**Submission to the National Disability Strategy beyond 2020**

**Children and Young People with Disability Australia**

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# 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 more than 5000 young people with disability, families and caregivers of children 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. We are pleased to be able to provide a submission to the development of the new National Disability Strategy (NDS).[[1]](#footnote-2)

CYDA’s submission covers:

* How and why children and young people should be meaningfully engaged in decision making processes[[2]](#footnote-3)
* Required areas of action to realise the NDS outcomes areas
* The development of an outcomes framework and strategy to delegate roles and responsibilities and support accountability processes.

More specifically, the submission outlines several priority areas of action that the NDS must include to ensure the proposed six outcome areas are fulfilled. These priority areas include the realisation of inclusive education as outlined by the United Nations *Convention on the Rights of Persons with Disabilities 2006* (CRPD) and recommendations for appropriate supports and supply and demand interventions to enable young people with disability to find and maintain meaningful employment. Other priority areas outlined in our submission include the need for equitable, timely and appropriate information provision, the provision of adequate social security and access to safe and accessible housing.

The submission also outlines CYDA’s recommendations for greater accountability measures across departments and jurisdictions. This includes the development of an outcomes framework to accompany the new NDS and the development of an independent oversight function to monitor and report on progress against the NDS. CYDA also recommends investment in human rights-based disability representative organisations to provide systemic advocacy and the development of improved data collection processes as key mechanisms to ensure accountability.

Our submission affirms that one area of a child or young person’s life cannot be understood without viewing them holistically. This includes understanding their previous experiences and encounters with systems, both positive and negative. As such, solutions for outcomes areas can not be siloed to single departments. A collaborative, whole-of-government approach is essential for improved outcomes and greater inclusion for people with disability in Australia.

CYDA’s submission also draws attention to the inadequacies of the previous NDS in considering the distinct developmental and aspirational needs of children and young people and disability. As such, the new NDS and its priorities areas and proposed outcomes should be developed and evaluated with children with disability and their family and caregivers, and young people with disability.

# Recommendations

**Recommendations to meaningfully engage young people and children and their families and caregivers in decision-making processes**

* The new Strategy is underpinned by the life course approach and incorporates priority areas that reflect different needs across the lifespan
* Priority areas and consequential policies and programs are formed and evaluated with the meaningful inclusion of young people with disability and families and caregivers of children with disability
* Governments engage with disability advocacy and representative organisations to ensure young people and families and caregivers are engaged in consultation and co-design processes that are safe and inclusive

**Recommendation to ensure the inclusive education**

* The Commonwealth and state and territory governments undertake major systemic reform as outlined in *Driving change: A roadmap for achieving inclusive education in Australia* to fulfil Australia’s CRPD obligations and the NDS outcome areas

**Recommendations to provide targeted and support for students’ career-planning and address state and territory inconsistencies**

* Increase tailored supports for young people for young people with disability to engage in work experience and/or paid employment during school years
* The recommendations for students with disability in the *Looking to the future: Report on the review of senior secondary pathways into work, further education and training* be adopted and evaluated
* Improve national consistency in post-school transition activities, building on what works best around the country
* Include young people with disability and families in every stage of developing new post-school transition activities
* Ensure post-school transition programs are well-structured, outcome-oriented and student-focused
* Start post-school planning activities for all students with disability by at least the age of 15
* Improve data collection about post-school transition programs, including their uptake, implementation and outcomes
* Review funding arrangements in all states and territories for school and post-school programs for students with disability

**Recommendations to address low expectations of young people with disability and address direct and indirect discrimination in the workplace**

* Counter the narrative of ‘low expectations’ for young with disability through concrete actions and monitor post-school outcomes for students with disability
* Increase targeted, evidence-based interventions addressing the negative and misinformed attitudes of employers. These development strategies must include the meaningful involvement of young people with disability
* Assure that the Australian Human Rights Commission, and other independent oversight agencies, receive sufficient resourcing to safeguard the rights of young people with disability in the workforce
* Continue and increase investment in regular community and employer attitudes surveys and research to monitor changes over the duration of the next NDS

**Recommendations to develop fit-for-purpose employment programs and supports**

* Improve monitoring and public release of caseload and outcome data of young people with disability in employment programs
* Ensure young people with disability across Australia can access age-appropriate employment programs that are designed to address barriers to employment

**Recommendations to provide an adequate safety net and improve access to accessible housing**

* Ensure timely and appropriate information and support is available for young people to assist them to secure income support payments
* Review and amend the DSP eligibility requirements to ensure that it does not prevent young people with disability to receive earnings from a wage
* Provide an adequate safety net for young people with disability that reflects the contemporary cost-of-living, inclusive of the increased living-costs associated with having a disability
* Increase in the development of social housing that meets accessibility standards
* Introduce regulations of accessibility requirements in all new housing in line with universal design best-practice principles

**Recommendations to provide timely and appropriate information and support**

* The commitment and establishment of a reporting framework for Commonwealth and state and territory systems and governments to demonstrate equitable and appropriate information provision for different cohorts within the disability community
* Any future community targeted information provision and support initiatives be developed with people from disability from the relevant communities (i.e. initiatives targeting young people must include young people)
* Monitoring the effectiveness of targeted information provision initiatives or supports
* Increased investment in individual advocacy services, particularly in developing child and youth specific disability advocacy organisations in each state

**Recommendations to develop clear mechanisms for accountability and safeguarding**

* Develop a robust outcomes framework with clear delegation of, and accountability around, responsibilities between national, state and territory and local governments
* The outcomes framework is in line with the CRPD and reflects the different needs of people with disability across the life course
* The outcomes framework must include clear oversight protections across systems in all jurisdictions to safeguard children and young people from abuse, discrimination and neglect, and eliminate the use of restrictive practices in all settings
* Establish an independent body to monitor and report on the progress of governments in accordance with the outcomes framework

**Recommendations to sufficiently resource systemic advocacy**

* Ensure there is always a funded national children and youth representative organisation (CYDA) under Australia’s obligations under the CRPD
* Boost funding to Disability Representative Organisations providing strategic and systemic policy advice to government to ensure the rights of people with disability are upheld

**Recommendations to develop consistent and comprehensive data collection mechanisms and reporting requirements**

* Develop consistent and comprehensive data collection, that includes disaggregated data for different age-groups, disability-type and demographics within the disability community
* Develop clear and consistent data reporting requirements across jurisdictions
* Co-design the new National Disability Data Asset with young people with disability

# Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5000 young people with disability, families and caregivers of children 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, and it undertakes the following to achieve this:

* 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 welcomes the opportunity to contribute to the development of the next National Disability Strategy (NDS). The ten-year scope of the NDS, and our ability to make vast improvements to community inclusion over this time, will have significant impacts on the lives of children and young people with disability. During this time, we can protect, support and empower children and young people with disability to have a childhood, adolescence and early adulthood just like everyone else. We can ensure that they will have every opportunity to learn, build relationships and meet new people, find a job in line with their skills and aspirations and live independently in a home they choose. Ultimately, done well, the NDS can support children and young people with disability to thrive – in the now and as they transition into adulthood.

While the previous NDS outlined a welcomed vision and plan for a more inclusive and just society, ten years later, children and young people with disability continue to experience systemic neglect and significant barriers to social and economic inclusion. They continue to be left out of conversations and decision-making that affects their lives and are denied opportunities and rites of passage that their peers without disability assume as a given.

This submission covers:

* How and why children and young people should be meaningfully engaged in decision making processes
* Required areas of action to realise the NDS outcomes areas
* The development of an outcomes framework and strategy to delegate roles and responsibilities and support accountability processes

CYDA’s submission draws on our previous survey and research work, including:

* 2019 National Education Survey
* *Pathways for young people with disability after school (*n=86)[[3]](#footnote-4)
* [*Time for change: The state of play for inclusion of students with disability*](https://www.cyda.org.au/images/pdf/time_for_change_2019_education_survey_results.pdf) (n=505)
* [Towards inclusive education: A necessary process of transformation](https://www.cyda.org.au/images/pdf/towards_inclusive_education_a_necessary_transformation.pdf) (2019)
* [Post school transition: The experiences of students with disability](https://www.cyda.org.au/resources/details/85/post-school-transition-the-experiences-of-students-with-disability) (2015)
* [Strengthening Participation of Children and Young People with Disability in Advocacy](https://www.cyda.org.au/resources/details/86/strengthening-participation-of-children-and-young-people-with-disability-in-advocacy) (2014)

CYDA has also attached the following work we have been involved in or commissioned to support our points:

* [*What is inclusive education?* Fact sheet](https://www.cyda.org.au/resources/details/58/what-is-inclusive-education)
* [*Driving change: A roadmap for achieving inclusive education in Australia*](https://acie.org.au/2020/09/30/driving-change-a-roadmap-for-achieving-inclusive-education-in-australia/)

In October 2020, CYDA hosted the inaugural National Youth Disability Summit, a five day, online virtual summit designed by and for young people with disability. Some of the broad themes and topics that emerged throughout the Summit have been included in this submission.

The Summit included four consultation sessions asking young people with disability what they would like to see included in the next NDS. The topics covered by the sessions included education, employment, living a good life, and choice and wellbeing. CYDA will produce a separate reporting collating the themes and ideas that emerged from these sessions to ensure that young people’s voices, opinions, and ideas are amplified.

The current submission also includes two case studies to illustrate the impact of systems failures on the lives of children and young people with disability.

# Children and young people with disability must be meaningfully engaged

**Recommendations**

* The new Strategy is underpinned by the life course approach and incorporates priority areas that reflect different needs across the lifespan
* Priority areas and consequential policies and programs are formed and evaluated with the meaningful inclusion of young people with disability and families and caregivers of children with disability
* Governments engage with disability advocacy and representative organisations to ensure young people and families and caregivers are engaged in consultation and co-design processes that are safe and inclusive

While the previous NDS states that it reflects and reinforces the ‘life course approach’, and takes ‘into account a person’s likely needs and aspirations over their lifetime’, specific mention of children and young people is largely absent from the document. To understand the life experiences of a person with disability, the NDS must bring a more critical lens to how our services and systems are supporting or failing people with disability at different points in their life transitions, and how these inadequacies have flow-on impacts across the life course.

For example, despite it being well-established that a child or young person’s early experiences with the justice system are linked with their future interactions and outcomes, and that existing (albeit limited[[4]](#footnote-5)) data[[5]](#footnote-6) indicates that children and young people with disability are overrepresented in the justice system, the previous NDS’ Rights protection, justice and legislation outcomes area did not include any priority actions to support the cohort.

By not acknowledging different life stage needs, the Strategy limits its view of children and young people with disability to just their disability. Fundamentally, children and young people with disability are children and young people. For the NDS to achieve its vision of ‘an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens’, it needs to acknowledge and value children and young people’s identities, aspirations and dreams.

To understand what children and young people with disability want and need, the NDS and the departments actioning the priority areas must meaningfully engage with this cohort on their terms and in accessible and inclusive ways.

In a report commissioned by CYDA in 2014, “Strengthening Participation of Children and Young People with Disability in Advocacy”[[6]](#footnote-7), it is noted:

“Participation by children and young people in advocacy and change-making can not only improve and foster positive change in their own lives, but also influence the lives of others. When young people’s participation is supported, meaningful and engaged, multiple benefits accrue. Their perspectives and experiences bring a unique contribution and can result in rights-based empowerment, enacted citizenship and improved relationships. This has the potential to shape policy, to increase the relevance and responsiveness of organisations they use, and to influence change in their communities in positive ways.[[7]](#footnote-8)”

Participation can occur at different levels, including at a:

* Local/individual level: such as decision making and influencing change for daily living.
* Structural level: influencing change in systems, such as within education and community.
* Systemic level: influencing change at a society/policy level.[[8]](#footnote-9)

The 2014 report provided evidence on the many benefits stemming from the inclusion of children and young people with disability in participatory activities. These include individual benefits for young people themselves, benefits for the organisations they are involved with, for informing policy, and systemic benefits for wider communities. However, the report noted:

“There are a range of barriers that discourage, prevent or actively exclude children and young people from participating. Some of these are social and cultural barriers, such as attitudes and low expectations. Others are practical — participation processes which limit the depth and involvement of children and young people’s influence, such as one-off, adult-led consultations. These barriers to participation are magnified for children and young people with disability, particularly younger children and those with higher or more complex support needs.[[9]](#footnote-10)”

The ongoing impact of these barriers was highlighted by young people who attended CYDA’s 2020 National Youth Disability Summit (NYDS).

*“Politicians don’t have lived experience of the systems they are designing. So, they don’t necessarily know the ways of enacting systems change that are going to best benefit the people that exist within the system”* - Young participant at the 2020 NYDS

Young people with disability rarely have opportunities to meaningfully engage with government policy development processes or consultation; and there is a long way to go to ensure these processes are genuinely inclusive and built on co-design principles.[[10]](#footnote-11) At the national level, policy impacting children and young people with disability sits across multiple policy portfolios, including:

* *Employment policy, services, income support* – Services Australia, Department of Social Services (DSS) and Department of Educations, Skills and Employment (DESE)
* *Youth policy* – Department of Health
* *Disability services* – DSS and National Disability Insurance Agency (NDIA)
* *Abuse, neglect, child protection and juvenile justice* – DSS, NDIS Quality and Safeguards Commission, Attorney General’s Department
* *First Nations policy and programming* – National Indigenous Australians Agency.

At the state and territory level there are also multiple departments and agencies, and again there is little opportunity and few formal structures for young people with disability and families and caregivers of young children to be involved. The machinery of government approaches to policy‑making and program delivery for children and young people with disability create structural barriers and mean that governments generally have difficulty in holistically considering the needs of young people with disability and involving them in consultation and/or policy development.

Additionally, children and young people with disability often face barriers to participating in consultative process because of inaccessible processes (including inadequate information delivery, meeting structures, interpreters, assistive technology), and we have seen little evidence that government consultative processes are responding to these needs adequately. This notion was echoed in the Social Deck’s recent consultation report to help shape the next NDS, which confirmed young people ‘do not find current mechanisms used by governments to engage on these issues appealing, suitable or easy to access’.[[11]](#footnote-12)

*“As a young person myself, I've been told 'No you can't speak' or 'you're not old enough' so it's so lovely to see older people especially respect that the future is ours to take. And that out decisions and our voice is important*.” - Young participant at the 2020 NYDS

For children and young people with disability to engage with government safely, confidently, and meaningfully, extensive pre-briefing, tailored accessibility support and post-briefing support is needed. This support is best provided by disability advocacy organisations like CYDA, and state/territory-based organisations for work in those jurisdictions. Our organisations have the skills and expertise to ensure safe, meaningful and supported engagement activities. Peer support and peer work approaches have also been shown to be effective in consumer participation and engagement.[[12]](#footnote-13)

# The National Disability Strategy outcome areas remain unrealised

The six outcome areas identified in the previous NDS remain relevant, because they have not yet been realised. The next section of our submission will outline what CYDA recommends as some of the necessary steps and levers to accomplish the proposed outcomes and work toward a more inclusive and just society.

While the current submission talks to priority areas that are closely aligned with particular outcome areas of the previous NDS, CYDA urges the new NDS to recognise that all outcome areas are interrelated and dependent on each other’s success. For instance, a young person with disability’s experience in the workforce cannot be understood without the context of their experiences in the education, health and housing systems. Similarly, a child or young person’s health and wellbeing outcomes cannot be understood without the context of economic security, personalised supports or inclusive community attitudes.

The table below outlines the required areas of actions identified by CYDA and the related outcome areas included in the previous NDS. In line with CYDA’s human-rights based approach and the previous NDS’s human rights imperative, the ‘Rights protection, justice and legislation’ outcome area relates to each identified area for action. In any instance, where children and young people with disability do not have full and effective participation and inclusion in society and do not experience equality of opportunity, their human rights are violated.

|  |  |
| --- | --- |
| **Required areas of action** | **Related outcome areas** |
| Ensure inclusive education | **Learning and skills**  Economic security  Inclusive and accessible communities  Health and wellbeing  Personal and community support  Rights protection, justice and legislation |
| Provide targeted and support for students’ career-planning and address state and territory inconsistencies | **Learning and skills**  **Economic security**  **Personal and community support**  Inclusive and accessible communities  Rights protection, justice and legislation |
| Address low expectations of post-school transitions of young people with disability | **Learning and skills**  **Economic security**  **Inclusive and accessible communities**  Health and wellbeing  Rights protection, justice and legislation |
| Address direct and indirect discrimination in the workplace | **Economic Security**  **Rights protection, justice and legislation**  Personal and community support  Inclusive and accessible communities  Health and wellbeing |
| Develop fit-for-purpose employment programs and supports | **Economic security**  **Personal and community support**  Learning and skills  Health and wellbeing  Rights protection, justice and legislation |
| Provide an adequate safety net when young people cannot find work | **Economic security**  **Personal and community support**  Health and wellbeing  Rights protection, justice and legislation |
| Timely and appropriate information provision | **Personal and community support**  **Inclusive and accessible communities**  Health and wellbeing  Rights protection, justice and legislation |
| Improve access to accessible housing | **Economic security**  **Inclusive and accessible communities**  **Health and wellbeing**  Learning and skills  Rights protection, justice and legislation |

## Ensure inclusive education

**Recommendations**

* The Commonwealth and state and territory governments undertake major systemic reform as outlined in *Driving change: A roadmap for achieving inclusive education in Australia* to fulfil Australia’s CRPD obligations and the NDS outcome areas

**What changes should be monitored**

* For an extensive list of short, medium and long-term outcomes required to achieve inclusive education, please see*Driving change: A roadmap for achieving inclusive education in Australia*
* Increased % school attendance
* Increased % higher levels of education attainment
* Decreased % early school leaving rates
* Increase % of students with disability completing year 12
* Decrease % of suspensions and expulsions
* Increase % of student engagement
* Increase % of student’s reporting feelings of inclusion, belonging etc. (factors of engagement)
* Decrease in funding allocated to segregated schools or settings (with the ultimate goal to phase out segregated education entirely)
* Decrease % of children and young people being subject to restrictive practices in education settings (which the ultimate objective being the elimination of the practice)
* Increase % students with disability transitioning into VET, tertiary education or open employment (in line with their aspirations) post-school

The NDS outcomes – particularly the Learning and Skills outcome – cannot and will not be realised until education settings and systems include students with a disability on an equal basis and ensure all students are valued as contributors and learnings. Achieving inclusive education “requires recognising the right of every child (without exception) to be included and adapting the environment and teaching approaches in order to ensure the valued participation of all children.”[[13]](#footnote-14) Inclusive education is more than a student with disability simply being present in early education, school or tertiary education settings, but rather entails the full participation and full membership of all students within the school community.[[14]](#footnote-15)

Evidence shows that inclusive education “has positive benefits for everyone”[[15]](#footnote-16) – students with and without disabilities, as well as teachers and the broader school community. For all students, inclusive education facilitates social development, socially inclusive attitudes, improved education outcomes and communication and language development.[[16]](#footnote-17) To the contrary, there is no evidence base to support segregated education in any form, including in special schools, special units or special classrooms.[[17]](#footnote-18)

Fundamentally, inclusive education is in line with the United Nations *Convention on the Rights of Persons with Disabilities 2006* (CRPD) and the *Convention on the Rights of the Child 1989* (CRC) – of which Australia is a signatory to both. These Conventions contain clear standards and obligations on the rights of children and people with disability to equal access to education[[18]](#footnote-19), including the emphasis that no form of segregation constitutes inclusive education. Australia’s ratification of these Conventions articulates the Australian Government’s commitment and responsibility to protect, respect and promote the rights of all children and young people with disability to receive a quality, free and inclusive education.

Despite the known benefits of inclusive education and Australia’s obligations to achieve inclusive education, governments in Australia continue to provide ongoing funding ongoing commitment to resourcing and supporting special class and special school placements.[[19]](#footnote-20) In the case of Victoria, not only has inclusive education not been realised, but 2019 data shows that enrolment rates in special schools have increased by 53 per cent since 2010.[[20]](#footnote-21)

Gatekeeping – whereby ‘power holders’, such as principals and medical practitioners, “create, mobilise, recreate and reinforce structural barriers” to accessing education ­– also remains a consistent barrier for students with disability. In 2020, a research report[[21]](#footnote-22) was published with the aim to determine the extent and distribution of gatekeeping and restrictive practices in Australia. Drawing on a national sample, the study found that more than a third (37 per cent) of the 745 families surveyed reported that they were told by educators, medical practitioners and allied professionals that segregation would be in the best interests of their child. Concerningly, the study also found that nearly a quarter of families (24 per cent) reported that restrictive practices were used to manage behavioural challenges.

**Types of restrictive practices[[22]](#footnote-23)**

**Restraints**

* **Physical restraint**: Using physical force to immobilise a student or reduce their movement. This can be done by holding a student’s torso, arms, legs, or head (while they are sitting, standing or lying down) so that they cannot move freely.
* **Chemical restraint**: Providing medication to a student so as to subdue a student’s behaviour. This does not include the use of medication prescribed by the student’s medical practitioner, unless the medication is used above or below the prescribed dosage or frequency authorised.
* **Mechanical restraint**: The use of a device, including harnesses, straps, clothing, or equipment, to subdue a student or restrict their movement.

**Seclusion**

* Seclusion is the confinement of a student in a room or area from which their free exit is prevented. Seclusion is regarded as a restrictive practice when the student has been removed from the environment and placed in the space against their will (as opposed to a calming space the child chosen to enter)

In total, the study found that over 70 per cent of families reported experiencing gatekeeping or restrictive practices. The most commonly reported practices were ‘inadequate education or teacher assistant support’ (54 per cent) and ‘inadequate opportunities and support to develop and maintain peer friendship’ (48 per cent). The researchers from the study determined that the survey data represents a widespread practice of a serious violation of human rights in Australian education settings.

The findings from the study are consistent with CYDA’s own research, and gatekeeping was also explored at a recent education hearing of the Disability Royal Commission. Between August and September 2019, CYDA conducted a National Education Survey to understand the experience of children and young people with disability in their school education[[23]](#footnote-24). There were 505 young people with disability and families and caregivers of children with disability who responded to the survey.

The survey had representation from all states and territories, all age groups and from metropolitan, regional, rural and remote Australia. The majority of respondents were from families of students with disability (97%), with the balance of respondents being students with disability.

Our study found that that students with disability are routinely excluded in their education, with many being segregated from ‘mainstream’ schools and classrooms, not attending school full-time, refused enrolment and excluded from school activities. Suspensions and expulsions are also familiar practices, showing the lack of understanding and support for students with disability.

Findings from the study also showed that students with disability experience unacceptably high levels of abuse and violence at school, including bullying and restrictive practices such as restraint, seclusion or both of these.

Max’s story in Appendix A highlights the impact of the use of restrictive practices.

Families did **not** believe:

* students with disability received adequate support in their education
* that they were communicated with regularly about the student’s learning progress
* that teachers had high expectations of the student, or
* that teachers had the required training to provide a supportive and enriching education environment.

For a more comprehensive understanding of the findings from CYDA’s National Education Survey, please see the supplementary data included in Appendix B.

Recently, at the 2020 National Youth Disability Summit*,* CYDA heard directly from young people with disability about what they believed were the barriers to experiencing an inclusive education. The group talked about how their needs in school settings were often disregarded, ignored and misunderstood. They observed that those in power in education settings often did not listen to young people with disability, choosing to instead make assumptions about what was best for them and their education.

*“‘Being an Aboriginal, LGBTI+ person with disability has meant that none of my identities are taught* *in school. This has made my experience difficult both in my institutions but also in my own shaping of who I am. I felt left out. Felt different. Felt like I don’t belong. Like the default is white, abled and heterosexual. I have experienced discrimination from teachers and lecturers, such as being told that I was ‘too sick’ to be at university. And constantly being in detention at school because the system just wasn’t designed for someone like me.’’* – Young participant at the 2020 NYDS

The group also discussed what helped or enabled them experience an inclusive education. The importance of educators asking young people with disability what they need, instead of assuming they know best, was a primary finding. To improve the education system, the group talked about the need for ‘educating the educators’. This included providing education, co-designed by those with lived experience of being a young person with disability at school, TAFE or university, to educators and other students without disability alike.

What is clear is that despite 10 years of the NDS and the 15 years (and multiple reviews) of the Disability Standards for Education, the rights of children and young people with disability to experience an education on the equal basis as others continues to be grossly violated. While the intentions of the NDS Learning and Skills outcome area to ‘focus on reducing the disparity in educational outcomes for people with a disability and others’ is well-intentioned, this will never be achieved until governments, systems and education settings are accountable for providing inclusive education settings where all students’ potential to thrive in their education is fostered.

To realise the NDS outcome areas, the phasing out of segregated education and the realisation of inclusive education (as defined by the CPRD which Australia has endorsed, but not fulfilled) for students with disability must be a priority.

The Australian Coalition for Inclusive Education (ACIE), an initiative which brings together organisations that share a commitment to advance inclusive education in Australia, has developed a 10-year plan31 (*Driving change: A roadmap for achieving inclusive education in Australia*) to help realise inclusive education and prevent the violence, abuse, neglect and exploitation of students with disability. This plan has been endorsed by specialist organisations across the country.

CYDA recommends the uptake of *Driving change: A roadmap for achieving inclusive education in Australia* to promote equitable education outcomes for children and young people with disability. Apt for the NDS, the *Roadmap* details a 10-year plan to achieve inclusive education, with short-term and medium-term outcomes that will lead to this longer-term goal. The *Roadmap* also includes the key levers for change that are needed to realise these outcomes, including the commitment and shared responsibility of the Australian and all state and territory governments.

CYDA has attached a copy of *Roadmap* to our submission.

## Provide targeted and support for students’ career-planning and address state and territory inconsistencies

**Recommendations**

* Increase tailored supports for young people for young people with disability to engage in work experience and/or paid employment during school years
* The recommendations for students with disability in the *Looking to the future: Report on the review of senior secondary pathways into work, further education and training* be adopted and evaluated
* Improve national consistency in post-school transition activities, building on what works best around the country
* Include young people with disability and families in every stage of developing new post-school transition activities
* Ensure post-school transition programs are well-structured, outcome-oriented and student-focused
* Start post-school planning activities for all students with disability by at least the age of 15
* Improve data collection about post-school transition programs, including their uptake, implementation and outcomes
* Review funding arrangements in all states and territories for school and post-school programs for students with disability

**Indicators to monitor**

* Increased % of young people with disability participating in meaningful work experience during their school years
* Increased % of young people with disability engaged in part-time employment during their school years
* Increased % of students feeling supported to consider their aspirations and post-school prospects and options
* Increase % confidence in students with disability about their post-school options
* Year level that students are first engaging with post-school planning activities
* Funding and resource levels from respective education departments to provide post-school programs and activities for students with disability

While CYDA agrees fully with the intent of the previous NDS to improve pathways from school to further education, employment and lifelong learning, ten years on, young people with disability still experience inequitable post-school outcomes. A major influence on disparate outcomes is a young person’s experiences and career supports in the lead up to their school completion.

In 2015, CYDA released a report[[24]](#footnote-25) into the experiences of young people with disability during their post-school transitions. The report found that, while the transition from school is a critical period and young people have a variety of options, “many young people with disability however have extremely poor post school transition experiences…[which] is impacting negatively on life outcomes, where there is low participation in employment and tertiary study, and social exclusion remains high. While there are pockets of good post-school transition practice, generally programs and preparation for this transition are fragmented with minimal coordination and guidance regarding what should occur during this time.”[[25]](#footnote-26)

Sadly, the situation today for students with disability remains very similar to that outlined in the above report.

As shown in Figure 1C (see Appendix C), the majority of respondents in CYDA’s 2019 post-school survey (80.2 per cent) reported that their school did not provide support or appropriate information about career planning, and more than half reported that they did not receive adequate support to think about and plan for their future (57.8 per cent), or that they did not find the assistance and information available through their school to be useful (52 per cent).

Fewer than one in five students report receiving assistance in understanding their strengths and skills for post-school transition; practical assistance such as resume-writing; or assistance to plan any study or training. Additionally, parents reported feeling a significant degree of responsibility for the career-planning process, and note that the support provided is generally not tailored to students with disability, and therefore options are limited.

Comments from young people and families in our 2019 post-school transition survey demonstrates the limited support available in many places:

“*Very little assist[ance] was given due to lack of options and lack of funding to individually support my son*” - family of a young person with disability 19-20 years old, metropolitan VIC

“*Career counselling available was of extremely poor quality and not suited to the current issues for school-leavers. Huge disconnect between a regional public high school in a low-SES area about post-school life and particularly on scholarships to universities and open days, etc*.” - young person with disability over 25 years old, metropolitan VIC

“*Only Work-Related Skills subject for VCAL no other assistance*” - family of a young person with disability 17-18 years old, regional VIC

“*My daughter attended TAFE one 1/2 day a week and school 4 days on a life skills curriculum with a 2 hour a week extended work experience placement external to the school. I coordinated this program for my daughter. This is not normally available in NSW schools.*” - family of a young person with disability 19-20 years old, regional NSW

“*Support for assessment for NDIS SLES program*” - family of a young person with disability 19-20 years old, metropolitan ACT

Around three quarters of our survey respondents agreed that much more needs to be done to support post-school planning and to help students to achieve their goals (73.2 per cent). Suggestions for further investment include assistance with life skills, more teacher support, tailored work experience with interest and abilities, more community integration for students and more information for families.

Participation in work experience, paid and unpaid, during the last years of secondary schools is consistently a strong indicator of post-school success,[[26]](#footnote-27) however in our 2019 post-school survey, less than half of respondents reported having the opportunity to undertake work experience and had assistance to organise this.

Additionally, young people with disability who exit school with a job are more likely to maintain a positive career trajectory than those who do not.[[27]](#footnote-28) With most employers requiring applicants to hold previous work experience[[28]](#footnote-29), more needs to be done to support young people with disability to partake in work experience and part-time employment during their school years to support their full transition to the labour market.

Our 2019 post-school transitions survey also highlighted the disparities of school career programs across different states and territories in terms of their approaches and resourcing. Around 80 per cent of our survey respondents (n=68) reported that they have received a form of career planning at school, however for most students this did not start until the later years of high school. Almost 30 per cent of these students reported they started receiving career-planning support in Year 12, with around 45 per cent receiving support in either Year 10 or 11 (see Table 2C, Appendix C). Fewer than five per cent reported receiving support in Year 9.

Additionally, many families report they are not aware of these programs. This may be for a number of reasons, including the student not finishing school or not being provided appropriate support and opportunities to develop skills due to lower expectations and exclusion.

Reflections from young people[[29]](#footnote-30):

“*Year 12, yes, but it was very limited - one session with a teacher to talk about what we were thinking of doing. Many people were pushed earlier into trades at TAFE, rather than focusing on them getting into university. Students with disabilities that impacted on their results, who stayed until year 11 and 12 were pressured into segregated 'life skills' classes, meaning they did not receive their HSC (this happened to my brother, even though he has ASD, but was completely capable of completing the HSC)*” - young person with Disability aged over 25 years old, metropolitan VIC

“*Begin the process a lot earlier than end of year 11. Presume competence. Inform, encourage and support families to be involved in the process. Give them all the options and assist in making these happen. Education department to work with NDIS to understand, support and fund real transitions*” - family of a student with disability aged 17-18 years old, metropolitan NSW.

The *Looking to the future: Report on the review of senior secondary pathways into work, further education and training[[30]](#footnote-31)*, to which CYDA provided a submission[[31]](#footnote-32), highlighted the importance of starting the transition from school and career planning activities early, with specific recommendations that all students with disability should have an individual post-school transition plan.

Students with disability may require extra or different support for their transition from secondary school, and it is beneficial to start the career planning earlier. A number of studies have confirmed that post-school transition planning for young people with disability needs to include five key areas:[[32]](#footnote-33)

1. Student-focused planning
2. Student development
3. Family involvement
4. Program structure
5. Interagency collaboration.

CYDA recommends taking a unified approach across the country and introducing career-planning activities that include the five key areas for all students with disability by the age of 15 years. To build the skills of the students, it will be important to include practical subjects as well as work experience or exposure to different work industries where students have expressed interest.

It is critical that young people with disability, and families, are involved in the development of any new transition planning activities or programs from the beginning and throughout the development and implementation process.

“Working with young people in defining the problems and issues that affect them can lead to new understandings about the source of such problems as well as potential responses. Young people’s involvement also helps to build credibility and rapport for the project and ensure that their values and attitudes are accounted for.

Pragmatically, a Participatory Design approach helps us to develop interventions that are engaging to young people and therefore are more likely to be used, increasing the overall reach and impact of the intervention.”

-Young and Well Cooperative Research Centre, 2012[[33]](#footnote-34)

## Address low expectations of post-school transitions of young people with disability

**Recommendation**

* Counter the narrative of ‘low expectations’ for young with disability through concrete actions and monitor post-school outcomes for students with disability

**Indicators to measure**

* Increase % young people with disability completing year 12
* Decrease % young people with disability entering ADEs
* Increase % students with disability transitioning into VET, tertiary education or open employment (in line with their aspirations) post-school
* Increase % in students with disability feeling that their school, and others ‘around them’, have high and expectations of their post-school outcomes

Expectations of post-school outcomes, by the young person with disability and those around them, are known to be linked with employment outcomes[[34]](#footnote-35), with those who are perceived with low expectations facing increased barriers to employment. Discriminatory attitudes from schools, communities, and government and policy approaches gatekeep the young person’s possibilities and undermine their right to social and economic participation on an equal basis.

CYDA’s 2015 research into the post-school transitions experiences of young people with disability[[35]](#footnote-36) found that systemic low expectations regarding the capability, value and individuality of the young people consulted heavily impacted on their post-school transition experiences.

Reflections from young people with disability[[36]](#footnote-37):

*“Year 12, yes, but it was very limited - one session with a teacher to talk about what we were thinking*

*“People treat you like you’re dirt and talk down to you. Some act like they might catch it off you if they stand too close. They lie and dismiss you so they don’t have to deal with you.*

*“Discrimination at school and failure to provide supports I’m legally entitled to meant I lost access to supports and developed severe mental health issues. I’m still unemployed.”*

*“I tried the employment services but they could not help me as they said I was too disabled.”*

*“I wish my teachers had believed in me.”*

*“My teacher said I could not work with animals. I did a transition program working one day a week over two terms at the local pound”*

Five years later, low expectations from those around young people with disability continue to be a significant barrier. Almost two thirds (63.7 per cent) of respondents in our 2019 National Education Survey[[37]](#footnote-38) reported feeling that the school did not have high expectations of the student with disability regarding employment or further education after school. Further, our post-school survey also found that 70 per cent of the young respondents were not encouraged to complete or to choose subjects to lead a good ATAR score for higher education (see Table 3C, Appendix C).

For many young people with disability, and particularly young people with intellectual disability, transition from school directly into Australian Disability Enterprises (ADEs) is still presented as the best or only option.[[38]](#footnote-39) Often characterised as low-skilled work-experience, ADEs do not offer people with disability the ability to develop transferable skills that could lead to open employment or a full wage[[39]](#footnote-40). In 2014, less than one per cent of people with disability in ADEs moved into open employment[[40]](#footnote-41).

Further, the segregated nature of ADEs and below minimum wage young people in ADEs receive is a clear violation of a multitude of human rights under the CRPD.[[41]](#footnote-42) They exclude young people with disability from the rest of the community and exploit their labour for a wage[[42]](#footnote-43) that prevents them the ability to live independently.

Despite this, according to recent NDIA data[[43]](#footnote-44), of the young participants in the NDIS who are ‘employed’, 35 per cent of this group are working in ADEs. In comparison, only 41 per cent of young NDIS participants who are employed are in open employment and receive an award wage.

Hannah’s story in Appendix A highlights how the attitudes and low expectations held by people around young people with disability withholds their ability to learn and thrive.

To enable young people with disability to experience equitable employment outcomes, when they first transition into the labour market and then into adulthood, the NDS must include funded interventions targeting those who hold misinformed perceptions and low expectations of what young people can achieve in their schooling and post-school.

## Address direct and indirect discrimination in the workplace

**Recommendations**

* Increase targeted, evidence-based interventions addressing the negative andmisinformed attitudes of employers. These development strategies must include the meaningful involvement of young people with disability
* Assure that the Australian Human Rights Commission, and other independent oversight agencies, receive sufficient resourcing to safeguard the rights of young people with disability in the workforce
* Continue and increase investment in regular community and employer attitudes surveys and research to monitor changes over the duration of the next NDS

**Indicators to monitor**

* Increased % of young people with disability in open employment
* Increased % confidence of employers using equitable hiring processes
* Increased % application of employers using equitable hiring processes
* Increased % employer rates of awareness and understanding of the rights of people with disability and anti-discrimination legislation
* Increased % uptake of government-funded workplace adjustment supports

Societal attitudes ultimately can determine what a young person with disability can achieve in the workforce. While it essential to ensure that young people with disability are equipped with the same resources as their peers as they transition into the labour market, such as a quality and inclusive education, NDS interventions also need to target direct and indirect discrimination within the workforce. For example, despite higher education attainment being well linked with employment, employment outcomes for graduates with disability remains lower than those without disability. In 2019, undergraduates with a disability had a full-time employment rate which was six percentage points lower than undergraduates without disability (66.6 per cent compared to 72.6 per cent).[[44]](#footnote-45)

Lack of awareness and misconceptions about people with disability remain a significant barrier to employment, including for young people. A decade on from the influential *Shut Out* report identifying that few employers were willing to hire people with disability[[45]](#footnote-46), and the completion of the first ten-year NDS, almost two thirds of employers are largely uncommitted to employing jobseekers with disability[[46]](#footnote-47). Despite research finding that people with disability take fewer days off and less sick leave, and have a higher retention rate[[47]](#footnote-48), a recent community survey[[48]](#footnote-49) demonstrated that there are persistent underlying community beliefs that people with disability are less productive employees than those without disability.

Concerningly, this same survey demonstrated that one in five people agreed or strongly agreed that employers should be allowed to refuse to hire people with disability, with a further one in four ambivalent on the topic. Compounded by the discriminatory lens with which society often views young people, it raises the question that even if young people with disability were fully equipped with every skill and resource necessary to thrive in the workforce – would the workforce ever even grant them a fair chance?

Employers’ lack of confidence about the process of employing people with disability and the potential need to make workplace adjustments has also been reported as a barrier.[[49]](#footnote-50) In an effort to increase employer demand, in 2017 the Department of Social Services commissioned a review[[50]](#footnote-51) into employers’ (in open employment) attitudes and beliefs around hiring people with disability. The report found that employers regarded hiring people with disability as ‘extra work’, and the perceived extra support and supervision requirements acted as a major barrier to recruitment. Contrary to this, ABS data shows the majority (82 per cent) of unemployed persons with disability do not require additional support from their employer to work.[[51]](#footnote-52) Further, employers with previous experience working with people with disability tend to hold favorable attitudes toward workers with disability compared to those who have not.[[52]](#footnote-53)

The recruitment process, and lack of inclusive recruitment processes, can also be a barrier to employment for people with disability.[[53]](#footnote-54) At the recent National Youth Disability Summit, CYDA consulted with a group of young people with disability on some of the barriers and enablers to finding and maintain employment. The young people commented that through current recruitment processes their abilities were dismissed before employers even had the chance to get to know them and the value they could add. Further, some commented that they feared disclosure of their disability will decrease their chances of getting a job.

Whether it stems from lack of experience, misunderstanding or overt discrimination – the result is the same for young people with disability. Their right to work on an equal basis to others is denied along with all the social, health and financial benefits that come with meaningful employment.

An important mechanism in ensuring employers comply with human rights charters and anti-discrimination legislation is independent oversight agencies, such as the Australian Human Rights Commission (AHRC). In 2018-29, more than a quarter (27 per cent) of disability complaints received by the AHRC were about employment.[[54]](#footnote-55) The AHRC then acts on these complaints and works with people with disability and the employer to resolve to the complaint. Without sufficiently resourced bodies, individual complaints risk going unheard and discriminatory employers will not be held accountable. Additionally, there is currently little capacity to investigate systemic issues, with compliance monitoring relying on the individual complaints model.

Intervention is required to address the existing negative and misinformed attitudes society holds about young people with disability. In line with evidence, these interventions are required at multiple inter-related policy levels; the personal, organisational (i.e. workplaces and employers) and government and legislative levels.[[55]](#footnote-56) Young people with disability must be meaningfully involved in every stage of these processes for the interventions to address what needs to be changed effectively.

**“Personal-level policies** are directed at changing the attitudes of individuals towards people with disabilities

**Organisational-level policies** attempt to improve attitudes towards people with disabilities in various life domains, such as education, employment and health. Policy types include training, complaints mechanisms and targeted information programmes, which seek to mitigate the power disadvantages experienced by people with disabilities, by changing the behaviour and attitudes of people without disabilities

**Government-level policies** are initiated by governments and attempt to influence attitudes by mandating behaviour change. This level consists of the policy statements and laws that define actions reflective of positive attitudes, together with the means for implementation and monitoring. Examples are anti-discrimination legislation and inclusive education.”[[56]](#footnote-57)

At the organisational level of intervention, negative attitudes about employing young people must be addressed. This includes addressing misconceptions about young people with disability’s capabilities and informing employers of people with disability’s legislative rights. The skills, talents and distinct worldviews young people with disability can bring to the workforce must also be highlighted.

## Develop fit-for-purpose employment programs and supports

**Recommendations**

* Improve monitoring and public release of caseload and outcome data of young people with disability in employment programs
* Ensure young people with disability across Australia can access age-appropriate employment programs that are designed to address barriers to employment

**Indicators to monitor**

* Comparison of employment outcomes for young people with disability across different employment programs and supports (including state programs and under the NDIS)
* Decrease % of young jobseekers with disability in jobactive
* Increase % of young jobseekers with disability in Transition to Work
* Decrease % of young jobseekers in Disability Employment Services
* Increased % of six and 12-month employment outcomes for young with disability using employment services or programs
* Increased % satisfaction among young jobseekers with disability using employment programs or services

There is currently no national employment program for young people with disability. Some find themselves in jobactive, a program which was found by a Senate Inquiry not to address the barriers to employment for jobseekers with disability or young people.[[57]](#footnote-58) A portion[[58]](#footnote-59) find themselves in Transition to Work – a youth-specific employment program that addresses both supply and demand sides of employment – though access to the program is heavily restricted by a range of eligibility criteria. Others can find themselves in innovative, youth and disability specific programs, such as under Jobs Victoria Employment Network or Skilling Queenslanders for Work, but access to state-based programs generally require the young person to not be receiving unemployment income support.

While Australia does have the Disability Employment Service (DES), a service for people whose disability is assessed as the main barrier to them gaining employment, the program is not fit-for-purpose for supporting young people with disability. Research has found that DES’s approach is too narrow and restrictive, and does not appropriately accommodate for the complex, lengthier, and diverse nature of the school-to-work transition for young people with disability.[[59]](#footnote-60) Despite this, as at August 2020[[60]](#footnote-61), 14 per cent of the DES caseload was aged 24 years or younger.

For the portion of young people who are eligible for NDIS funding, the youth-specific School Leaver Employment Supports (SLES) is an option. SLES is a support designed to help young people with disability prepare, look for and gain employment as they transition from school to employment. However, due to the funding and outsourcing nature of the program, there is no clear evaluation data to determine if the support is effective or if there is consistency across providers. Despite this lack of data, NDIA figures[[61]](#footnote-62) show that the rate of young participants in paid work only increased by three percentage points (from 15 percent to 18 per cent) approximately a year after entry into the Scheme. This seems to suggest there is limited effectiveness of the SLES program to date and indicates specific evaluation work is greatly needed to explore this further.

While young people with disability are currently scattered across a variety of employment programs, it is difficult to determine from public data where exactly young people with disability are and if the programs they are in are supporting them to achieve employment outcomes. For example, jobactive caseload data, which represents a variety of Australia-wide programs, lacks any detail around young people with disability. Considering how influential early experiences in the labour market are for longer-term employment outcomes, significant improvement is required for data collection processes – to support researchers and policy-makers, and to ensure current gaps can be clearly identified in order to be addressed by governments.

The varied programs also largely differ in how they understand the ‘problem’ of unemployment, and as such, provide different problem solutions.[[62]](#footnote-63) This means that some young people with disability are exposed to programs that incorporate punitive measures to ‘push’ young people into employment, irrespective of suitability or fit. Alternatively, others are included in programs that recognises the increased structural barriers young people with disability face in the labour market and are designed to ‘pull’ them into employment opportunities.

A coordinated approach to employment programs and supports for young people with disability across Australia is clearly needed, including investment in supports for young people with disability’s specific needs. These programs should be evidence-based, target both supply and demand factors of unemployment, and be developed on the principle that young people with disability are both capable and willing to work. To ensure the program elements align with the needs of young people with disability in the labour force, the program must meaningfully include young people with disability in the design process.

## Provide an adequate safety net when young people cannot find work

**Recommendations**

* Ensure timely and appropriate information and support is available for young people to assist them to secure income support payments
* Review and amend the DSP eligibility requirements to ensure that it does not prevent young people with disability to receive earnings from a wage
* Provide an adequate safety net for young people with disability that reflects the contemporary cost-of-living, inclusive of the increased living-costs associated with having a disability

**Indicators to monitor**

* Monitoring of demographics factors of people with disability meeting access for the Disability Support Pension
* Increase % of young people with disability accessing the Disability Support Pension
* Decrease % of people with disability living below the poverty line

In acknowledging the increased barriers young people with disability face in gaining employment, adequate income support is essential to ensure an acceptable standard of living, as also outlined by the previous NDS. Nearly half of young people with disability aged 15 to 24 years (49 per cent) rely on income support payments, compared to 14 per cent of people aged 15 to 24 years without a disability.[[63]](#footnote-64) However, since the release of the previous NDS, how and what young people can access as a safety net has changed.

In 2012, changes to the eligibility criteria for the Disability Support Pension (DSP) meant that many young people must instead apply for Jobseeker or Youth Allowance, which provide a significantly lower rate of pay than the DSP.[[64]](#footnote-65),[[65]](#footnote-66),[[66]](#footnote-67) The stringent criteria has also added increased barriers for people with disability on the DSP to gaining employment, with rates of receiving earnings dropping by 1.7 percentage points between 2009 and 2018 (from 9.3 per cent to 7.6 per cent).[[67]](#footnote-68)

Recent research[[68]](#footnote-69) discussed that changes to the DSP eligibility requirement has created additional administrative burden for individuals, which in turn has had disproportionate impacts on who accesses the DSP. People who receive support to complete their DSP application claim form are more likely to have their claim granted than those who complete the form without assistance. The research highlighted the importance of information provision and support in ensuring people with disability get equitable access to the supports they are entitled to.

A total of 55.8 per cent of CYDA post-school survey respondents report receiving income support payments, with DSP the most common of these. A significant portion of survey respondents do not receive any income support payments (Table 4C, Appendix C).

As at June 2019, data shows that approximately 10.5 per cent of all recipients of Jobseeker[[69]](#footnote-70) and Youth Allowance – 31,798 people – are 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 Jobseeker 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
* 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 is highlighted in Figures 2C and 3C in Appendix C.

In understanding a young person’s economic security, it is essential to look beyond just rates of receiving payments and the types of payments received, and to examine if the payments are even substantial enough to provide an acceptable standard of living. The social sector[[70]](#footnote-71) has long advocated for an increase in social security payments, with current payments being so inadequate that those who rely on them are overrepresented in living below the poverty line[[71]](#footnote-72).

Citing contributing factors such as increased barriers finding employment and in turn, the increased reliance on income support payments, a 2020 ACOSS research report[[72]](#footnote-73) showed that a more than a third (37 per cent) of adults experiencing poverty have a disability. The research also acknowledged that these rates are likely to be an under-estimate, with person with disability generally having extra costs of living than those without disability.

For income support payments, such as the DSP or Youth Allowance, to truly provide economic security, the payments must be reviewed and amended to reflect the contemporary costs of living. In line with ACOSS’s research[[73]](#footnote-74), the base-line payments at minimum should be raised to provide an adequate and dignified standard of living for all people receiving income support. On top of this, income support payments should also incorporate supplement payments that reflect the differences in costs-of-living between individuals, such as increased the costs associated with living with a disability.

## Provide timely and appropriate information and support

**Recommendations**

* The commitment and establishment of a reporting framework for Commonwealth and state and territory systems and governments to demonstrate equitable and appropriate information provision for different cohorts within the disability community
* Any future community targeted information provision and support initiatives be developed with people from disability from the relevant communities (i.e. initiatives targeting young people must include young people)
* Monitoring the effectiveness of targeted information provision initiatives or supports
* Increased investment in individual advocacy services, particularly in developing child and youth specific disability advocacy organisations in each state

**Indicators to measure**

* Increase # of children and young people, and families and caregivers accessing support from child and youth-specific disability advocacy services
* Decrease in disparate rates between age groups and demographics accessing government provided supports and services
* Decreased disparity of meeting NDIS access rates between different communities/cohorts, including those with English as their first language, socio-economic status, gender, disability type, area, etc.
* Decreased disparity of plan utilisation rates between different communities/cohorts, including those with English as their first language, socio-economic status, gender, disability type, area, etc.
* Increased % average plan utilisation for all people with NDIS plans

At the recent 2020 National Youth Disability Summit, CYDA posed the question to group of young people with disability what supported (or hindered) them to make decisions and choices that were important to them. The young people spoke about how integral information delivered at the right time and in an appropriate manner was in supporting them to live the life they would like to live.

The young people spoke about when wanting to make decisions, or access supports that would support them to make the choices in life they value, they are often not provided with information that is digestible or appropriate. In the words of one group member, “Sometimes I find that information about decisions is formatted into a language that I cannot understand. I think it is important that when it is presented, it is enabling in a way that I understand.”.

When a follow up question was put to the group as to how they would like to receive information, the group members had diverse preferences, including visuals, bullet points, verbal presentations and easy read. Emphatically, the group also agreed that information that is designed to support them should be free of jargon and complicated legal terms.

The worldviews of the young people in the session highlights the disparities different groups experience in accessing different supports and services in the community. People with disability, young or older, are not a homogenous group, so when information provision takes on a ‘one-size-fits-all’ approach, some groups – such as people with low literacy and numeracy skills or whose native language is different from the language used in publications – are likely to be disadvantaged.

For instance, looking at the NDIS, a major achievement stemming from and since the initial NDS – some groups have benefitted more from the service reform than others. While the NDIS creates the opportunity for many to have greater choice and decisions in their life, without adequate and appropriate information and support provided alongside the personalised system, many people with disability are also worse off.[[74]](#footnote-75)

Recent research[[75]](#footnote-76) has explored the experiences of socially and economically marginalised individuals in interacting with the NDIS. The research found that many in the study sample had not even heard of the NDIS, and if they had, had no idea about how to apply for it or whether they would be eligible. The study found that when disability is overlaid with the marginalisation that comes from socio-economic disadvantage, the capacity for people with a disability to participate in a complex program like the NDIS becomes problematic, and concluded that improved communication with potential participants is needed, particularly for people from socio-economically disadvantaged and socially isolated groups.

For those who do gain access to the NDIS, there are also considerable differences in plan utilisation rates for different communities. Recent data[[76]](#footnote-77) released by the NDIA shows a trend in increased plan utilisation for children from higher socio-economic backgrounds. For NDIS participants aged 0 to 6 years old, there is 12 percentage points difference in average plan utilisation between the lowest decile (indicating the areas with the highest socioeconomic disadvantage) and the highest decile (54 per cent compared to 66 per cent). For NDIS participants aged 7 to 14 years of age, the difference was 7 percentage points between the lowest and highest deciles (65 per cent compared to 72 per cent).

These data show two points: current support and information for all children and families to engage fully with the complex service system is clearly inadequate, and that also that people experiencing additional forms of disadvantage, such as those from lower-socioeconomic backgrounds (who generally have lower ‘human capital’, such formal education attainment) face increased barriers.

To increase equity of choice and control in an individualised funding system, research[[77]](#footnote-78) identified effective information provision strategies. Information should be (i) accessible and diverse in format, mode, source and location; (ii) personalised and targeted to their lives and context; (iii) accurate, consistent and timely; (iv) from a trusted source (including professionals and peers); (v) independent; (vi) culturally appropriate; (vii) actively promoted to ‘hard to reach’ groups, such as those underrepresented in the NDIS and other face-to-face personalised services and (viii) gender appropriate, whereby the service provider acknowledges that carers are disproportionality female and considers gender-related barriers to sourcing information, such as time and carer duties.

While this data and literature relates primarily to the NDIS, barriers from inadequate information and support exist far more broadly for children and young people with disability. Inadequate and inappropriate information provision has been highlighted by CYDA members across a range of topics and processes, including understanding their rights, accessing income support, such as the Disability Support Pension, to understanding one’s own sexuality and identity.

Information equates to power, and this objective of the new NDS should not be overlooked or under considered. In understanding the diversity of communication strengths and needs of children and young people, it is important to consider the evidence that indicates a single mechanism will not be able to provide an all-encompassing solution. Rather, a commitment to, and public reporting from, each system and Commonwealth or state and territory department that intersects with the lives of people with disability will be required to provide adequate, timely and appropriate information. Existing information provision gaps and pitfalls by each system should reviewed and further developed (with people with disability) to meet individuals’ different needs and ensure all people with disability in Australia can access the information they need, where and when they need it.

One of the key mechanisms that should be considered by governments in the commitment to equitable information provision is increased investment in individual advocacy organisations. Individual advocacy organisations can offer different groups independent and timely information, personalised information that matches their lives and context, culturally appropriate information and be trusted source of information – all factors that support informed decision making.

While there is a shortage of individual advocacy services in general across Australia, with long wait lists and many organisations closing their books for periods of time, there is a critical gap for children and young people with disability. There are very few specific advocacy services for this cohort, and limited capacity to meet their needs within mainstream disability advocacy services. In many states and territories there are no specialised services, and we hear many reports of the difficulty young people, families and caregivers have in accessing the support they need.

## Improve access to accessible housing

**Recommendations**

* Provide an adequate safety net for young people with disability that reflects the contemporary cost-of-living, inclusive of the increased living-costs associated with having a disability
* Increase in the development of social housing that meets accessibility standards
* Introduce regulations of accessibility requirements in all new housing in line with universal design best-practice principles

**Indicators to measure**

* Increase % young people with disability living independently
* Increase % of young people with disability living independently
* Decrease % of young people with disability experiencing homelessness
* Increase # in social housing meeting accessibility requirements in 3, 5, 7 and 10 years
* All new houses developed from 2023 onward meet a minimum accessibility requirement
* No young people living in residential aged care facilities

Access to safe and stable housing supports a person’s mental health, health and ability to participate in employment, education and social life. As outlined by the CRPD, the ability for people with disability to choose a place of residence where they would like, and with who they would like on the equal basis of others is human right. Housing was identified by CYDA’s Co-Design Committee as a key theme for the 2020 National Youth Disability Summit; particularly the lack of accessible and affordable housing options for young people with disability. As expressed by one of the participants at the Summit, “Housing is a platform to live in the greater society”.

Despite this, young people with disability continue to face increased barriers to securing safe, accessible and appropriate housing – as both a person with a disability and a young person. As a person with disability, there is a lack of appropriate social and affordable private housing that meets their living needs. This includes living in an appropriate home that meets physical and safety needs, but also the proximity of the housing to accessible transport, services and community facilities that supports a person to participate in society as a full citizen.

As a young person, young people with disability also face the generational disadvantage of securing housing in an increasingly volatile housing market. Sustained growth in house prices in major cities, combined with demographic and labour market restructuring over the past 20 years has contributed to today’s young people restricted ability to secure housing, both ownership and renting.[[78]](#footnote-79)

Young people on income support – of which young people with disability are grossly overrepresented – are especially marginalised, with the payment amounts being so inadequate that there is a scarce amount of rental properties that are affordable. Recent research[[79]](#footnote-80) analysing the rental market found that even if the rates of the income payment doubled, a person on Youth Allowance looking for a share-house can afford less than 1 percent of rentals across Australia. The research also found that a person receiving the DSP could afford 0.2 percent of rental properties in Australia. These findings do not factor in the increased costs of living incurred by people with disability, nor the suitability of the housing, both of which make appropriate housing even more difficult to find.

While funding through the NDIS is enabling some young people with disability to secure housing, the young people with disability attending the Summit only saw this as a limited solution to a much bigger social problem. Firstly, this funding is only available to a portion of NDIS participants, which is again, only a small portion of people with disability. Secondly, the young people viewed the concept of receiving funding to live in homes or sites only with other people with disability as a continuation of segregation from the community. Like any other young person would, Summit participants spoke about the importance of housing choice and its links to independence and adulthood; how moving out of home was a rite of passage; and that they wanted to live with their friends and partners (or alone) without being restricted by rigid funding rules.

One young person added that though receiving individualised funding was game-changing in supporting them to live in an accessible home, they still faced barriers in their ability to visit family and friend’s homes – an integral aspect of social participation. This is echoed by recent University of Melbourne research[[80]](#footnote-81) into accessible housing, with approximately 81 per cent of survey respondents reporting they could not visit their friends and family because of inaccessible housing. The respondents commented that this had negative impacts on their ability to participate in social events, and in turn, added to feelings of loneliness and isolation.

The young people with disability at the Summit recommended that interventions and investment in accessible and affordable housing options be targeted at the mainstream housing market. They want to be supported to find homes in areas they wanted to live, with who they want to live with, like anyone else; with the assurance that there is a minimum standard of accessibility features in the home and the surrounding community. They also want these options to be open to all young with disability, not just those who might receive additional funding or be from higher socio-economic backgrounds.

As such, CYDA recommends one element of providing equitable opportunities for young people with disability to live independently and in homes that are aligned with their aspirations and needs must be to increase the level of social security payments (see ‘Provide an adequate safety net when young people cannot find work’ section of submission). Further, there needs to be an increase in social housing to negate the inadequacies of the private housing market, with these social housing developed to meet accessibility requirements.

While the previous NDS included a priority action to improve provision of accessible and well-designed housing and to support greater uptake of universal design, with few exceptions the housing industry has largely not responded or met this.[[81]](#footnote-82) To ensure the new NDS has more impact in providing accessible housing for people with disability, CYDA endorses the call of the Australian Network for Universal Housing Design to introduce regulation of accessibility in all new housing in line with universal design best-practice principles.[[82]](#footnote-83)

# Accountability

## Develop clear mechanisms for accountability and safeguarding

* Develop a robust outcomes framework with clear delegation of, and accountability around, responsibilities between national, state and territory and local governments
* The outcomes framework is in line with the CRPD and reflects the different needs of people with disability across the life course
* The outcomes framework must include clear oversight protections across systems in all jurisdictions to safeguard children and young people from abuse, discrimination and neglect, and eliminate the use of restrictive practices in all settings
* Establish an independent body to monitor and report on the progress of governments in accordance with the outcomes framework

While the vision and intent of the initial National Disability Strategy outlines a hopeful picture for a just and inclusive society, without any significant accompanying financial investment, or accountability or reporting frameworks, there has been little progress against many of the outcome areas ten years later.

“The NDS lacks actions and measurable outcomes to address systemic human rights violations, lacks resourcing in implementation, monitoring and evaluation across its policy outcome areas and lacks accountability and implementation mechanisms. Disaggregated data and the collection of information on the situation of women and children with disability are not built into the NDS”

- Disabled People’s Organisations Australia, 2019[[83]](#footnote-84)

Between the presence of the previously agreed upon National Disability Agreement, and then the later development of the National Disability Insurance Scheme (NDIS), there exists a myriad of outdated or misaligned agreements between governments. As a result, roles are blurred, and responsibilities have been dissolved.

Beyond the notion of governments falling flat on a commitment, this dissolution of responsibilities has life-changing consequences for people with disability. Too often, CYDA hears stories of children and young people with disability ‘falling through the gaps’ due of the lack of clarity of responsibilities between national and state and territory systems. This has never been more evident than now, with the ongoing Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability highlighting the neglect children and young people with disability experience across systems and their intersections including, but not limited to, the NDIS, education, health, justice, out-of-home care and housing.

There is currently no harmonised legislation in Australia about who provides safeguarding and protections for children and young people with disability against violence, abuse, and neglect. There is also significant variation between jurisdictions about complaints, reporting, and investigation mechanisms.

To realise the next Strategy and ensure children and young people do not suffer the burden of bureaucratic pitfalls, the following is required:

1. Establishment of a robust outcomes framework
2. An independent body to report on the progress of governments
3. Genuine commitment by government.

The outcomes framework should include clear delegation of responsibilities between national, state and territory and local governments and include shared ownership by all departments that people with disability intersect with. The outcomes included should be established from a foundation of human rights as per the CRPD. The outcomes framework should also include clear oversight protections across systems and governments to safeguard children and young people and eliminate the use of restrictive practices in all settings.

The outcomes framework must incorporate the different developmental needs across the life course. This includes clear outcomes for ages 0-3, 4-5, 6-8, 9-14 years 15-18 and 18-25 years. To reflect the aspirations of children and young people, this cohort and those important in their lives (specifically, parents, families and caregivers) must be meaningfully included in the framework’s development.

To monitor the progress of governments in achieving the agreed upon outcome, there should an independent oversight agency responsible for producing annual, publicly available reports. Further work must be undertaken in consultation with people with disability and Disability Representative Organisations to determine where this function will best sit. Regardless, whether this function is undertaken by leveraging existing agency strengths, such as the Australian Human Right Commission, or developing a new, purpose specific oversight agency – this must be fully resourced to ensure it is able to maintain consistent, timely and rigorous reporting (as opposed to the previous NDS’s Implementation Plans).

Similar to that of the Closing the Gap agreement, the NDS reporting should be tabled in parliament to ensure that the Federal Government respond publicly to the Strategy’s progress.

Fundamentally, there needs to be genuine commitment from governments across the country. Australia already has existing Disability Standards and anti-discrimination legislation, yet the injustices and exclusions people with disability continue to experience remain widespread. Financial investment in implementation will be a critical element of ensuring the new NDS is effective in achieving its objectives and supporting the development of a more inclusive society.

## Sufficiently resource systemic advocacy

* Ensure there is always a funded national children and youth representative organisation (CYDA) under Australia’s obligations under the CRPD
* Boost funding to Disability Representative Organisations providing strategic and systemic policy advice to government to ensure the rights of people with disability are upheld

An essential mechanism to ensure the NDS is meeting the ongoing needs of the diverse communities within the disability community is to sufficiently resource the systematic advocacy work conducted by human-rights based Disability Representative Organisations, such as CYDA. Systemic advocacy work is integral to support the work of policymakers and governments, change community attitudes and ensure that people with disability’s human rights are being upheld.

CYDA is the only national representative organisation for children and young people with disability, representing children and young people from the ages of 0 to 25 years, across disability types. Our board includes young people with disability and family members of children with disability, and our work is guided by and commits to the principles and rights recognised in the CRPD. The majority of CYDA’s staff are either people with a lived experience of disability or family members of a person with disability.

CYDA has over 5,000 members from around Australia with the majority being families of children with disability and young people with disability. We have a vast national reach through our communications and social media networks, including 19,090 Facebook and 5,181 Twitter followers, and 3,300 subscribers to our fortnightly e-news at the time of writing, and we have an emerging youth-specific Instagram following. In 2019-20 our social media reach was over 1 million (average reach of 84,000 per month).

Our work focusses on the reform and change of social systems and structures that discriminate against, or contribute to, the abuse and neglect of children and young people with disability. The systemic issues affecting the rights of children and young people with disability are extremely broad, spanning a large range of government portfolios and topic areas including child protection, health, education, employment, the NDIS, quality and safeguarding. This means that children and young people’s voices need to be heard through participatory processes across a wide range of policy areas, facilitated by their national representative organisation.

Disability Representative Organisations are often asked by government to measure their success and justify the funding we receive for systemic advocacy. The Department of Social Services is currently conducting a review of all its funded disability advocacy, including systemic and individual advocacy. However, it is often hard to measure the full impact or outcomes that funded systemic advocacy have on shaping government policy and addressing the systemic barriers faced by people with disability. Advocacy and social change are long-term actions, with advocates and community members fighting for many changes for years before they are made.

An example of a shorter-term impact of systemic advocacy is media take-up of our work, or our submissions being referenced in inquiry reports or informing recommendations; in this example however, we cannot influence if, when, or how government adopts the recommendations.

The reach and impact of our communications channels is a key metric for helping the community and stakeholders understand the rights of children and young people with disability. The way we have worked to share information during the COVID pandemic is an example of this. Few messages were targeted children and young people with disability and their families, and CYDA and other systemic advocates stepped in to fill this gap, translating changes in government information and highlighting the impacts for children and young people with disability. Systemic advocacy organisations like CYDA are a credible and trusted source of information[[84]](#footnote-85) and play a critical role in shaping community attitudes to children and young people with disability.

## Develop consistent and comprehensive data collection mechanisms and reporting requirements

* Develop consistent and comprehensive data collection, that includes disaggregated data for different age-groups, disability-type and demographics within the disability community
* Develop clear and consistent data reporting requirements across jurisdictions
* Co-design the new National Disability Data Asset with young people with disability

It is often difficult for representative and advocacy organisations, researchers, services and the public alike to fully understand the success (or pitfalls) of programs and policies affecting people with disability because there is a lack of sufficient data. Publicly available disaggregated data is particularly lacking.

As a representative organisation, CYDA uses multiple avenues to understand the experiences of children and young people so we can best provide an informed voice on the social issues important to them. One of these avenues is the use of data. However, often CYDA is unable to ascertain information specific to children and young people with disability, with available data being aggregated at higher population levels. That, or the data just does not exist.

The lack of data about children and young people with disability in different systems and settings can have real and significant impacts for their support and outcomes. For example, concerningly, relevant data is remarkably thin in the youth justice system. Data about the number of children and young people with disability within youth justice systems, the support they receive, and their outcomes, are limited, but what is available indicates that a significant majority of detainees have one or more disability.

A recent report by the South Australian Training Centre Visitor found that, in a sample of detainees in a youth training centre, nine of 10 young people had disability-related needs. This is the clearest data we have on disability prevalence as the relevant government department “has advised [the Training Centre Visitor] that it is unable to collect data about disability.”[[85]](#footnote-86) Similarly, 89 per cent of young people detained in Western Australia’s youth detention facility were found to have at least one “severe neurodevelopmental impairment.”[[86]](#footnote-87)

In many cases, broader data examining youth justice and youth detention populations also omits disability indicators. A word search of the most recent youth justice publications from the Australian Institute for Health and Welfare, *Youth Justice in Australia 2018–19*[[87]](#footnote-88)and *Youth detention population in Australia 2019*[[88]](#footnote-89)finds zero mention of either ‘disability’ or ‘disabilities.’

Once children and young people with disability have entered the criminal justice system, the support they can access is generally limited and the approach to support provision is inconsistent. As the South Australian report noted, “this inability [to collect data about detainees’ disability] suggests a limited systemic capacity to understand and diagnose, let alone provide for, the range of needs of children and young people in detention who have a diagnosed or undiagnosed disability. It also limits understanding of factors applicable to specific populations and the ability to respond appropriately to those needs (e.g., by providing specialist disability training to staff).”[[89]](#footnote-90)

As outlined in the ‘Develop clear mechanisms for accountability and safeguarding’ section of our submission, there is significant variation between jurisdictions about complaints, reporting, and investigation mechanisms that safeguards children and young people with disability against violence, abuse, and neglect. This lack of reporting mechanisms risks children and young people ‘falling through the gaps’ and experiencing harm that is preventable.

CYDA has also experienced barriers in gaining data about harmful practices used in education settings. One of the ongoing challenges is that there is no consistent data routinely collected in Australian schools on the rates of restrictive practices, including restraint and seclusion. CYDA has previously tried to obtain data on restraint and seclusion from state and territory governments through Freedom of Information requests. Some jurisdictions have been able to provide this information at an aggregate level, but others, such as the Victorian Government, have refused to provide this information because it is too administratively burdensome. In general, the data collected across jurisdictions is piecemeal and does not provide the full picture of children and young people’s experiences.

For example, for NSW, CYDA has only be able to access information that is held by the Employee Performance and Conduct Directorate, which means there must have been an allegation made against an employee. Complaints are held and managed by schools, and therefore the NSW Education Department has advised it cannot provide full information on restraint and seclusion in schools. Further, there is no data on the extent of restrictive practices in early childhood services.

While data does exist around school completion rates of young people with disability, there is inadequate data to understand rates of engagement, which in turn impacts rates of early school leaving. For example, there is no coordinated effort to understand rates of feelings of ‘school-connectedness’ or similar among children and young people with a disability – a facilitator of student engagement. Without understanding these underlying factors, policymakers risk developing policies and programs that do not address the barriers students with disability face.

CYDA has also been unable to attain disaggregated data about outcomes for young people in employment programs and supports, including mainstream employment programs, such as jobactive, state-based employment programs and supports funded under the NDIS.

While CYDA welcomes the new NDIS data sharing resources, we note that this data only incorporates those who are eligible for the Scheme and should not be over emphasised to understand the needs of all people with disability. In understanding the diversity of the disability community, efforts need to be improved to capture the experiences of all people with disability. For instance, the ABS Survey of Disability, Ageing and Carers, one of the richest sources of data on Australians with disability lacks as detailed information on the social and economic aspects of life for this of people living in cared accommodation as opposed to those who live in private dwellings.[[90]](#footnote-91) By leaving our specific cohorts in national data collection, future policy development risks marginalising some groups.

CYDA agrees with the NDS Position Paper that an improved strategy for data collection – particular consistent and disaggregated data – across service systems is required, however we caution the Council of Australian Governments (COAG) Australian Data and Digital Council to ensure the new mechanisms do not disempower the disability community. Learning from the Aboriginal and Torres Strait Islander community, pushback from the community has rightly shown that groups who are being ‘researched’ often do not have fair and just opportunity to contribute to decision making on what data should be collected, how and why.[[91]](#footnote-92) As such, the new National Disability Data Asset should be co-designed with young people with disability and their representative organisation to ensure data collectors do not overlook or misunderstand issues that are important to the cohort.

# Appendix A: Detailed case studies

## Max’s story

*Max’s story highlights the impact of the use of restrictive practices and the need for system reform.*

Max\*, 8, has autism and has been repeatedly suspended from a Perth primary school this year despite only being allowed to attend two hours a day.

His mum Laura\* says the school tried to push Max out “for months”, treating him like a “complete criminal” and isolating him in an office without any peers.

Sadly, this was not Max’s first experience of being isolated and restrained. He began his schooling at a Perth Catholic school where, as a five year-old, he was put in an office for up to two hours at a time while a staff member sat at the door with their back to him. His parents learned about this after insisting on the creation of a communication book documenting his day.

On the advice of Max’s psychologist, they withdrew him from the Catholic school and he was enrolled at the public primary. But despite an encouraging start, Laura says Max was later deemed “too much of a challenge”.

“They started calling me every minute to pick him up, sometimes by 10am, and then from probably halfway through term one this year, they said to me, ‘He only can come in for two hours a day – nine ‘til eleven – that’s it’,” she says.

The impact on the family was “huge” and they had to pay support workers to assist at home.

“I was home-schooling him basically, which was their job, and they’d ring me up and say, ‘Don’t bring him to school today, NAPLAN’s on. We can’t have him distracting the other children’,” Laura says.

“And the thing is, he wasn’t even in the classroom. At this point they’d put him in an office all by himself with a teacher’s aide.”

Laura says the school would never tell her and her husband what led to Max’s behaviour.

“We’d say to them, ‘What was the antecedent? The behaviour doesn’t occur unless something’s triggered it. What were the steps that led to that? What was requested of him, or how did it progress?’

“They could never tell us that, or they’d say, ‘It came out of the blue, there was no reason’.

“But there’s never no reason, and that to us was a big sign of their lack of understanding of him as a whole person.”

The situation progressed, with Max receiving “suspension after suspension”. On one occasion, he used his elbow to smash a window after being shut in an office with an aide for continuing to throw Lego into a hallway.

“They knew … at this school that one of the biggest anxiety provokers [for Max] was feeling trapped and caged in, and that would be enough to escalate him to a point of dysregulation where he’d just act out,” Laura says.

When the school rang her to pick Max up, she was told he had been suspended for property damage but not that he had been injured.

“So I’m aghast when I arrive and I see him bandaged up and the deputy principal’s telling me to take him to the doctor, he might need stitches.”

Max’s parents told the school they wouldn’t withdraw him unless a better option could be found. The school consulted with the state education department and made alternative recommendations.

“[This school] was amazing,” Laura says. “They had kids just like Max who were high functioning, very intelligent, but with behavioural issues.”

The family knew it had a waiting list and so told his primary school that unless they could get a place at the alternative school they would stay put and increase his hours to full-time.

“We knew that they didn’t want that, because they have been trying to get him out for so long and reduce his hours.

“It’s just even ridiculous that you have to play these kinds of games.”

Max has received a temporary place at the new school and Laura says he is “a new child” since beginning there, making friends and looking forward to attending.

“He said to me, ‘None of the teachers follow me to the toilets Mum’,” she says.

“They treat him like a human.

“It reinforces even more how detrimental I feel the last school was for him.”

\*Names have been changed

## Hannah’s story

*Hannah’s story highlights how the attitudes and low expectations held by people around young people with disability withholds their ability to learn and thrive.*

When Hannah\* reached Year 11, her Perth high school stopped her academic studies and pushed the specialist disability program student to work at an Australian Disability Enterprise (ADE).

For Hannah, who has Prader-Willi syndrome and a mild intellectual disability, this meant working for a not-for-profit agency for $2 an hour, where her jobs included washing and folding clothes – tasks she’d been doing at home since age 10.

“There’s such low expectations for these kids,” says Hannah’s mother Cath\*.

“The only thing that was offered to them was the ADE pathway.

“I was just so shocked … that the high schools just basically, I felt, gave up on them.”

Hannah disliked her work with the ADE, which included two terms in a warehouse sorting rubbish from saleable items, but she stuck with it, thinking the agency would offer her a retail traineeship that could lead to open employment.

In her third term, she worked at one of the organisation’s retail shops folding clothes and sweeping, but wasn’t allowed to talk to customers or operate the till. At the same time, Hannah had secured her own voluntary position at a cat refuge, where she used a computer, checked microchips and administered medication.

“That was her level – she’s [got] very good computer skills – and all she was allowed to do [at the ADE] was fold clothes and sweep floors,” Cath says.

The ADE position came to an end when, after one of Hannah’s shifts, an education assistant (EA) took $50 from her “and basically accused her of stealing it”. Although her support worker verified that the money was Hannah’s, Cath says the EA wouldn’t accept this and Hannah had a “major meltdown” in the back kitchen.

She says the agency immediately dismissed Hannah but didn’t tell her.

“She didn’t even know about it. It got dumped on me to tell her.”

Following this, the school teacher who had arranged the ADE placements told Cath that Hannah was “too hard” and nothing else could be found for her.

Her classroom teacher disagreed, and allowed Hannah to look for work herself. Hannah arranged voluntary work at a boarding kennel, which she took up independently.

Hannah believed she would be staying on to complete a Year 13 at the school, which had been offered the previous year. But in the September of Year 12, Cath was told by email that the school year would be finishing that month and Year 13 would not be offered.

Parents complained and the school let the specialist program students stay until the end of the year, but without their regular teachers, instead splitting the group between its Year Eight and Nine classrooms. It was a difficult time for Hannah, who experienced health struggles.

The school sent a reference home at the end of Year 12, and Cath was shocked to see some of Hannah’s skills, such as ironing and washing clothes, graded as merely ‘developing’. She contacted Hannah’s teacher who said the school used a standard template, so all the specialist program students had received the same reference. The teacher offered to change it to reflect Hannah’s true capabilities.

Hannah has three older siblings who attended mainstream school and Cath says Hannah received nothing like the “quite massive” effort put into establishing career pathways for mainstream students.

“They’re pushing them out with nothing.

“And the ADEs, they don’t even employ them full-time. They only give them a few hours.”

None of the six students in Hannah’s program got jobs after graduating in 2017, Cath says, and three years later they remain unemployed.

When Hannah first left school she was very keen to work, handing out resumes to local businesses. She also started a TAFE course but struggled without a personal support worker there with her, so withdrew.

“For about a year there she lost all hope,” Cath says.

Now 20, Hannah receives four full days of support through her NDIS package, but Cath says this support is not achieving goals but rather “just filling in the day”, with much time spent at home playing games.

“She wants her life to be worthwhile. She wants to be connected to society. She wants to contribute to society.

“She does not want to just be babysat.”

Hannah had a great experience at a mainstream primary school and Cath now wishes she had continued in mainstream education through her secondary years.

“Her disability did not compromise her education – the education system did. They gave her no opportunities, no alternatives but working for an ADE for $1.90 an hour.”

**\*Names have been changed**

# Appendix B: Supplementary data from CYDA’s National Education Survey

The data included below is from CYDA’s National Education Survey conducted between August and September 2019 to provide important information on the experience of children and young people with disability in their school education. There were 505 young people with disability and families and caregivers of children with disability who responded to the survey.

The survey had representation from all states and territories, all age groups and from metropolitan, regional, rural and remote Australia. The majority of respondents were from families of students with disability (97%), with the balance of respondents being students with disability.

Table 2 demonstrates the rate of ‘macro-exclusion’ in education, whereby students are denied formal education opportunities. Macro-exclusion is a clear form of segregation that is straightforward to identify.

**Table 1B. Educational segregation and exclusion\***

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **AUS** | **VIC** | **NSW** | **WA** | **QLD** |
| No of students with disability | 505 | 141 | 119 | 85 | 82 |
| % were enrolled in segregated education in either dual enrolment with a special school or attending a special school | 24.2 | 32.6 | 22.7 | 28.2 | 13.4 |
| % who attended a ‘mainstream’ school were separated from their peers either on a full-time basis in a special unit, or withdrawn to the special unit for instruction in combination with attending a regular class | 15.5 | 8.5 | 18.5 | 22.4 | 15.9 |
| % who have been refused enrolment | 12.5 | 9.2 | 10.9 | 5.9 | 25.6 |
| % who did not attend school full time | 16.6 | 22.0 | 12.6 | 10.6 | 11.0 |
| % who were suspended in the last year | 14.7 | 12.8 | 13.5 | 16.5 | 15.9 |
| % who were expelled in the last year | 1.8 | 1.4 | 1.7 | 3.5 | 1.2 |

\*While data were collected from ACT, TAS, SA, NT there were insufficient numbers to do jurisdictional comparisons

Table 3 shows the rates of ‘micro-exclusion’ experiences by students with disability. Micro-exclusion refers when students are not valued members of the school community and are denied opportunities to fully participate in the curriculum and school life. The survey results showed one in ten students with disability has been suspended and many on multiple occasions.

**Table 2B. School cultures for inclusion\***

|  | **AUS** | **VIC** | **NSW** | **WA** | **QLD** |
| --- | --- | --- | --- | --- | --- |
| % who were excluded from events or activities at school in the last year | 40.2 | 40.4 | 42.0 | 42.4 | 32.9 |
| % who did not have an Individual Education Plan (IEP) in place | 17.8 | 22.7 | 10.9 | 22.4 | 18.3 |
| % of families who didn’t know if an IEP was in place | 9.1 | 12.1 | 10.9 | 3.5 | 8.5 |
| % of families who were not involved in the development of the IEP | 36.4 | 44.0 | 29.4 | 37.7 | 39.0 |
| % of families who were 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 | 57.2 | 54.6 | 58.0 | 54.1 | 63.4 |
| % who disagreed that teachers and support staff had the training required to provide a supportive and enriching education environment for students with disability | 52.1 | 52.5 | 56.3 | 50.6 | 48.8 |
| % who disagreed that the student receives adequate support in their education | 48.9 | 45.4 | 53.8 | 52.9 | 41.5 |
| % who disagreed that there was regular communication with the family/caregivers about the student's learning progress | 34.7 | 29.8 | 38.7 | 36.5 | 35.4 |
| % who disagreed that teachers and support staff had high expectations of the student and their learning | 29.7 | 34.0 | 33.6 | 23.5 | 23.2 |
| % who disagreed that family/caregivers of the student were made to feel welcome at school | 23.4 | 23.4 | 27.0 | 23.5 | 20.7 |
| % who disagreed that the student was made to feel welcome at the school | 18.2 | 15.6 | 19.3 | 21.2 | 15.9 |

\*While data were collected from ACT, TAS, SA, NT there were insufficient numbers to do jurisdictional comparisons

Table 4 demonstrated the rates of violence against and abuse of students with disability. Shown below, almost half of students with disability have been bullied by either their peers or by teachers and school staff, and one in three students with disability has been subject to the restrictive practices of restraint and seclusion.

**Table 3B. Abuse and neglect\***

|  | **AUS** | **VIC** | **NSW** | **WA** | **QLD** |
| --- | --- | --- | --- | --- | --- |
| % who experienced bullying at school in the last year | 47.9 | 48.2 | 44.5 | 55.3 | 46.3 |
| % who experienced restraint or seclusion in the last year | 30.9 | 29.1 | 29.4 | 37.7 | 31.7 |
| % who experienced both restraint and seclusion in the last year | 11.1 | 9.9 | 10.1 | 15.3 | 9.8 |
| % who experienced restraint in the last year and the most common form was physical restraint, followed by psycho-social, mechanical and chemical restraint | 21.0 | 18.4 | 16.8 | 24.7 | 25.6 |
| % who experienced seclusion in the last year and the settings for seclusion included solitary confinement with and without supervision in a room, classroom or staff office | 21.0 | 20.6 | 22.7 | 28.2 | 15.9 |

\*While data were collected from ACT, TAS, SA, NT there were insufficient numbers to do jurisdictional comparisons

# Appendix C: Supplementary data from CYDA’s *Pathways for young people with disability after school* post-school survey

The below data is from CYDA’s 2019 national post-school survey, *‘Pathways for young people with disability after school’.* The survey was conducted between November and December 2019 with the aim 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 responded to the survey. 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).

*Respondents’ demographic data*

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

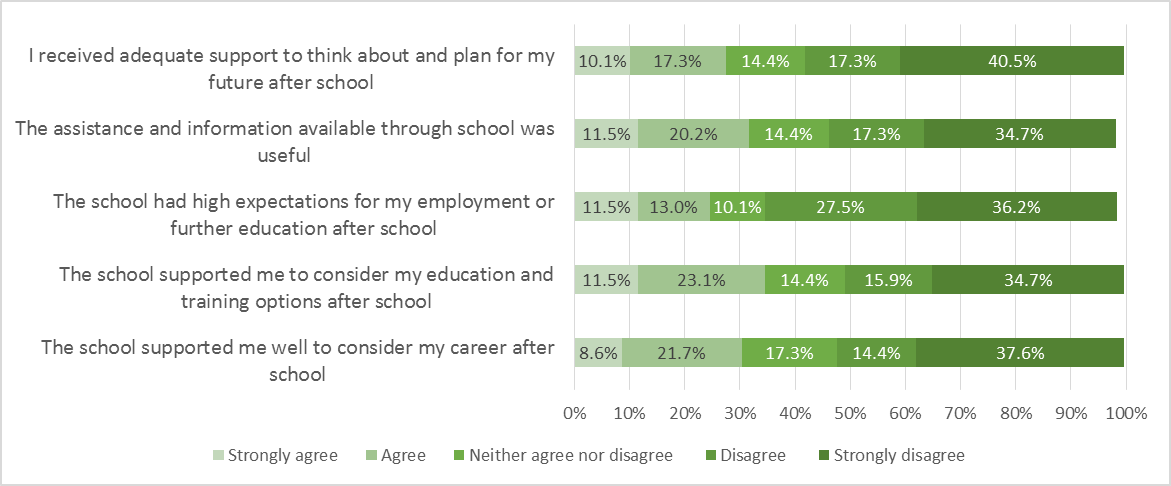
| **Demographic characteristic** | **Number** | **Percentage** |
| --- | --- | --- |
| Gender | | |
| Male | 55 | 63.9% |
| Female | 27 | 31.3% |
| Prefer not to say or not specified | 4 | 4.6% |
| Language and cultural background | | |
| English speaking background | 75 | 87.2% |
| Non-English-speaking 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% |
| 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% |

**Provide targeted and support for students’ career-planning and transition and address state and territory inconsistencies**

**Table 2C. 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% |

**Figure 1C. Respondents’ level of agreement with statements around the transition support they received**



**Address low expectations for students and young people with disability**

**Table 3C. 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% |

**Provide an adequate safety net when young people cannot find work**

**Table 4C. 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/Jobseeker Allowance | 2 | 3% |
| Youth Allowance | 4 | 6% |

**Figure 2C. Trends from 2009 to 2019 of Newstart/Jobseeker 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 3C.** **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

1. Please note, this submission was written prior to the release of the Department of Social Services’ introductory paper *Improving outcomes for people with disability under the National Disability Strategy and the National Disability Insurance Scheme*. Our discussion around outcomes frameworks and measurements therefore predates the material in this paper. [↑](#footnote-ref-2)
2. CYDA uses the term ‘meaningful participation’ to highlight the difference between attending an activity

   and truly being part of it. Instead of just being there when an activity is happening, meaningful participation means an individual is fully included and participating in the way that they want to, with any support that is needed for them to do so. For more information, see our new fact sheet: *Understanding ECI language.* <https://www.cyda.org.au/resources/details/227/understanding-eci-language> [↑](#footnote-ref-3)
3. Referred to in our submission as ‘post-school survey’ [↑](#footnote-ref-4)
4. Please see the ‘Develop consistent and comprehensive data collection mechanisms and reporting requirements’ section for CYDA’s commentary on the inadequacies of data collection the experiences of children and young people in the justice system [↑](#footnote-ref-5)
5. CYDA. (2020). *Response to Disability Royal Commission Criminal justice system issues paper*. Available at https://www.cyda.org.au/images/pdf/response\_to\_drc\_criminal\_justice\_system\_issues\_paper\_august\_2020.pdf [↑](#footnote-ref-6)
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14. For a more detailed explanation of inclusive education, please see *What is inclusive education?* Fact sheet attached to the submission [↑](#footnote-ref-15)
15. Cologon, K. (2019). *Towards inclusive education: A necessary process of transformation*, for CYDA, p.5. [↑](#footnote-ref-16)
16. ibid [↑](#footnote-ref-17)
17. ibid [↑](#footnote-ref-18)
18. See Articles 28 and 29 of the CRC and Article 24 of the CRPD, and CRPD General Comment No.4 Right to Inclusive Education. [↑](#footnote-ref-19)
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