supports outside the NDIS when these are not included in the NDIS plan. The interface issue with the NDIS and other systems such as health and education need to be urgently resolved by the NDIA and state and territory governments.

During the planning stage, families reported the NDIS was not designed for children and there is a lack of family-centred practice. NDIS plans consider children and young people in isolation from their families despite extensive research which shows the development and wellbeing of children and young people is facilitated through supportive home learning and support environments. Families can be denied support and services as these are considered to be ‘parental responsibility,’ and there is a push to medicalise the supports in the plan rather than consider the natural environments and supports in the community which promote the wellbeing and development of children and young people.

“This year we have not been able to access support for any social community inclusion for our eldest son with autism. NDIS deemed it parental responsibility. We cannot take him to social events like a sport group with someone available to

³⁸ Oliver, M. (2013). The social model of disability: thirty years on, *Disability & Society*, pp.1024-1026.

³⁹ This section of our submission is informed by our members and results from a national survey conducted by CYDA in July 2019 of 189 young people with disability, and families and caregivers of children with disability about their NDIS experience. It is also informed by our 2019 National Education Survey conducted in August and September 2019 of 505 families and students with disability. Further information is provided in Appendix B, our submission to the Tune Review.

solely focus on him. He has to have a support person with him to guide him through the difficulties that arise from social difficulties.”

— Family with two children in the NDIS, metropolitan South Australia

The lack of knowledge by the National Disability Insurance Agency (NDIA), Early Childhood Early Intervention (ECEI) partners and Local Area Coordinators (LACs) about disability, development transitions for children and young people, and family-centred practice was criticised by families. They also need to work with multiple staff rather than having a one single point of contact throughout the planning process, which proves challenging.

The emergence of thin markets, long wait lists and little choice of service providers in local communities is providing challenges and this issue is more pronounced for families living in regional, remote or rural areas as well as children with complex needs and those from culturally and linguistic diverse backgrounds.

Families also reported that once the NDIS plan is approved it can be difficult to know what the next step is, how to use the funds or how to find and compare providers. This can contribute to under-spending and under-utilisation of plans.

There are considerable concerns with the review and appeals processes, including the language used by the NDIA staff and its partners which is confusing and unclear. Families reported issues with the lack of clear timeframes when requesting a review decision as well as the stress and financial pressure to cover the services while waiting for a review decision.

“Plans didn’t reflect child’s support needs and contained inaccurate information. A large proportion of funds were allocated to things we didn’t ask for or need (i.e. incontinence nurse) whilst things that would have made a tremendous difference were denied.”

— Family of a child aged 7-9 years, metropolitan Victoria

Guarantee direct supports are safe, appropriate, and come from a rights-based approach

CYDA would like to endorse the submission to this inquiry from Reframing Autism, provided in April 2020. In particular, CYDA emphasises our support for Reframing Autism’s discussion of best practice support services for children and young people:

“Reframing Autism has grave concerns about the provision of any therapy or intervention which “normalises” Autistic people or suppresses intrinsic Autistic behaviours. We also reject any intervention which suggests (whether tacitly or explicitly) that a non-autistic neurology is superior or even preferable to an Autistic one.

Reframing Autism specifically rejects the use of any therapy or intervention which utilises a system of rewards and punishments to modify Autistic behaviours and train Autistic individuals to act and perform non-autistically, or which are intensive in nature.”⁴⁰

Therapies or interventions along these lines reflect the medical model of disability and take a ‘curative’ approach to autism, denying children’s fundamental human rights. CYDA considers there

⁴⁰ Reframing Autism, *Submission to the Select Committee on Autism*, April 2020, Submission 24.

is a risk that by adopting a diagnosis-specific approach to disability policy (such as the development of a National Autism Strategy) this medical approach becomes more embedded, rather than taking a rights-based approach.

It is CYDA's view that the NDIS and other government systems should ensure that support services provided to children and young people with disability are safe and appropriate and that they respect and uphold individuals' human rights.

Address the interface issues between the NDIS and other systems

Although the NDIS is more than five years old in many parts of the country, considerable issues remain in the way that the Scheme interacts with other systems that affect the lives of children and families. This includes the education system, as well as other government systems including health,⁴¹ child protection and out-of-home care,⁴² and youth justice. Continuing interface issues for children and young people and their families/caregivers navigating these systems lead to poorer outcomes and can contribute to tragic outcomes for children who fall through the cracks between systems.⁴³

Our 2019 education survey results showed that almost 60 per cent of respondents are out-of-pocket for a range of supports or equipment and have paid personally to enable a student with disability to access and participate in education.⁴⁴ Recent data collected through the COVID-19 pandemic shows this has become an even greater challenge during periods of remote learning.⁴⁵

"Being asked to have the child do schooling online, which is basically impossible for a child with ADHD and ASD. This will require full-time oversight by me, which means I can't work!"

— Family of a child aged 7-12 years old, metropolitan NSW

"We desperately need ideas on how to utilise remote/online (Zoom, WhatsApp video calls etc.) supports for our daughter (intellectual impairment and autism) as my husband and I are both working from home and finding it very hard to keep our daughter occupied while we need to have online meetings ourselves. We need help to facilitate her interactions with her social group too, to give her something to look forward to during the week - she is very social and is struggling to cope without seeing her regular support workers and friends."

— Family of a young person aged 18-25 years, metropolitan Queensland

⁴¹ Summer Foundation. (2018). Insight into Design Issues in the Health and NDIS Systems Interface, Summary report to the Department of Health and Human Services, <https://www.summerfoundation.org.au/wp-content/uploads/2018/07/design-issues-health-ndis-interface-june2018.pdf>.

⁴² Macmillan, J. (2018), 'NDIS transition could see children with severe disabilities withdrawn from out-of-home care,' ABC News (17 Feb), available: <https://www.abc.net.au/news/2018-02-17/ndis-transition-children-disabilities-withdrawn-out-of-home-care/9456650>.

⁴³ Roberts, G. & Swanston, T. (2020), 'Death of 4yo Willow Dunn came after 'sustained mistreatment', Brisbane detective alleges,' ABC News (29 May), available: <https://www.abc.net.au/news/2020-05-29/willow-dunn-death-mistreatment-alleged-child-family-commission/12300306>; Smith, R. (2020). 'Neighbours repeatedly warned authorities about two teens kept in squalid Brisbane room,' *news.com.au*, (29 May), available: <https://www.news.com.au/national/queensland/news/neighbours-repeatedly-warned-authorities-about-two-teens-kept-in-squalid-brisbane-room/news-story/5dfc3245eb0f82734e6c9f9fe2dadaa8>.

⁴⁴ CYDA (2019). *Time for change: The state of play for inclusion of students with disability*.

<https://www.cyda.org.au/resources/details/147/time-for-change-the-state-of-play-for-inclusion-of-students-with-disability>

⁴⁵ Dickinson, H., Smith, C., Yates, S., & Bertoul, M. (2020). *Not even remotely fair: Experiences of students with disability during COVID-19*. Report on CYDA's Education Survey 2020, for CYDA.

Investigate and address gender inequality and promote inclusion

Another area of inequity currently playing out through the NDIS is gender, with male-identifying people over-represented among participants.⁴⁶ Further investigation is needed around why women, girls, and gender diverse people are under-represented in the Scheme. This may be of particular interest to the Committee given the evidence around the under-diagnosis of autistic women and girls as well as gender diversity among autistic people.⁴⁷ It is critical to ensure the NDIS and its workforce are cognisant of gender diversity, trained in intersectionality and promote genuine inclusion for all people with disability.

⁴⁶ NDIS. 2020. Quarterly Report Appendices. <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

⁴⁷ Cooper, K., Smith, L. & Russell, A. (2018) Gender Identity in Autism: Sex Differences in Social Affiliation with Gender Groups, *Journal of Autism and Developmental Disorders*, 48(12): 3995-4006.

Appendix A: Results from CYDA's 2019 post-secondary survey and supplementary information

CYDA conducted a national survey between November and December 2019 '*Pathways for young people with disability after school*' to collect information about the experience of senior students with disability and their families with career planning and post-school options.

In total, 86 people had responded to the survey at the time of writing this submission. This included representation from all states and territories, and from metropolitan, regional, rural and remote areas. The majority of the respondents were from families of young students with disability (81.3 per cent), followed by students with disability (18.6 per cent) and teachers and other school staff (3.4 per cent).

Key findings are presented below in support of our submission.

Introduction

Respondents' demographic data

Table 1. Demographic characteristics of senior students with disability (n=69)

Demographic characteristic	Number	Percentage
Gender		
Male	55	63.9%
Female	27	31.3%
Prefer not to say or not specified	4	4.6%
Language and cultural background		
English speaking background	75	87.2%
Non-English-speaking background	11	12.7%
Aboriginal	0	0
State / territory		
VIC	29	33.7%
NSW	25	29%
QLD	10	11.6%
WA	4	4.6%
SA	5	5.8%
ACT	9	10.4%
TAS	3	3.4%
NT	1	1.1%
Location		
Metropolitan area	50	58.1%
Regional area	24	27.9%
Rural	10	11.6%
Remote	1	1.1%
Age of senior student with disability		
15-16 years	14	16.2%
17-18 years	18	20.9%
19-20 years	20	23.2%
21-22 years	9	10.4%
23-25 years	13	15.1%

Demographic characteristic	Number	Percentage
Over 25	12	13.9%
Type of school		
Government	54	62.7%
Non-government (e.g. faith-based, private school)	25	29%
Distance education or e-learning	3	3.4%
Other	7	8.1%

Address exclusion in schools

Ongoing segregation in Australian schools

Table 2. School setting of survey respondents (n=83)

School setting	Number	Percentage
Mainstream school	47	56.6%
Special school	21	25.3%
Dual enrolment	5	6%
Other	13	15.6%

Table 3. Type of class of survey respondents were/are enrolled (n=70)

Type of class	Number	Percentage
Regular class	42	60%
Special unit	19	27.1%
Other (combination of both)	17	24.2%

Low expectations for students and young people with disability

Table 4. Students with disability who completed ATAR score of survey respondents (n=83)

Students with disability who completed ATAR score	Number	Percentage
No	58	69.8%
Yes	17	20.4%
Don't know	7	8.4%

Develop tailored transition support for students with disability

Lack of appropriate support for students' career-planning

Figure 1. Respondents' level of agreement with statements around the transition support they received

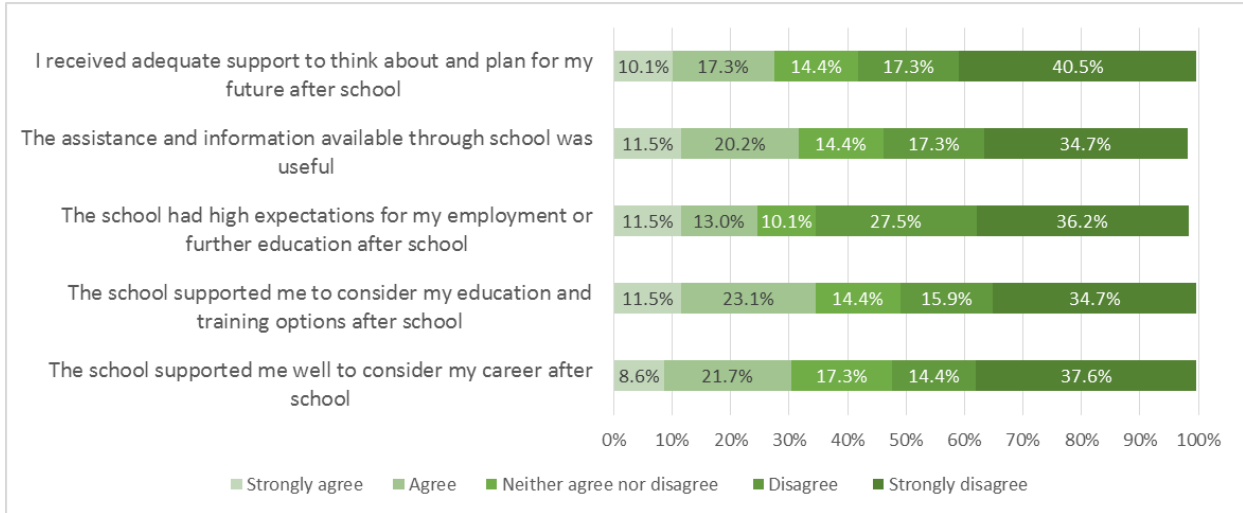


Table 5. Career-planning support reported by students (n=67)

Type of support	Number	Percentage
Individual career counselling and advice	20	29.8%
Opportunity to participate in career related activities (e.g. workshops, seminars, information sessions)	19	28.3%
Individual assistance with planning any study or training post-school (e.g. university, TAFE, traineeships or apprenticeships)	13	19.4%
Assistance in understanding your strengths and skills for your post-school transition	12	17.9%
The opportunity to undertake work experience and assistance to organise this	31	46.2%
Information about upcoming University or TAFE information sessions or expos	15	22.3%
Practical assistance such as resume writing, assisting with job applications, assistance with applications to university or TAFE	11	16.4%
Other	23	34.3%

Inconsistencies around the country

Table 6. Current school programs to support pathways after school

State / territory	Program	Purpose
Australian Capital Territory	Pathways Website	<ul style="list-style-type: none"> • A Website assisting young people with their transitions and career planning however not specific for students with disability
New South Wales	School to Work Program	<ul style="list-style-type: none"> • The School to Work Program is for all students in NSW public schools with a secondary enrolment and actively supports their informed, planned and quality transitions through school and particularly from school for each student. It also includes collaboration with primary schools to coordinate career related learning as student's transition from Year 6 to Year 7.
Northern Territory	Transition from School Services	<ul style="list-style-type: none"> • Provide support for students with a disability when they leave school to go to further education, employment or community access programs. The transition process can begin in Year 9 or 14 years of age.
Queensland	<ol style="list-style-type: none"> 1. Senior Education and Training (SET) plans 2. My Future, My life 	<ol style="list-style-type: none"> 1. SET Plans are completed with all students during Year 10. 2. My Future, My life is an Initiative designed to help students with disability achieve the goals they have set for themselves in their SET plans. This early intervention strategy has been developed to provide practical assistance to young people with disability in their final years of school to begin their transition from school. My Future, My Life is run by a non-government organisation
South Australia	<ol style="list-style-type: none"> 1. Better pathways program 2. Transition Centres 3. The Transition Program 	<ol style="list-style-type: none"> 1. Provides coaching and mentoring services to students with disability. The program assists students to create, pursue and achieve their vocational goals. This is done through one-on-one support with a dedicated worker. 2. The Transition centres offers a range of courses for secondary students with disability to develop their employability skills. It is also a consultative service for teachers and leaders in the school to facilitate the planning and successful transition to post school options. 3. This 12 month training program is designed to assist final year students with disability and learning difficulties to make a smooth transition from school to future pathways

Tasmania	My Education	<ul style="list-style-type: none"> • An online resource that guide all students from Kindergarten to Year 12. It supports students to identify their personal interests, values, strengths and aspirations, and teaches them how to use this knowledge to make decisions about their future learning, work and life opportunities. • My Education 7–12 is an online tool, ME Online. This tool will connect your child to resources, materials and data that will assist them in developing a life and career plan.
Victoria	Transforming career education. Career Education Funding CEF replaced Managed individual pathways (MIPs) funding in 2019.	<ul style="list-style-type: none"> • Supports schools to provide career education activities for all students in Years 7 to 12. • Additional funding is provided to schools with Student Family Occupation (SFO) densities greater than a threshold value to support young people at risk of disengaging or not making a successful transition to further education, training or secure employment. • PSD: Program for students with disability.
Western Australia	Transition Planning Program	<ul style="list-style-type: none"> • To assist young people with a disability make a smooth transition to adult life. Transition planning activities are from 8 to year 12.

Starting planning earlier

Table 7. Year when student with disability start receiving career planning support (n=68)

Year level when student with disability start receiving career planning	Number	Percentage
Year 9	3	4.4%
Year 10	15	22%
Year 11	15	22%
Year 12	19	27.9%

Provide more information to students with disability and their families

Improve support for parents and family members

Table 8. Parent involvement in career planning process of their child (n=54)

Parent involvement in career planning process	Number	Percentage
Not involvement	23	42.5%
Very little involvement	12	22.2%
Involved in planning meeting with DHS and not school (program before NDIS)	3	5.5%
Involvement in transition meetings, expos, open days meeting with providers	14	25.9%
Parents did the career planning	3	5.5%
Parent involved in subject selection meetings with school staff	1	1.8%
School provided parents with formal feedback on potential ATAR and engagement with Coordinator	1	1.8%
Learning support teacher helped and helped student and parent but not the career teacher	1	1.8%
Parent involved in two planning meetings in a year	1	1.8%
School offered insurance for work experience	1	1.8%
Info session about tertiary study.	1	1.8%

Provide relevant information to organisations in students' lives

Table 9. Source of assistance or information available other than school (n=67)

Assistance or information available out of school for post school pathways	Number	Percentage
Disability Employment Services	20	29.8%
JobActive Employment Service	2	2.9%
Support by education or training provider to participate and maintain enrolment	12	17.9%
Online and web searches	11	16.4%
Community Service organisation	12	17.9%
NDIS provider or disability provider	30	44.7%
Advocacy organisation	4	5.9%
Other	24	35.8%

Deliver strong outcomes for students with disability after school

Employment outcomes for young people with disability

Table 10. Current post school activities of survey respondents (n=61)

Current post school activities	Number	Percentage
Currently in a day program	13	21.3%
Currently working full-time in an ongoing permanent position	1	1.6%
Currently working full-time in a fixed or short term position	1	1.6%
Currently working part-time in an ongoing permanent position	6	9.8%
Currently working part-time in a fixed term or short term position	3	4.9%
Currently working in a casual position	7	11.4%
Currently looking for work	7	11.4%
Currently not looking for work	8	13.1%
Currently studying/training part-time	12	19.6%
Currently studying/training full-time	8	13.1%
Currently undertaking a traineeship or apprenticeship	2	3.2%
Currently undertaking voluntary work	15	24.5%
Other	20	32.7%

Table 11. Type of employment of survey respondents. (n=37)

Type of Employment	No	Percentage
Working in the general labour market	18	48.6%
Working in an Australian Disability Enterprise ADE	4	10.8%
Other	18	48.6%

Table 12. Type of award wages of survey respondents (n=37)

Type of award wages	No	Percentage
Receiving full award wages	14	37.8%
Receiving less than full award wages	16	43.2%

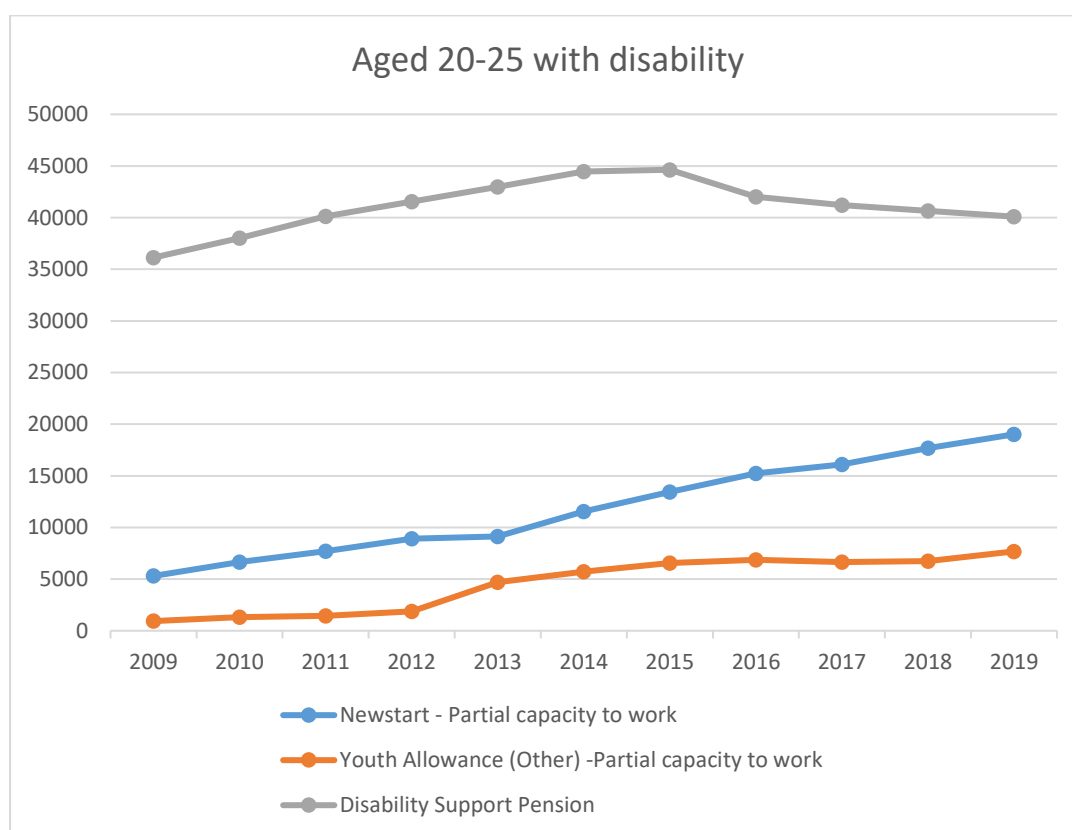
Don't know	7	18.9%
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Income support programs

Table 13. Survey respondents receiving income support payments (n=66)

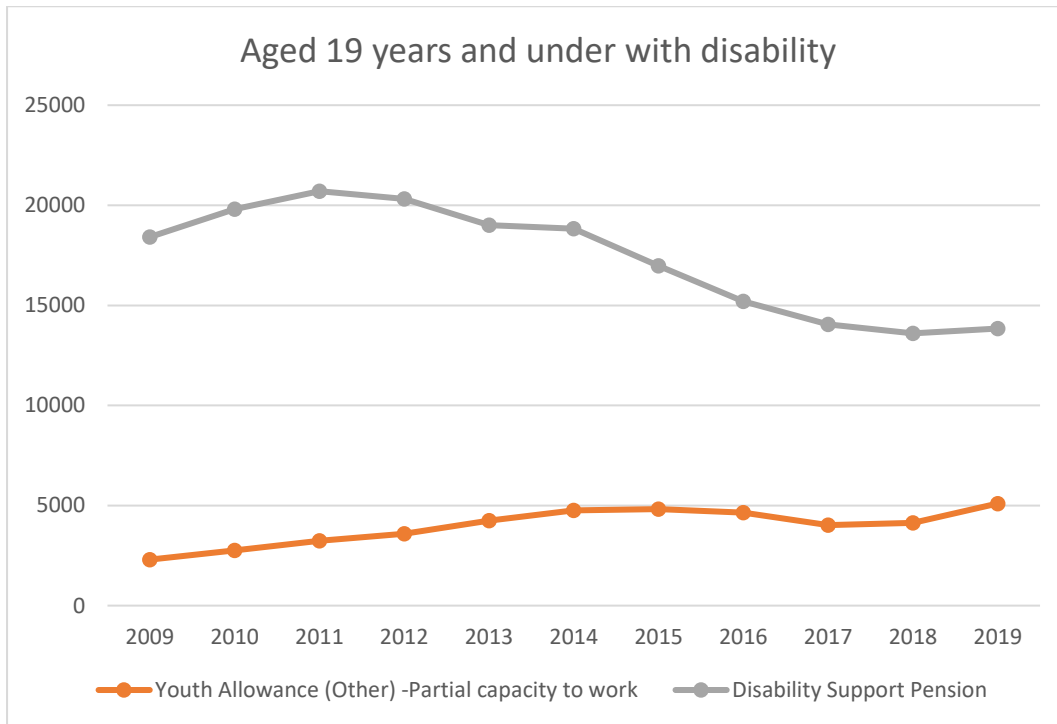
Type of income support payments	No	Percentage
Not receiving income support	18	27.2%
Disability Support Pension (DSP)	42	63.6%
Newstart Allowance	2	3%
Youth Allowance	4	6%

Figure 2. Trends from 2009 to 2019 of Newstart Allowance, Youth Allowance with partial capacity to work and Disability Support Pension recipients aged 20 to 25 years



Source: Department of Social Services data provided to CYDA

Figure 3. Trends from 2009 to 2019 of Youth Allowance with partial capacity to work and Disability Support Pension recipients aged 19 years and under



Source: Department of Social Services data provided to CYDA

Access to further education

Table 13. Highest level of education of survey respondents (n=81)

Highest level of education	Number	Percentage
Postgraduate Degree	0	0
Graduate Diploma	1	1.1%
Graduate Certificate	1	1.1%
Bachelor Degree	4	4.9%
Advanced Diploma and Diploma	0	0
Certificate III / IV	4	4.9%
Year 12	38	46.9%
Year 11	11	13.5%
Year 10	6	7.4%
Year 9 or below	20	24.6%

Appendix B: CYDA's submission to the Tune Review, October 2019



**Children and Young People
with Disability Australia**

Improving the NDIS for children and young people with disability and their families

Children and Young People with Disability Australia Submission – October 2019

**Establishing a Participant Service Guarantee and removing legislative red tape
review**

Contents

Executive Summary.....	2
Recommendations.....	4
Introduction.....	6
Review the NDIS for children and young people with disability to ensure evidence-based practice ..	7
Streamline access to the NDIS	9
Improve information about the NDIS across access, planning and plan implementation	12
Improve the NDIS planning process.....	14
Build the capability of NDIA, ECEI and LAC’s planners.....	16
Address thin markets and underutilisation of plans	17
Reform the NDIS internal reviews and appeals process	20
Address NDIS interface issues	22
Participant Service Guarantee Service Standards	23

Authorised by:

Mary Sayers, Chief Executive Officer

Contact details:

Children and Young People with Disability Australia

E. marysayers@cyda.org.au

P. 03 9417 1025

W. www.cyda.org.au

Executive Summary

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 – 25 years. CYDA has an extensive national membership of over 5,000 young people with disability, families and caregivers of children and young people with disability, and advocacy and community organisations.

CYDA's purpose is to systemically advocate at the national level for the rights and interests of all children and young people with disability living in Australia.

This submission is informed by our members and results from a national survey conducted by CYDA in July 2019 of 189 young people with disability, and families and caregivers of children with disability about their NDIS experience. It is also informed by our 2019 National Education Survey conducted in August and September 2019 of 505 families and students with disability.

While CYDA supports the National Disability Insurance Scheme (NDIS), the implementation has been plagued by implementation challenges. Therefore we welcome the establishment of the NDIS Participant Service Guarantee and the review of the current legislation.

Even before entering the scheme, families of children and young with disability encounter challenges with the NDIS eligibility criteria and the difficulty in obtaining medical diagnostic reports and assessments to prove the child's disability. This provides significant costs and stress to families, and inequitable access for children living in families experiencing poverty or hardship. Many find it hard to access to the scheme without support or advocacy services. Families are also concerned their child only receives support for what is considered the "primary disability" rather than support for the full spectrum of needs

The information about accessing the scheme, and throughout the planning and implementation process has been confused. Families are unclear on what the scheme can and cannot fund and are not supported to access services and supports outside the NDIS when these are not included in the NDIS plan. The interface issue with the NDIS and other systems such as health and education need to be urgently resolved by the NDIA and state and territory governments.

During the planning stage families reported the NDIS was not designed for children and there is a lack of family centred practice. NDIS plans consider children and young people in isolation from their families despite extensive research which shows the development and wellbeing of children and young people is facilitated through supportive home learning and support environments. Families are denied support and services as considered "parental responsibility, and there is a push to medicalise the supports in the plan rather than consider the natural environments and supports in the community which promote the wellbeing and development of children and young people.

no having access to the NDIS draft prior approval and the need of face to face discussions as telephone meeting not always appropriate to engage young people and children with disability and their families /caregivers. Pre-planning support for all children and young person with disability and their families is an urgent need to improve NDIS plans and participants outcomes.

The lack of knowledge by the National Disability Insurance Agency (NDIA), Early Childhood Early Intervention (ECEI) partners and Local Area Coordinators (LACs) about disability, development transitions for children and young people, and family-centred practice was criticised by families. They also need to work with multiple staff rather than having a one single point of contact throughout the planning process, which proves challenging.

The emergence of thin markets, long wait lists and little choice of service providers in local communities is providing challenges and this issue is more pronounced for families living in regional, remote or rural areas as well as families with culturally and linguistic diverse backgrounds.

Families also reported that once the NDIS plan is approved don't know what is the next step, how to use the funds or to find and compare providers and resulted in underspending and underutilisation of plans.

The review and appeal process has also been identified as problematic including the language used by the NDIA staff and its partners which is confusing and unclear. Families reported issues with the lack of clear timeframes when requesting a review decision and the stress and financial pressure to cover the services while waiting for a review decisions.

We make a number of recommendations for improving the NDIS for children and young people with disability for the Participant Service Guarantee including three new principles, specifically for children and young people with disability: *early intervention*, *family-centred practice* and *evidence-based practice*. We also recommend two other principles for all participants which are *accountable* and *consistency*.

A summary of the major legislative changes recommended to the National Disability Insurance Scheme (NDIS) Act 2013 are:

- Amend the sections 25 and 26 to ensure that pre-existing diagnostic/assessment information can be used and to ensure children with disability and developmental risks who will benefit from early intervention can access the scheme.
- Amend Section 34 particularly subsection (e), (g), and (h).
- Amend Section 37 to enable review of plan before finalisation and allow 20 working days to request changes after plan notification.
- Amend Section 100 subsection (6) including a timeframe of 20 working days for the reviewer to make a decision, or in the event of requesting more information an extension of 28 days will apply.

Recommendations

Review the NDIS for children and young people with disability to ensure evidence-based practice

- Conduct a review of the NDIS for children and young people with disability aged up to 25 in consultation and co-design with families, young people with disability, advocates, researchers and Aboriginal and Torres Strait Islander and Culturally and linguistically diverse stakeholders
- Ensure NDIA partners and staff are trained fully in family-centred practice
- Develop tools and resources for families so they feel empowered in enacting evidence-based choice and control on behalf of their child

Streamline Access to the NDIS

- The NDIA and state and territory governments work together to trial new models of health and diagnostic assessment so children and young people with disability can access the NDIS, with a particular focus on hard to reach cohorts
- Simplify the process for eligibility for children and young people with disability allowing previous diagnostic reports or assessments to be sufficient evidence when the condition has not changed
- Provide interim plans for families of children from 0 to 6 years old while awaiting the full suite of diagnostic evidence needed to prove eligibility.
- The NDIA regularly monitor access to the scheme by hard to reach cohorts of children and young people with disability
- Provide increased funding for advocacy services to assist families of children and young people with disability access the NDIS and help with the planning process

Improve information about the NDIS across access, planning and plan implementation

- Simplify the terminology used across the NDIS scheme, using easy simple keywords
- Develop consistent and accurate information spanning access, planning and plan implementation
- The NDIA continually monitor the information needs of the current and prospective NDIS participants and their families/caregivers and provide accessible information
- Amend NDIS Act 2013 Section 34, particularly subsections (e), (g) and (h)
- Develop resources about providers, their responsibilities and alternatives for when the families of children and young people with disability experience thin markets

Improve the NDIS planning process

- Offer pre planning support families of children and young people with disability to improve the quality of NDIS plans and outcomes
- The NDIS Act 2013 (Section 37) be amended to enable review of plans before finalisation and allow 20 working days to request changes after draft plan notification

Build the capability of NDIS, ECEI and LAC's planners

- Require NDIA planners, LAC and ECEI workforces to receive training in family-centred practice, child and youth development and empowerment

- Provide regular and transparent reporting on families of children with disability and NDIS participants' satisfaction with the planning process

Address thin markets and underutilisation of plans

- Provide support coordination for all children and young people with disability during implementation of NDIS plan.
- The NDIA and state and territory governments provide active market stewardship to ensure children and young people with disability receive the right services and supports at the right time
- The NDIA urgently review the provision of equipment and assistive technology and thin markets for these supports
- The Thin Market Framework considers service availability for children and young people with disability as distinct from adult services

Reform the NDIS internal reviews and appeals process

- Amend NDIS Act 2013 Section 100 subsection (6) including a timeframe of 20 days for the reviewer to make a decision, or in the event of requesting more information an extension of 28 days will apply
- The NDIA inform participants and their families/caregivers through a written communication about their NDIS funding while the review of the reviewable decision is in course
- Review and simplify NDIS terminology related to reviews
- Hold NDIS reviews face to face (when possible) enabling participants to have an advocate at the review
- Reform the AAT appeals process, and resolve issues earlier to prevent escalation to the AAT

Address NDIS interface issues

- Increase transparency about the work of the Disability Reform Council and the NDIA to address NDIS interface issues and monitor progress over time
- Consider the legislative changes that may be required to clarify roles and responsibilities between the NDIS and other government funded services
- The NDIA and state and territory governments provide accessible information to current and prospective NDIS participants about what the NDIS will fund, and where people can access other services

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 – 25 years. CYDA has an extensive national membership of over 5,000 including young people with disability, families and caregivers of children and young people with disability, advocacy and community organisations.

CYDA's purpose is to systemically advocate at the national level for the rights and interests of all children and young people with disability living in Australia and undertakes the following to achieve its purpose:

- Listening and responding to the voices and experiences of children and young people with disability.
- Advocating for children and young people with disability for equal opportunities, participation and inclusion in the Australian community.
- Educating national public policy-makers and the broader community about the experiences of children and young people with disability.
- Informing children and young people with disability, their families and care givers about their citizenship rights and entitlements.
- Celebrating the successes and achievements of children and young people with disability.

CYDA welcomes this opportunity to provide a submission to Mr David Tune AO PSM, Expert Reviewer for the establishment of the NDIS Participant Service Guarantee and removal of legislative red tape.

This submission is informed by our members and results from a national NDIS survey conducted by CYDA in July 2019 of 189 young people with disability, and families and caregivers of children with disability about their experiences of the NDIS. It is also informed by our 2019 National Education Survey conducted in August and September 2019 of 505 families and students with disability.

This submission makes a number of recommendations to improve the operation of the NDIS for children and young people with disability along with what needs to be included in the Participant Service Guarantee to ensure children and young people with disability have evidence-based supports.

Review the NDIS for children and young people with disability to ensure evidence-based practice

Recommendations

Conduct a review of the NDIS for children and young people with disability aged up to 25 in consultation and co-design with families, young people with disability, advocates, researchers, Aboriginal and Torres Strait Islander and culturally and linguistically diverse stakeholders

Ensure NDIA partners and staff are trained fully in family-centred practice

Develop tools and resources for families so they feel empowered in enacting evidence-based choice and control on behalf of their child

The importance early childhood, adolescence and early adulthood for lifelong inclusion, employment, economic independence and wellbeing is well known. The NDIS was essentially initiated in an adult paradigm, and then adapted to fit the context of children and young people with disability.

The development of children and young people with disability needs to be considered as a normal process, just like it is for children without disability, and the importance of the home environment, along with other educational and community environments cannot be underestimated. The same general features of development and learning apply to children with disability to those without.

Children with disability, like all children, develop through their relationships with the important people in their lives. Sensitive and responsive caregiving is a requirement for the healthy neurophysiological, physical and psychological development of a child. The attachments that children form with parents and caregivers create the central foundation from which the brain develops. Children's ongoing learning depends upon having repeated opportunities to practice developmentally appropriate skills in everyday situations with support ('scaffolding') from attuned and responsive caregivers.¹

The family environment influences the development and behaviour of children with intellectual and developmental disability and experience of having a child with disability almost inevitably has a significant impact on the family and they also need support. However the current NDIS current frameworks consider the child or young person in isolation of their families and the important role they provide in supporting their child to develop, but also in providing caring responsibilities.

The Early Childhood Early Intervention (ECEI) pathway has been plagued with problems from a process and from an evidence-based practice perspective. The research tells us that family-centred practice is the 'gold standard' of early intervention, however families surveyed by CDYA report that the needs of the family to provide a safe, supportive and enriching environment is not considered in NDIS processes

"The ECEI planners do not provide a family model considering simply the child and do not consider the importance of prompt early intervention" Family of a child aged 4-6 years, metropolitan Queensland

¹ Department of Education and Training (2010) Early childhood intervention reform project <https://www.education.vic.gov.au/Documents/childhood/providers/needs/ecislitreviewrevised.pdf>

Additionally, families report that they are offered clinically based therapy services in their plans which are based on traditional models of one-on-one support for the child with disability, as opposed to building the capacity of the family to support the development of the child, and to participate in universal services like preschool, education and other community environments.

“This year we have not been able to access support for any social community inclusion for our eldest son with autism. NDIS deemed it parental responsibility. We cannot take him to social events like a sport group with someone available to solely focus on him. He has to have a support person with him to guide him through the difficulties that arise from social difficulties.”
Family, with 2 children in the NDIS, metropolitan South Australia

The notion of choice and control is a foundational underpinning of the NDIS, however families new to disability report not being able to understand what is best to include in their child’s plans. There is the need for capacity building for families to understand what is important to include in their child’s plan that will help the child in their learning and development, alongside the family’s support needs.

CYDA organisational members report to us that evidence-based practice in early childhood intervention has gone backwards since the commencement of the rollout. This includes a loss of expertise from the sector, including trans-disciplinary practice which is a key feature of evidence-based early childhood intervention. They also report that private providers have a vested interest in maintaining individual clinical based interventions with the child, which are cheaper to provide, rather than home-based capacity building for the whole family.

The transition for children following participation in the ECEI pathway is also vexed. While the evidence about brain development shows the importance of the early years up until 25 as a critical window for early intervention, to only have an early intervention pathway that goes to aged six is problematic. This cut-off also comes at a time when one of the most critical transitions happens when children transition to school. CYDA members report that these transitions have deteriorated since the introduction of the NDIS as there are often gaps between when the child start school and when they receive the necessary adjustments at school. Before the NDIS, early childhood intervention providers often assisted families negotiate this difficult transition. Additionally many children do not get a formal diagnosis until after six as they may have a cluster of developmental issues that are yet to have a formal diagnosis. Therefore limiting early intervention children aged up to 6 means many will miss out on important support.

Many families tell CYDA they need to go through a stressful process of proving their child still has a disability to continue to be eligible for the NDIS, which is covered in later sections of this submission.

In order for the NDIS to operate as a true insurance scheme, where the lifetime costs are smaller because children and young people with disability have been supported in their development and learning, we recommend a complete review of the NDIS for children and young people under the age of 25. This review needs to consider all the stages of development from early childhood, adolescence and transition to adulthood to insure the NDIS is fit for purpose. This must be informed by the evidence base and deep consultation with families, young people with disability, advocates and researchers.

Streamline access to the NDIS

Recommendations

The NDIA and state and territory governments work together to trial new models of health and diagnostic assessment so children and young people with disability can access the NDIS, with a particular focus on hard to reach cohorts

Simplify the process for eligibility for children and young people with disability allowing previous diagnostic reports or assessments to be sufficient evidence when the condition has not changed

Provide interim plans for families of children from 0 to 6 years old while awaiting the full suite of diagnostic evidence needed to prove eligibility.

The NDIA regularly monitor access to the scheme by hard to reach cohorts of children and young people with disability

Provide increased funding for advocacy services to assist families of children and young people with disability access the NDIS and help with the planning process

Our NDIS survey found 50% of families / caregivers of children with disability had barriers to accessing the NDIS².

This included challenges in sourcing the required evidence and diagnostic assessments, difficulties understanding the scheme and unclear information about the NDIS.

The burden on families to provide the diagnostic evidence to prove eligibility to the NDIS provides a major barrier for participation. Families reported the NDIA does not allow the use of previous diagnostic assessments as valid evidence. This is a major hurdle for families of children and young people with disability to cover the costs of medical expenses. For example the Autism CRC found that the cost of accessing private autism assessment in Australia could be up to \$2,750 when accessing private services with the median cost being \$580³.

It is well known that families facing poverty and disadvantage face significant barriers to accessing services generally and there is under-diagnosis of disability. This makes it harder for children and young people with disability living in these families to receive services to support their disability and be included in mainstream services such as education and health, let alone secure the assessments required to prove eligibility to the NDIS.

The NDIA needs to review its approach to 'evidence for eligibility' to ensure it does not provide major barriers to children and young people with disability who should be eligible but are locked out because of cost, limited access to health and allied health services or existing evidence is not considered as adequate.

It is also important to acknowledge that some children may have more than one disability or have complex needs. Therefore NDIS funding should not be limited to primary disability diagnosis as this

² CYDA NDIS Survey 2019

³ Taylor, L et al 2016. Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards? Autism Co-operative Research Centre, Brisbane.

will disadvantage participants and their families to access the right support and services to cover all their needs.

“Deafblind was not recognised as a disability originally had deaf as primary vision as secondary took 6 months to fight this” Family of a young person with disability aged 18-25 years, metropolitan NSW

For 17.1% of CYDA survey respondents they reported wait times to access the scheme were extremely long, with many waiting more than 12 months to enter the NDIS.

“It took twelve months from applying to receiving funding. Early in in the piece someone made an error and deemed I had not submitted all the information. I spent two hours at month three on the phone with them while they clarified it had been their mistake and actually the application could proceed. During this time they did not write or communicate to me that they believed there had been an error I just had to call repeatedly to ask them what was going on. After this initial confusion was sorted it took another 9 months to progress to being funded. Every time I called I was told it was my fault as I had made a mistake initially (despite it being clarified that I hadn’t). During these 9 months I had a 10 year old child that was suicidal.” Family of a child aged 10-12 years, Metropolitan Victoria

“It took about 9 months from the time of eligibility confirmation to get plan 1” Family of a child aged 7-9 years, Metropolitan NSW

“Wait time was ridiculous. 14 months from the time our referral was put in to the time i received the phone call we had received funding. Then another 2months to get a plan into place.” Family of a child aged 4-6 years, Regional NSW.

In June 2019 the Minister for the National Disability Insurance Scheme (NDIS), Stuart Robert announced changes to decrease delays of children with disability entering the scheme including a six month interim plan of \$10,000 for children who are eligible for the NDIS, are not categorised as complex and in a risk of waiting more than 50 days to get a plan⁴ and since mid-August the NDIA staff is calling families who have waited more than 50 days since receiving access decision to discuss interim plans⁵ . While we welcome this initiative, it does not address the challenge of families who are struggling to access the medical evidence to prove eligibility.

In the early years children may experience developmental risks but may not yet have a formal diagnosis and this disadvantages them and their families from receiving early intervention support that they may have received under previous state and territory systems.

In order to overcome these issues CYDA recommends amending the sections 25 and 26 of the NDIS Act to ensure that pre-existing diagnostic/assessment information can be used and to ensure children with developmental risks who will benefit from early intervention can access the scheme.

⁴ NDIS. Children to get faster access to NDIS supports. <https://www.ndis.gov.au/news/2990-children-get-faster-access-ndis-supports>

⁵ NDIS. Next steps to address wait times in accessing Early Childhood Early Intervention. <https://www.ndis.gov.au/news/3491-next-steps-address-wait-times-accessing-early-childhood-early-intervention>

Another challenge identified by families of children and young people with disability is that the ECEI, LAC's or Planners disregarding the evidence provided due to lack of understanding and families needing to explain several times the same information.

"Finding a location to meet and travel First planner had no experience with disability and was completely overwhelmed by scope of plan and amount supporting documentation provided. Every time we do a plan review, we have to go over everything again which is frustrating for my son and me" Family of a child aged 10-12 years, Metropolitan VIC

Automatic access to the NDIS for children and young people with disability or with developmental delay who were receiving funds prior the scheme from Commonwealth, States or Territories should be within 20 working days. CYDA confirms through its NDIS survey that many were experiencing delays.

"We were referred by DHS. It took ages and was very process intensive." Family of a child aged 10-12 years, regional VIC.

"We're told we might be transitioning early and then DHHS changed their mind. DHHS also promised \$3k+ of consulting to assist the process and then withdrew that offer without explanation." Family of young person aged 18-25 years, metropolitan VIC

The NDIS Act 2013 currently does not have a provision to respond to families with children and young people with disability in crisis, for example those experiencing family violence, the death of parents/primary carer, migrants with a refugee status, families in temporary accommodation. In these urgent situations the access decision to enter the NDIS should be within five working days.

Advocacy and support services for families are at breaking point since the introduction of the NDIS, and many families find it difficult to access these services to assist them negotiate the NDIS access process. The NDIS has been implemented without increased funding to Australian Government National Disability Advocacy Program (NDAP) funded services or state and territory funded advocacy services, with some jurisdictions also withdrawing funding. Additionally information services previously funded by state and territory jurisdictions have lost disability specific information funding, which has not been picked up by the Information Linkages and Capacity Building (ILC) grant rounds.

Improve information about the NDIS across access, planning and plan implementation

Recommendations

Simplify the terminology used across the NDIS scheme, using easy simple keywords

Develop consistent and accurate information spanning access, planning and plan implementation

The NDIA continually monitor the information needs of the current and prospective NDIS participants and their families/caregivers and provide accessible information

Amend NDIS Act 2013 Section 34, particularly subsection (e), (g) and (h)

Develop resources about providers, their responsibilities and alternatives for when the families of children and young people with disability experience thin markets

CYDA is concerned that information about access to the scheme for families of children and young people with disability very limited and in general not clear for prospective and current NDIS participants. This is particularly challenging for those living in regional, rural or remote areas. Access to information in different formats such as online, phone advice, hard copy, Easy English, information in different languages, videos with captioning, need to be part of the accessibility package. At the first point of contact, the NDIA, ECEI or LAC needs to verify the family or young person with disability understand the access process and how to navigate their NDIS journey. This could include asking family/caregivers of children and young people with disability after their first meeting how they want to receive the information, whether they want to bring informal support such as other family members or friends, or need formal support such individual advocacy service or from organisations with ILC grants their local area and connect with them.

15.7% of CYDA NDIS survey respondents experience challenges applying for the NDIS due to lack of information, not knowing the support and services covered by NDIS, how it works, how to start the process or to develop a plan.

“Inconsistency in funding, Lack of communication Lack of clarity on what is/isn’t included and why” Family of a child aged 0-3 years, Metropolitan NSW

“A lot of confusion about what I needed to have.” Family of a child aged 16-18 years, Metropolitan VIC

“I wanted to self-manage the first year of NDIS for both my disabled children BUT the NDIS and the LAC staff could NOT tell me how to do this. An entire lever arch file later (a BIG lever arch file) and I gave up on the NDIS entirely. I did not spend a cent that year as I could not figure out how to.” Family of a child aged 10-12 years, regional QLD

The lack of accessible information was reported during the planning stage where families experienced poor quality plans and outcomes for the child or young person with disability. Families said planners provided incorrect information, they had to deal with multiple staff, and there was inconsistency of information and a diminishing of family and participant's choice and control. This generated financial burden and stress for families.

The terminology used by the NDIA staff and allied partners is not clear with much use of jargon and hence there is a need to simplify the NDIS terminology. Further information should also be given to what is ‘reasonable and necessary’ under the NDIS Act. Therefore CYDA recommends

amendments to Section 34 of the NDIS Act 2013 particularly subsection: “ (e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide; (g) the support is not prescribed by the National Disability Insurance Scheme rules as a support that will not be funded or provided under the National Disability Insurance Scheme and (h) the funding of the support complies with the methods or criteria (if any) prescribed by the National Disability Insurance Scheme rules for deciding the reasonable and necessary supports that will be funded under the National Disability Insurance Scheme.”⁶.

The literal interpretation of sub-section (e) in section 34 of the NDIS Act 2013 has disadvantaged families of children and young people with disability and a refusal of funds for services or support deemed a “normal parental responsibility”. Families are the experts of what the child or young person with disability needs so their input and information is important for the funding allocation of support and services. This also goes against the gold-standard approach of family-centred practice

“Caused a lot of stress trying to get across the difference between caring for my son and additional time required because of his disability vs what NDIS considered parental responsibility” Family of a child aged 0-3, Regional QLD

There is a complete lack of information about how to navigate the NDIS service system including providers and support coordination services and how to assess the quality of the provider. This more pronounced for families living in regional, rural or remote areas with few registered providers or providers with long waiting lists.

⁶ NDIS Act 2013, Section 34 <https://www.legislation.gov.au/Details/C2013A00020>

Improve the NDIS planning process

Recommendations

Offer pre planning support families of children and young people with disability to improve the quality of NDIS plans and outcomes

The NDIS Act 2013 (Section 37) be amended to enable review of plans before finalisation and allow 20 working days to request changes after draft plan notification

CYDA NDIS Survey results show that 71% of young people and family/caregivers of children and young people with disability experienced difficulties with the NDIS planning process.

Families, as the key caregivers of children and young people with disability, report they are invisible in the scheme. They say plans are being developed which fail to recognise the important role families' play and the importance of community supports which will enrich the child and young person's life.

NDIA staff and ECEI and LAC partners are said to prioritise individual therapies in plans rather than consider all the environments children and young people need to support their development and wellbeing. The majority of learning for children and young people occurs in their home, community and educational environments. Therefore individual therapy cannot be a major driver of development – what drives development is children's meaningful participation in everyday activities and environments.⁷ The reliance on medical models, rather than natural supports for children and young people and their families was criticised by our survey respondents.

"Denied support worker hours, denied riding for the disabled, denied help with support workers for after school hour care. Planner didn't know what after school care was! All occurred at planning meeting." Family of a child aged 4-6 years, regional Queensland

"Respite was difficult to get as "parental responsibility" kept getting quoted, even though the single parent was not able to do these parental responsibility due to physical & mental health issues". Family of a child 10-12 year old child, metropolitan NSW

"I would still like more services around inclusion and getting my son out in the broader community. There is a lot of camps and programs for people with disabilities but not a lot of stuff that intersects into mainstream groups." Family of a child aged 10-12 years, metropolitan Melbourne

The other significant challenge for families with children and young people with disability is being unable to work because of the care requirements. They report that they would like to work, but are unable to, because caring for their child is seen as their "parental" responsibility. There is little understanding of the higher-level support provided by families to meet their child's everyday needs. Forcing families to live on low incomes or poverty because they are unable to work will not ultimately assist the child or young person live a good life.

⁷ Centre for Community Child Health (2011). DEECD Early Childhood Intervention Reform Project: Revised Literature Review. Melbourne, Victoria: Department of Education and Early Childhood Development. <https://www.education.vic.gov.au/Documents/childhood/providers/needs/ecislitreviewrevised.pdf>

Our survey also confirms families experience long delays of up to 12 or 18 months to receive NDIS funding approval. Some of the issues mentioned were administrative mistakes by NDIA staff or allied partners and high staff turnover.

“Rollout was 1st Oct 2019 Brotherhood of St Laurence set up office 15 Feb 3 month wait from planning meeting to implementation, basically poor advocacy” Family of a young person aged 18-25 years, Metropolitan VIC

“Unable to access NDIS system for 4 months due to incorrect key code due to their typing a birthday in incorrectly then finding they had marked account 'other' not 'mother' so unable to access anything.” Family of a child aged 13-15 years, Regional QLD

Families reported not being informed about what to bring to planning meetings or being overwhelmed by collecting the evidence and reports for planning meetings. There were also reports of plans having supports that were not requested, or underfunding of plans. Planner capability was cited as a key challenge.

It has been found that the quality of NDIS plans relies on the two factors: the knowledge and experience of the NDIA staff or allied partners and the level of advocacy support families and participant receive before and during the planning process⁸. To overcome this issue CYDA recommends that the NDIA should provide pre-planning support to all participants and their families.

Currently families of children and young people with disability do not have access to the draft plan and only see what is included in the plan once it is approved. Many respondents stated that they hadn't been provided with a formal communication or explanation about when a service or support is underfunded or unfunded. CYDA recommends to amend the NDIS Act 2013 Section 37 and add access to draft plans giving 20 working days to participants and their families after notification to request changes.

Families of children and young people with disability believed they had to liaise with too many NDIS staff during planning process and no explanation when the ECEI, LAC's or Planner leave the organisation or is moved to another team. The turnover of staff means there is no continuity in information provision and it is reported there is variable levels of knowledge and expertise about disability which impacts on families.

⁸ Joint Standing Committee on the National Disability Insurance Scheme: Transitional arrangements for the NDIS, page 39. 15 February 2018.

https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/Transition/Report

Build the capability of NDIA, ECEI and LAC's planners.

Recommendations

Require NDIA planners, LAC and ECEI workforces to receive training in family-centred practice, child and youth development and empowerment

Provide regular and transparent reporting on families of children with disability and NDIS participants' satisfaction with the planning process

The respondents to CYDA NDIS survey reported planners did not have the experience, knowledge or qualifications relevant to the role and hence the plans were not tailored to the needs of children and young people with disability. The family/caregivers said the support for carers is not included in the plans and there are funding shortfalls. The lack of family-centred practice will mean children and young people with disability to obtain the right services and support.

"Planners do not have the qualifications or necessary experience to deal with PWD who have complex needs" Family of a child 13-15 years, regional VIC

"Planner was inattentive, lack of knowledge, read from a script, did not try to understand, was rude, provided a plan that was less than previous supports from DSC, provide no core support, despite full documentation, would not discuss her qualification, would not review plan or discuss or explain reason the way the way was given, had to cancel bonded core support workers whilst in review, lots a year of rapport building and enabling transition to school, (school refusal due anxiety disorder) required 4 months to rebuild, Planner unaware of autism presentation in females or PDA, was unaware of the Ehlers DANLOS/Marfan's, not included in diagnosis, so no physical supports provided, unable to contact NDIS, different people, different stories/advice, Review process STRESSFUL, the language used is difficult to understand, staff twisted enquiry in knots and creates stress for the career, Poor understanding of mental health impact on careers caring for those with MENTAL health issues, respite not provided, not understanding of financial impact when careers unable to obtain employment, when caring for teen with mental issues 24/7" Family of a child 13-15 years, metropolitan WA

Another difficulty mentioned by our survey respondents was the lack of consistency between planners leading to underfunding through not having enough knowledge, ignoring relevant information or misinterpreting medical records.

NDIS planners, LAC's and ECEI staff need to be trained in and attuned to the individual circumstances of the children and young people with disability and their families. This includes families in crisis, parents with a disability, CALD families, families experiencing family violence, children living in out of home care, Aboriginal and Torres Strait Islander families, grandparents raising children, families living in rural or remote areas. NDIS plans and support required must reflect and acknowledge all these circumstances.

Staff knowledge is also required in child and adolescent development and transition to adulthood as the needs and goals will change for children and young people with disability and their families over time and they will need guidance throughout these transitions.

Address thin markets and underutilisation of plans

Recommendations

Provide support coordination for all children and young people with disability during implementation of NDIS plan.

The NDIA and state and territory governments provide active market stewardship to ensure children and young people with disability receive the right services and supports at the right time

The NDIA urgently review the provision of equipment and assistive technology and thin markets for these supports

The Thin Market Framework considers service availability for children and young people with disability as distinct from adult services

There were 67% of CYDA NDIS survey respondents who had some difficulty or not been able to access the right services and supports needed.

Challenges in accessing the right services and supports for children and young people with disability were present across all geographic locations, as outlined in the following table. However it was more difficult in regional and rural and remote locations.

Location	Number of survey respondents	% with barriers to accessing the right services and support
Metropolitan	121	63%
Regional	52	71%
Rural and remote	16	87%

There were multiple barriers to accessing the right services and support for children and young people with disability as outlined in the following table

Barriers to accessing supports and services	Number
Not enough services available in the area	37
Plan doesn't allow for services needed	25
Waiting lists	23
Support coordination challenges including difficulty in navigating services, time and self-management	16
Workforce capability	15
Equipment and assistive technology	11
Accessibility of the service including flexibility and location	8

Cost of services and funding shortfall between NDIS plan and services and supports needed	8
Respite and family support not being available/funded	8
Interface issues with other systems	4
Other/unspecified	17

Not having the right services and availability in the area plus the plan not allowing for the services needed were reported as the top issues for children and young people with disability.

“There is a severe shortage of therapist, support workers, treating doctors and long wait lists. Even when signed up with a service, there is a shortage of available appointments. We have accepted, in desperation, untrained and (previously) unacceptable support workers just to have another pair of hands on board. All the wonderful skill development that we previously could work on has now become purely survival.” Family, young person aged 18-25 years, metropolitan New South Wales

Other challenges included the long waiting lists for services, lack of service availability and no services to choose from especially for families with CALD background where language is a top barrier. These issues decrease the choice and control by NDIS participants and their families.

“Not a lot of support in my area. Support workers/therapists come from outside the area and therefore add transport costs. Have to go to review to become plan/self-managed so I can find support networks.” Family of a young person aged 16-18 years, metropolitan Victoria

“Long waiting list for therapists. No consistency in support workers that change every fortnight.” Family of a child aged 10-12 years, metropolitan New South Wales

“Living in the western suburbs there is a dearth of services and supports. So even when one has a plan, it's difficult to find suitable qualified and experienced professionals to hire”, Family of a child aged 10-12 years, metropolitan Victoria

Respondents to the survey provided multiple examples of difficulty in accessing Assistive Technology (AT) and equipment which is essential for children and young people children's changing needs, for example maintaining or updating the AT or equipment. It is not clear for families the criteria to access AT or funds under the Capital Supports Budget.

“Electric wheelchair required new batteries and charger, but because this wasn't included in the original plan, we had to wait until the new plan was in place to get this item as the provider wouldn't let us pay for them outside of the NDIS.” Family of a young person aged 18-25 years, Australian Capital Territory

“It took over twelve months to get new ankle foot orthotics for my daughter - I had to go to my local member of parliament I was so frustrated. My daughter was 6 years old and had been wearing them since she was 3 years old. I also had to fight for a budget in her new plan for a replacement set - god forbid she has the audacity to grow in the next 12 months!! Planners are too 'insurance' focused; I am trying to build my daughters capacity NOW so she is a more capable adult - but all the planners can see is trying to save money.” Family of a child aged 7-9 years, regional Victoria”

Waiting over 18 months for essential equipment for my son's physical disability has been a joke. He has also been in a too small of wheelchair for two years and NDIS kept fobbing everything off. Thankfully now the new wheelchair is being made, but two years of my son being in a too small of wheelchair has caused physical pain and issues and increased anxiety. NDIS is supposed to help the participant, not make them worse"
Family of a child aged 10-12 years regional Queensland

CYDA recommends to have a time frame of 30 days to approve Assistive Technology (AT) and equipment. There should also be funding for maintenance and repair of AT and equipment so families don't need to request a review of their plan to enable this.

Our NDIS survey participants tell us there is a mix of experiences depending on whether the child or young person with disability is on their second, third or fourth NDIS plans. Some families reported improvements and others were disadvantaged due to funding cuts or a service or support approved in first plan not included in the next plan without explanation. It was also identified in the transition from 6 to 7 years old children the funds were drastically cut. Families also confirm the collection of evidence and assessment to justify the funding increase the level of stress from families.

Access to support coordination is another challenge in the implementation process. Many families of are not aware how to start using the funds once the plan is approved, where to find support workers and what to ask to providers to compare services. This issue was confirmed in the last COAG Disability Reform Council Quarterly Report where only 42% of participants received funding support coordination and 22% of participants who received an approved NDIS plan were uncertain of what to do next or where to go for further assistance⁹. CYDA believes that support coordination should be guaranteed to all children and young people with disability. This will help address the issue of underutilisation of plans.

⁹ COAG Disability Reform Council Quarterly Report June 2019. <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

Reform the NDIS internal reviews and appeals process

Recommendations

Amend NDIS Act 2013 Section 100 subsection (6) including a timeframe of 20 days for the reviewer to make a decision, or in the event of requesting more information an extension of 28 days will apply

The NDIA inform participants and their families/caregivers through a written communication about their NDIS funding while the review of the reviewable decision is in course

Review and simplify NDIS terminology related to reviews

Hold NDIS reviews face to face (when possible) enabling participants to have an advocate at the review

Reform the AAT appeals process, and resolve issues earlier to prevent escalation to the AAT

The lack of opportunity to review the draft plans increases the number of internal reviews of NDIS decisions. Families state long waits for reviews without timeframes for a response from the NDIA is causing gaps in support, services and equipment for children and young people. The NDIS Act 2013 (section 100) regarding review of reviewable decisions, literal (2) states that the NDIS participant must make a request for review within the three months after receiving the notice, in literal (6) states the reviewer must, as soon as reasonably practicable, make a decision¹⁰. However, the long waiting periods for a review discourages families from seeking a review. CYDA recommends Section 100 literal (6) is amended to add a timeframe of 20 working days for the reviewer to make a decision as long as the reviewer has all the evidence to decide, or in the event of requesting more information an extension of 28 days will apply.

Families of children and young people with disability are neither informed about what happens with the funding while the review of the reviewable decision is underway. Therefore CYDA recommends participants and their families/caregivers are informed about this process through a written notification.

CYDA is concerned about the unclear terminology used by the NDIA regarding reviews and the NDIS Act should be amended and clarify the review process. For example, there are current challenges with terminology that is not legislated like “light touch reviews” which are used to change the type NDIS plan management and to correct administrative errors. CYDA suggest clearer wording to describe small review changes and describe the specific circumstances to this type of review. Additionally, plan reviews which are regularly due after 12 or 24 months of the current plan can be confused with the “internal NDIS reviews”. Understanding the NDIS language is important to all participants and their families hence an overhaul of current language is needed in the Act and in NDIS processes.

Our organisational members report NDIA reviewers are making phone calls to participants using jargon terms such as “R and N” and unclear language to review decisions. The reviewer must give the opportunity for families of children with disability and participants to have an advocate to help with the review process. A face to face meeting with the necessary supports for all participants should be available.

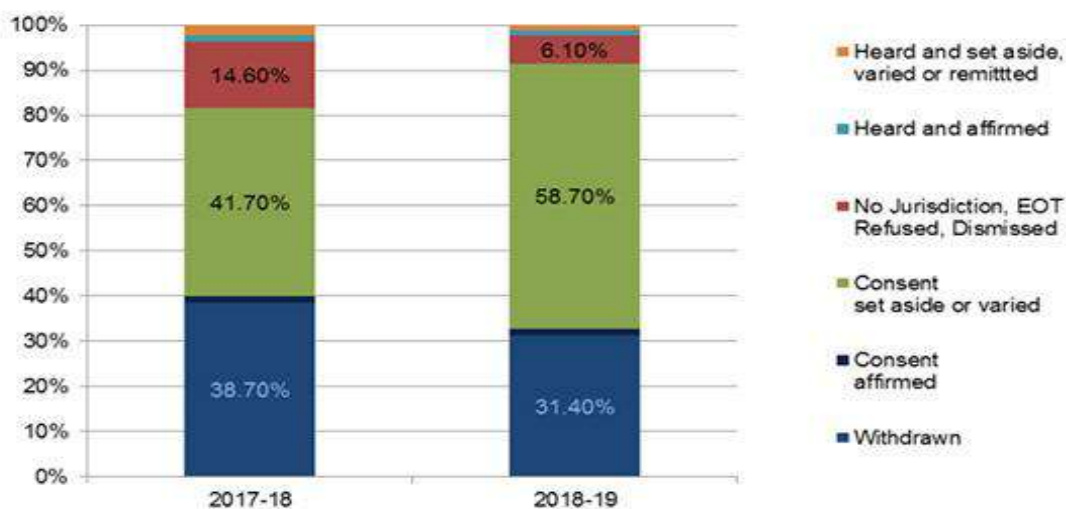
¹⁰ NDIS Act 2013. Section 100. <https://www.legislation.gov.au/Details/C2013A00020>

The Commonwealth Ombudsman received 1,528 complaints about the National Insurance Agency, 256 percent increase from the 429 complaints received the year before¹¹. These complaints are the results of the poor communication practices and long waits for decision making by the NDIA and legislative and administrative changes are urgently needed in this area.

When participants are not satisfied with the internal review decision, they can appeal externally to the Administrative Appeals Tribunal AAT however evidence shows that only 802 cases were lodged to the ATT related to the NDIA and from those 441 were finalised¹², this number is much lower comparing to complaints to the Commonwealth Ombudsman. The appeal process is legalistic and complex, discouraging participants about their right to review, diminishing their choice and control.

The AAT has presented figures for their NDIS cases for 2017/18 and 2018/19¹³:

Comparison of outcomes



What the above data shows is that only a small percentage of cases appealed to the AAT are actually heard by the Tribunal but the majority of cases are withdrawn or conciliated with the NDIA before hearing with a potential undue influence by the NDIA. The appeal process can be quite intimidating and many participants and their families don't have access to individual advocacy or legal advice to sit in equal terms with the NDIA.

CYDA recommends to review the AAT appeal process and legal supports for participants recording reasons for withdrawing or negotiating with the NDIA as prerequisite before the hearing audience to the AAT.

¹¹ Commonwealth Ombudsman Annual Report 2017-2018.

www.ombudsman.gov.au/_data/assets/pdf_file/0031/89383/Commonwealth_Ombudsman_AnnualReport_2017-18.pdf

¹² Administrative Appeals Tribunal. 2017-2018 Annual Report. <https://www.aat.gov.au/about-the-aat/corporate-information/annual-reports/2017-18-annual-report/2017-18-annual-report-at-a-glance>

¹³ Probono Australia. The Administrative Appeals Tribunal affirms less than 2% of NDIS decisions appealed by participants. <https://probonoaustralia.com.au/news/2019/10/the-administrative-appeals-tribunal-affirms-less-than-2-of-ndis-decisions-appealed-by-participants/>

Address NDIS interface issues

Recommendations

Increase transparency about the work of the Disability Reform Council and the NDIA to address NDIS interface issues and monitor progress over time

Consider the legislative changes that may be required to clarify roles and responsibilities between the NDIS and other government funded services

The NDIA and state and territory governments provide accessible information to current and prospective NDIS participants about what the NDIS will fund, and where people can access other services

While the NDIA, the Disability Reform Council (DRC) and the Senior Officials Working Group (SOWG) are working on resolving interface issues across a range of areas and clarifying the principles to determine responsibilities¹⁴, there is little publicly available information about progress in addressing these issues. There is a lack of clarity on how eligible and non-eligible NDIS participants are provided with services and support, particularly when state and territory governments are withdrawing services. Additionally, service providers of last resort need to be identified so that no child or young person with disability is without support. The review of the legislation provides an opportunity to clarify accountability and responsibilities so participants are not left without a service.

One interface issues for children and young people with disability is in education. Our NDIS national education survey conducted in August and September 2019 with 505 respondents found 57.5% (289) families of students with disability have paid personally (out of pocket costs) for specific supports or equipment to enable access and participation of their child in education. There were 77% (389) students with disability who were NDIS participants and 15.2% (76) of these used NDIS funds to assist in accessing education¹⁵. Families remain unclear who is responsible for providing these supports, and further consultation and research is needed about the education interface with the NDIS.

The health interface issue for families of children and young people with disability is creating inequity in the scheme as many families on low incomes or have difficulty navigating the health system will have difficulties in obtaining the diagnostic evidence to enter the scheme.

The NDIS Act 2013 Section 34 describes the reasonable and necessary support and paragraph (f) states that the support will be funded by the NDIS if is not appropriately funded or provided through other general systems of service delivery¹⁶. In reality the experience for families is if their child is not eligible for a support because it is a state or territory government responsibility, it is left to the individual to try and find support without NDIA, ECEI or LAC staff explaining and connecting people to the right government department or agency. The NDIA, ECEI and LAC partners need to play a key role in providing information and connecting people with right services that are not provided

¹⁴ COAG. Principles to determine the responsibilities of the NDIS and other services systems <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

¹⁵ CYDA (2019) Time for change: The state of play for inclusion of students with disability, Results from the 2019 CYDA National Education Survey <https://www.cyda.org.au/inclusion-in-education>

¹⁶ NDIS Act 2013, section 34. <https://www.legislation.gov.au/Details/C2018C00276>

under the NDIS. There is also need states and territories and the NDIA to collect data on the support services provided to children and young people with disability and to identify service gaps.

Participant Service Guarantee Service Standards

CYDA believes that the addition of separate principles specifically for children and young people with disability and their families are needed and suggest three additions: *early intervention*, *family centred practice* and *evidence-based practice*.

We also recommend two other principles for all services which are *accountable* and *consistency*. The following table provides an overview of the suggested standards for new principles and additions to the standards provided in the discussion paper.

Principle	Description	Service Standard
Early intervention	The NDIS will provide information, assessment and support at the earliest point when a child experiences disability or developmental delay with the option to waiver evidence requirements	The NDIA ECEI and LAC partners understand disability in children and young people and will inform and assist them in finding support and services or connecting with other government's services to minimise developmental risks. Support coordination is provided as an option for all plans involving children and young people with disability
Family-centred practice	The NDIA will recognise the important role families play in the lives of children and young people with disability and supporting their learning and development	The NDIA will provide plans that support the child and young person with disability, but also recognise the important role families and carers play The NDIA will promote the use of family-centred practice in ECI services under the NDIS
Evidence based practice	The NDIA and its partners will include support and services based upon evidence-based practice for children and young people with disability	The NDIA will include services and supports to enable the full participation of children and young people in the community including facilitating access to mainstream services, community environments and activities

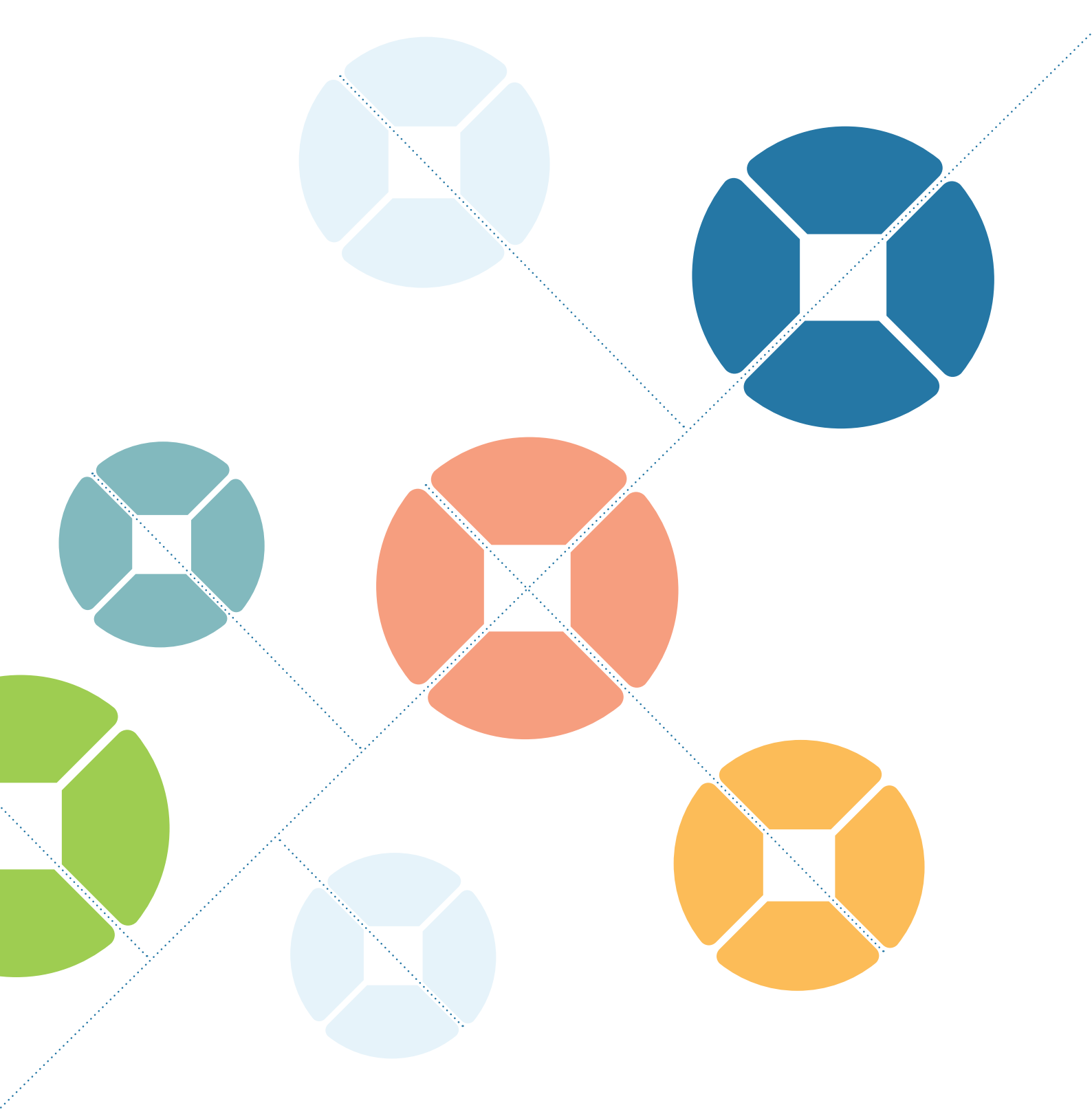
Principle	Description	Service Standard
Timely	The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen	<p>The NDIA will support children and young people with disability and their families/ caregivers overcome the barriers to providing evidence for eligibility and will provide interim plans until confirmation of access.</p> <p>The NDIA will allow automatic entrance to the NDIS for participants who were receiving support or services from Commonwealth, states or territories</p> <p>Once the NDIA has appropriate information, access requests are to be made in 20 working days</p> <p>The NDIA will enable advocates, support people and/or other necessary supports for families and prospective NDIS participants during access, pre planning, planning, implementation and the review process.</p> <p>Participants are offered a planning meeting within 10 working days of receiving their 'access met' decision.</p> <p>A draft plan is sent to the participant and their family for review within 20 days so they can request modifications or adjustments</p> <p>Plans are approved within 10 days of the final planning meeting, following the provision of all necessary evidence.</p> <p>Plan amendments are considered within 10 working days of the request.</p> <p>Specialist Disability Accommodation or AT/equipment requests are made within 20 days of the information being provided.</p> <p>Internal review decisions are made within 25 working days of the request after the necessary evidence has been provided. An extension of 20 working days can be made to enable provision of further information</p>

Principle	Description	Service Standard
Engage	The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.	<p>The NDIA has ongoing consultation with a wide range of different participants in the scheme, including children and young people and families/carers and advocates</p> <p>The NDIA regularly reports on consultation outcomes in the quarterly NDIA report</p> <p>The NDIA undertakes deep consultation and co-design with Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse groups, and people with disability living in rural and remote communities to improve NDIS access and operation.</p>
Expert	NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability.	<p>NDIA staff and partners will have a high level of training and knowledge about disability, combination of disabilities, participants with complex needs as well as a good understanding of supports needed for participant family/caregivers.</p> <p>The NDIA will train staff in a life course developmental approach across childhood, adolescence and transition to adulthood.</p>
Connected	The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.	The NDIA and state and territory governments work together to improve data and reporting about people with disability who are both eligible and ineligible for the NDIS and their access to universal and state funded services to identify service gaps
Valued	Participants, their families, carers and other support persons feel valued in their interaction with the NDIS, and know where to go if they need further assistance	<p>NDIA to provide assistance through ECEI, LACs to participants and their families during access, planning and implementation process and keep records of further assistance requested and provided.</p> <p>The NDIA will keep records when a person is not eligible for NDIS and referred to other government and community services organisations (linked to service standard connected)</p>

Principle	Description	Service Standard
Decisions are made on merit	The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.	NDIA will allow participants to review the draft of their plans and will give 20 working days to the participant to provide feedback, or request small modifications. The NDIA will provide a full explanation of the funds approved in the NDIS plan as well as the rationale when a service or support requested was unfunded and underfunded
Accessible	All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals	The NDIA will provide information in accessible formats and seek feedback from participants and advocates about their understanding of the scheme and support available. The NDIA will undertake genuine co-design ¹⁷ with Aboriginal and Torres Strait Islander people, people from culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and families of children and young people with disability to ensure and inclusive NDIS and ensure barriers to the scheme are addressed
Accountable	NDIA staff and its allied partners are responsible for all the decisions made with a positive or negative impact on participants life and take the appropriate actions to amend decisions when need be.	The NDIA and its partners are accountable to all participants for the decisions they make and there are accessible avenues for making complaints and having them resolved
Consistency	NDIA allied partners provide in all jurisdictions uniform clear and accurate information to all participants and their families/caregivers to avoid misleading information.	The NDIA will develop further staff training on uniform clear and accurate information so the information is the same for all jurisdictions

¹⁷ Co-design is a process used to create products, services and programs. It brings people in as 'design partners', giving a voice to those who are often excluded from the design process. Decision-making, design, information sharing and project planning are among the equal roles between trained designers and design partners, see for example https://www.futuresocial.org/what_is-co-design/

Appendix C: Driving change: A roadmap for achieving inclusive education in Australia



Driving change: A roadmap for achieving inclusive education in Australia

Driving change: A roadmap for achieving inclusive education in Australia

Realising inclusive education in Australia and preventing violence, abuse, neglect and exploitation of students with disability is an urgent national priority

A transformation in education is needed to ensure Australia complies with the United Nations Convention on the Rights of Persons with Disabilities (CPRD)

All Australian children must be welcomed and supported at their local school and provided with a high quality inclusive education. Sadly, for too many children and young people with disability, this is not the case.

They continue to experience violence, abuse, neglect and exploitation. They are also discriminated against, segregated from their peers, and ultimately denied the kind of inclusive education that 50 years of evidence tells us best prepares them for life and success. We know that inclusive education is essential for creating the inclusive society we should already be experiencing in Australia.

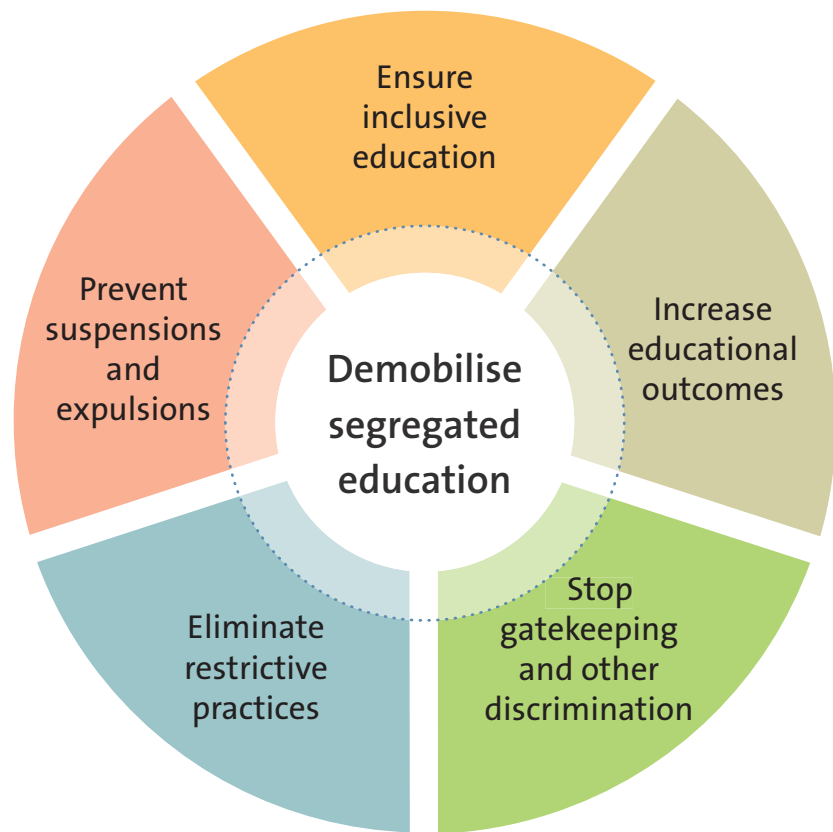
All our children deserve better and the Disability Royal Commission is now giving us the opportunity to bring to light these wrongs and make long overdue changes to the education system.

The Australian Coalition for Inclusive Education (ACIE) is a national coalition bringing together organisations that share a commitment to advance inclusive education in Australia and across state and territory education systems, including government and non-government schools.

We know that inclusive education is essential for creating the inclusive society we should already be experiencing in Australia.

Our roadmap for change

Inclusive education recognises the right of every child and young person – without exception – to be welcomed as a valued learner and genuinely included in general education. It involves ensuring that learning environments and teaching approaches support full participation of all children and young people on an equal basis regardless of individual attributes or characteristics.



Our Roadmap for achieving inclusive education in Australia is underpinned by six key pillars to help realise inclusive education in Australia and prevent the violence, abuse, neglect and exploitation of students with disability.

These pillars are drawn from the evidence base and embed the rights of students set out in the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD).

The Roadmap for achieving inclusive education in Australia has two key sections: the outcomes that need to occur, stepped out over the next 10 years, and the key levers for change needed to realise these outcomes.

1

Outcomes required to realise inclusive education and prevent violence, abuse, neglect and exploitation of students with disability



Demobilise segregation

Segregated education does not provide a pathway to an inclusive life for people with disability.

Segregated education **is not** inclusive education.

As the United Nations' CRPD states, "segregation occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities."¹

● Short-term outcomes (1–2 years)

A target is set that by 2023 there are no new enrolments of students entering the first year of primary school in special school, or special units/special classes in 'mainstream' schools.

There is research (quantitative, qualitative and longitudinal) on the consequences of segregated and non-inclusive education and its impact on:

- emotional and mental wellbeing of students
- academic achievement, attainment and outcomes
- employment pathways
- health outcomes
- housing solutions
- juvenile justice
- complementary and compensating support services
- life expectancy
- lifetime costs.

To identify system issues and barriers, there is independent research into the factors that families have taken into account when choosing segregated education.

The Australian and state/territory governments lead the development of and commitment to a plan to demobilise segregated education for all students, which includes milestones, key performance indicators, and monitoring and accountability.

The transition timetable is child-centred.

There is a commitment to no new investment in segregated infrastructure at a state/territory or national level.

There is broader application of existing and new models of best-practice teaching and educational practice to support inclusion of all students.

New models have been co-designed with young people with disability, and they are involved in the change as paid community advocates.

There is funded individual advocacy and support for the transition for students and families.

The community, families, educators (including early childhood) and education system leaders recognise that segregation is not effective and there is support for the transition to inclusive education.

Existing support programs and services are refocused to promote de-segregation and transition (e.g. My Time funding, Inclusion Support Program (early childhood and before and after school care), the National Disability Insurance Scheme (NDIS), Early Childhood Early Intervention services).

1 UN CPRD, General Comment 4, Article 24: Right to Inclusive Education.

Demobilise segregation

● Medium-term outcomes (3–5 years)

There are no new enrolments in special schools in primary and secondary levels (via a grandfathering method), and special units/special classes in ‘mainstream’ schools are closed.

There are policies and legislation in place to support a reduction in segregated education over time, including changes to state and territory legislation that currently supports ministerial (or equivalent) enrolment override.

The rights of students with disability to inclusive education is reflected in education policy and practice, and the myth of parental choice in segregation is debunked.

It is widely understood by parents, educators and the community that transition to inclusive education is achievable and should not be feared.

There is no further investment nationally or in the states/territories in a dual-track education system that segregates students with disability, and current specialised settings are re-purposed for general student populations.

● Long-term outcomes (5–10 years)

Segregated education no longer exists in Australia.

All primary and secondary schools are welcoming and inclusive of students with disability, with measured improvement in academic achievement and employment outcomes.

Ensure inclusive education

Inclusive education recognises **the right of every child and young person** – without exception – to be welcomed as a valued learner and genuinely included in general education. It involves ensuring that learning environments and teaching approaches support full participation of all children and young people on an equal basis regardless of individual attributes or characteristics.

● Short-term outcomes (1–2 years)

Pre-service teaching units and assessment adequately embed inclusive education principles across curriculum delivery.

There is widespread and high quality teacher and principal professional development in inclusive education.

The Australian and state/territory governments have agreed to a 10-year Inclusive Education Plan, developed alongside people with disability, experts and advocates.

There is a positive narrative for inclusive education as an expectation and human right, which includes positive media coverage for students, teachers, schools and the broader community.

Students, parents, unions, professional associations and education system employees can

all articulate what inclusive education is – and what it isn't – in line with the UN CRPD.

Principals, teachers, professional associations and unions are advocating for all elements of inclusive education and no further investment in segregated settings.

The components, evidence and benefits of inclusive education are well known and able to be described by teachers and principals.

Families have robust, transparent and independent complaints mechanisms when their child does not experience inclusive education (e.g. an independent tribunal or commission established by national harmonised legislation and implemented locally).

● Medium-term outcomes (3–5 years)

States and territories have a transparent improvement framework for inclusive education that is rigorously monitored and reported against, with an independent national oversight body/commission overseeing this work.

Schools and school systems are held accountable for inclusive education (e.g. via a transparent and independently assessed scorecard of schools).

National data are collected on the experience of students with

disability in inclusive education (or not) from existing and new sources across a range of data points:

- student voice and satisfaction
- attendance
- learning and engagement
- educational achievement
- post-school transition and outcomes
- support and adjustments
- funding provided and spent
- inclusive education Key Performance Indicators (KPIs) monitoring change over time.

● Long-term outcomes (5–10 years)

Inclusive education is normalised in practice for students with disability.

2 Children and Young People with Disability Australia (2019) Fact Sheet 1, 'What is inclusive education?'

Improve educational outcomes

Students with disability in Australia experience considerably poorer educational outcomes than non-disabled students. Around a third of people with disability aged 20 or over have completed Year 12-level schooling – compared with 62 per cent of people without a disability.

● Short-term outcomes (1–2 years)

The school community embraces all learners and the value of students with disability to all learners is well known.

The role of teachers' aides in the Australian school system is independently reviewed, with recommendations for the future to ensure strong educational outcomes based on research and best practice.

All students with disability experience high learning and development expectations and have an Individualised Educational Learning Plan. This plan is developed in consultation with the family, the student and the school.

All pre-service teacher training includes how to differentiate curriculum for students with disability, and there is upskilling of the current teaching workforce.

The Australian Curriculum provides examples and modelling of how to differentiate curriculum.

The educational outcomes and post-school pathways of students with disability are routinely collated and publicly reported.

The relationship between educational outcomes and being a valued member of the school and class community is well known, and efforts to improve are articulated in school improvement planning.

Students with complex communication needs (CCN) are supported in their right to a comprehensive communication system relevant to their individual requirements, allowing them to participate, access the curriculum, learn and achieve with equity.

● Medium-term outcomes (3–5 years)

Best practice in educating students with disability is occurring in Australian schools and independently monitored through school improvement methods.

All students with disability are learning the same curriculum as their peers, reasonably adjusted and differentiated to their needs.

Personalised learning plans based on Universal Design for Learning are developed for all learners, including those with and without disability, so Individualised Education Plans are no longer needed.

● Long-term outcomes (5–10 years)

Increased retention of students with disability until year 12.

Increased rates of young people with disability enrolled in higher education and vocational education and training.

The gap in attainment and educational outcomes for students with disability and other learners is closing.

Stop gatekeeping and other discrimination

'Gatekeeping' occurs when there is formal or informal denial of access or informal discouragement of children with disability attending their school of choice. It may include school staff saying that a child is better off going to another school, a special school or a school with a special unit because their school doesn't have enough resources or the skill to support the child. It may also include refusing to enrol a child with disability, only offering part-time hours, or encouraging home-schooling. It is discriminatory, devaluing and demeaning.

● Short-term outcomes (1–2 years)

Gatekeeping is well defined and:

- families know how to identify it, and what to do if it occurs
- there are consequences for schools that engage in gatekeeping.

Families have robust, transparent and effective mechanisms to make complaints and have them remedied at a school level, and access to an independent national oversight body/commission if the complaint is not resolved.

Schools are required to record the number of enrolments they have refused or discouraged and the reasons why.

Families have a process to provide feedback on their enrolment experience, and systemic and individual issues are addressed.

Regional offices are working with schools to identify and understand why students with disability are not enrolled at or attending their local or closest close.

There is zero tolerance of gatekeeping in the Australian school system, with punitive consequences if this does occur.

● Medium-term outcomes (3–5 years)

Gatekeeping does not occur.

School performance is measured by inclusivity and embracing all learners.

The ratio of students with disability compared to the rate in the community is reflected in school enrolments (to prevent quasi-segregation via 'lighthouse' schools conducting best practice).

Eliminate restrictive practice

'Restrictive practice' is any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability. This can include physical, mechanical or chemical restraint. It can also include psycho-social restraint, which involves using intimidation or threats to control a person. Restrictive practices are cruel, inhumane and degrading.

● Short-term outcomes (1–2 years)

There are clear definitions of restrictive practices in education and these are well known by educators, parents and school system employees.

There are independent senior practitioners for preventing restrictive practice in every jurisdiction and they provide expertise in alternatives to these measures.

A multi-layered approach (e.g. wrap-around supports) is developed within each school to be responsive and proactive in supporting students to minimise the use of restrictive practices.

Cases of restrictive practice are independently investigated and reviewed to identify root causes and systemic issues.

There is an understanding of how to regulate against restrictive practices.

Data are routinely collected and transparently reported, including applications for the use of restrictive practices, unauthorised restrictive practices occurring and prevention activities.

Teachers are trained in alternative empathetic supports and approaches so that restrictive practices are eliminated.

Policies and procedures are developed to support inclusive education, as opposed to behaviour control.

Students are able to voice their concerns and be heard.

All primary and secondary schools are required to develop a plan for reducing and applying a strong human rights based standard to restrictive practices.

● Medium-term outcomes (3–5 years)

There is recognition that there is no such thing as a low or no risk restrictive practice.

There is a strong and enforceable regulatory regime to prevent restrictive practices in school.

Restrictive practices, including restraint and seclusion, are eliminated.

Stories of success in reducing and eliminating restrictive practice are shared.

There are strong consequences for schools and educators that use restrictive practices.

Schools have developed a culture of flexibility and accommodation to support all students.

Prevent suspensions and expulsions

Suspensions and expulsions are familiar practices in the school experiences of students with disability, which shows the lack of understanding and support available. Almost 15 per cent of students with disability surveyed by CYDA in August and September 2019 had been suspended in the previous 12 months; 1.8 per cent were expelled.³

● Short-term outcomes (1–2 years)

Data on suspensions and expulsions of students with disability are routinely collected and publicly reported across the states and territories (e.g. number of suspensions/expulsions, gender and age of student, length of suspension, reasons, actions taken following suspension to prevent future suspensions and expulsions).

Each state and territory is required to have policies and practices that seek to reduce and eliminate suspensions and expulsions for students with disability, taking a whole-school approach.

Legislation is enacted in each jurisdiction to prevent suspensions and expulsions of students with disability.

Families have robust, transparent and independent complaints mechanisms to appeal and complain about suspensions and expulsions.

Schools and teachers are trained to prevent in-school and out-of-school suspensions and expulsions, and to make adjustments and modifications to keep students engaged in their learning.

When a student is suspended more than once, an independent investigation is undertaken to ensure the school's compliance with policies.

The impact of suspensions and expulsions on students is captured (e.g. student voice).

● Medium-term outcomes (3–5 years)

The number of suspensions and expulsions of students with disability is decreasing.

Schools and school systems are held accountable for reducing suspensions and expulsions of students with disability (e.g. via a scorecard of schools that is transparent).

School suspensions are only considered as a last resort for the most serious behavioural transgressions and in response to grave risks to health and safety.

● Long-term outcomes (5–10 years)

All students with disability are wholly included full-time, or there is a short-term plan to get them back to school full-time.

³ Children and Young People with Disability Australia (2019) *Time for Change: The state of play for inclusion of students with disability, Results from the 2019 CYDA National Education Survey*

2

Key levers for change



Key levers for change



a. Legislative/policy change

Recommendations

- All law and policy reform should comply with the CRPD.
- Review the Disability Discrimination Act, noting that anti-discrimination legislation can only go so far in helping to realise inclusive education.
- Meaningfully review the Disability Standards for Education, in line with the CRPD.
- Develop a National Inclusive Education Act, proactive rather than discrimination-based legislation.
- The Australian and state/territory governments commit resources and collaborate to develop and implement a new National Disability Strategy and National Disability Agreement (NDA), which provides for inclusive education and includes:
 - the development of an endorsed 10-year Inclusive Education Plan
 - shared responsibility to improve education systems and schools to ensure inclusive education, including indicators and outcomes
 - educational improvement targets and outcomes for students with disability that are reflected in the National School Reform Agreement
 - clear responsibilities for advocacy outside of the NDIS, including individual advocacy for families and young people with disability.
- Reform school funding models and move to functional needs-based funding (e.g. the Tasmanian model).
- Develop a national accreditation framework for inclusive education (along the lines of the National Quality Framework for Early Childhood Education).
- Audit education legislation in states and territories and amend or develop new legislation to realise inclusive education.
- State and territory education jurisdictions develop state-based inclusive education policies (inclusive of Catholic and independent schools sectors).
- Establish an independent national oversight body/commission for complaints resolution, with 'own motion' powers to conduct systemic inquiries into violence, abuse, neglect and exploitation of students with disability in the education system.

All our children deserve better and the Disability Royal Commission is now giving us the opportunity to bring to light these wrongs and make long overdue changes to the education system.

b. Monitoring/accountability

Recommendations

- Deliver on the Australian Government Department of Education, Skills and Employment's commitment to complete an evaluation of the Inclusion Support Program (ISP).
- Commit to post-evaluation investment in the ISP linked to indicators of outcomes, and shared responsibility to improve mainstream education services per a new NDA.
- Invest in information to support better inclusive practice and funding to support students with disability.
- Deliver on the Australian Government Department of Education, Skills and Employment's commitment to review the loading for students with disability and invest in continuous improvement of the NCCD (Nationally Consistent Collection of Data on School Students with Disability).
- Commit to post-review investment in the NCCD linked to indicators of outcomes, and shared responsibility to improve mainstream education services per a new NDA.
- Develop an inclusion scorecard for schools that has official status, is transparent and independently assessed (e.g. along the lines of the Australian Children's Education and Care Quality Authority). This includes:
 - educational inclusion
 - student voice/feedback
 - family feedback
 - number/proportion of students with disability
 - intersectional representation (gender, CALD, First Nations, out-of-home care, rural and remote, etc).
- Develop a National Minimum Dataset for education of students with disability (that can be analysed by state/territory, region, sector, demographic characteristics such as gender), including:
 - student voice and satisfaction
 - attendance
 - learning and engagement
 - educational achievement
 - support and adjustments
 - funding provided and spent
 - transition to inclusive education KPIs – experience and outcomes
 - retention, post-school pathways and transitions
 - educational achievement (e.g. NAPLAN)
 - educational adjustments (e.g. NCCD)
 - intersectional data (CALD, First Nations, out-of-home care, rural and remote, etc)
 - suspensions/expulsions and restrictive practices
 - number of students home-schooling.

c. Parent education/support

Recommendations

- Provide further funding for independent disability advocacy for families and young people with disability, to ensure students can have their rights to inclusive education upheld.
- Invest heavily in parent education, starting early in a child's life, so they are aware of children's rights to and benefits and outcomes of inclusive education and move away from thinking children need 'special' education.
- Support family involvement in achieving inclusive education.
- Invest in a national, state and territory-supported campaign/ a broad communications strategy to increase community understanding of the importance of inclusive education. This should include case studies, social change narratives and whole-of-community messaging.

d. Teacher education

Recommendations

- Research and develop the evidence base of best practice models and ensure this is widely disseminated (e.g. using co-teaching and peer tutoring, rather than teachers' aides).
- Train teachers in team-based approaches and collaborative models to support students with disability, including family-centred practice.
- Develop a national standard for inclusive education in pre-service teacher training.
- Fund postgraduate qualifications in inclusive education and strategically use and reward expertise across education systems to support schools in inclusion.
- Increase the numbers of teachers with disability.
- Invest in professional development for principals and teachers in inclusive education and preventing discrimination, violence, abuse and neglect of students with disability.

e. School cultures for inclusion

Recommendations

- Adopt approaches for teaching diverse classes using methods such as universal design for learning approaches.
- Develop resources and toolkits for families and educators on inclusive practices.
- Develop additional measures for student success other than NAPLAN and ATAR (e.g. an inclusion index).
- Reward educators and schools for good practice (e.g. through remuneration, status and profile).
- Measure and evaluate whole-of-school inclusive practice using new and existing models.

f. Student agency and voice

Recommendations

- Involve students with disability in democratic processes at the school and at regional and state/territory levels.
- Provide accessible information that allows students to safely learn about their rights and the process to complain.
- Develop programmatic responses for activating student voice.
- Seek feedback from students and ex-students with disability about what works, especially from those with complex communication needs and intellectual disability.
- Incorporate student voice in educational policy and practice.

The Australian Coalition for Inclusive Education (ACIE) is an initiative bringing together organisations that share a commitment to advance inclusive education in Australia and across state and territory education systems, including government and non-government schools.



The Australian Coalition for Inclusive Education would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was, and always will be Aboriginal land.

Driving change: A roadmap for achieving inclusive education in Australia developed by the ACIE is endorsed by the following organisations.

